'Let the world dream otherwise': The slow disaster involving PPE and distancing in health and social care communication

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‘Let the world dream otherwise’: The slow disaster involving PPE and distancing in health and social care communication

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Thesis submitted for the degree of Doctor of Philosophy

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DECLARATION

I declare that no part of the work referred to in this thesis has been submitted in support of an application for another degree or qualification of this or any other university or institute of learning.

STATEMENT OF COPYRIGHT

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ABSTRACT

For intermittent periods between 2020 and 2022 during the Covid-19 pandemic, the general population of England was required to wear a face-covering in public spaces. Rules which prevented touch and proximity (described as 'social distancing') were also introduced and repeatedly altered over time. Further items of personal protective equipment (PPE) were required to be worn by people in health and social care roles and environments in different combinations and circumstances over the same period. These artefacts, combined with the denial of touch and proximity, created physiological, psychological, and cultural barriers to communication.

My research establishes the barriers and facilitators of health and care interactions in the presence of PPE and distancing, identifies the wider socio-political and cultural determinants which influenced these barriers and facilitators, and recognises the consequences for disaster recovery and emergency preparedness.

The case-based thematic analysis of survey responses of 464 people and interviews with 33 participants in August-December 2020, and the subsequent re-interviewing of nine interview participants in March-May 2022, identified that people who gave and/or received health or social care were susceptible to 'communication distress': the term I use for the suffering caused by the inability to be understood and/or to fully understand as a result of the adverse body-mind sensory and cognitive experience endured when interacting in the presence of PPE and distancing. This and other deficiencies in social interaction, and ever-changing departures from the normative order, gave rise to moral uncertainty and societal 'anomie'.

Sensitisation and habituation to the physical and psychological experience of PPE and distancing was influenced by the quality of the pre-existing resources, relationships, skills, and circumstances of those who interacted; the quality and availability of PPE artefacts; the equipment and infrastructure required to facilitate remote communication; and the quality of

explicit and implicit communication emanating from the authorities responsible for the infection control measures, especially the levels of contradiction within.

Communication distress in the face of the threat to health posed by Covid-19 interacted with the concurrent and pre-existing factors of structural violence, epistemic injustice, and betrayal of trust in the manner of a syndemic. As a result, some participants experienced moral distress and moral injury both through their professional and social roles and/or through their experiences as people in need of health and care support.

Societal prescriptive forgetting was encouraged by media outlets which supported the government of the time, and by people in influential positions who had a vested interest in the construction of a post-Covid culture which reverted to the pre-pandemic status quo: a narrative which was at odds with persistent PPE-wearing and distancing in health and care communication. The initial objectification of health and social care workers as ‘heroes’ with unlimited coping capabilities exacerbated subsequent demonisation and, combined with exhaustion and moral injury, prompted some people to question their professional care-giving identities and practice their own ‘self-compassionate disconnection’, making substantial changes to their work/life balance as a form of self-care. Communication distress was also a factor in ‘institutional distancing’: the pre-existing and/or Covid-related absence of support services which led to an increase in the unacknowledged burden of unpaid family care.

This research documents a governmental and societal failure to acknowledge the extent of communication distress, its causes, and its consequences. In the face of the high probability of another event which will require the use of PPE and distancing in health and care communication, I conclude that this syndemic is an unrecognised, yet ongoing, disaster of gradual onset.

This thesis can inform policymaking in the development of current health and social care services, in disaster recovery and the rebuilding of trust, and in preparedness planning for future circumstances which will require the use of PPE and distancing.

CHAPTER 1: INTRODUCTION

We wear the mask that grins and lies,

It hides our cheeks and shades our eyes –

This debt we pay to human guile;

With torn and bleeding hearts we smile,

And mouth with myriad subtleties.

Why should the world be over-wise,

In counting all our tears and sighs?

Nay, let them only see us, while

  We wear the mask.

We smile, but, O great Christ, our cries

To thee from tortured souls arise.

We sing, but oh the clay is vile

Beneath our feet, and long the mile;

But let the world dream otherwise,

  We wear the mask!

Paul Laurence Dunbar (1895, p.21)

I begin with this poem as an indicator of the content and structure of this thesis. It offers an insight into how the embodied exposure to PPE-wearing and distancing resulted in the moral distress and exhaustion of people involved in health and social care which has contributed to an ongoing and unacknowledged slow disaster – a concept I will expand upon in Chapter 7.

After describing the background and the aims of my work, in this thesis I offer a narrative review of the existing literature on the physical and cultural aspects of communication with an emphasis on health and social care interactions. I consider what was known about the embodied experience of communication, the effect of distancing and occlusion – the process whereby something is hidden or obscured from view – on how we communicate, and the physiological and sociopolitical contexts of PPE and distancing. In the following chapter, on Methodology, I explain how my positionality has shaped the study, and I describe the rationale behind the methods used. The analysis is then offered in three sequential sections: ‘Being There’ considers the intrinsic physiological and psychological effects of being with PPE and distancing; ‘What Lies Beneath’ is an exploration of the extrinsic factors which exacerbated or ameliorated these effects; and ‘Consequences’ considers the effects of these intrinsic and extrinsic factors on the participants. In Chapter 7, I discuss the implications of my findings for the immediate and longer-term wellbeing of the participants and the society in which they live. I conclude with a recommendation for action to address these implications.

1.1 Background

My PhD project is funded by the Economic and Social Research Council (ESRC) via the Health, Wellbeing and Society pathway. This pathway facilitates an interdisciplinary focus on the social determinants of health and well-being in society to support the ESRC's delivery goals of 'influencing behaviour and informing interventions' and 'creating a vibrant and fair society' (NINE DTP, n.d.). Medical anthropology is my 'home' academic discipline, which I reached via a multidisciplinary BSc (Hons) with the Open University, concurrent with my career as a massage therapist in palliative care, combining interests in human biology (specifically sensory neuroscience), social sciences, and public health.

For my Masters in Research Methods in 2018-19 I piloted 'massage ethnography', a novel research method which foregrounded touch, proximity, and non-verbal communication to facilitate dialogues with people living with life-limiting conditions who are under-represented in research. My original PhD project, 'The role of complementary therapy in palliative care – attitudes and experiences in and beyond the hospice' (NINE DTP, 2019), was approved for progression in June 2020 but, from March 2020, touch and proximity were prohibited throughout the population to reduce the spread of Covid-19, preventing access to my field sites in a hospice, care home and complementary therapy community clinic. It was clear that the crisis would have cultural and practical repercussions beyond the term of my PhD funding and the decision to suspend my studies was made.

In the interregnum I repurposed my knowledge of touch and communication by applying effectuation principles (Sarasvathy, 2001): decision-making based on the idea that one can repurpose one's resources to create one's future. I used some of the underpinning theories and literature from my initial plans to write a separate research proposal to investigate the effects of PPE and distancing on healthcare communication. The project, entitled 'Behind the Mask', was granted funding by Durham University Covid-19 Response Fund.

Between 1 July and 31 December 2020 I executed the project in the role of Research Assistant, and my supervisor Prof Jane Macnaughton supported and guided me by assuming the Principal Investigator role. The aims of ‘Behind the Mask’ were to:

1. Identify how, why, for whom, and to what extent PPE and distancing affects communication in health and social care

2. Identify how, and to what extent, care givers and receivers adapt to the circumstances

3. Develop theories which can then be scrutinised in subsequent research aimed at identifying ways to promote effective communication behaviours and strategies

The ‘Behind the Mask’ project produced:

1. A descriptive analysis of the recruitment survey (n=464)
2. Interviews (n=33) for subsequent analysis
3. Theories for subsequent investigation.

The unexpectedly large number of survey responses refocused the resources of the short-term project from analysis to further data-gathering, hence the quantity of interviews. The Covid-19 pandemic (see timeline, Appendix A) created circumstances amounting to a massive and unintended ‘breaching experiment’ – a test that seeks to examine people’s reactions to violations of commonly accepted social rules and norms (Goffman, 1963; Garfinkel, 1967). The survey responses and interviews captured experiences which deserved all the passion and resources of a PhD project, and I pivoted my plans accordingly. While secondary analysis of this data is central to this thesis, the necessity to comprehensively revise my PhD project allowed me to exploit the passing of time: in 2022 I re-interviewed nine of the ‘Behind the Mask’ participants, giving the study a longitudinal element which proved revealing.

1.2 Aims and objectives

The research questions for this thesis were:

1. What barriers and facilitators existed when communicating in health and social care settings in the presence/absence of face-coverings, PPE, and physical distancing in England between early 2020 and mid-2022?
2. What were the wider socio-political, economic, and cultural determinants affecting the communication taking place in health and social care contexts during this time?
3. What were the consequences of the experience on the lives of those who participated in these health and care interactions?

Towards these aims, my objectives were to identify and critically analyse:

1. the barriers and facilitators to effective communication in health and social care interactions in normal circumstances
2. how infection control measures (i.e. face-coverings, PPE, and distancing) affected the experience of communication in health and care
3. the structural inequalities and cultural factors which influenced the contexts, mechanisms and outcomes of health and care communication in the presence of evolving infection control measures
4. how, to what extent, under what circumstances, and with what unintended consequences, did clinicians, patients/clients and carers adapt – or fail to adapt – to evolving infection control requirements

This PhD project involved a series of work packages:

1. Between March and May 2022, re-interviewing of nine of the original 33 interview participants who had been interviewed for ‘Behind the Mask’ between September and December 2020

2. Inferential analysis of quantitative data from the ‘Behind the Mask’ survey

3. Case-based and temporal thematic analysis of interviews with the 33 ‘Behind the Mask’ interview participants, including the integration of the second interviews conducted with nine participants in 2022

4. Merging of descriptive and inferential quantitative analyses and qualitative thematic analyses, combining the thematic content from each participant with the thematic analysis which had been conducted on the survey free-text data as part of the ‘Behind the Mask’ project (895 survey free-text responses from n=339 respondents)

5. Literature reviews to explore novel themes and concepts which emerged from the analyses

6. Comparison of the emergent themes against the theories developed in the ‘Behind the Mask’ project

Because this thesis extends from the ‘Behind the Mask’ project, the methodology, analysis, and results of that project are integrated into the reporting on the processes involved in the subsequent work packages described above.

CHAPTER 2: LITERATURE REVIEW

This narrative literature review considers a range of themes relating to the embodied experience of communication and its social contexts in the absence and presence of Covid-19. It is the product of a review done in preparation for the process of analysis. In unprecedented times, I anticipated as best I could the information with which I would need to equip myself to make sense of the data. I did not anticipate those insights that eventually did emerge in my analysis: themes of structural violence; epistemic injustice; moral injury; the concept of the syndemic; slow disaster. The literature on these unanticipated themes is introduced as they arise in Chapters 6 and 7. In this chapter, I consider the literature for the physiological and cultural contexts which underpin my approach.

Biocultural approaches are those that explicitly recognize the dynamic interactions between humans as biological beings and the social, cultural, and physical environments they inhabit (Dufour, 2006). MacLachlan (1997, p.11) explains: *'Once the involvement of your biological sense organs is recognised as part of the process of culture, the psychological and physiological implications of culture become not only more apparent but also more credible'*. The mechanisms of communication are an example of how biology and culture interact because of the integral roles of sensory stimulation, perception, and interpretation.

2.1 The mechanisms of communication

I use Finnegan's definition of communication (Finnegan, 2014, p.32):

> *'the actions and experiences created by and through people as they interact, affective no less than cognitive. It includes interacting at a distance as well as bodily co-presence at a given temporal moment, and not just messages transmitted from one party to another but all the multidimensional contacts going on within and among groups of people, all the emergent processes through which people mutually – and to multiply varying degrees – interconnect with each other'*

I consider the mechanisms of communication as defined by Finnegan (2014, p.8):

> *'all channels open to human interaction, whether auditory, visual, kinesic, proxemic, tactile or olfactory [...] through human-made artefacts and through [...] facial expressions, dress or bodily positionings'*.

Communication is a joint accomplishment of both the affordances of objects and of human behaviours (Caronia & Mortari, 2015). We experience the world and its objects, and the world experiences us, through our bodies. 'Kinesics' is the scientific study of the body movements involved in communication, including gestures, facial expressions, eye behaviour, touch, and posture, especially as they accompany vocal speech (Danesi, 2006). 'Proxemics' is the study of human use of space and the effects that population density has on behaviour, communication, and social interaction (Hall, 1966).

In *The Phenomenology of Perception*, Merleau-Ponty (1962 [1945], p.146) draws from neurological and psychological studies and combines them with reflections from the philosophical canon, describing the body as *'our general medium for having a world'*. A person's embodied behaviours – their gait, gestures, facial expressions, posture, and ways of using and wearing things – is known as their 'hexis' (Bourdieu, 1977, p.87). The body is the medium through which subjective feelings, perceptions, sensations, and consciousness are generated, and through which intentions are made visible (Merleau-Ponty, 1962 [1945], p.146). When one observes the message in one's tissues, the act places the body into the mind (Gallagher, 2015, p.xii; Frank, 2013 [1995], p.xii).

The embodied experience of person-to-person communication is multifaceted. Multimodal non-verbal communication (Ingold, 2000; Tanner, 2017) occurs through touch, movement, proximity, gestures, facial expression, eye contact and gaze, breathing, posture, and vocalization both prosodic (volume, pitch, and intonation) and paralinguistic (coughs, laughter, crying) (Payne, 2007, p.149). Communication incorporates intentional and unintentional verbal and non-verbal stimuli, encoding and decoding these cues, taking into account the relationships between cues (which can contradict each other), the feelings, personalities and cultures of the communicators, and the situations in which the communication occurs (Mehrabian, 1972, p.vii). Facial cues include static features like age, gender or ethnicity, and changeable features like gaze direction, lip movements or emotional states (Bruce & Young, 1986). Despite substantial differences in the way people from different cultures communicate – e.g., the involvement of touch, gestures, proximity and eye contact (Hall, 1966) – specific facial expressions which convey anger, disgust, fear, joy, sadness and surprise may be culturally universal (Ekman, Sorenson, & Friesen, 1969). The sentiment of the spoken word, and the reaction to others' words and behaviours, involves the ability to express and observe a complex vocabulary of non-verbal facial expression. The lexicon of non-verbal communication is construed from specific combinations of subtle movements of the facial muscles (Finnegan, 2014).

Experiments conducted within the sphere of psychology and neuroscience give insight into the facial and bodily mechanisms of communication. A person's emotions are expressed through face and body, but when there is a contradiction between cues, the cues from the face rather than the body usually take precedence when the viewer is trying to interpret what emotion is being conveyed (Mondloch, 2012). Conversely, recognition of an emotion in the face is notably improved when the person's bodily expressions and environmental context are congruent with that emotion (Kret, Roelofs, Stekelenburg, & de Gelder, 2013).

Whilst communication is inherently a sensory experience, it is not a linear sequence but a continuous and simultaneous interaction of many variables that move, change, and affect each other over time (Berlo, 1960). Communication occurs at a micro level – via individual identity, motives, and cognition; a meso level – by way of organizations and groups; and a macro level – through perspectives on society and culture (Hartmann, 2017). The direction of interaction is another variable: one-way from sender to receiver, in which the sender tries to shape the meaning-making of the receiver; two-way, in which two or more people construct new meanings together; and omnidirectional, which involves organisations as social actors (van Ruler 2018). Strategic communication focuses on how an organization presents and promotes itself through the intentional activities of its leaders, employees, and communication practitioners (Hallahan et al, 2007, p.7).

These wide-ranging multiple stimuli require processing for sense to be made of them.

2.2 Habituation and sensitisation

When we interact with the world, we subconsciously sift through our sensory stimuli to select only those cues that are of interest. Those choices are governed by a pattern-making tendency (M. Douglas, 1966, p.36). ‘Selective attention’ or ‘saliency mapping’ is the process through which we identify and select the most appropriate stimuli to which we should respond while supressing signals deemed irrelevant (Itti & Koch, 2001; Krauzlis, Lovejoy, & Zenon, 2013). A out-of-the-ordinary stimulus is salient and is more likely to induce a response. Habituation describes decreased responsiveness to a stimulus with repeated presentation (Thompson & Spencer, 1966). It is important for cognitive tasks such as interpersonal communication because it filters out irrelevant sensory stimulation such as the feeling of one’s clothes or the background blur and buzz of passers-by and brings the individual’s focus to important stimuli such as their interlocutor’s speech, tone, facial expression, and gestures. The opposite of habituation is sensitization: the increased responsiveness to a stimulus with repeated presentation, especially if the stimulus is annoying or aversive.

The dual process theory of Groves and Thompson (1970) describes habituation and sensitization as two independent processes – one showing a gradual reduction in sensitivity (habituation) and one with incremental increase (sensitization) – which develop independently in the central nervous system and interact to produce the final behavioural response. The organisms susceptible to habituation and sensitization range from the microscopic to a whole society, and the stimuli can be as simple as the sensation of air on one's face or as complex as the prolonged and orchestrated audiovisual messages of a multimedia propaganda campaign. Blumstein (2016, p.255) observes: '*the public may become sensitized to real or manufactured threats repeated by the press*'.

Multiple unfamiliar sensory cues (such as face coverings, PPE, and novel computer-based communication methods), lack of familiar cues (such as facial recognition and facial expression, proximity and touch), and the complex cultural signals which are carried in these stimuli (Berlo, 1960) disrupt the familiar patterns through which we perceive the world. This unfamiliarity can interfere with communication because it offers competition for the message which the communicator is trying to convey.

The importance of habituation is demonstrated in people whose neurodivergence features an 'always-on' awareness of sensations usually screened out by neurotypical people. Low levels of habituation strongly correlate with memory and attention issues which can be problematic to the person experiencing such high-volume sensory stimuli, or to the people around them who lack understanding of their neurodivergent experience and are discomfited by their reactions and coping strategies. This accounts for the diagnosis of a range of conditions associated with neurodivergence (J. Booth et al., 2005; Gitelman, 2003), which are often pathologized to the point of being misinterpreted as *'mental disorders'* (see Schmid, Wilson, & Rankin, 2015, p.2).

Sensitization may be useful if it helps humans and other species avoid potentially risky or costly situations: a 'hazard' is something which can cause harm, and 'risk' is the likelihood and severity of the harm which could result from the hazard. While a hazard and its attendant risk can exist without anyone being aware of them, a 'threat' is the presence of something which is *perceived* to be likely to cause damage or danger. Unless people feel strongly able to control a threat, fear is likely to lead to a defensive and negative response

(Floyd, Prentice-Dunn, & Rogers, 2000). The mechanisms which alert us to a threat are inherent in human physiology.

2.3 General Adaptation Syndrome

An individual’s experiences and interactions with the world are embodied and have a visceral effect. General Adaptation Syndrome (GAS) (Selye, 1936) is the neuroendocrine response to unresolved emotional stress which affects the body’s immune functions on a cellular level. Though Selye’s understanding of the biochemistry has been superseded, GAS is a concept still considered to have heuristic value (Fink, 2009, p.552). GAS is embodied in three phases: alarm, adaptation, and exhaustion. In the alarm stage, powerful feelings caused by a stressor trigger a cascade of hormones and neurotransmitters to evoke a necessary and normal ‘fight-or-flight’ response. Adaptation normally occurs when the stress passes, and the body’s homeostatic regulation returns the neurochemicals to their pre-stress levels. If adaptation fails, and hormones continue to be produced in response to an alarm for which they are no longer appropriate, the person enters the exhaustion phase, where unbalanced levels of hormones affect the body-mind on a cellular level, inducing physical and emotional pathologies including forgetfulness, emotional lability (e.g., tearfulness, anger), and physical fatigue.

This syndrome, embedded in the physiological, is profoundly affected by sociocultural factors which moderate the level of stress. This two-way link between neurobiology and the sociocultural sphere has been established and developed by trauma clinicians such as van der Kolk who identifies the sociocultural circumstances which can provoke, or mitigate against, the development of GAS (van der Kolk, 2014, p.38). He identifies the centrality of relationships and community to wellbeing, and the transformative power of language and communication. These factors create specific physical and cultural environments which influence the mechanisms of GAS. When trust is lost and communication fails, the circumstances are set for the neuroendocrine response of GAS to unfold.

This interpretation of GAS is important because it explains the interconnectedness of body and mind in the viscerally stimulating experience of interacting in the presence of PPE and distancing. These objects and behaviours interfere with communication and relationships in two ways: they obscure normal communication cues provided by the face and body while concurrently contributing their own physiological and cultural stimuli.

2.4 The meaning of masks and other PPE artefacts

Objects communicate, and the messages they convey can be overt or covert, intended or unintended. They can also contain contradictory signals which are subject to change over time and context. Any object, such as a surgical mask, can gain agency when used for a specific means and, as such, becomes the carrier of meaning(s) (Tilley, 2001). Appadurai (1986) explains that objects acquire meaning through their social and cultural context and as such, an object can take on a life of its own. Marcus (1988) advocates following an object (for example, a surgical mask) as it circulates through its different contexts and is interpreted by diverse stakeholders when attempting to understand the life of that artefact from an anthropological perspective.

The paraphernalia of infection control – various types of masks; goggles, visors, and head coverings; gloves, aprons, and bodysuits – are objects which communicate complex and dramatic messages which sometimes contradict the intentions of their primary use. Their multilayered embodied and politically intense complexities were explored by Lupton, Southerton, Clark & Watson (2021), who conducted a sociomaterial analysis of face masks specific to the Covid-19 pandemic. They described how, for many people, masks were integrated into their more-than-human assemblage of microbes, fluids, inhaled and exhaled gases, their garments, their technologies such as spectacles and hearing aids, and those posessions which become part of one's taken-for-granted embodiment such as keys, wallets, and smartphones. They also describe the communicative complexities arising from circumstances where people could not, or refused to, wear a face covering, and how the mask – and its absence – became a profound communicator of political beliefs and personal identity. Their analysis drew upon Bennett's concept of 'thing-power': *'the curious ability of inanimate things to animate, to act, to product effects dramatic and subtle'* (J. Bennett, 2004, p.351)

My research concerns three kinds of PPE artefacts known collectively as 'masks': surgical masks, respirators, and face coverings.

FIGURE 1: Me wearing a Type IIR surgical mask, experiencing the misting effect on the inner surface of my glasses from the mask funnelling my outbreath into my eyes (Lambell, 2024a)

Surgical masks are designed for 'source control' – i.e., worn to filter the wearer's outbreath, thus protecting the people around them by reducing the amount of pathogen in the environment (MHRA, 2020). The most common Type IIR version (Figure 1) has a fluid-repellent exterior which also offers the wearer some protection against droplets of blood, saliva, or other liquids. A 2008 test by the Health and Safety Executive concluded that surgical masks do not protect the wearer against pathogens present through coughing, sneezing, or speaking, or from droplets which become aerosols through evaporation (Gawn, Clayton, Makinson & Crook, 2008, p.4). An FFP3 face-fitted respirator is required to protect the wearer from airborne particles (Figure 2).

FIGURE 2: Me wearing an FFP3 respirator mask, with some misting on my lenses (Lambell, 2024b)

FFP stands for ‘filtering face piece’, and the 3 denotes a higher level of filtration. The Health and Safety Executive stipulates that people who wear an FFP3 mask must first undergo a ‘fit test’ to ascertain the correct size to provide a tight seal on the face and must subsequently only use that size and brand of mask (HSE, 2019). Some FFP masks have an exhalation valve to make it more comfortable to wear (Figure 3). However, while the valve maintains the ‘wearer protection’ function of the mask, the stream of out-breath released through the valve means the mask does not have a ‘source control’ function (Staymates, 2020).

FIGURE 3: Me wearing a valved FFP3 respirator mask, no misting on my lenses (Lambell, 2024c)

‘Face-coverings’ encompass a wider range of homemade or shop-bought cloth covers worn for source control in non-healthcare settings, according to the Department for Health and Social Care (DHSC/Cabinet Office, 2020). I made the face-covering pictured in Figures 4 and 5 from materials found in my mother’s house. Following a pattern from the internet, I cut a circle of fabric from a tea towel and sewed it to create an internal pocket, into which I inserted three layers of non-woven medical gauze for added filtration, before adding elastic ear straps.

Despite the differences, in common discourse the term ‘mask’ has been used as an overarching description for all three types of covering. The descriptions above explain their explicit purposes as stated by the manufacturers in compliance with the HSE. However, the communication of these purposes, and the *meanings* of the objects as interpreted by a wide range of stakeholders, was more complex and fluid. This is the subject of my research.

FIGURE 4: Me wearing my home-made face covering – with misted glasses (Lambell, 2024d)

FIGURE 5: The inside of the mask, with its pocket for additional filtering gauze (Lambell, 2024e)

Masks feature throughout history and across cultures as a form of expression, as well as a method of concealment and separation. Riisgaard and Thomassen (2016, p.75) use an extract from poet WB Yeats' 1910 poem *The Mask* as an illustration of the visceral effect of observing mask-wearing:

> *'…It was the mask engaged your mind*
> *And after set your heart to beat,*
> *Not what's behind…'*

According to Mauss (1973 [1935]), the person *is* the mask, and the mask can be considered as 'a technique of the body'. Anthropologists have long commentated on the use of masks in rituals and ceremonies, and how their symbolism underpins cultures (Boas, 1922; Goldman, 1975; Levi-Strauss, 1982 [1975]; Tonkin, 1979: Lynteris, 2018). Masks can bring people together and/or divide them: Descola (2021) describes how a mask can be ascribed different meanings by different people, and observes that conflict can result from these differences, while Riisgaard & Thomassen (2016, p.75) assert that the power of masks used in ritualised protest lies in their transformative ability to unify and transcend.

In an infection control context, objects which have the function of protecting people from harm have themselves been considered offensive. In their ethnography of the West African Ebola outbreak of 2014-17, H. Brown & Marí-Sáez (2020) describe how the meaning of PPE artefacts evolved as the epidemic progressed due to their powerfully multi-valent nature which transmitted conflicting messages of safety and threat. For practitioners, the embodied, sensory, and affective experience of the material qualities of their equipment helped workers to feel safe, but not their patients: the practitioners reported that patients stopped attending when they started using aprons and gloves in routine encounters. Abney (2018) describes how FFP3 respirator masks used to contain tuberculosis were social objects imbued with negative connotations of stigma and shame, and Lynteris (2018) considers how anti-plague costumes have historically been considered the *cause* of infection rather than its prophylaxis.

In an interaction affected by the presence of PPE, communication is also affected when those objects obscure facial and bodily signals.

2.5 How PPE obscures communication

Covering the mouth can obscure the sound of speech as well as obscuring the shapes the mouth makes during speech. This interferes with the complex interplay between auditory and visual cues which influence verbal communication (McGurk & MacDonald, 1976). Masking eyes and mouth can also cause the misinterpretation of emotions: fear and surprise are particularly susceptible for being confused with each other (Wegrzyn, Vogt, Kireclioglu, Schneider & Kissler, 2017). The perceived intensity of intended emotions (i.e., the emotion that the actor intended to convey) is reduced by the presence of a surgical mask for all expressions except for anger. Additionally, when viewing all expressions except surprise, masks increased the perceived intensity of non-intended emotions (i.e., emotions that the actor did not intend to convey) (Tsantani, Podgajecka, Gray & R. Cook, 2022).

Research conducted by Barrick, Thornton & Tamir (2021) after the imposition of face-coverings in the Covid-19 pandemic indicated evidence of habituation: the more people had interacted with others who were wearing masks, the more they had learned to focus on visual cues from the eye area of a face which was not obscured by a mask.

Recognition of emotions on a covered face is affected by cultural context, as seen by the work of Kret & de Gelder (2012): the young, mostly female, white, Western psychology student participants who were presented with two photographs of the same face – one covered by Islamic headdress and another identically occluded by a cap and scarf – were more likely to see a happy expression on the face covered by secular clothing while the expression of the niqab-covered face was more often interpreted as fear.

In their review of existing research into the reading of faces occluded by medical masks, Pavlova & Sokolov (2022) found that interpersonal interactions can be rendered ‘inefficient or even perplexing' by the way masks prevent the reading of the wearers' emotions (though people who are accustomed to reading partly veiled faces may be less affected). Ross & George (2022) discovered that this effect can be mitigated if the observer can also see their interlocutor's bodily posture and gestures, or 'hexis', defined earlier in this chapter as a tendency to hold and use one's body in a certain way.

The removal of common communication cues was a new experience for the majority of the population but, prior to the pandemic, people with sensory or cognitive impairments were already living with such deficits.

2.6 Pre-existing barriers to communication

Statistics published by the Department for Work and Pensions (DWP) in 2020 indicated that 21% of the UK population reported having one or more disabilities. Of these, 1.8 million people had hearing loss, 1.7m had impaired vision, 1.9m had learning disabilities, 1.3m had social/behavioural impairments and 3.8m had mental health impairment (DWP, 2020). Carers and family members are a key communication tool for people with a range of sensory and cognitive impairments (Age UK, 2016; Luxford et al., 2015), though the Association of Sign Language Interpreters (ASLI) advises that there are confidentiality and ethical concerns surrounding the use of family members to interpret in healthcare conversations with sensitive content (ASLI, 2020).

Non-verbal facial cues are a fundamental element of British Sign Language (BSL), the primary language for UK's estimated 70,000 Deaf people born without hearing or who became deaf before the age of five and who have their own culture and community – indicated by a capitalised 'D' (SignHealth, 2014). For the majority of deaf people in the UK, BSL is their first language with English as a second or third language (British Deaf Association, 2020). Rather than being a signed equivalent of English, BSL has its own grammar and structure and is a three-dimensional language which relies on body movements, gestures and facial expressions. It does not translate well onto a two-dimensional video screen, and an interpreter wearing PPE will fatigue quickly (ASLI, 2020).

Trait alexithymia is an impairment in recognizing and communicating one's own emotions, and difficulty distinguishing feelings from the bodily sensations of emotional arousal (Nemiah, Freyberger, & Sifneos, 1976). The incidence of alexithymia in the general population is thought to be 10% (Linden, Wen, & Paulus, 1995; Salminen, Saarijärvi, Äärelä, Toikka, & Kauhanen, 1999), and it is thought that severe degrees of alexithymia occur in at least 50% of individuals with autism (Berthoz & Hill, 2005; Hill, Berthoz, & Frith, 2004; Lombardo, Barnes, Wheelwright, & Baron-Cohen, 2007). Behavioural experiments have shown that alexithymia is linked to poorer recognition of emotional expressions in faces (R. Cook, Brewer, Shah, & Bird, 2013; Grynberg et al., 2012). The 'Reading the Mind in the Eyes' test (Baron-Cohen et al., 2001) is used to detect impairments in the ability to infer the mental states of others, including intention and knowledge, often found in autism.

A person's hexis combines with these more abstract mental habits, perceptions, and moral intuitions to form their dispositions and sensibilities – their 'way of being' or 'habitus'.

2.7 Habitus

In health and social care interactions, the interlocutors bring with them the behaviours and beliefs they have formed from their interactions with and in general society. Habitus is defined by Bourdieu (1977, p.86) as *'a subjective but not individual system of internalised structures, schemes of perception, conception, and action common to all members of the same group or class'*. These 'internalised structures' and 'schemes of perception' structure the subject's world-view and their 'apperception' of the world in which they suppose they exist. 'Apperception' is *'the mental process by which a person makes sense of an idea by assimilating it to the body of ideas they already possess'* (Ulich, 2021).

As the Covid-19 pandemic unfolded in society, people's habitus was challenged as the concept, then the reality, of the need for non-pharmaceutical infection control measures including face-coverings and distancing began to take hold – and there was a spectrum of attitudes to the pace and shape of its acceptance, from some who were anxious to adopt measures as soon as they perceived a risk, to those who adopted them when prescribed by law, to others who resisted the measures on principle. Mills, Rahal, & Akimova (2020) found that a range of socio-behavioural factors influence public adherence to infection control interventions, including the understanding of how a virus is transmitted; risk perception; levels of trust and altruism; perceived barriers, and individual traits.

2.8 Distancing: 'social' v 'physical'

'Social distancing' was the term used by Public Health England (PHE) to describe '*measures to reduce the contact people have with each other'* (PHE, 2020b). However, the original definition of 'social distance' is *'the degree of sympathetic understanding that functions between person and person, between person and group, and between groups'* (Bogardus, 1959, p.7). The internalised apperception of group and class is at its heart. The Bogardus Social Distance Scale (Bogardus, 1925), used to study prejudice and intergroup relations, measures respondents' perceived sense of intimacy or closeness to those in groups that are different from their own. The scale was originally created to understand the sociological context of American racial and ethnic conflict (Wark & Galliher, 2007).

The interaction of the physical and the social elements of distancing were experienced in the Ebola outbreak in Western Africa: H. Brown & Marí-Sáez (2020) describe how the habitus of practitioners changed. Separation and distance were a strategy for coping with the difficulty of trusting others whose PPE usage and distancing habits could not be verified. Diagnostic touch was replaced by physically distanced interrogative questioning and, for some kinds of care, distancing was extreme to the point that services simply stopped altogether due to impracticality combined with the perceived threat inherent in touch and proximity.

By using the term ‘social distancing’, public health bodies in the Covid-19 pandemic were alluding to a nomenclature coined by Hall (1963, p.1003) whose study of ‘proxemics’ described *‘how man [sic] unconsciously structures microspace – the distance between men [sic] in the conduct of daily transactions’*. His concern was cultural: that closer distances may produce negative reactions to those who felt intruded upon due to eye contact, odour, vocal volume, body language. He specified a distance of two to three metres as a comfortable range for meeting strangers and labelled this category ‘social distance’, compared to the closer ranges of ‘intimate’ and ‘personal’ distances tolerated by friends, family, and partners, or the more distal ‘public distance’ acceptable for presentations and similar circumstances.

Research into the use of the term ‘social distancing’, conducted between February and June 2020 (Sørensen, Okan, Kondilis, & Levin-Zamir, 2021), highlighted that the cultural implications meant that its use to describe physical distancing was misleading. The study’s conclusion repeated the calls during that time from academics and public health practitioners to rebrand ‘social distancing’ as ‘physical distancing’ to emphasize the possibilities of socializing at a distance to reduce social isolation while maintaining infection control compliance. This strategy was recommended by the World Health Organisation (WHO) on 20 March 2020 (WHO, 2020b), but the UK government continued to refer to ‘social distancing’ throughout the pandemic.

Mishra & Rath (2020) argue that social solidarity plays a pivotal role in bridging social distance at a time when physical distance is required, and that the public health risk would be reduced by developing a collective consciousness in society during a pandemic. The alternative is a deterioration in social norms and interactions.

2.9 Anomie

Norms are the authoritative standards or binding principles of the correct way to act which serve to guide, control, or regulate the acceptable and proper behaviour of a group or society. According to Weber (2019 [1921]), authority is power whose use is considered just and appropriate by those over whom the power is exercised. Weber identified three types of legitimate authority: traditional (such as that bestowed by inheritance and class), rational-legal (i.e., that bestowed by the electorate in a democracy), and charismatic (arising from the exceptional personal qualities of an individual and their hold over their followers). In times of challenge and change, the interconnectedness of power, authority, and moral standards creates a dynamic landscape in which ‘anomie’ can arise.

‘Anomie’ is a deficiency in social interaction involving individuals’ departures from, or lack of regulation by, the normative order (Durkheim, 1984 [1893], pp.291-309). A moral uncertainty ensues as a result of a normlessness where *‘the conditions of life are changed’* and *‘the standards according to which needs were regulated can no longer remain the same’* (Durkheim, 1960 [1897], p.253).

The relevance of anomie on healthcare communication in the context of the Covid-19 pandemic is addressed in a study by Bierman & Schieman (2020) which indicated that infection control measures, particularly distancing, resulted in greater subjective isolation and community distrust, in turn adversely impacting psychological distress. This effect was stronger in older respondents, resulting in a greater escalation in psychological distress. These findings not only support the argument that harm to social integration and mental health is caused by the anomie of rapid social change, but also how the context of an individual’s life course can differentiate how vulnerable a person can be to disintegrative social forces.

Powell, K. Kendall, Cislaghi, & El-Osta (2021) argue that anomie cannot be overlooked when planning an integrated public health response – the dominant narrative of personal self-care which drives public health messaging must be supplemented with a collectivist approach that addresses the structural inequalities which drive anomie. However, the political landscape into which the pandemic emerged in England was one of libertarian conservatism, encapsulated in the success of the campaign to withdraw the UK from the European Union under the slogan: ‘take back control’. It did not have collectivism at its core.

2.10 The effect of politics and ideology

‘Psychological reactance’ is a motivational response against rules, regulations, or attempts at persuasion that are perceived as threatening one’s sense of control, autonomy, or freedom of choice (Brehm, 1966; Steindl, Jonas, Sittenthaler, Traut-Mattausch, & Greenberg, 2015). A tendency to experience psychological reactance is a personality trait correlated with a range of phenomena, including allegiance to political ideologies which eschew interventionist policies on public health (Irmak, Murdock, & Kanuri, 2020; Ma, Dixon, & Hmielowski, 2018). The UK’s political pushback against the European Union’s influence was a form of psychological reactance championed by charismatic populist Boris Johnson, who gained legitimate authority as the UK’s prime minister in the months immediately prior to the pandemic’s outbreak – first when the Conservative Party placed him in the post by choosing him as its leader in July 2019, and then in December that year when the country’s electorate gave his party an overwhelming mandate with 43.6% of the popular vote.

In their rapid review of the evidence on behavioural knowledge and messaging on face coverings for the general public, Mills et al. (2020) said levels of social cohesion and trust in government are important for adherence to mask-wearing and distancing. Taylor & Asmundson (2021) suggest that psychological reactance can be fuelled by poor communication when promoting adherence to infection control measures. This could be seen when individualism percolated into the official advice on infection control measures: an analysis of UK mask policy (So & Baker, 2020) concluded that policymakers were not systematic in the sort of evidence they attended to. They approached the question of mask-wearing in an individualist way (‘will it save me?’) instead of a broader communal way (‘would a community that wears masks be safer?’). Therefore, the use of face-coverings was initially mis-framed as a medical intervention solely to protect the wearer rather than a social measure of public health source control (van der Westhuizen, Kotze, Tonkin-Crine, Gobat, & Greenhalgh, 2020).

Psychological reactance is particularly problematic when the politicians who espouse these values also have the responsibility for the introduction and management of rules and regulations which they themselves then break. The non-conforming behaviours of members of the government and their staff have been cited as having a direct detrimental effect on infection control compliance in the form of the ‘Cummings effect’ (Fancourt, Steptoe, & Wright, 2020, p.12): a loss of trust *‘demonstrating how dangerous “leader exceptionalism” can be for collective citizenship and social unity’*. The phenomenon is named after UK Prime Minister Boris Johnson’s special adviser, Dominic Cummings. Johnson told a press conference on 24 May (*BBC News*, 2020b) that Cummings had *‘no alternative’* but to travel over 250 miles from London to North-East England on 27 March for childcare *‘when both he and his wife were about to be incapacitated by coronavirus’*, yet Cummings did so in contravention of both the 14-day isolation period for anyone with Covid symptoms and of the national ‘stay at home’ lockdown instruction. Johnson said:

> *‘[Cummings] followed the instincts of every father and every parent – and I do not mark him down for that. Looking at the very severe childcare difficulties that presented themselves to Dominic Cummings and his family, I think that what they did was totally understandable’* (*BBC News*, 2020b)

Cumming's disclosures about his behaviour, and Johnson's supportive response to it, correlated with the sudden and steep decline in markers of public trust and confidence in the government as measured by University College London's Covid-19 Social Study (Fancourt, Steptoe & Bradbury, 2022).

The confused signals caused by resistance to the rules by the people who made them are exemplified in this photograph of a UK government cabinet meeting on 17 September 2021 (Figure 6). Journalists were invited in to record the Cabinet ignoring its own guidance – the room is crowded, windows closed, and no-one is wearing a face-covering (P. Walker, 2021).

FIGURE 6: UK Cabinet meeting, 17 September 2021. Ben Stansall/AFP/Getty ©The Guardian

Mills et al. (2020) describe how, as regulations were relaxed, re-introduced, and re-framed over time, the framing of mask-wearing as a 'personal choice' reinforced the precedence of individualistic desires and perceptions over societal needs. This affected behaviour by exposing the population to overly optimistic risk assessments of not contracting or transmitting the virus, incorrect judgements about the role of proximity, and 'othering' by those who differentiated themselves from vulnerable groups perceived to be at a higher risk.

The title of Lakoff's comprehensive examination of the state of global health security, *Unprepared* (2017), encapsulates the fragility and uncertainty he exposed in the machinery of disaster preparedness. The failure to acknowledge that preparedness *'is a journey, not a* *destination'* (Lakoff, 2017, p.167) had led to an international disconnect from the importance of knowing about societal vulnerabilities and addressing them proactively, rather than reactively. As Lakoff predicted, this neglect adversely affected the implementation of techniques of intervention, including the maintenance of stockpiles of medical countermeasures.

When the pandemic reached the UK, ideology had had a direct effect on the supply of PPE. Austerity had led to the neglect of preparedness management (Marmot, Allen, Goldblatt, Herd, & Morrison, 2020), despite a clear warning in 2008 that emergency planners needed to anticipate a widespread demand for FFP3 masks because surgical masks were likely to be insufficient protection in a pandemic (Gawn, Clayton, Makinson & Crook, 2008, p.24). The focus on cost savings meant that the DHSC applied 'just in time' supply chain principles to materials which would normally be stockpiled in case of emergency (DHSC, 2020a, p.13). The confusion and delays in the adoption of a clear policy on the use of non-surgical face coverings affected uptake. National and international bodies spent time trawling and debating the evidence base of randomised controlled trials (RCTs), but high quality non-RCT evidence which provided more relevant information was overlooked (Greenhalgh, 2020). The World Health Organisation initially advised against the use of face-coverings, not least to preserve scarce stocks of surgical masks for health workers (WHO, 2020a). This fed into misunderstandings of how respiratory viruses are spread and fuelled the arguments of those triggered to anger by psychological reactance.

Conflicting messages from members of the government and their agencies about public health measures take on further relevance when considered from the perspective of literature specific to the context of health and social care. A review of literature on the effects of conflicting health information by Carpenter et al. (2016) sheds light on what happens when when there is a lack of consistency in health messaging, such as infection control directions. Confusion among patients and providers makes people unsure whom to trust. In those circumstances, people defer to the source they consider to be most credible (Hilton, Petticrew, & Hunt, 2007). When experts lack consensus, lay people can perceive this as evidence of incompetence or intentional bias (Shanteau, 2000), which has a knock-on negative effect on the uptake of other health behaviours about which experts do agree (Nagler, 2014). Conflicting information may also heighten risk perception (Han, Moser, & Klein, 2006), increase anxiety (Pollock, Grime, Baker, & Mantala, 2004), and motivate people to choose information sources and interpretations that are most consistent with what they want to believe (Keselman, Browne, & Kaufman, 2008; Kunda, 1990).

So far, I have explored the literature in the context of how PPE and distancing affected communication for the general population. I now turn to literature specific to health and social care contexts.

2.11 Practising healthcare in person with PPE

Touch, and the politics of touch, took on different and more conflicted and complex meanings in healthcare settings at the onset of Covid-19 (C. Douglas, 2021). The experience of in-person interaction suddenly changed, as PPE can cover up so many cues that a familiar person may be unrecognisable. As the pandemic unfolded, ever-changing rules and conventions affected what was and was not acceptable in terms of PPE-wearing, touch, and body proximity, both in clinical settings and in society generally. This presented continual challenges of assimilation into cultural norms.

Having the patient in the room provides medical professionals with valuable diagnostic information: the non-verbal behaviours associated with demonstrative suffering give information about symptoms (Heath, 2002); gaze and body orientation at the beginning of a consultation can set the agenda for a the doctor-patient consultation (Robinson, 1998), and non-verbal communication can motivate patients to open up with valuable information about concerns not directly related to the initial reason for the consultation (Duggan & Parrott, 2001). Sensory input provides professionals with the knowledge they need to make diagnoses, care for their patients/clients and communicate with other health and care professionals (Lupton & Maslen, 2017). Key diagnostic tools are inspection, palpation (touch), percussion (tapping) and auscultation (listening via a stethoscope) (Ranson & Abbott, 2017), while the sense of smell provides rich diagnostic cues (Shirasu & Touhara, 2011) and can signal when a person is intoxicated or failing to self-care. Touch and the sense of smell are affected by the wearing of gloves and masks, while remote medicine – consultation by telephone or video – entirely deprives the clinician of these sensory cues. Extra time and thought must be applied to communication to compensate for these losses.

Being cared for by staff in PPE can add an extra layer of distress to patients who may already be anxious. To minimise the barriers caused by infection control measures, techniques can be used which, in part, draw from the knowledge of people who have experience of pre-existing communication impairments, such as using gesture, repetition and body positioning (PHE, 2020e). Having well-fitting PPE improves clinicians' body language by minimising fatigue and movement restrictions (Mitchell, 2020).

Photographs of the smiling face of the clinician can be attached to their PPE, reducing distress and allowing the patient to connect with the person. PPE Portraits was an art intervention developed by The PPE Project, conducted by Mary Beth Heffernan, to improve Ebola care in Liberia and Monrovia in 2014 (Figures 7 and 8) which was later reported as beneficial when used in Californian healthcare settings during the Covid pandemic (Brown-Johnson et al., 2020; Heffernan, 2020).

FIGURE 7: Art Professor Mary Beth Heffernan and Hygienist Morris Zolu surrounded by fellow hygienists and nurses as they prepare to make his portrait image for the PPE Portrait Project, February 26, 2015. They are in the ‘Green Zone’ of the ELWA II Ebola Treatment Unit (ETU) in Paynesville, Liberia, operated by the Liberian Ministry of Health. Dr. Moses Massaquoi, Chair of Ebola Case Management, invited Heffernan and photographer Marc Campos to Liberia to introduce the use of PPE Portraits in ETU.
© Mary Beth Heffernan, PPE Portrait Project (2015), photo by Marc Campos. Reproduced with permission (Heffernan, 2015a)

FIGURE 8: Wearing his PPE portrait, Hygienist Morris Zolu looks back from the Red Zone to the donning area at ELWA II ETU.
© Mary Beth Heffernan, PPE Portrait Project (2015), photo by Marc Campos. Reproduced with permission (Heffernan, 2015b)

2.12 Accommodation of pre-existing communication barriers

When face masks make it harder for people with cognitive impairment to communicate, the resulting distress can result in behaviour that may cause harm to the person themselves or others. Clinicians were required to conduct a risk assessment to determine whether the risks involved in wearing masks (forceful outbursts with potential injury, or unsafe mask removal, or the serious impact on one's physical and mental wellbeing from the inability to communicate, or to follow habitual routines) were greater than those involved in not wearing them (PHE, 2020e, p.22). Care England recommended steps to make PPE seem less frightening (PHE, 2020e, p.22): greeting clients without a mask through a window before entering the space; explaining that the mask helps other people to stay safe and that the mask is part of regular working clothes; approaching the making of masks as a craft activity; playing a game trying to guess what expression people are making behind masks; using a pre-existing non-verbal language such as Makaton or British Sign Language (BSL) to develop shared non-verbal signals for the expressions usually read from faces.

Generic voice-to-text apps such as Google Translate were adopted by clinicians to show the patient their words as they are spoken. These encounters led to the development of software which formalised the improvised use of technology. The Cardmedic^{TM} smartphone app is one example: it consists of pre-prepared flashcards containing essential information to facilitate communication, and a range of clinical scenarios in large type and voice which can be translated into several different languages (Grimaldi, 2020).

A guide to managing communication with hearing-impaired people during Covid-19 restrictions was produced by the ASLI (2020), and in September 2020 the DHSC distributed clear masks (Figure 9) to help doctors, nurses and carers communicate better with patients who rely on facial expressions to support communication, including people with hearing loss, learning disabilities, autism, dementia, foreign language speakers and their interpreters (DHSC, 2020d). The mask, manufactured by an American company, is described as 'single-use', 'not for use in a clinical setting', and 'not CE marked in the UK' (Hearing Dogs for Deaf People, n.d.). Other designs with a clear window were available, such as the adapted FFP3 mask in Figure 10 which carries the CE mark indicating that it meets European safety requirements.

FIGURE 9: The ClearMask™. In Section 5.4.2, care home manager Alex describes how her use of clear masks was vetoed by the local authority due to 'standards'. Source: Hearing Dogs for Deaf People, n.d.

FIGURE 10: Me wearing an FFP3 mask with added window to allow visual access to the mouth. In Section 5.2.5, GP Deborah comments on the 'odd' aesthetic of the design of clear masks (Lambell, 2024e)

2.13 Healthcare at a distance

In-person conversations are vital to the process of healthcare delivery, evaluation, and improvement whether orchestrated or spontaneous, directed to a particular aim or without specific purpose, amongst peer groups or between carers and cared-for (Macdonald, 2016). But in response to the onset of the pandemic in early 2020, Standard Operating Procedures were changed (NHS, 2020a) to make remote methods of communication the main mode of contact between patients and staff, and between the staff themselves, reducing opportunities for spontaneous ‘small talk’ and ‘catch-ups’ as well as curtailing more orchestrated conversations around quality control and service development.

The new procedures specified that in-person encounters should deal with as many issues as possible in one consultation. This meant care was more likely to be delivered by a health professional who was unfamiliar with the role and/or the patient (NHS, 2020b, p.8). These restrictions came at a time when an unprecedented number of difficult and urgent conversations were taking place between care workers, dying patients and their families and friends (PHE, 2020f). Meanwhile, the monitoring of pre-existing treatment plans had been paused (NHS England, 2020), leading to scarce resources coupled with a care backlog which, as predicted by Propper, Stoye & Zaranko (2020), extended beyond the pandemic. House calls and other services provided by health and social care professionals were already being curtailed by longer-term pre-existing trends (Griffiths et al., 2019; Rolewicz & Palmer, 2020).

From the early stages of the imposition of infection control measures, clinicians improvised communication solutions using existing equipment such as smartphones and tablets (Wittbold et al., 2020). Voice and video calls on devices owned by patients or clinicians were brought into play to allow excluded friends and family members to communicate with patients, with clinicians facilitating when the patient was too ill to do so independently. They also circumvented the need to repeatedly don and doff (put on and remove) PPE in order to speak to colleagues and/or patients and allowed clinicians in unfamiliar roles to be supported by more experienced staff at distant facilities.

Prior to the pandemic, telemedicine was being adopted as an additional method of communication to improve efficient use of resources. Telemedicine puts extra demands on the clinician and the patient. Both the patient and the practitioner need to learn new technology, find ways to create intimacy at a distance (Oudshoorn, 2008) and navigate the unmet need for sensory information (Lupton & Maslen, 2017). As part of the pre-pandemic adoption of telemedicine, clinicians were advised to consider it only for uncomplicated consultations as it is inferior to face-to-face consultations for data-gathering, counselling, or rapport-building, and increases the chance of miscommunication (Fairhurst, Dover & Innes, 2018).

An evaluation of the roll-out of 'Attend Anywhere' video consultations identified its benefits and drawbacks prior to the pandemic (Wherton & Greenhalgh, 2020). Video consultations were considered most appropriate for routine follow-up of chronic, stable conditions. Clinicians generally considered it clinically inappropriate and unsafe to use remote consultations for poorly-defined and less predictable ailments, rare conditions, and those where specialist tests or treatments were unavailable locally. Occasionally, patients who were reluctant to attend hospital (e.g., because of past trauma) were able to engage with the service. Clinicians were advised not to use the telephone to communicate bad news or sensitive results due to limitations on gauging reaction, or to rely on asynchronous communication with patients by email, smartphone, or other web-based messaging apps, due to information security concerns (Fairhurst, Dover & Innes, 2018, p.6).

However, infection control measures and the reallocation of workloads forced clinicians, some of whom were unfamiliar with the complexities of breaking bad news and dealing with end-of-life situations, to conduct sensitive conversations remotely. Evidence-based guidance for health professionals (Parry, 2020; Parry, Mannix, & Pattison, 2020) was developed to support communication skills during the pandemic. It emphasised the need to establish the safety and privacy of the recipient of the call prior to breaking bad news or engaging in sensitive content, and to allow the health professional the time and resources to prepare themselves physically and emotionally for making the call.

The importance of peer support amongst health and social care professionals became ever more vital in the face of unprecedented psychological and physical demand (Kisely et al., 2020; Shanafelt, Ripp, & Trockel, 2020). However, effective healthcare workplace counselling methods usually rely on in-person communication, such as ‘Schwartz rounds’ (Chadwick et al., 2016; The Point of Care Foundation, 2020a) – a structured forum in which all staff, clinical and non-clinical, come together to discuss the emotional and social aspects of a case – or ‘Balint groups’ (Kjeldmand & Holmstrom, 2008) – a similar forum exclusive to a specific grade of staff.

‘Team Time’ (The Point of Care Foundation, 2020b) was an online adaptation of Schwartz rounds. ‘Covid Confidential’ (P. Bennett et al., 2020) was a form of electronic debriefing for healthcare workers which permitted users to confidentially record their stories in either spoken or written form to a website to provide the immediate emotional benefit of offloading negative experiences while forming a repository of frontline stories which identifies the most important concerns faced by its users. A team at Nottingham University produced an online learning and support package for health and care workers to address the specific demands of Covid-19 (Blake et al., 2020).

The forced adoption of remote medicine due to the pandemic accelerated a pre-existing process of change to ‘digital first’ care, where engagement with technology is required to access in-person services. There was a strong belief amongst healthcare management in May 2020 that the NHS needed to seize the opportunity and encourage greater digital interaction between staff and between patients and clinicians despite the potential exclusion of those unable to engage with the technology. One respondent in a survey of NHS communications staff dismissed concern over those who do not have access to the necessary hardware or software as *‘pearl-clutching about leaving people behind’* (Nichols, Underwood & Hollings, 2020, p.23). Such exclusion is known as the ‘digital divide’.

2.14 The digital divide

Ramsetty & Adams (2020) highlight five main components of the digital divide in the context of the social determinants of health: the built environment including regional internet infrastructure, access to free public internet in community buildings, and precarity of housing; the social and community context, encompassing cultural expectations and mistrust of technology and/or the medical community; general and digital literacy; economic stability which allows access to up-to-date devices and software; and the accessibility of the healthcare interaction itself, including factors associated with the appropriateness of the hardware technology or software interfaces for both patient and health practitioner, for example, when patient comorbidities affect their ability to engage, or when technology packages are chosen for financial reasons rather than usefulness.

Blank, Duton, & Lefowitz (2019) reported that an estimated 18% of the UK population are non-users of the internet – mostly those who are older, less well off, and less educated. In 2018, 23.3% of disabled people were non-users of the Internet, 49% of households on incomes between £6,000 and £10,000 per annum had no internet connection, and 84% of those over the age of 60 years expressed the view that nothing could help them get online (Office for National Statistics, 2019). These groups correlate with those most likely to require health and social care (Marmot, Allen, Boyce, Goldblatt, & Morrison, 2020).

Summary

This literature review narrates the biosocial themes I investigated prior to analysing the survey and interview data. Unanticipated themes which became apparent to me during the analysis required investigation of the associated literature, which is introduced in the sections in which those themes are discussed: Section 6.1 considers structural violence; 6.2 explores epistemic injustice; 6.3 introduces moral injury; 7.2.1 outlines the concept of the syndemic, and 7.2.3 describes slow-onset disaster.

CHAPTER 3: METHODOLOGY

This chapter describes my own personal context during this work, my theoretical approach, and the complex methodology I used, combining quantitative and qualitative methods to fully explore material generated in the exceptional circumstances of the Covid-19 pandemic.

3.1 Positionality

My 14-year career as a massage therapist underpins a dual interest in both the biological and cultural elements of embodied communication, and I have drawn theories from a range of disciplines. This reflects the observation by Tobi & Kampen (2018) that challenge-based, rather than discipline-based, approaches are required to deal with complex problems.

Positionality also refers to the stance or positioning of the researcher in relation to the social and political context of the study (Rowe, 2014, p.628). My positionality as a researcher is shaped by the social, cultural, and political influences of my life course. Ingold states:

> *...Anthropology's purpose, in my view, is... to draw on what we learn from our education with other people to speculate on what the conditions and possibilities of life might be.'* Ingold (2018, p.112)

As a mature student, my *'education with other people'* (as Ingold describes it) is richly experiential – the formal and theoretical elements are a more recent introduction. During my time as a massage therapist in a palliative care outreach team I observed inequities in care, some of which were due to communication difficulties caused by the clients' physiological, psychological, and cognitive impairments. This could be mitigated when staff and volunteers made a conscious effort to adapt communication methods to accommodate client needs. The team noted that clients tended to disclose meaningful information during and after massage sessions. The stimulation of the parasympathetic nervous system and the patient-centred ritual of care associated with massage seemed to optimise the ability to speak for those who struggled to do so due to their condition, particularly those with neurodegenerative disorders.

My father was my disabled mother's carer. In 2017 I gave up my job and my home to nurse my father towards the end of his life and to take over my mother's care – a situation which continues to date. My position as a carer for my mother has had a direct influence on this project: it took longer than anticipated to complete because the consequences of the pandemic increased her reliance on me while concurrently reducing social services' ability to provide domiciliary care. This had the effect of extending the longitudinal element of the study: the repercussions of PPE-wearing and distancing unfolded further than they would have, had I completed my analysis and reflections sooner. Also, the care interactions from my own experience gave an autoethnographic understanding of the theories which emerged from the data – I witnessed the epistemic injustice suffered by our health and care workers and felt my own moral distress and anomie.

Researcher positionality could be perceived as binary, with clear distinctions between insider – holding the experiences and knowledge of the interlocutors – and outsider – observing events as a novel experience. Dwyer & Buckle (2009, p.60) posit an in-between position:

> *'insider and outsider are understood as a binary of two separate pre-existing entities, which can be bridged or brought together to conjoin with a hyphen. This hyphen can be viewed not as a path but as a dwelling place for people'*

My experience of the fluidity of the insider-outsider continuum was like that of Arber (2016) in her role as nurse/researcher in a hospice, who describes her perspectives as two ends of a positionality continuum along which a researcher moves – and is moved – back and forth, influenced by the aspects of their identity which most interests and draws in their interlocutors, while being respectful and keen to learn about experiences and knowledge which can never be claimed as common to researcher and researched. By being aware of the fluidity of the continuum, in the difficult pandemic circumstances I was able to maximise the aim of data-generation: '*to find ways to enable the participants to share what they thought rather than what they thought I wanted to hear*' (Milligan, 2014, p.249). For the self-advocacy group and carer representatives, they wanted a researcher to hear and learn from them; for health and care practitioners, I was considered 'one of them', reflected in the 'we' and 'us' pronouns they used in our conversations. My multifaceted experiences could also partly explain the number and range of recruited participants – although the resultant interviews suggest involvement was motivated by the saliency of the subject matter and epistemic injustice suffered by experts by experience. However, the profound nature of the shared experience of the pandemic made us all 'insiders', as can be seen from the etymology of the word 'pandemic' from the Greek 'pan' = 'all' and 'demos' = 'people'.

3.2 Ontology and epistemology

In terms of the purpose of the research, I am aware that I espouse 'reflexive pragmatism' (Gergen, 2015, p.287), which sees research as situated within the social world, with an explicit ethical stance and aim for intervention, rather than mere description or analysis. The experience of pivoting my research to create the Covid-specific project was an act of pragmatism which meant I was exposed to methods and epistemologies which required me to think differently.

My ways of thinking were challenged again during my January-March 2021 internship with Public Health England's Behavioural Insights Team, which was mainly composed of psychologists and behavioural economists who shared the Theoretical Domains Framework (Cane, O'Connor, & Michie, 2012) as the common underpinning structure for all activities, including research design and analysis. Exposure to this epistemology was useful in two respects. It allowed me to experiment with applying this analytical framework to the 'Behind the Mask' data, which ultimately led to my rejection of it due to its failure to fully capture the complexities at play or to allow consideration of mechanisms which did not fit the framework. It also gave me insight into the decision-making mechanisms and cultures at play in England's public health structure during the unfolding pandemic.

This exposure to ways of thinking beyond my home discipline also helped me understand that researchers do not have to commit to one ontology (the way of understanding *what is*) and epistemology (the way of understanding *what it means to know*), or a single type of analysis; there is no one-to-one correspondence between ontology/epistemology and types of analysis (Onwuegbuzie & Combs, 2010, p.412). Methods are not uniformly linked to paradigms (Bergman, 2008, 2010; Sandelowski, 2000). I identify with Johnson's observation (2022, p.12) that the extreme pressures of Covid restrictions which forced researchers to adapt and adjust every aspect of themselves – practically, personally, methodologically and epistemically – has brought a new understanding of how to conduct myself as a medical anthropologist, not least through the realisation that exploration of the diversity of experience can be extended by integrating, as a central tenet, different forms of access which extend across physical and virtual boundaries.

The 'Behind The Mask' project used a critical realist framework. Critical realism combines a realist ontology (the belief that the world exists independently from our beliefs and constructions) with a constructivist epistemology (the belief that our knowledge is our own construction, created from a specific vantage point, with no possibility of achieving a purely 'objective' account) (Maxwell, 2012, p.vii). I used this approach for a retroductive purpose: to discover the underlying mechanisms which could explain observed phenomena. However, to fully explore the temporal aspect of all the participants' experiences, for this thesis I moved to a perspective of social constructivism: that phenomena which individuals perceive as reality are shaped by social structures and conventions (Gergen & Davis, 1985). I did so with an abductive purpose: to understand social life in terms of the actors' meanings and motives (Blaikie & Priest, 2019, p.93).

Rather than pre-setting thematic categories which corresponded to the theories generated in 'Behind the Mask', I tested those theories against the themes which I identified and developed as the participants told their stories. This approach acknowledges the complexity of the factors in play for each of the participants and foregrounds the unfolding personal experiences of the participants using a style of social research advocated by Byrne (2013, p.221): *'case-based and congruent with the complexity of the frame of reference'*. The move from a population approach to a case-narrative approach acknowledges the fluidity and temporal aspects of the perpetual dialogue between the individuals and their environment (Abbott, 1992, p.65). According to Befani, Ledermann & Sager (2016, p.184), this shift in position is compatible with the aims and objectives of this study, as both realist and constructionist approaches acknowledge the importance of context.

The Covid-19 pandemic forced the population to live without touch and proximity and occluded our means of communication in a way that would have been unforgivable had it been suggested as a form of research experiment. Attempts to make meaning from this cruel imposition has engaged a diverse range of epistemologies and methodologies. Research methods, whether quantitative or qualitative, are a toolkit of different ways to ask and answer questions, but the distinction is often misinterpreted as a separation of research paradigms – defined by Kuhn (2009 [1962], p.190) as *'the entire constellation of beliefs, values, techniques, and so on shared by members of a given [scientific] community'*.

Researchers are often identified as being either a 'Quants' or a 'Quals' person, and with good reason: our abilities in maths or language are identified at an early age and we lean towards what we're told we're good at. By that measure, my lifelong aversion to maths and my enjoyment of writing and being with people mark me out as 'Quals'. But to extract as much information as possible from the data available to me in restricted circumstances, I employed (and enjoyed) both qualitative and quantitative methods in this study design and, by pushing through my learned dislike of number-work, came to appreciate the strengths, limitations, and nuances of both families of techniques.

My choice of anthropological approach is guided by an ethic of care, as described by Ingold:

> *'What drives anthropologists, in the final resort, is not the demand for knowledge but an ethic of care. We don't care for others by treating them as objects or by explaining them away. We care by bringing them into presence, so that they can converse with us, and we can learn from them'* (Ingold, 2018, p.131)

In the hope of generating an understanding which could contribute to the amelioration of suffering in future pandemics, I aimed to learn from the study's participants by bringing them into presence. By being aware of the positionality and subjectivity of the constructionist approach, I aimed to maximise their voices in my interpretation by systematically analysing the full content of their interview transcripts and survey responses. I augment my understanding of their experiences, opinions, and beliefs by referring to the findings of a quantitative descriptive and inferential analysis of the survey (described in Section 5.1).

3.3 Design

The design of this thesis is entangled with, and shaped by, a pragmatic opportunism which dictated subject matter and processes. While pandemic restrictions severely limited the methods available to researchers, the 'Behind the Mask' material had been generated at a profound point in history, in the extreme circumstances which are the focus of the study. This PhD is, in effect, the continuation, extension, and conclusion of a project designed in extremis. Throughout the project, I kept a research journal of my personal reflections. This documented the experience of pivoting my original plan, repurposing my literature review, formulating a new research question, the transition of that short-term project into a substantial new doctoral-level inquiry, and the trajectory of its formulation and execution.

The pandemic closed down my ability to pursue my original PhD research question by restricting the methods available, which meant I had to find ways to conduct research, and a research question of salience to my original scope of inquiry. This unsettling combination of circumstances meant I had to guard against the tendency to give primary attention to the available methods of study over the ends I hoped to achieve. This primacy of method over aim is described as 'methodolatry':

> *'a combination of method and idolatry, to describe a preoccupation with selecting and defending methods to the exclusion of the actual substance of the story being told. Methodolatry is the slavish attachment and devotion to method that so often overtakes the discourse in the education and human services fields'*
>
> (Janesick, 1994, p.215)

The design of this study had a number of iterations as a consequence of the pragmatic nature of the project and its unexpectedly large response to the initial 'Behind the Mask' recruitment survey. The quantity and diversity of the data generated by the survey and interviews raised questions as to next design steps, particularly with regard to analytical methods, so a number of approaches were trialled and rejected before this final choice was made for the thesis.

3.4 Recruitment

A survey (Appendix B) was used as a recruitment tool. The survey was distributed between mid-August and the end of October 2020, a window of time in England which began with the maximum amount of freedom after the initial imposition of pandemic measures, and ended with the announcement of a second national lockdown (J. Brown & Kirk-Wade, 2021).

I distributed the survey through a pragmatic two-stage snowball dissemination process. Firstly, I utilised my pre-existing connections with Healthwatch and Parkinson's UK (PUK) and was given their permission to attend their online meetings to promote the survey to request that they share the survey link, and to explain the need to target seldom-heard communities. As a result of these presentations 14 participants approached me directly without completing the survey, to volunteer as participants either because they had been in attendance or because they had been recruited by an attendee. I did not insist on them completing the survey because the written format might have been off-putting for those with additional communication and/or learning needs.

While it was not my intention to focus entirely on the experiences of people who had pre-existing conditions which would affect communication, I recognised that a study which did not seek to include them could perpetuate epistemic injustice in research. For this reason I also emailed national charities representing such people (SENSE, Motor Neurone Disease Association, Parkinson’s UK), and they shared the survey link through their official channels and promoted it on their websites. My membership of two Professional Standards Authority-accredited registers for non-conventional therapy practitioners (the Complementary and Natural Healthcare Council and the Federation of Holistic Therapists) and my Nursing Support Worker membership of the Royal College of Nursing gave me access to key stakeholders who shared the link through their personal networks. My collaborators with whom I had been working for my original PhD project (hospice, care home, community therapists) also distributed the link through their personal networks, and I took advantage of other informal social networks to reach campaign groups such as Everydoctor. Snowball recruitment led to the link being shared beyond these groups by some of the people I had reached.

3.5 Data generation

3.5.1 *'Behind the Mask' survey*

The 'Behind the Mask' survey (Appendix A) was initially designed as a pragmatic tool at a time when in-person interaction was prohibited for the purposes of research. The survey was designed, distributed, and analysed using Durham University's secure JISC Organisation account. Access to the survey opened on 13 August 2020 and closed on 31 October 2020. It aimed to recruit participants for a small number of interviews from which to develop programme theories through qualitative thematic analysis. The survey was structured to provoke respondents to reflect and arouse their interest in talking to me, while eliciting enough information to apply purposive selection to anyone who expressed a wish to be interviewed by providing their contact details at the end. It had sought to recruit members of the public who were over 18 and current UK residents who had experience of giving and/or receiving health and/or social care in the presence of PPE and distancing, particularly if they had pre-existing communication needs. For those respondents who worked in health or care, the survey was purposely structured to encourage them to firstly reflect on their experiences, opinions, and beliefs as private individuals, with their own vulnerabilities, feelings, and opinions, before they considered the issues through the perspective of their professional identity.

The first survey question asked respondents to indicate if they had impairments affecting their hearing, vision and/or speech, and/or another impairment which affected their ability to communicate. There was also an option to indicate *'none of the above'*. Respondents were then asked to reflect on different aspects of communication in the presence of face-coverings, PPE, and distancing. Following a prompt to stimulate reflection, respondents were offered a series of statements and were asked to select only those statements with which they agreed. The first series of 11 statements were preceded with the prompt: *'think about the times when you have been talking with a person who is wearing a face mask'*.

Seven statements followed the prompt: *'How does being near a person in full PPE make you feel? That is, someone in a mask, visor, gloves and gown'*, and six statements followed the prompt: *'Keeping our distance means that we must avoid shaking hands, hugging, or giving comforting touch to each other, such as placing a hand on someone's shoulder. How has that affected you?'*.

Respondents were then requested to indicate whether they or someone close to them had required healthcare or social care. A positive response took the respondent to the question: '*Did you speak to a care professional face-to-face about these needs?*' and a prompt to choose one of a selection of statements: *'No, I dealt with it myself'; 'No, I followed advice from an NHS website'; 'No, I was given advice over the phone'; 'Yes, via video'*; and '*Yes, in person'*. The respondent was then asked to choose a statement which rated the quality of the interaction on a five-item scale from *'Not at all'* to '*Yes, and it was a better experience than before the pandemic'*.

For each prompt, respondents were given a free-text opportunity to elaborate on their thoughts and experiences if they chose to do so. The survey contained five opportunities for all respondents to give open-ended responses on: communicating with a mask-wearer (which provoked 109 comments), interacting with people wearing full PPE (71 responses), and being unable to touch while communicating (89 comments), receiving an episode of care (168 descriptions), and their thoughts on the quality of that care (107 opinions).

The survey respondents were then asked whether they had *'a job which involved caring for people in a health or social care role'*. If the respondent answered 'no', the survey took them to the final page, which invited all participants to leave their email address if they would like to be contacted to be interviewed about their experiences of communicating in health and care situations while wearing PPE.

For the 281 respondents who identified as workers in health and care, they were offered the opportunity to describe their role, which produced 269 free-text responses. They were then given a list of nine items of PPE, plus the options *'other'* and *'nothing'* and were asked to indicate which ones they wore. For those who chose 'other', 12 people took the opportunity to give free-text details.

Thirteen statements concerning the comfort and ease of use of PPE followed the prompt: *'Thinking about the PPE you wear at work, which of these statements do you agree with?'* and an opportunity to give *'comments about the comfort and ease of use of your PPE'* garnered 108 comments. The prompt: *'How do you feel when you are engaged in conversation at work while wearing PPE?'* was followed by 15 statements for consideration, and the request for *'thoughts about communication while wearing PPE'* elicited 56 responses.

Respondents were then asked: *'In your healthcare role, do you normally use touch when you are communicating?'* and were invited to select one of four answers: *'Yes, instinctively'*; *'Yes, if the situation requires it'*; *'Rarely'*; and *'No'*. Ten statements followed the prompt: *'How have you managed the need to avoid touch when communicating in your role at work?',* and an invitation to describe *'the effects of distancing and gloves'* drew 59 comments.

Respondents were finally asked: *'Have you used any particular methods or techniques to get around barriers to communication caused by your PPE and/or your distancing?'* 95 respondents selected *'yes'* and, of those, 92 gave descriptions of *'communication techniques used [to get around barriers to communication], and the outcome'*.

Of the 464 survey respondents, 339 took the opportunity to write one or more free-text responses while 125 limited their interaction with the survey to the selection of statements with which they agreed.

3.5.2 *Interviews*

Fourteen people were recruited for Phase One interview independently of the survey after I gave online presentations about the project to Healthwatch and Parkinson's UK. These respondents contacted me on the email address I gave in my presentation and were interviewed first, beginning on 2 September 2020. Of the survey respondents, 166 provided their email addresses indicating a wish to be interviewed. The high response rate, and indications that a high proportion of those respondents wanted to speak to me, led to the adoption of a triage system when choosing who to contact for interview. As the responses came in, each of the survey submissions were individually analysed for indicators of experiences of health or care interactions in the presence of PPE and/or distancing. Where there was no evidence of episode of care during pandemic, the respondent was rated as low priority to be contacted for interview. Indicators that the respondent had been involved in an episode of care led to a 'medium' rating; and the 'high' category was allocated to cases where an indication of involvement in episode of care was accompanied by one or more other relevant characteristic: a professional health or social care role (paid or voluntary); an acute episode of clinical care; pre-existing complex communication impairment; ongoing complex health or social care requirements; and/or an active caring role. When a response came in that was rated 'high', I contacted the respondent by email to invite them for interview.

When the survey closed on 31 October 2020, 58 respondents had been triaged as 'High', and all had been contacted. 24 replied and interviews had been arranged with them, from which four withdrew. One invited his wife to join him. Consequently, 21 people were interviewed after being recruited via the survey, but one (Participant 15) was excluded after interview when his identity could not be verified, and it became apparent in the conversation that he had not experienced a health or care interaction under pandemic restrictions. The last interview of Phase One took place on 10 December. There were three interviews where I interviewed two people at the same time (husband/wife, two support workers from the same organisation, two volunteers from the same healthcare charity). A focus group was the preferred option for eight members of a self-advocacy organisation for people with learning disabilities and autism.

Despite being prevented from being 'in the field' in the traditional sense, I had at my desk a notebook into which I made notes of the impressions, key insights, and emerging themes as I conducted the video and telephone interviews, annotating them with time stamps to complement the recordings I later transcribed. The field notes and my research journal facilitated the generation of themes and the vignettes.

Phase One interviewing totalled 28 hours and 49 minutes. All interviews were recorded, and I transcribed them verbatim myself. All were conducted by video call except for Barbara (due to weak internet connectivity), Eddie (who kept his camera off), and Gary (at his request).

Plummer (1995) observes that the storytelling process flows through social acts of domination, hierarchy, marginalisation, and inequality. It was important for me to be mindful of the dynamics between the story tellers (i.e. the interviewees), the coaxer (i.e. the interviewer – myself) and the consumer (i.e. the analyst – again, myself).

Glesne & Peshkin (1992, p.67) conceptualize interviewing as *'the process of getting words to fly'* by creating circumstances which *'stimulate verbal flights from important others who know what you do not'*. With Glesne & Peshkin's words in mind, I conducted the interviews using the approach suggested by Fraser (2016, p.184): studying the socio-historical contexts of participants' lives; responding to different communication styles; facilitating a climate of trust; allowing participants to ask questions of their own; revealing my own investment in the research; sharing some of the interpretations I made as they emerged; and, appreciating the politics involved with making knowledge. The interviews had a loose structure: I asked respondents to describe their health and social care interactions in the presence of PPE and distancing, and their reflections of those experiences in the context of their lives. The respondents were also asked for their thoughts on what would improve communication.

Multiple perspective interviews involve interviewing members of a social group separately and triangulating their accounts during analysis to gain insights into the functioning of the group (Vogl, Schmidt & Zartler, 2019). This research technique has been used to consider an intervention or experience from the different ontological and epistemological perspectives of dyad or triad combinations in a care situation, i.e. the patient and their own informal carers and professionals (M. Kendall et al., 2009). The common connection – 'group membership', as it were – for this study is the shared experience of healthcare interactions during the pandemic in England as it unfolded in 2020. There was one clear dyadic connection where a mother and son were interviewed separately.

The products of the 'Behind the Mask' project were a descriptive analysis of the survey's quantitative data and a thematic analysis of the open-ended responses to the survey prompts, combined with the notes from the Phase One interviews which I was concurrently conducting and transcribing. My supervisors and I decided that the data warranted exploration as a doctoral thesis, and I set about re-drafting a thesis plan to take pragmatic advantage of the volume and profound qualities of the data to benefit from the opportunity to incorporate a longitudinal aspect to the study by re-interviewing participants after an 18-month interval, which would give valuable insight into the unfolding consequences of the effects of PPE and distancing on their lives. All Phase One interview participants were invited for re-interview in February 2022 and a purposive selection was made from the 20 who responded.

The theories developed in 'Behind the Mask' guided me to identify the criteria for 'information power'. The concept of 'saturation' (Glaser & Strauss, 1967, p.61) is a way of judging when enough data generation has occurred. 'Saturation' means that the researcher is seeing similar instances over and over again, despite looking for groups that stretch diversity of data as far as possible. Malterud, Siersma, & Guassora (2016) propose an alternative concept, 'information power', as a way of judging when enough participants have been reached: the more a sample provides information relevant to the study in the context of five key factors, the lower the number of participants required in that sample. Those factors are: the aim of the study; sample specificity; use of established theory; quality of dialogue; and analysis strategy. Because I already knew the narratives of the interview participants, I could prioritise those whose stories were rich with the perspectives of being both caregivers and receivers in a range of settings. I had the option to increase the number of Phase Two participants, but I felt that, after the ninth participant had been re-interviewed, information power had been reached on the key themes.

Phase Two interviews took place between March and May 2022, leading in with the question: 'What has happened in your life since we last spoke?' The interviews were conducted using the same interview strategy described above until 'information power' and 'saturation' were reached on the themes central to the research questions. The nine participants, who were re-interviewed one-to-one, were offered face-to-face meetings as per the updated ethical approval, but all opted for a repeat of the Teams or telephone experience. The total time spent on Phase Two interviewing was 10 hours and 14 minutes and, again, I transcribed all recordings verbatim.

Table 1 lists the participants by their pseudonym, in the order they were interviewed. Those who were re-interviewed in 2022 have their names in bold capitals. The table outlines the caregiving and care receiving experiences they had, any pre-existing factors affecting the ease with which they could communicate, and how they were recruited. It also identifies those who were interviewed together.

TABLE 1: Interview participants **Page 1**

Code	Pseudonym (BOLD indicates reinterviewed)	Care-giving experience	Care-receiving experience	Pre-existing factors affecting communication	Recruitment method
1*	Des	Advocacy group co-ordinator	None disclosed	None disclosed	Presentation Interviewed together
2	Lucy	Advocacy group development worker	Weekly blood tests at health centre	Autism	
3	Joyce	Director of Services for an autism advocacy organisation	Required in-person specialist care for two close relatives	None disclosed	
4	Fran	Advocacy group sessional worker; support worker for Pete (her brother)	Telephone consult for skin problem; required urgent home visit for father	None disclosed	
5	Alan	Advocacy group core worker	None disclosed	Learning disability	
6	Stephanie	Advocacy group core worker	None disclosed	Learning disability	
7	Pete	Advocacy group sessional worker	Telephone consult for hayfever	Cerebral palsy	
8	Aidan	Advocacy group sessional worker	None disclosed	Autism	
9**	**PAULA**	Health and Social Care development worker for Carers Support	Daughter gave birth in hospital, she and baby both needed in-patient care	None disclosed	Presentation Interviewed together in 2020
10	Liz	Learning Disabilities development worker for Carers Support	None disclosed	None disclosed	

TABLE 1: Interview participants **Page 2**

Code	Pseudonym (BOLD indicates reinterviewed)	Care-giving experience	Care-receiving experience	Pre-existing factors affecting communication	Recruitment method
11 ***	Barbara	Member of a local Area Action Partnership; history of advocacy for people with mental health issues	Long-term remote monitoring of blood pressure involving repeated telephone consultations; son (Carl) was long-term in-patient in spinal injuries unit	None disclosed	Presentation
12	**MAGGIE**	NHS and private CAMHS therapist; carer for mother with dementia, and for father when he returned home with long-term effects of Covid; cares for baby grandson	Father was in intensive care with Covid	None disclosed	Survey
13	**DAVE**	Primary Care Centre manager; part-time church deacon	In-patient on Covid ward	None disclosed	Survey
14	**ALEX**	Head of training for a care home group; family carer for grandmother	Wife gave birth in hospital	None disclosed	Survey
16 #	Sally	Home-visiting Namaste Care therapist for hospice dementia service	None disclosed	Hearing impairment	Survey
17	**EDDIE**	Chair of a charity supporting visually impaired people	Telephone consults, resisted hospitalisation for urinary infection	Blind	Presentation

TABLE 1: Interview participants **Page 3**

Code	Pseudonym (BOLD indicates reinterviewed)	Care-giving experience	Care-receiving experience	Pre-existing factors affecting communication	Recruitment method
18	Veronica	Community-based Specialist Occupational Therapist, specialising in older people's mental health	Fractured spine and subsequent sepsis in 2018, daughter had new baby	None disclosed	Survey
19	Noreen	Tai Chi teacher in care homes and the community	Ongoing treatment for non-Hodgkin's lymphoma	None disclosed	Survey
20 ##	Alison	Volunteer co-ordinator, Healthwatch	Emergency admission with obstructed bowel, in-patient and outpatient care	None disclosed	Survey
21	Linda	Parkinson's UK support volunteer; sole carer for husband who had Parkinson's	Husband required telephone and in-person specialist consultations to treat hallucinations and an in-person GP practice consultation for ongoing pre-cancerous skin condition	None disclosed	Presentation Interviewed together
22	Audrey	Parkinson's UK support volunteer; had been carer for husband, who had died with Parkinson's	None disclosed	None disclosed	
23	**BETH**	Specialist perinatal mental health nurse	Treatment for gestational diabetes; gave birth by Caesarean in hospital, in-patient stay	None disclosed	Survey

TABLE 1: Interview participants **Page 4**

Code	Pseudonym (BOLD indicates reinterviewed)	Care-giving experience	Care-receiving experience	Pre-existing factors affecting communication	Recruitment method
24	Charlotte	Manager of a service for people with Usher syndrome	In-person GP appointment for ear syringing; was preparing for an out-patient appointment at a specialist eye hospital	Profound Deafness and restricted vision	Survey
25	Vicky	Specialist pain physiotherapist	Urgent medical procedure to investigate and treat breast lump; husband with Type I diabetes had eye surgery	None disclosed	Survey
26	**NATALIE**	Dietician on intensive care unit	Urgent appointment to investigate possible recurrence of breast cancer	None disclosed	Survey
27	Geoff	Motor Neurone Disease (MND) Association branch member, involved in peer support	2x daily domiciliary care for activities of daily living due to his MND; telephone consultations and home visits from specialist nurse	None disclosed	Geoff's survey Interviewed together
28	Catherine	MND Association branch chair, runs carer support group; carer for husband Geoff	Diabetes care by telephone	None disclosed	

TABLE 1: Interview participants **Page 5**

Code	Pseudonym (BOLD indicates reinterviewed)	Care-giving experience	Care-receiving experience	Pre-existing factors affecting communication	Recruitment method
29	Laura	Parkinson's UK branch chair; sole carer for husband with Parkinson's	Dentistry, ultrasound for injured shoulder; online counselling; acupuncture; husband had telephone consultation with neuropsychiatrist and visited out-patients for specialist assessment and procedure	None disclosed	Survey
30	Gary	Specialist pain physiotherapist	None disclosed	Dyslexia	Survey
31	Dorah	None disclosed	Emergency in-patient admission for chest pain; 4x weekly domiciliary care for activities of daily living due to MND	Speech impairment due to MND	Survey
32	Carl	None disclosed	Long-term in-patient in spinal injuries unit	None disclosed	Survey
33	**DEBORAH**	GP; trainer of health coaches for the Personalised Care team	Father-in-law received treatment for prostate cancer	Hearing loss, became apparent due to mask-wearing	Survey
34	**LOUISE**	Advanced nurse practitioner, specialising in respiratory nursing; has national role	Admitted to hospital with suspected Covid (testing not available to confirm)	None disclosed	Survey

KEY FOR TABLE 1:

* Participants 1-8 were members of a self-advocacy group which offered a national support service for people with autism and/or learning disabilities and provided companies with training and consultancy for organisations to support their adherence to statutory requirements on information accessibility. The group organised the online meeting with the purpose of inviting me to listen to their experiences.

** Participants 9 and 10 were both paid staff of Carers Support, a charity which provides information, support and help for people who provide unpaid care to a family member, partner, friend, or neighbour who could not manage without their assistance due to an illness, disability, substance misuse or mental health.

*** Participant 11’s work with the Area Action Partnership involved the co-ordination of representatives of health, housing, police, fire, voluntary organisations, local councils, and businesses.

Participant 15 was excluded because, at interview, his identity could not be verified and it became apparent that he had not given or received care in the presence of PPE or distancing.

Participant 20 was a paid staff member of a local branch of Healthwatch, the independent health and social care champion with statutory powers established under the Health and Social Care Act 2012, accountable to local authorities, advising on the public’s needs and experiences of health and social care.

3.6 Analysis

The high number of survey participants increased confidence that a nomothetic approach – i.e., investigating generalisations across groups – would be warranted. Conversely, the richness of the data and, particularly, the salience of the individuals' life stories in relation to the research question demanded a more idiographic approach – i.e., investigation of the individual or unique. J. Smith, Flowers & Larkin (2009) suggest a relationship between the two: idiography can locate generalisations in the particular, thus allowing those generalisations to be developed more cautiously while avoiding the flaw identified by Kastenbaum (1985, p7, cited in Datan, Rodeheaver & Hughes, 1987, p.156) inherent in conclusions drawn from the 'indeterminate statistical zones' generated by solely nomothetic methodologies: they *'construct people who never were and never could be'*. This reflection guided my choice of analytical approach.

3.6.1 Quantitative analysis

The statistical data were post-coded to create variables for analysis. For example, binomial variables were derived directly from binary responses (agreement/non-agreement) and statements to indicate presence or absence of emotional conflict or ambivalence. Ordinal variables were created *post-hoc* by combining binary responses to question groups within the survey for the purpose of categorising the responses.[1] The initial descriptive and classificatory analysis of survey data was conducted using SPSS software. In addition to descriptive analysis, all comparisons between groups and emergent clusters employed non-parametric (or 'assumption-free') statistical tests. Chi-Square tests were used to analyse between categorical variables (e.g., respondents who reported communication impairment

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[1] Five-point scales were created from respondents' signalled agreement with binary statements contained within the survey. The survey contained binary responses that were thematically organised into question groups. Statements were scaled for each group of questions on the following basis: Agreement with negative statements *only* = 1; Agreement with more negative than positive statements = 2; Agreement with equal numbers of positive and negative statements = 3; Agreement with more positive than negative statement = 4; Agreement with positive statements *only* = 5.

compared to those who did not). Mann-Whitney U tests were used to determine differences between two groups (e.g., Communication impairment/no communication impairment). Independent Kruskal-Wallis tests were used to effect comparisons between more than two groups (e.g., Conventional/CAM/Dual; Care giver-receiver/caregiver only/care-receiver only/no care interaction, as explained in Section 5.1). Hierarchical cluster analysis[2] was performed to further explore patterns of expressed attitudes and beliefs. A cluster analysis is: *'a class of data reduction methods used for sorting cases, observations, or variables of a given dataset into homogeneous groups that differ from each other'* (Yim & Ramdeen, 2015). Clusters of response patterns were therefore identified on the basis of similarity of response to key survey statements. Arranging response patterns together and classifying these as belonging to different broader groups provides a means of applying some organisation to individual survey responses which at first sight might appear highly individualised or even chaotic.

3.6.2 Qualitative analysis

The qualitative data from the survey's open-ended responses was examined case-by-case from the Excel spreadsheet exported from the JISC survey. Each respondent was allocated a unique identifying code which corresponded with the order in which their response was received – i.e., the first to submit was named 'S001' and the last was named 'S464'. Where the respondent was also an interview participant, their allocated pseudonym was also included. The identifier also included cluster membership for each respondent – 'habituated', 'conflicted' or 'sensitised'. These blunt labels served as a heuristic device by giving a broad indication of the respondent's position regarding their choice of the statements indicating emotional responses to communicating in the presence of PPE and distancing. This added a layer of context when analysing an individual's survey free-text

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[2] Sokal & Sneath (1963) identified that the technique of cluster analysis originated in biology and ecology and this technique has been reasonably widely employed in social science analysis, recently enjoying a resurgence due to techniques developed for analysing complex data sets (Haynes, 2018).

responses and, where applicable, the content of their subsequent interviews. Obviously, this heuristic had not been calculated for those interview participants who did not complete the survey. However, the cluster analysis gave an overall awareness of the complexities and heterogeneity of emotional responses to the presence of distancing and PPE in interactions, which alerted me to the danger of making assumptions in the thematic analysis.

Each of the 339 commenting respondents was considered as a ‘case’, and I collated each person’s open-ended entries to be considered as a totality. This allowed me to see if there was a correlation between experiences and opinions. I then created topic summaries (Braun & Clarke, 2021, p.77). The topic summaries included aspects of issues featured in the survey (e.g., the comfort and ease of use of PPE; the consequences of enforced denial of touch) and other topics which I identified as a result of the respondents taking the opportunity to expand upon underlying and associated issues (e.g., pre-existing managerial attitudes to PPE supply; trust in authority). I collated the content from the cases under these headings, capturing the range of responses around the topics. I attempted to retain a sense of each individual respondent’s narrative by accompanying the relevant quote with their other responses and the cluster name which was allocated to them via the cluster analysis.

While analysing the survey free-text data, I checked the reliability of the cluster analysis by noting the extent to which the tone of the text reflected their choice of survey statements with which they had agreed – i.e., the source of the cluster analysis. I concluded that, overall, clustering was a reliable and useful heuristic which accurately summarised the combinations of their statement selections. Not only did the cluster heuristic give insight to an individual respondent’s feelings, but it also helped to indicate the complexity of the interactive forces which drive communication: it became clear that feeling reconciled to PPE and distancing did not necessarily result in positive communication outcomes, or vice versa. Once this was done, I turned to the analysis of interview data.

At the point of transcription, pseudonyms were ascribed to all interview participants and the people they spoke about in their interviews. Identifying details, such as the names of towns, were also removed.

My approach to thematic analysis was designed to preserve the narrative of each individual's experiences and opinions. To know my participants better, I scrutinised each transcript in turn for its own topics and themes, rather than taking a theme-focused approach across the transcripts. For an interview which had more than one participant, I treated the dataset as one entity but identified individual speakers throughout to preserve their different experiences and opinions.

A common creative writing device is *'in medias res'*, starting a story in the middle rather than from the beginning of the sequence of events. This was described by the Roman poet Horace in his advice to writers, *Ars Poetica* (Horace & Sisson, 1975 [c. 19]). My participants commonly expressed their own real-life stories out of sequence and iteratively, foregrounding and repeating matters which were most salient to them, so it was often the case that closely interconnected quotes were dispersed across the text, and, for those who were interviewed 18 months later, across both transcripts. Also, what at first sight seemed like a throwaway comment was sometimes a key to understanding within and across the participants' stories. For example, Natalie did not mention her pre-pandemic cancer history until our second interview, despite obliquely referencing 'check-ups' during her first interview.

A systematic approach was taken to the analysis of each interview. The text of each transcript was rearranged thematically and, to avoid losing valuable insights which seemed trivial or irrelevant at face value, no words were omitted. Each theme-related passage in the rearranged transcript was preceded by a summary of the content describing the topic and its thematic implications. The associated quotes were then replicated in full, each quote with its own reference code. This would allow me to refer back to the source to check the context of the quote when conducting the reflective thematic analysis. Frequently, a passage of speech had multiple facets and implications across themes. Where this was the case, the passage of text was copied and included in all the relevant summaries: e.g., Louise's description of her combined physical and emotional discomfort when treating a Covid-positive patient while wearing the substandard PPE about which she had lodged complaints appeared repeatedly under themes such as 'embodied experience', 'epistemic injustice' and 'structural violence'.

The modified, thematically-analysed transcripts were arranged with a temporal flow, beginning with all themes relating to their circumstances prior to the imposition of PPE and distancing, progressing to their experiences, opinions and beliefs about PPE and distancing unrelated to a health or care context (reflecting the approach taken in the survey design), then their experience of PPE and/or distancing in the context of giving and/or receiving care, followed by the consequences of their experiences. Systematic coding indicated the source of each passage, which allowed me to merge the first and second transcripts of the nine participants who had been interviewed twice. This created a comprehensive narrative which captured the longitudinal aspects of their evolving experiences, opinions, and beliefs. Appendix C is an example transcript and Appendix D is its corresponding analysed text.

The act of unravelling the participants' narratives and reconstructing them in a linear way was in itself a form of analysis: my reflections on the process guided me towards an understanding of their experiences as an ongoing and unacknowledged disaster. The method reflected Erikson & Peek's observation that, because disaster stories challenge the Aristotelian rules of plot (i.e., consisting of an identifiable beginning, middle, and end), they should instead *'be seen as yet another current in the continuing flows of ongoing history, understandable only by tracing that current back in time [...] and then ahead in time'* (Erikson & Peek, 2022, p55)

Once the thematic narrative modification of all transcripts was complete, I returned to the survey's quantitative and qualitative findings and drew them together with the analysed interview data to conduct a systematic reflexive thematic analysis as described by Braun & Clarke (2021). Taking each of the three research questions in turn, beginning with the question foregrounding the embodied experience of communicating in the presence of PPE and distancing, and engaged this analytical process: I systematically searched each of the modified transcripts and the qualitative dataset and drew out the summaries relating to the research question. These were sorted with the aid of the provisional thematic codes which had been identified during the interviewing process in 2020 as part of the development of programme theories, and from notes I had made during the first and second round of interviews. As required, I would refer back to the original transcript to sense-check the comment within the context of its surrounding text and the flow of the conversation. I critically evaluated the content against those theories and revised, modified, deleted, or expanded the themes in the process described by Dey (1993, p.124). This approach was adopted to test the programme theories and avoid forcing the data into codes and categories which did not reflect its actual content. I linked 'the personal with the political' (Fraser, 2016, p.193) to investigate how the participants' stories correlate with the theories and phenomena considered in my literature review and the programme theories being tested while allowing new themes and theories to emerge. I then found commonalities and differences between the participants, continually checking that the written analyses being produced corresponded to the stories told as well as to the thesis objectives. Once I had exhausted the themes relating to the first research question, I repeated the process to investigate the wider determinants affecting communication in care contexts, and a third time to explore the consequences on the lives of the participants.

3.6 Reporting

'Ethnography' refers to the product as well as the process. Pandemic restrictions limited what I was able to do, thus decoupling me from both definitions of ethnography. However, I wanted to find an approach to reporting which would give voice to the participants in a manner approaching ethnography as described by Mol (2003, p.15): *'We can listen to Mr. Gerritsen as if he were his own ethnographer.'* To this end, the reporting of my findings takes an eclectic form.

Though this is, in effect, a mixed methods project, the statistical analysis of the survey is adjuvant to the substantive body of this thesis. The key quantitative findings are incorporated into the text to augment, enhance, and modulate reporting of the qualitative findings rather than make their own positivist case – my aim is to draw in readers to whom numbers speak, and lead them into the 'Big Q' (Kidder & Fine, 1987) exploration of the research questions, using the tools and techniques of the qualitative paradigm.

I established a protocol for identifying and reporting the participants' words. Survey respondents were allocated a number which matched the temporal order in which they completed the survey, prefixed with a capital 'S' and suffixed with the date of completion in the format DD/MM/YY: e.g., S001-15/08/20. For the interviews, at the point of transcription pseudonyms were ascribed to all interview participants and the people they spoke about. Each interview participant was allocated a number which corresponded with the order in which they were interviewed. This number was used as an identifier for referencing the content of transcripts. Line numbers were generated for each transcript, and the reference style was established: the figure preceding '/' indicates the speaker, the second figure corresponds to the line on that participant's transcript. The reference was then suffixed with interview date. For the nine participants who were re-interviewed, the suffix 'X' after the line number indicates that the reference corresponds with the transcript of their second interview conducted in 2022., e.g., a quote from Louise's second interview which begins on line 67 is identified as 34/67X-31/03/22.

The direct quotes from interviews and open-ended survey responses used in this thesis are as transcribed. These quotes are *italicised*. However, sometimes in interviews the participant's natural style of storytelling resulted in a rich but fragmented, iterative, and circular transcript. In these cases, I have drawn together the participant's dispersed description of an event to create a vignette using the storytelling style of Seabrook's ethnographies (Seabrook, 1982a, 1982b, 1984)

Each vignette is based on a single interviewee's words, except for one vignette composed from transcripts of separate interviews with a mother and son (Barbara and Carl), who described the same event. Each vignette has the person's verbatim quotes at its heart, but I have added scene-setting detail (e.g., descriptions of the environment) drawn from my impressions of the interview. In doing so, I drew from my own experiences of similar healthcare environments and interactions, particularly in the case of health workers whose work, like mine, required making home visits to people in distress. I adjusted pronouns (e.g., from the first person to third person) and tenses for rhetorical purposes and engaged narrative license to interpret the prosodic, paralinguistic, and other non-verbal communication contained within the recordings.

The product is similar to the illustrative vignettes described by Willis (2018) as a method of presenting complex, situated accounts in a way that is accessible and useful. However, because I draw upon a single participant's account, it is not a pure 'composite narrative' as defined by Willis (2018, p.472), where the similar experiences of more than one participant are combined and presented as the experience of one individual. That said, there is an element of such multi-participant synthesis in the incorporation because, to provide background detail for illustrative purposes, I draw on my own relevant lived experience as a health professional, family carer, and patient in the presence and absence of the infection control measures. Consequently, the vignettes are constructed using my own perceptions and interpretation of their words, filtered through my own experiences and beliefs generated through a lifetime of being a giver and receiver of care. I cannot claim to be an objective bystander in those scenes. To mitigate for my presence of my own voice in the vignettes, I follow the advice of Willis (2018, p.474): for academic rigour, composite narratives require 'transparency': a clear link between the original data and the final story. With this in mind, I provide the transcript line reference source for the material in the vignette. I present each vignette in a panel in a different font to the body text of the thesis and, when transcript material is used verbatim, the text is *italicised*. In addition to securing informed consent from all participants, after writing the vignettes I contacted each of the participants whose interviews had contributed to them to specifically offer them an opportunity to read and edit the vignettes in which they featured. One read and approved the vignette, while the rest either gave consent for their use without reading them or did not reply to my offer.

As this is a mixed methods project, key quantitative findings from the statistical analysis of the survey are incorporated into the text but are not intended to foreground frequency of numbers above salience of stories, mindful of the observation of Braun & Clarke (2021, p.102): *'Theme importance is not determined by numerical frequency so much as salience and importance to addressing the research question'*.

3.7 Ethics

The Covid-19 pandemic adversely affected the lead-in time and chances of approval for any research project which required ethical approval from the National Health Service Health Research Authority (NHSHRA) Research Ethics Committee (REC) during that time due to that body's need to focus on acute Covid-related research needs. Therefore, I took a pragmatic approach when designing the 'Behind the Mask' project. I used the HRA decision tool developed with the Medical Research Council (MRC): '*Do I need NHS REC review?*' (MRC/NHSHRA 2020) to identify the boundaries of the Behind the Mask project design. The algorithm said I did not need REC review *'where participants have been identified independently of the NHS'* (MRC/NHSHRA 2020, p.9) or *'social care'* (NHSHRA n.d.:10) *'provided that it is reviewed by …University REC'* (MRC/NHSHRA 2020, p.11). I could recruit health professionals and patients, including those who have been '*identified… because they have a condition that was diagnosed by the NHS*' (MRC/NHSHRA 2020, p.9), if I did not use NHS or social care organisations to access my sample. However, I did follow the guidance of the NHSHRA (2018, p.5) which advises that *'the methods and procedures used to seek informed consent and the level of information provided should be proportionate to: the nature and the complexity of the research; the risks, burdens and potential benefits (to the participants and/or society); and the ethical issues at stake'*.

Full ethical approval for 'Behind the Mask' was secured via Durham University Anthropology Ethics Committee prior to commencement of that study (Appendix E). A revision of that permission was granted in August 2021 (Reference: *ANTH-2021-07-17T17_49_57-mlpj92)* to conduct the secondary analysis of the 'Behind the Mask' interviews and to extend the original permission to conduct online or telephone interviews for the duration of this PhD project. The extension stated that permission for in-person interviews would be applied for on a case-by-case basis, depending on the level of infection control restrictions at the time, but this was not required because all further interviews were conducted online or by telephone as the request of the participants.

A data management plan for the 'Behind the Mask' project (Appendix F) was devised in consultation with my supervisors under Durham University regulations, and this was continued for the PhD project as part of the extension of the ethical approval.

Informed consent was secured in a two-step process which accommodated pandemic restrictions by eliminating the need for physical contact with materials: an information sheet (Appendix G) and consent form (Appendix H) was emailed to the participant and, at the start of each recording, the participant was reminded of its contents and a discussion took place to establish the participant's understanding. Their verbal consent was recorded. For those re-interviewed in 2022, the conversation was conducted again, the content of the consent sheet was revisited, and verbal consent recorded.

For the meeting with members of the self-advocacy group I followed the first statutory principle of the Mental Capacity Act 2005: *'A person must be assumed to have capacity* *unless it is established that they lack capacity'* (Department of Constitutional Affairs 2007, p.19). However, I took extra steps to ensure that consent given by members of the group was fully informed by corresponding prior to the meeting with Des, the group co-ordinator, who had a preparatory meeting with members. On the day we met online, I explained the project again and answered their questions before securing recorded verbal consent from the participants. There was one attendee whose responses made me doubt that they had fully understood the context and implications of the meeting, so I excluded their small contribution from the transcript and did not include their attendance in this thesis.

In the initial 'Behind the Mask' ethics application, the possibility was discussed that sensitive and distressing subjects may arise from the subject matter in the survey and interviews. This was addressed by the inclusion in the survey of a statement signposting respondents to sources of support. A debrief sheet (Appendix I) with similar suggestions of support, was also approved for distribution to participants following interview. Moreover, when participants were interviewed during our conversations I reminded them of this and re-iterated the importance of their wellbeing. I attempted to guide the conversation in a way that helped them name services relevant to their unique circumstances and which would be the most natural resource for them to utilise, if needed.

The organisations and individuals involved in the project remain anonymous and pseudonyms have been used to protect the integrity of the research, as well as the organisations and individuals.

CHAPTER 4: BEING THERE

When I embarked on this research, I had not expected to hear so many instances of deep and multifaceted distress, exhaustion, and despair amongst my participants, nor had I anticipated seeing such a strong link between their embodied experience and the issues of power and justice which underpinned this wide-ranging emotional distress. Through this thesis I establish that connection between cause and effect and identify the factors which mitigated or exacerbated their distress. The connections are made in three stages: I first establish the extent and nature of the intrinsic biocultural factors of PPE and distancing experienced by the participants (Chapter 4: ‘Being There’). I then describe the external factors which made these experiences more or less tolerable (Chapter 5: ‘What Lies Beneath’). I then go on to explore the consequences of these intrinsic and extrinsic factors on the lives of those participants (Chapter 6: ‘The Consequences’). My findings then lead to a discussion of a new understanding of the cumulative effects of these experiences (Chapter 7: ‘From Pandemic to Syndemic’), which reveals that the voices of the participants, heavy with unacknowledged moral injury and distress, were not speaking from a concluded phase of history but were providing me with waymarkers in an unfolding gradual disaster which has implications for ongoing preparedness for British society.

I begin with an insight into the body-mind sensations provoked by PPE, reported by multiple interview and survey participants, by describing the experience of Natalie, an intensive care unit dietician.

4.1 THE BODY-MIND EXPERIENCE OF WEARING PPE

Vignette 1: Natalie

The shaft of light through the bedroom curtain stung Natalie's eyes as she woke late from a restless sleep, head pounding, throat burning. She turned to the bedside table for a sip of water, but she must have finished it all in the night. She used to refill the glass if she got up for a wee, but she was so dehydrated these days that she didn't seem to need the loo as much overnight. She felt so ill. She tried to call for her husband, Simon, but his name left her mouth as a husky croak. Maybe it's Covid? She got up, slowly, filled a pint glass with water from the bathroom tap and drank it, quickly. And another. The test swab stung exquisitely, rasping on the bone-dry mucous membrane. In the mirror she could see the ghost of her mask – the angry rash marked out its shape on her face. How ironic it was that she felt so dry, yet it was the moisture of her out-breath that wreaked havoc on her skin. Natalie took the lateral flow test slide back to the bedroom, laid it on the table next to her refilled glass, took two paracetamol and flopped back into bed. This would be the third Saturday in a row lost to a cracking headache.

It had only been a few weeks ago that at the start of the weekend she'd bounce out of bed and run a steady 5k to prepare for her next marathon. As she strode, she'd reflect on the week's working days – Thursday and Friday – as a dietician on the wards. She loved being part-time and she loved the variety, listening to the patients and getting a feel for how best to approach their nutritional needs, figuring out what to say and how to say it, to motivate and encourage rather than chastise or

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judge. But then the pandemic hit, and she was redeployed to manage the parenteral feeds for unconscious Covid patients on ITU. That’s when she learned what ‘donning’ meant. Over her tunic and trousers goes a gown with full-length sleeves, a hairnet, a FFP3 mask (fit-tested for a good seal), a visor or goggles, and two lots of nitrile gloves. Then the sweating begins, and the clock starts ticking on your tolerance – *‘when you've got the full-on, you really just want to get to the nitty-gritty and just get it all off. Because it just, it does, it really does make you feel awful. And you’re shouting, making yourself hoarse just to be heard. The heat just builds up, and builds up, and builds up. And the feeling of claustrophobia sets in because the whole of your mouth is all enclosed, and there's no air escaping anywhere, and there’s no air getting in – well, there must be air getting in but, you know – it doesn’t feel like there’s air getting in. And it just – it feels like you’re kind of just surrounded, like, wrapped in plastic, breathing in your own fumes. And the light-headedness… the dehydration and dizziness… And: “I must sit down… And I really – this – this is just horrible…” Ach! Just the thought of it’.*

She looked at the clock – 15 minutes was up. Just one line on the LFT. So, it’s only the after-effects of wearing PPE. Again.

Drawn from 13/10/20 interview: 26/422, 26/437, 26/563, 26/640, 26/577, 26/582

4.1.1 Physical discomfort

Natalie's physical discomfort was commonplace amongst participants. The statement: *'I am distracted by the discomfort of wearing PPE'* was selected by 115 (40.8%) of the 282 survey respondents who self-identified as health or care workers. The most frequent complaint was overheating, with 186 (66%) of the 282 respondents who self-identified as health and care workers indicating agreement with the statement: '*I get too hot in my PPE*'. In a case-by-case analysis of 108 open-ended responses about the comfort and ease of use of PPE, 21 respondents mentioned 'overheating' (19.4% of the 108 who gave a descriptive response); 13 described 'discomfort' (12%). Two interview participants and three survey respondents described how menopausal symptoms were exacerbated by PPE.

'It makes it hard to breathe' was the second most frequently selected statement, chosen by 178 (63.1%) of healthcare respondents. Twelve survey respondents described breathing issues in their open-ended descriptions. A self-employed support worker and massage therapist wrote of how masks caused their clients to '*keep breathing into their own eyes'* [S184-26/08/20], while an NHS Clinical Psychologist wrote that their mask made them feel '*like I'm breathing recycled air'* [S353-18/09/20].

Six survey respondents wrote of how the effort to be heard through the mask caused vocal strain and exhaustion. In her survey response Noreen, a Tai Chi teacher for care home residents, wrote:

> *'I find I raise my voice so that others can hear better through the three layers and can sometimes end up with a sore throat by the end of the day'* [S338-14/09/20]

'My PPE causes skin problems' was a statement selected by 101 of the self-identifying care workers (35.8%), while *'My PPE pinches and rubs on my face'* was chosen by 81 (28.7%). Ten free-text responses also mentioned skin irritation and infections. A hospital doctor wrote:

> *'Wearing a mask is causing me to get spots all across my chin and neck, a problem which I'm hearing from a lot of healthcare workers'* [S368-20/09/20]

PPE artefacts such as latex gloves also caused itchiness, allergic reactions, and eczema, as reported by a children's mental health nurse:

> *'Eczema really bad on my hands, skin on my face (under the mask) is now in bad condition'* [S188-27/08/20]

Friction from the mask's elastic straps caused problems for a nurse in an acute hospital:

> *'…the back of my ears are sore at the end of the day shift where the elastic has been'* [S428-24/09/20]

Rubbing and irritation were amplified by the presence of visual and hearing aids, as described by a survey responder who was a hospital technician in a hearing implant department:

> *'As I wear glasses and a cochlear implant processor behind my ear, the surgical mask or visor always affects these two items, making it uncomfortable to wear'* [S388-21/09/20]

Many spectacles-wearers described difficulties with the interaction between glasses and mask. A holistic and wellbeing therapist wrote:

> *'I have to hold the mask in place with tape to stop it slipping as I have glasses. I have a sore face from the tape'* [S204-30/08/20]

Sensations could reach intolerable levels for people with a heightened awareness of physical stimuli. Autism advocate Joyce said:

> *'…the sensory issues are massive with these masks on'* [03/191-02/09/20]

4.1.2 Sensory occlusion

While the wearers' senses were being stimulated by these physical discomforts, other senses such as vision, hearing, and touch were being stifled. Gloves interfered with *'sensitivity to the client's tissue'* (massage therapist, S239-01/09/20). Five survey respondents wrote of how their gloves prevented or hindered palpation for pulses, veins, and subtle lesions (community mental health nurse, S191-27/08/20; hospital worker, S351-17/09/20; advanced nurse practitioner Louise, 34/590-10/12/20; GP, S355-19/09/20). A social care worker who used massage [S442-30/09/20] wrote of how gloves interfered with '*informed touch*' – the interplay between tactile sensory input and its translation into applied touch with therapeutic intent.

The most reported sensory occlusion was sight. The statement *'It obstructs my vision'* was selected by 146 healthcare respondents (51.8%). Participants commonly described how masks directed the moist out-breath upward onto the interior surface of spectacles and visors, creating an opaque film of moisture which obscured vision (as illustrated in Figures 1, 2 and 4 in Section 2.4). Of the 108 open-ended comments from survey participants working in care, 18 (16.7%) were specifically about this phenomenon, which was also described by most of the spectacle-wearing interview participants.

Louise, who conducted house calls in her role as an urgent care advanced nurse specialist, described in her interview how weather conditions could exacerbate the mist effect on both her visor and spectacles:

> *'…last weekend, it was really rainy, and wet and horrible. And I got all my PPE and went into someone's house and you just steam up. So you often have double layer steam. I had to go back to the door, acclimatize, demist myself, before I went back in to the lady to speak to her'* [34/88-10/12/20]

Charlotte, who was deaf and had severe visual impairment due to Usher syndrome[3], said in her interview that the combination of mask and fogged spectacles can make communication *'actually quite a painful experience, if your glasses are fogged, they can't speak, their breathing is sort of out of sync'* [24/70-07/10/20].

In her interview Linda, who was the sole carer for her husband who had Parkinson's, described her emotional response to the misting of her spectacles:

> *'…the thing with masks, I find, that gives me a bit of anxiety as well, because I can't see with my glasses on'* [21/300-01/10/20]

Masks could also cause spectacles to slip, as reported by a health clinic therapist:

> *'I have to wear glasses, the hoops around your ears interfere with my glasses and they fall down my nose* [S249-01/09/20]

The masks themselves could also directly obscure sight by riding up and rubbing on the eyelashes, as described in the survey response of an NHS Clinical Psychologist [S353-18/09/20], or encroaching on the visual field, as described by an holistic therapist who worked in care homes for adults with learning difficulties [S288-02/09/20].

The statement *'It obstructs my hearing'* was selected by 50 survey respondents (17.7% of those identifying as health or care workers). While many descriptive responses which elaborated on this indicator were concerned with the inability to see other's mouths (which will be explored in greater depth in Section 4.2.1), PPE also affected hearing by tangling with hearing devices, as described in my interview with Charlotte, the co-ordinator of a service for people with Usher syndrome [24/74-07/10/20].

The PPE itself also created sounds which distracted the sense of hearing. A mental health nurse wrote in their survey response of how their PPE made *'rustling noises'* [S191-

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[3] Usher syndrome (Deafblind UK, 2023) is a condition which causes deafness, vision loss due to retinitis pigmentosa, and balance problems due to damage to the inner ears.

27/08/20], while a massage therapist wrote of how their visor was knocked '*when I am lifting people's legs onto my shoulders'* and *'the buckling makes a noise'* [S239-01/09/20].

4.1.3 Behaviours altered by physical inconvenience of PPE

The need to attend to the discomforts and impediments of PPE changed the physical behaviours of health and care workers.

For health and care professionals, PPE must be removed and discarded ('doffed') between patients and to access food, drink, and toilet breaks, then fresh PPE must be put on ('donned') to resume interactions. The statement: '*I get less done because of the time it takes to put on and take off'* was selected by 59 of the health and care workers (20.9%). In her first interview, nurse Louise described PPE procedures as *'strange, and a big massive change, I think, to all professionals'* [34/91-10/12/20], but 16 more months of familiarisation with PPE did not change her experience of time required to don and doff [34/142X-31/03/22].

The management of surgical masks became a constant inconvenience affecting the behaviours of Pete and Fran, who were part of the group interview of self-advocates for people with additional communication needs. Pete had cerebral palsy which affected his speech, and his sister Fran was his facilitator. Because of his involuntary body movements, Pete found it difficult to keep the mask in place. Fran said Pete's mask *'keeps coming off his nose, I have to keep pulling it back up and tweaking it. Because when he moves his head it falls down'* [04/333-02/09/20]. Pete said: *'It does my head in'* [07/335-02/09/20].

To save time, health workers reported skipping comfort breaks to reduce the number of times they were required to doff and re-don, leading to further visceral discomfort. '*Being unable to eat and drink when needed*' was a survey option selected by 81 (28.7%), '*being unable to take toilet breaks when needed*' was selected by 29 (10.3%). Ten free-text responses mentioned ‘dehydration’. A nurse who specialised in chronic pain wrote of the cognitive consequences:

> ‘*I get dehydrated and dizzy’* [S394-22/09/20]

Eighteen months after her first interview which formed the basis of the vignette at the start of this chapter, dietician Natalie was working in an out-patient clinic, but the need to keep her surgical mask in place still contributed to her dehydration:

> *‘…when you’ve got someone sat there, you don’t want to take your mask off to have a drink. So I would spend the whole of the clinic not having a drink, because it was patient after patient after patient’* [26/128X-29/04/22]

The danger of dehydration and denial of easy access to toilets prevented one survey respondent with a kidney condition from contemplating work which would involve full PPE. They had been a patient-facing carer in elderly residential rehab unit [S364-19/09/20].

Ultimately, discomfort focussed many healthcare workers’ thoughts on finishing the shift. A survey respondent who was a therapist in a health clinic wrote:

> *‘...you just want to get on and get home so you don’t take breaks as you normally do’* [S249-01/09/20]

Interview participant Veronica, a community-based occupational therapist (OT) specialising in older people's mental health, described how her discomfort truncated a home visit:

> *‘I came out, desperate to get my mask off. I’m at the age when I have the flushes as well, so I thought I was dying at one point, you know, and I just couldn’t wait to get out’* [18/295-24/09/20]

4.1.4 Sensitisation to PPE-wearing

Natalie’s story at the start of this chapter illustrates the interconnectedness of mind and body, and how sensitisation can occur. During the timeframe of this study, the sense of threat was complex and involved both the presence and absence of PPE: PPE could be considered a threat to breathing, vision, and the ability to function, but the wearer also had their own perception of the threat posed by the invisible but present viral hazard. Joyce, the Director of Services for an autism organisation, explained how this tension was a reason for diverse behaviours and beliefs amongst neurodivergent clients:

> *‘…our guys, it's a 50-50 split, I would say: we are 50% of people who want it enforced, they want everybody wearing them, no excuses, sensory issues or anything like that? Not good enough. And we have 50% of people who can’t wear them’* [03/192-02/09/20]

The distribution of perceptions, beliefs, and opinions within and between groups is considered in Section 5.1.

Natalie was one of five survey respondents who used the word ‘claustrophobia’ in her free-text responses. The physical symptoms of claustrophobia described on the NHS website (NHS, 2023) are similar to the primary physiological sensations of PPE-wearing: sweating, hot flushes, shortness of breath or difficulty breathing, a choking sensation, feeling sick, headaches and dizziness, a dry mouth, a need to go to the toilet, and feeling disorientated. A further psychological symptom of claustrophobia – a fear of dying – was also justifiable in health and social care workers: the reason for wearing the PPE was to protect themselves and others from a novel and deadly coronavirus, and it was their job to care for people regardless of the patient’s infection status.

Interview participant Beth, a pregnant perinatal mental health nurse, described the occluded vision, embarrassment, claustrophobia, and altered behaviours which stemmed from her spectacles being fogged by masked breath:

> *'…it feels quite intense. I feel like I'm going to end up eating the mask, because then you try and breathe out a bit instead of it fogging up the glasses, and you just – Yeah, I've not mastered a very elegant way of wearing it at all, if I'm honest. But "claustrophobic" is, if I was to pick a word, it's that'* [23/415-05/10/20] *[…] 'you see all these things on Facebook and they're like: "How do you think surgeons have survived all this time?" I'm like: "Well, I'm not a frickin' surgeon. I still feel suffocated by a mask. I don't care who you are, I'm never going to get used to it"'* [23/404-05/10/20]

A person's mental health history could exacerbate an adverse reaction to the sensation of PPE. A massage therapist with a hearing impairment described in their open-ended survey response how previous trauma sensitised them to the sensation of mask-wearing:

> *'As a child I suffered physical abuse and was strangled with a cloth around my face and throat. I lost conscious and struggled to breathe. Wearing a face mask has been very difficult for me and triggers the emotional trauma within my body, making me feel really anxious'* [S059-25/08/20]

The visceral body-mind intolerance of PPE was too debilitating for some. Anxiety or emotional trauma featured in open-ended descriptions from five survey respondents, while seven survey respondents said their need to avoid PPE had prompted them to avoid work. However, this did not offer complete respite because, for a varying periods, face-coverings were also required in non-care environments. The distress of wearing PPE rendered housebound a social care support worker and their children, including a nine-year-old boy who had learning disabilities. They wrote:

> *'I found PPE so uncomfortable and distressing I have been on sick leave for 6 months from my job [...] I barely leave the house. If I have to go somewhere that involves wearing a mask, I just don't go [...] My kids are missing out on their usual activities and clubs because I just can't manage to wear a mask'* [S439-26/09/20]

For some of GP Deborah's mental health patients '*even the idea of putting a mask on makes them super-anxious'* [33/101-10/11/20]. This, and/or the sight of others wearing masks, prevented them from attending in-person healthcare appointments [33/100-10/11/20].

Interview participant Laura was sole carer for her husband Henry who had Parkinson's. She described his struggle:

> *'Henry's had Botox. So they were getting quite close. But he took his mask off because he nearly fainted. So they had to lie him down and had to then suddenly get him on the bed and put him in the [recovery position]'* [29/504-21/10/20]

Specialist OT Veronica said in her interview that when assessing people for cognitive impairment, altered behaviour due to the inability to tolerate the sensory overload of masks could be misinterpreted as cognitive deficit rather than an anxiety reaction to the stimuli:

> *'It's just like sensory overload, isn't it? They can't tolerate masks. It's too distracting, it's too uncomfortable, and it causes an awful lot of anxiety, which then impacts on function even more. Then you start to get a negative response when actually it's anxiety, it's not cognition ... Behaviours are changing, but it's more in response sometimes to the mask'* [18/136-24/09/20]

4.1.5 Habituation to PPE-wearing

While the sensation of wearing PPE evoked a heightened response in some participants, the survey revealed how the physical experience of PPE-wearing was perceived differently by different healthcare workers. The 282 respondents who identified as health and care workers were offered three positive statements: 80 agreed to the statement '*It's easy to get on and off'* (28.4%); 60 selected *'It fits me well'* (21.3%); and 33 chose *'I can move naturally in my PPE'* (11.7%). Though 44.7% did not agree with any statements which suggested comfort and ease of use, conversely 20.6% exclusively chose a combination of comments which indicated a positive experience.

The open-ended responses of 10 survey respondents explicitly described becoming habituated to wearing PPE:

> *'[...] earlier in the pandemic, I was really resistant to the idea of wearing lots of protective gear in order to be able to go back to work. it just felt horrible when I pictured trying to connect to people through all that, and trying to make it a relaxing experience. I thought of giving up and quitting my job, after 11 years [...] As time has gone by, I have become more accepting of this'* [massage therapist S173-26/08/20]

Some written responses emphasised how they were motivated to acclimatise to PPE because it allowed them to continue working safely:

> *'I have got used to it'[...] 'If I want to do my job and do it well and feel protected then I have to get on with it'* [domiciliary care worker S275-02/09/20]

A holistic therapist who worked in care homes with adults with learning difficulties wrote of how both clinician and care-receiver were becoming habituated:

> *'Wearing masks has become the new normal for myself and my clients and I don't think anyone finds it strange anymore. Even my clients with autism and learning difficulties seem very accepting of me wearing PPE and most are happy to wear a mask themselves'* [S288-02/09/20]

Three of the respondents used their open-ended responses to describe being previously habituated to wearing PPE because their job required it prior to the pandemic. However, one nurse who was also a massage therapist wrote of how their habituation did not extend beyond their clinical role:

> *'I am used to it [PPE] as a nurse. Outside of that it is pretty awful'* [S296-03/09/20]

This cognitive acceptance of the trade-off between physical comfort and the facilitation of normal activities was acknowledged by 90 health and care practitioners (31.9%) who selected the statement: *'If wearing PPE means I can be in the room to have a difficult conversation, it's a price worth paying'*

Laura's first medical interaction in the presence of PPE seemed alien, but PPE became normalised through repeated exposure to it:

> *'I've been at the dentist and I've been in the hospital and I've been for an x-ray [...] and that was very weird, the first time I went in, that was like very space age [...] once I got over that first one, it didn't, you know – it's just the norm now'* [29/493-21/10/20]

Volunteer co-ordinator Alison described in her interview how, when she was an in-patient, her nurses reported a range of tolerance levels for the PPE they wore:

> *'Some of them were saying that they'd sort of just got used to it, although they found them very cumbersome and difficult. Some had sort of just got used to that, that was just another discomfort, another difficulty for them that they sort of just had to get on with. Others were really struggling. And I suppose again, it's further evidence that people deal with it very differently – other nurses said it was very, very difficult for them'* [20/158-01/10/20]

4.1.6 Comforting effects of wearing PPE

The facilitation of communication due to a sense of safety afforded by PPE was expressed by 41 health professionals (14.5%) who selected the survey statement: *'I feel safer, so I can express myself naturally'*. Advanced nurse practitioner Louise said in her interview that the presence of PPE added a sense of comfort through protection for both patients and professionals. However, she also acknowledged the tension between this comfort and the sensitising effect of its appearance:

> *'But the comforting bit is that you have got it, and comforting for your patients, who feel it as comfort as well. It's frightening because it's different. But it's comforting, because you've got it. So I get that, I do get that conflict there"* [34/602-10/12/20]

Family carer Laura described in her interview the potential for sensory comfort from masks as winter approached:

> *'I reckon once the cold weather comes, everybody will be glad of the mask, because it will keep your face warm* [29/645-21/10/20] *[...] Do you know how everybody nuzzles down into their scarf? Now they'll just be wearing their mask'* [29/648-21/10/20]

Nurse Louise described her habitual PPE-wearing as *'ingrained'* [34/591X-31/03/22] and spoke of her mask as a comforter, like an infant's *'dummy'* [34/584X-31/03/22]. Her anxiety came from the thought of *not* wearing PPE.

4.2 THE OCCLUDING EFFECT OF PPE ON COMMUNICATION

Covering the face and the body affects communication. When asked to reflect on their feelings on seeing a person in full PPE, 132 (28.4%) of the 464 survey respondents selected: *'I have trouble understanding what they're trying to say or do'*. This lack of communication had a range of causes.

4.2.1 Exposure of hearing impairment

When asked to think about times when they had talked with a person who is wearing a mask, 177 respondents (38.1%) chose the statement: *'I can't understand them because the sound is so muffled'.* and 82 (17.7%) selected: *'They don't sound like the person I know'*. Amongst the 282 healthcare workers, 71 (25.1%) selected the comment *'I don't sound like myself'*.

Face coverings also prevent the sensory interplay between the aural detection of the spoken word and the sight of facial expressions and movement of the lips, teeth, and tongue. A hearing-impaired social worker wrote in their survey response of the emotional and practical impact of being denied these cues to understanding:

> *'I feel more isolated and feel bad because I can't understand people [wearing masks], I now have to rely on friends to help me in shops and restaurants, it's embarrassing'* [S386-21/09/20]

In their written survey response, a hospital worker highlighted the added impact of obscuring other areas of the face, as well as the mouth, for those whose primary language was BSL[4]:

> *'For Deaf people, facial expressions are a key part of BSL, so it [a mask] isn't just a barrier for deaf (small d, hearing impairment) people'* [S351-01/09/20]

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[4] Facial expression is a fundamental element of British Sign Language (BSL), the primary language for the UK's estimated 70,000 Deaf people born without hearing or who became deaf before the age of five and who have their own culture and community – indicated by a capitalised 'D' (SignHealth, 2014).

Usher service co-ordinator Charlotte explained in her interview:

> *'…there are all sorts of difficulties that come with PPE. And it's important to see the whole of the face – cheeks, mandibles, nose, mouth – because it's about facial movements when you lip read, not just looking at the lips'* [24/125-07/10/20]

While lipreading is a communication skill consciously developed by people with hearing impairment, its universal importance in subconscious understanding and the transmission of the content and intention of verbal interactions became apparent when it was denied. Though 46 of the 464 survey respondents (9.9%) indicated that they had a hearing impairment, almost twice as many (82, 17.7%) selected the statement *'I rely on being able to see a person's lips to understand what they are saying'*. Moreover, 13 survey respondents who had *not* described themselves as hearing-impaired used the free-text prompt to describe being unable to understand because they were denied sight of their interlocutor's mouth. One cited additional difficulty understanding accents [family carer S340-14/09/20] and another said that having a first language other than English increased reliance on lipreading [massage therapist S229-01/09/20].

In her interview, GP Deborah identified unacknowledged cases of hearing loss – including her own:

> *'It's the patients who don't realise they're a bit deaf who are a problem, especially my older patients, because I think people don't realise how much they rely on being able to see your mouth when they're talking. And then the other thing that I've found is that I've realised that I'm probably a bit deaf because I didn't realise how much I rely on seeing people's mouth to talk'* [33/204-10/11/20]

4.2.2 Implications for a neurodiverse society

The importance of habituation and sensitization is demonstrated in people whose neurodivergence features an 'always-on' awareness of sensations usually screened out by neurotypical people. Low levels of habituation strongly correlate with memory and attention issues which can be problematic to the person experiencing such high-volume sensory stimuli, and/or to the people around them who lack understanding of the neurodiverse nature of society and are discomfited by the reactions and coping strategies of neurodivergent people. This accounts for the diagnosis of a range of conditions associated with neurodivergence (Booth et al., 2005; Gitelman, 2003), which are often pathologized to the point of being misinterpreted as *'mental disorders'* (see Schmid, Wilson & Rankin, 2015, p.2). Lucy, who described herself as autistic[5], spoke of her limited ability to read facial expression combined with aural overstimulation:

> *'I've come to realise over the years that I don't have a problem communicating with other autistic people. I mainly have a problem communicating with a lot of neurotypical people, because we don't communicate in the same way'* [02/354-02/09/20] *[...] 'The sensory issues that have, I've found a great way of summing up how it feels: when people wear a mask, neurotypical people, and you're communicating with them, it sounds very muffled, doesn't it? It's really hard to pick out the right words that people are saying. That's what it's like for me every day: the other sounds around, I can hear everything. So if I'm in a conference, that's what the person on the stage sounds like. It's like they're wearing a mask. I have to really focus to hear what they're saying. Now, I realise when people are wearing masks, I used to watch their lips an awful lot. If I was in a busy room, I would focus, I'd look at their lips and then I would pick out the words. But when I can't actually see someone's mouth, I'm really struggling even more than I realised, so I've realised that it's not about their facial expression – sometimes I don't read them very well –*

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[5] A person's relationship to their autism can be described by using person-first language and identity-first language, but there is not one preferred term (Buijsman, Begeer & Scheeren, 2022; Bury, Jellett, Spoor & Hedley, 2023; Kenny et al., 2016). When speaking, Joyce, Des and Lucy used the term 'autistic people' and Des spoke of 'the autistic community' rather than 'people with autism' – a phrase which Des used once for grammatical purposes. I have therefore adopted the identity-first terminology used by participants.

> *it's about seeing their mouth move and I can go by the shape or form, so it's a kind of a form of lip reading that I do without realising. That's the best way for me to communicate. So if someone's got their back to me, I struggle; if they're wearing a mask, I'm really struggling to understand what they're saying, which then gets me frustrated, which then means I lose the ability to communicate, which I was already struggling a little bit with, with sensory issues or whatever. So it really is affecting the way people communicate'* [02/357-02/09/20]

4.2.3 PPE affects kinesics

PPE-wearing alters bodily positionings, movement and gait, disrupting the fundamental communicative vocabulary of proxemics (the study of human use of space) and kinesics (the body movements involved in communication). In 108 open-ended responses about the comfort and ease of use of PPE, 'restriction' was referenced by 15 respondents (13.9%). PPE wearers were aware of the communicative value of the body and its movements, as observed in the written survey response of a hospice volunteer who visited those with advanced dementia and their partners:

> *'It is not just "facial" language that is important in communication but body language. A lot of communication is not oral'* [S024-19/08/20]

The statement: *'My PPE prevents me from moving normally'* was selected by 59 of the 282 respondents who identified as health workers (20.9%). An example of physical restriction was observed by Geoff, whose Motor Neurone Disease (MND) required him to receive daily help from domiciliary carers. Because he required a respirator, they wore the gowns and visors specified for those attending aerosol-generating procedures (AGPs) in addition to the gloves they had always worn pre-Covid, and the masks required by all carers. In his interview, Geoff said:

> *'It's awkward for them because, for example, if they're kneeling down, they're kneeling down on the gown, it's in the way, and they're trying to stand up they find they've stood on the gown at the back'* [27/267-19/10/20]

GP Deborah said that when she was communicating in BSL with a Deaf patient, their visors *'occasionally […] get in the way with gestures that are sort of more "up"'* [33/200-10/11/20]. Charlotte, the manager of a service which supports Deafblind people, described how spontaneous conversation through the medium of hands-on communication was thwarted by the paraphernalia and process of donning gloves and cleaning hands:

> *'The fluidity of "meet, grab, greet, communicate straightaway" had gone, because of all the prep that went into the PPE'* [24/110-07/10/20]

One survey respondent, who did not identify as a care worker, described how people wearing PPE *'stand and behave really awkwardly'* [S370-20/09/20], and a holistic therapist who worked from home wrote in their survey response of how the discomfort from mask-wearing seemed to alter non-verbal elements of communication [S081-25/08/20].

Veronica, whose work as an OT specialised in older people's mental health, described how masks changed the behaviours of both interlocutors, which was particularly challenging because her intervention is dependent on eliciting and observing authentic behaviour, which requires a carefully informal and casual approach. She said:

> *'For me, within my role, it's about observing behaviour. And the wearing of masks changes the person's normal behaviour as well as my own when I'm assessing somebody'* [18/52-24/09/20] *[…] 'as part of my assessment, because I need to observe a big task, an activity, and partly because of trying to be social, I would often say to somebody: "So would you describe yourself as sociable?" and […] I say: "Well, you haven't put the kettle on yet!" You know, that's my way of getting somebody to do an activity because really, I want to observe it, but without them*

> *realising that's what I'm doing. It's an important task for me to observe. But then they make the cup of tea and I can't drink it, I've got a mask on'* [18/325-24/09/20] *[...] 'they're showing that they've still got that social interaction and are still maintaining that social skill. But then when you don't drink it, it's like* <u>*you're*</u> *not being social'* [18/336-24/09/20] *[...] 'I need that therapeutic rapport. It's very difficult to get that therapeutic rapport when you're wearing a mask'* [18/518-24/09/20]

Most of the 282 survey respondents who identified as health workers indicated some level of behaviour change in an effort to be understood: 183 (64.9%) selected one or more of the four statements which investigated the extent to which respondents act differently when wearing PPE: *'I exaggerate my diction in order to be understood'* was chosen by 116 (41.1%); *'I have to exaggerate my body movements to be understood'* was selected by 92 (32.6%); 88 (31.2%) indicated agreement with *'I exaggerate my facial expressions in order to be understood'*; and *'I have to shout to be heard'* was chosen by 73 (25.9%).

Examples of consciously altered hexis to overcome communication barriers were offered by survey respondents and interviewees who described their compensatory behaviours. In an interview, GP practice manager Dave said of his staff:

> *'...even the more quiet and mousy and gentle of individuals is really animated, talking with their hands'* [13/192-18/09/20] *[...] 'there's a couple of staff here – don't stand next to them because their arms are going! You're thinking: "Woah! What's got into you?" and they're really, really into it'* [13/197-18/09/20]

Hospice worker Sally described how, prior to the introduction of PPE, she was already using exaggerated gestures to facilitate communication with people who had cognitive deficit, but this had become a key tool:

> *'I'm really aware we use a lot more gestural prompts than we used to, loads more, and lots of big movements, and exaggerating what we're saying, keeping things really simple and clear – which is something that we would do anyway, but I'm just really aware that we're really exaggerating that more than we would normally. You know, like: "Cup of tea" [makes large miming gesture of drinking from a cup and saucer] and all that carry on'* [16/40-22/09/20]

Volunteer co-ordinator Alison, who had a background in contemporary dance, said that when she was an in-patient, she had noticed people using more exaggerated facial and body gestures:

> *'…I noticed that some people – and not just staff, actually, other patients and friends and family – have had to, much more, use exaggerated gestures because they've lost this [gestures around face]. So people will use their hands much more. Their chest area opens […] People's demeanour, their body language, changed if they were really trying hard to put something over'* [20/178-01/10/22]

4.2.4 PPE hides identity

The statement: *'The mask can make the person unrecognisable'* was selected by 168 of the survey's 464 respondents (36.2%). Other PPE items can obscure identifying signs such as hair style, clothing, eyes, face, and skin. When multiple layers of PPE were worn on the head – such as goggles occluding eyes, visor covering face, plus mask obscuring mouth and nose – both the wearer's sensory occlusion and the observer's inability to see those identifying features of the wearer were intensified.

When interaction took place between two PPE-wearers, this layered occlusion was multiplied in what Natalie called '*a double PPE situation*' [26/447-13/10/20]. Sometimes, the levels of occlusion were such that it removed indicators of gender, age, role, status, or ethnicity, rendering a person unrecognisable to all but those who know them intimately:

> *'I have a photo of my son in full PPE and I recognise him from body pose, but not easy with strangers'* [S360-19/09/20]

Sally, whose team wore a face mask, apron, and gloves for their home visits to families living with dementia, said communication suffered because both their cognitively impaired clients and the people who lived with them were struggling to recognise the therapists in their PPE [16/31-22/09/20]. Veronica also voiced concerns about PPE interfering with her relationships with patients and their families in her OT role in the community:

> *'I came out and got socially distanced, and the relative came out. And I got to my car and I started taking my PPE off: "Oh, you don't half look different without your mask on!". So I thought: "Well, if you're thinking that, your relative hasn't seen me for who I am" [...] 'I'm thinking: "Have I got over what I wanted to get over? Have they seen me as friendly?"'* [18/296-24/09/20]

For those who did not want to communicate, there was comfort from having their identity hidden by a mask. One survey respondent wrote:

> *'I'm answering for my son but he prefers to wear a mask as it hides him'* [S345-14/09/20]

When nurse Louise was hospitalised with Covid, she found comfort from the anonymity afforded by PPE which attenuated her embarrassment from being cared for by her colleagues:

> *'Nobody knew each other. I felt that was the one good thing – it's that normally, I think they'd probably know me. But because everyone had got their pinny and their visor and their mask on, everyone was anonymous'* [34/720-10/12/20]

4.2.5 PPE as a replacement for social regulation

Maggie, a therapist in NHS children's services, said she also had friends who found masks a convenient way to comfortably withdraw from scrutiny:

> *'I know some people, some of my friends who've said that they don't want to take their masks off because it's easier to stick the tongue out without people seeing them! [...] 'They can go to the supermarket without putting their make-up on. They just stick a mask on'* [12/504X-08/04/22]

Louise, who holds a senior national nursing role as well as being an advanced nurse practitioner, described how a physical mask was replacing the development and maintenance of an embodied professional mask: the nurse's *'poker face'*. She speculated that this could become a training issue for student nurses, and for the general young population who were developing their social skills:

> *'...as a student nurse, I had to learn that as part of our training: "Keep the poker face on! Smile!" And I just think it's gonna be interesting for people, especially who are only coming into healthcare this last couple of years, that they are going to be sitting there looking like that: [pulls face] and not keeping their face straight. I would imagine that many a teenager are like that as well, behind their masks, they've got that face on!'* [34/713-10/12/20] *[...] 'I think we'll need some education on how to come from behind the mask! [Laughs]* [34/731-10/12/20]

4.2.6 PPE hides communicative expressions

The occlusion of expressions could create an emotional distance between interlocutors wearing face-coverings and PPE. This was indicated by survey responses to the statements concerning talking to someone wearing a mask: *'They seem less friendly because I can't see their facial expressions'* was a statement selected by 180 (38.8% of the 464 respondents), and *‘I feel uncomfortable because I can’t tell how they’re feeling’*, was chosen by 159 (34.3%).

In his interview GP practice manager Dave described how distress is caused when the embodied expressive habits of humans are occluded by PPE:

> *‘[PPE] immediately changes the whole way you interact with somebody. People with hearing impairments, it must be horrible. It is horrible for them, I know that. They tell us that it’s a challenge to be able to speak through a glass barrier, and you only see half the face. You don’t realise how expressionable we are as human beings. When we’re talking to people, hands and mouth and lips, and when you suddenly take that away it completely changes the dynamic of your interaction’*
> [13/60-18/09/20]

Volunteer co-ordinator Alison described how she was distressed that her mask made her unable to comfort a fellow patient in a waiting room:

> *‘When I went into [hospital] for my colonoscopy, there was an elderly lady came in’ […] But obviously, we were all masked up. And that moment where I was desperately trying to give her a smile, but obviously, you can only smile so much with your eyes, that was really frustrating for me, because I wanted to give her some sort of reassurance as a co-patient on the day’* [20/197-01/10/20]

Specialist pain physiotherapist Vicky had a similar hospital waiting room experience at the breast clinic for investigation of a lump she had found that day. She described in her interview how she felt masks prevented her from striking up a conversation with staff or fellow stressed patients:

> *‘...sitting in the clinic, you’re terrified. There’s no kind of communication, everybody was wearing their masks […] there was a couple of other women in the waiting*

> *room as well, but all socially distanced [...] I suspect if we weren't sitting there wearing masks, we might have sat and chatted, but I think everybody felt uncomfortable, especially in an environment like that, you don't know what these other women are going through – whether they've got anything worrying going on, counselling or anything like that. And I think in normal circumstances, I'd try and strike up a conversation, but I think the fear and the – just the whole circumstances completely changed the way it felt'* [25/391-09/10/20]

Clinicians described how they felt they had lost an important clinical tool when PPE and forced avoidance of touch removed their ability to offer non-verbal expressions of empathy. GP Deborah described how PPE made it a struggle to prevent the interaction from feeling merely transactional:

> *'It's just a barrier, that you don't have that same – I don't feel I can convey empathy in the same way. Um, and it just feels a bit more impersonal. And that's kind of the main sort of situation I've struggled with'* [33/33-10/11/20] […] *'it's a bit like trying to do your job with one arm tied behind your back'* [33/359-10/11/20]

Other clinicians echoed Deborah's anxiety at this loss of connection:

> *'…it's very difficult [...] Other person can't read my expression. Altogether a bit of a nightmare'* [community mental health nurse S162-26/08/20]

> *'I don't like that people/patients can't see my smile'* [complementary therapist in the NHS, S034-22/08/20]

While familiarity tended to reduce some adverse effects, the problems caused by the loss of expression remained constant. Eighteen months after her first interview, Deborah still struggled to communicate her empathy despite becoming habituated to wearing PPE:

> *'…we're so used to it now that I'm not aware of it being a barrier myself as such, I mean, it's just part of me' […] 'I'm just carrying on as normal, and I'm not trying to compensate for it, I'm not trying to work around it, it just is what it is. But I do think that it's – I still think it's probably not helpful. Because it adds to the, sort of [pause]… the sort of clinical-ness of the environment, it's harder to relax' […] 'You can't have that kind of same rapport, I think'* [33/155X-09/05/22]

The restrictions on non-verbal cues were two-way: both expression and detection were occluded. Patients' masks interfered with clinicians' history-taking and assessment. Deborah described in her interview how they prevented her from observing her patients for non-verbal cues when conducting her GP consultations:

> *'…it's taking more time, it's probably not as effective' […] 'normally I pick up on the cues that they're giving, it's like: "Oh, you look like you've got questions"' […] 'I'm not picking up those cues'* [33/73-10/11/20]

This inability to pick up on non-verbal cues extended to Deborah's reading of her colleagues, which prevented peer support:

> *'…we walk past in the corridor, and everyone's got their mask on […] I used to be like: "How are you?" and you'd kind of know, like: "Do I need to –?' You don't get that cue to know whether or not you can just go: "Hi!" and move on, or whether you're actually like: "Oh, are you okay?" And whether they actually need a bit of TLC and a bit of listening to. I do feel that our team is more fragmented, and there's less peer support. It's all a bit sad really'* [33/291-10/11/20]

This loss was reiterated in the survey response of a self-employed complementary therapist:

> *'It's more difficult to pick up on unsaid stuff – like, noticing if they seem under the weather or tense or low'* [S290-03/09/20]

4.3 PPE AS COMMUNICATIVE ARTEFACTS

Articles of personal protective equipment are artefacts which have two concurrent mechanisms affecting communication. As discussed in Section 4.2, they obscure the signals from the face, body, hair and/or and clothing beneath, but the PPE artefacts themselves are also objects which communicate. They have their own meanings, or 'biographies', which are formed through the interpretations of the people who engage with them. The perceived intent of PPE artefacts can radically differ between people, and they can change over time. The causes and consequences of diverse artefact biographies is explored in Section 5.4.3, but here I offer examples of PPE acting as artefacts which communicate.

4.3.1 Sight of PPE dominates clinical interactions

Alex, the head of training for a care home group, said the wearing of identical masks erased the personal differences in facial features and expressions. This meant that a previously successful tactic – resetting a scenario in which a person with cognitive deficit had become agitated by introducing different staff – no longer worked:

> *'We talked about having a "change of face", which is a common technique if someone's distressed, or someone's upset [...] But then that's not going to work if you look the same. She's got the same bloody mask on!'* [14/235-21/09/20]

GP Deborah described an incident where masks distracted a patient to the extent of causing harm: the purpose of the clinical interaction was forgotten because it was dominated by the presence of the PPE:

> *'I have a really good example of a lady with quite moderately advanced dementia who lives at home currently, but her short-term memory is so poor and, bless her, just having the mask is quite distressing to her' [...] 'she can't even get to the point where she can make her needs known, her medical – what she's come for, because she's distracted by the PPE, and that's just the mask at the reception desk, and that's*

> *before she's seen me who's got mask and gloves and apron. So when she's actually got to see me, she's just like: "What are you doing? What are you going to do to me? Why, why are you doing this? Why have you got all that stuff on?"'*
>
> [33/117-10/11/20]

4.3.2 Artefacts assert their own identity

I have previously examined how PPE hides identity. Here, I consider how artefacts themselves can project their own identity which becomes entangled with that of the wearer. The role of garments as identifying agents was exposed when PPE rules dictated the adoption of prescribed clinical clothing in place of civilian clothes. A children's mental health nurse described in their survey response how they had used civilian clothes to communicate approachability to their young patients, but the imposition of a uniform had a detrimental effect on rapport:

> *'Used to be easy to gain rapport as we wore our own clothes and this made it able for them to differentiate us from paeds nurses/A&E staff. Now they get us confused'*
>
> [S188-27/08/20]

Prior to Covid, doctors at Deborah's GP practice wore civilian clothes. This demarcation between doctor and uniformed clinical staff had not entered the consciousness of many patients who had assumed that female staff were nurses and male staff were doctors [33/258-10/11/20; 33/264-10/11/20; 33/275-10/11/20]. However, Deborah said adoption of scrubs by doctors amplified this pre-existing assumption [33/257-10/11/20] while also blurring professional identities and removing visual cues of individuality:

> *'…over 50% of GPs are female, but we still get assumed that we're the nurse. And our clinical practitioner, who was a paramedic, male, they all thought he was a doctor. And then putting everyone in scrubs made it all worse. Everyone completely didn't know who you'd be. And that did make things more difficult because then they*

> *come in and they say: "Oh, I saw the doctor last week". And I'm like: "Who?" And they're like – and I'm like: "No, you didn't" […] they don't know who they're seeing. Which is not good […] it's just happened a bit more since we all went into scrubs'* [33/259-10/11/20]

4.3.3 PPE as 'alien'

When survey respondents were asked '*How does being near a person in full PPE make you feel?',* one of the statements offered was: *'I feel like I'm in the presence of aliens, not humans'.* Of the 464 respondents, 97 (20.9%) agreed. Four respondents explored the 'alien' in follow-up written comments. A mobile massage therapist wrote of occluded identity:

> *'Talking with PPE on is alienating in many subtle ways, simply because so much of each other's faces are covered'* [S232-01/09/20]

A counsellor in a residential children's home wrote of fear: '*It just feels alien, I still find the image of humans wearing masks a little scary'* [S334-13/09/20], while the deliberately unfinished sentence written by a practitioner of non-conventional therapies hinted at sinister underlying factors, describing being near people in PPE as *'Dehumanising, slightly different than alien, there is a sense of depersonalisation, even preparedness, bit by bit, for.........'* [S097-25/08/20].

A visually impaired respondent who did not identify as a health worker felt that they, rather than the wearer, was the 'other', and described how they tried to mitigate for this:

> *'I feel like I'm the alien, and that I am subjecting them to risk, I make an effort to be more friendly and polite verbally'* [S304-08/09/20]

In her interview, Alison, a Healthwatch volunteer co-ordinator, described being a passenger amongst a busload of masked people as like being amongst the cast of a dystopian movie.

Her body-mind perception oscillated between being present as a fellow mask-wearer and as an external observer of an alien scene:

> *'...for me it felt like a choreographed dance, because everybody was facing the same way, looking ahead, masked up. It was like a scene from a movie'* [20/392-01/10/20] *[...] 'Everybody had the mask on which looks a bit like a beak, to me... [link interrupted] Alien'* [20/394-01/10/20] *[...] 'Something like a Hannibal Lecter convention going into town'* [20/404-01/10/20] *[...] 'It's almost like an out-of-body – for me, my body and my head and my mind keeps checking into – now and again it comes back to the real world, wherever that real world used to be'* [20/395-01/10/20] *[...] 'And you look around, and then you realise you're part of it'* [20/397-01/10/20]

The 'alien movie' metaphor was also evoked by Carl, who contemplated his witnessing of, and participation in, the introduction of PPE and distancing as a long-term in-patient in a spinal injuries unit as '*a curious transition period'* [32/88-29/10/20] *[...] 'it kind of felt quite so much like being part of a film. It seemed such an alien kind of way of being'* [32/83-29/10/20]

4.3.4 Sensitisation to the sight of PPE

In their written survey response, a paramedic practitioner in police custody who also had a private counselling practice described their patients' interpretations of the messages conveyed by PPE artefacts:

> *'I've been asked by patients to take it off... words used: "intimidating", "scary", "makes me feel like you think I'm dirty"* [S128-25/08/20]

Sally led a team of staff and volunteers who practised Namaste Care, a form of multisensory complementary therapy for people living with advanced dementia (described in Vignette 2).

The team had normally worn civilian clothing on home visits. Sally said clinical tunics, aprons and visors presented a medicalised identity which was at odds with the comfort care role of the therapists wearing it, and this communicated a confusing and sometimes distressing message:

> *'…we go out to the families wearing them, and the families get really confused. So a few of the families we visited thought we were nurses because they were wearing these tunics. Trying to then explain: "Well, no, we're this", which, I mean, trying to explain what Namaste Care is, it's always tricky anyway, but then when you're sitting there in a clinical uniform, it has caused some confusion, actually'* [16/416-22/09/20] *[…] 'And then we put a visor on. They look very clinical, don't they? So we've had people horrified that we're there to cart them off. One lady in particular thought I was there to take her to the workhouse'* [16/45-22/09/20] *[…] 'The decision behind wearing a tunic was obviously from an infection control point of view, you change out of it before you go home. So it was made for a good reason. But then how that decision is interpreted by the families is unintended, isn't it? We obviously had no idea that someone would interpret our visit as: "I'm going to cart you off to an institution". You're potentially causing harm there, aren't you? Unnecessary distress. If I'd turned up in my civvies, that hopefully wouldn't have happened. She just wouldn't have had that thought'* [16/441-22/09/20]

The 'personality' of the PPE artefacts was amplified by context, such as the body language of the wearers and the environment in which they were worn. Self-advocacy group co-ordinator Des described how a health trust created an image containing a clinical team wearing surgical masks with the intent to transmit a message of reassurance – 'we are all ready to care for you safely' – but the message received by an anxious audience was one of threat, due in part to the staging of the image:

> *'We were going to do a video with [name of local general hospital], to look at how it looks when lots of people are wearing face coverings. It can make people feel really anxious. We were sent a photograph recently from a team that works for a local health trust. And it was about engagement and involving people. You know the photograph I'm talking about, don't you? [Other interviewees nod]. They were all standing behind a desk with their facemasks, like this [arms crossed]. And it just looked like they were ready for a riot'* [01/482-02/09/20]

The influence of a person's mental health history on their reaction to the sensory experience of *wearing* PPE has been considered in Section 4.1.4, but it could also influence their reaction to the *sight* of PPE artefacts. A health care assistant on a forensic inpatient unit, who also had visual and hearing impairments, described their role as *'having close contact with distressed people who were often experiencing trauma, abuse and severe neglect'*. They wrote in their survey response of how their PPE was a major source of fear for their patients:

> *'I recognise the need to adhere to PPE guidelines, but working with such damaged traumatised individuals it is a huge barrier to care. [...] PPE adds anxiety, stress, and bewilderment to an already specialist service'* [S157-26/08/20]

For this social care worker, their own previous trauma was triggered by the sight of PPE. They wrote:

> *'I have a traumatic history which now results in non-epileptic seizures when I see photos or people using face coverings. I have become afraid to go outside where people are wearing a m***'* [respondent's asterisks] [S442-30/09/20]

These reactions were caused when PPE was present, but if PPE artefacts carry meanings of safety and protection for interlocutors, the sight of their *absence* can trigger anxiety.

4.3.5 Sensitisation to the sight of absent PPE

A notable proportion of survey respondents indicated a sense of comfort and protection from seeing someone in full PPE: 164 (35.3%) of the 464 respondents agreed to the statement: *'It's reassuring – they're fighting the virus'*. When asked to '*think about the times when you have been talking with a person who is wearing a face mask'*, 194 respondents (41.8%) indicated a sense of protection by selecting: *'I feel more comfortable because the mask is protecting me from the virus'* and 142 (30.6%) chose the statement *'I feel more at ease than if they weren't wearing a mask'*.

In interviews and free-text responses, the participants drew attention to the comforting effect of seeing PPE more by their descriptions of the fear they felt in its absence. Louise described the fear that she and her nursing colleagues felt from seeing an unmasked face:

> *'Before Covid I commuted every day to London, on the train, no problem'* [343/511X-31/03/22] *[…] 'That fills me with dread. I'm going next week. And my colleagues who do it, they're like: "I'm on the train, got my mask, and nobody's got a mask on! Oh, help!" You know, that's how we feel inside'* [34/515X-31/03/22]

In 2022, after infection control regulations had been withdrawn in non-clinical settings, the absence of masks caused substantial anxiety for some participants. Children's mental health therapist Maggie said:

> *'…we went to the pictures shortly after the masks went. We went to the pictures and it was a really unsettling experience. And we said: "We're not going back". Because we were in the same room as other people who were breathing! Weird! [Laughs] Yeah, we don't want to go back'* [12/458X-08/04/22]

Nurse Louise described her anxiety in her second interview:

> *'…we went, for the first time ever, out to a charity ball and stayed overnight. […] 'it wasn't until we were around the table, I was like: "Oh, there's all these hundreds of other people, I don't know about their Covid status". The lateral flows had stopped, the mandatory wearing of masks had stopped, and I had to psychologically have a talk with myself and say: "You're gonna have to get over yourself, because you're not gonna enjoy yourself"* [34/ 678-31/03/22]

Wrongly-worn PPE artefacts were also a commonly-reported sensitising factor. Advocacy group member Aidan, whose autism informed his work, said: *'…what really does frustrate me is the people that wear them, but don't wear them properly'* [08/256-02/09/20], while Aidan's colleague Fran concurred: *'Can I say I have the same problem as Aidan, I hate it when they've got their noses out'* [04/349-02/09/20].

4.3.6 Habituation to the sight of PPE

Habituation to the sight of PPE was indicated by 80 of the 464 survey respondents (17.2%) who, when asked: *'How does being near a person in PPE make you feel?'* agreed to the statement: '*I've stopped noticing, it's becoming normal'*. The most frequently selected statement when prompted to think about talking with someone in a mask was *'I can usually understand what the person is saying'*, chosen by 56% of respondents (260 of the 464 respondents). Statements which indicated the ability to foreground relevant signals were: *'The person behind the equipment shines through',* selected by 15.5% of respondents (72 people), and *'You can tell by someone's eyes if they're smiling behind the mask',* chosen by 204 people (44%).

Liz, a learning disabilities development worker, suggested that there could be circumstances where PPE was more distressing to the carer rather than the cared-for because the person requiring care had been habituated due to extended exposure in clinical settings:

> *'That's how my experience of talking to carers has been. Some [of the people they care for] have been very accepting of it. The fact that, you know, "it's just the thing that's happened when I haven't been very well"'* [10/173-14/09/20] […] *'I think it was more distressing to the carer rather than the cared-for, because the cared-for was seeing it in the hospital all day long, whereas the carer wasn't – this wasn't normal for them to have to put that on'* [10/179-14/09/20]

A clear indication of the mechanisms of habituation to the sight of PPE was reported by perinatal mental health nurse Beth, who said she and a consultant colleague had noticed that babies who were born before the imposition of PPE were more likely to be distressed by the novel sight of a mask than babies born in a time of mask-wearing (including her own baby):

> *'...for the babies now, it's not been too bad, but for babies that we were working with before, it's really been quite frightening… they just get more distressed because they don't understand why somebody is in a mask'* [23/207-05/10/20] *[...] 'there's been a couple of babies that definitely have found it really off, but there's definitely been one baby who just can't cope with it. It just really, really stresses him out'* [23/217-05/10/20] *[...] 'People would often say to [my baby], even on maternity leave: "Oh, it's got to be so strange". And in my head, I'm like: "Well, he doesn't know any different"'* [23/210X-14/04/22]

Beth's habituation to PPE in her clinical role made it less of an 'alien' experience when she was a new mother being cared for by health visitors in PPE:

> *'It was a bit weird, obviously, because we had to be in PPE all the time. But I guess being a nurse myself, although I'm a mental health nurse, I'm somewhat familiar and exposed to PPE, so it didn't feel completely alien despite us being in a pandemic'* [23/36X-14/04/22]

Factors which facilitate or obstruct the ability to override barriers to communication caused by PPE and distancing will be explored in detail in the next chapter.

GP practice manager Dave employed purposive communication through the performative wearing of PPE to habituate staff and patients to the sight and practice of PPE-wearing. He instructed his clinical staff to promote good practice by maximising their visibility while wearing protective artefacts:

> *'[I] actually got the clinical staff to set a good example by wearing masks all the time and wandering around the building. I mean, they're embarrassing, they're uncomfortable, they're horrible. And even the manager [points to self], who was probably one of the worst culprits, even if I go down onto the clinical floor now, I always wear a mask'* [13/51-18/09/20]

4.3.7 Artefacts which communicate __about__ PPE

The diversity of messages received by observers of PPE was so complex that additional artefacts were considered necessary to explain their presence or absence. Dave chose to wear a mask in non-clinical public places after they were no longer compulsory, which drew antipathy from some members of the public. So he displayed another artefact – his NHS identity badge – in the supermarket, with the aim of asking observers to consider his motivations:

> *'…you get funny looks: "Ooh! Look at that couple, they're doing the shopping and still wearing masks!" I try to wear my NHS badge when I'm going shopping, which is ridiculous – I hate being identified, you know? But I'll wear it and let people see the NHS lettering, and maybe that might give them something to think about, some stimulus to think about: "Well, actually, he works in the NHS, maybe I can understand why he is wearing a mask. Maybe he is more, you know, sensitive to the issues"'* [13/501X-04/04/22]

For those who did not wear masks, antipathy was anticipated from some mask-wearers. To defuse potential conflict, some participants with hidden disabilities adopted the use of a 'Sunflower lanyard'[6] (Figures 11 and 12) to indicate that their missing mask's biography was a story of difficulty rather than of defiance.

FIGURE 11: A Sunflower lanyard with information card (Hidden Disabilities, n.d.-a)

FIGURE 12: An alternative text option for the information card on a Sunflower lanyard (Hidden Disabilities, n.d.-b)

Advocacy worker Fran described how her partner tried hard to adhere to mask-wearing rules, *'but he got this [Sunflower lanyard] just in case he couldn't cope with [his mask] because he has panic attacks'* [04/209-02/09/20]. Despite being exempt due to her autism, Lucy associated the practice of mask-wearing with 'source control' for the protection of others. She carried her card as a coping strategy to be used in case she needed to abandon her mask due to sensitisation:

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[6] A Sunflower lanyard is a green piece of webbing decorated with a sunflower pattern, worn around the neck to identify the wearer as someone with a hidden health condition. A double-sided explanatory card can also be attached as a pendant. It aims to discreetly indicate to people around the wearer that they need additional support, help, or more time. The lanyard scheme was launched in 2016 and prior to the pandemic it had been adopted by airports, NHS establishments, and some commercial premises as a way to support customers and colleagues (Hidden Disabilities Sunflower, n.d.-c).

> *'I'm autistic and I have an exemption card. But I tried to wear [my mask], because I realise I'm wearing it for other people. I find it really hard to wear it, especially when I'm really anxious, so I have the exemption card in case I start to have a meltdown because the mask will have to come off if I'm having a meltdown. Because that's just the way I work. I start to breathe heavily. I get really anxious, I feel sick. That's why I have a card'* [02/224-02/09/20]

The consequences of the use of Sunflower artefacts are examined in Section 5.3.3.

4.4 PROXIMITY AND TOUCH IN SOCIAL LIFE

I now turn from the intrinsic experience of PPE artefacts to the issue of the forced avoidance of proximity and touch. Because the givers and receivers of care are, first and foremost, people, I begin by considering the role of touch and proximity in their ordinary lives before I explore the specificities of their health and social care interactions. I will first report the participants' pre-restriction attitudes to, and experiences of, touch and physical closeness in a non-clinical context. This will give context to the subsequent consideration of the effect of its withdrawal in social life. I will then consider participants' pre-restriction experiences of touch and closeness in care interactions before examining the participants' experiences of caregiving and care-receiving when touch and proximity was denied.

4.4.1 Touch as an instinctive form of social communication

Of the 464 survey respondents, 69.2% (321) agreed with the statement: *'A kind touch can get the message across when words fail'.* The place of touch in the lexicon of social communication was highlighted in six free-text survey responses, including that of a GP:

> *'Touching is a normal part of human communication'* [S355-19/09/20]

The subconscious and instinctive engagement of touch was described in the written response of a hearing-impaired provider of dementia care in a hospice:

> *'I naturally reach out to do it anyway without thinking'* [S021-19/08/20]

This instinctive and natural form of connection is developed into more formal and deliberate forms of communication when sensory and/or cognitive impairments restrict access to the mechanisms of interaction used by the general population.

4.4.2 Touch as a language

Carer support worker Liz, who specialised in learning disabilities, described families who solely communicated by touch. When the cared-for were non-verbal and/or had sensory impairments, only touch, rather than visual or verbal cues, was understood. Touch was sometimes the mechanism through which cared-for recognised the carer. For some, touch was essential for de-escalation when the cared-for was frightened or angry. Liz said:

> *'Those nonverbal families, those ones where their sight might not be particularly good and what was dependent was the actual touch on the cheek to say "you're all right" if, say, somebody was having a spasm, somebody was having a behaviour problem or something like that. Quite often they would just rub their hands, have that contact with the hands to say, "it's okay, there's somebody confident here with you, we know that you'll get through this period". And then sometimes the touch on the face. A lot of times people who do have sensory problems, it's that touch, that recognised touch from someone. Sometimes it's the only thing that the carer knows that the person will understand'* [10/200-14/09/20]

For people who have a combination of hearing and visual impairment, touch also has its own structured and formalised vocabulary, grammar, and cadence. Charlotte, who manages a service which supports her peers with Usher syndrome, explained:

> *'...for people who are Deafblind, touch is absolutely number one. Touch is communication and communication is touch, because we learn everything from touch'* [24/102-07/10/20] *[...] '"Hands-on communication"' [...] 'it's where the person uses sign language and then the communication partner does, but they put their hands over the signing person. So then they can follow the shape of the signs, which is tactile. So rather than just looking at the signs, as I'm showing you now, the person would sit or stand opposite, wrap their hands over the hand like this [indicates with hands], then they can follow the shape of the signs. That's tactile*

> *communication'* [24/104-07/10/20] *[…] 'there is a grammar that comes with touch' […] 'Haptemes, haptices, different pressures, different points, different intentions. It's the grammar of approach to touch and how it's used, how it's executed and how it's received'* [24/692-07/10/20] *[…] '…social haptics for deafblind people, we can use a system of touch on the back, so you can stand behind somebody who's deafblind, and draw a big square from the nape of the neck out to the shoulders, down to the loins and then across, so it shows a big square. And that's the room. And then the person understands: "Ah! So that's the outline of the room". And then you can place things in the room: where the door is, where the people are standing. And you can also give information about, you know, where the people are in the room, and then you can do a sign on the shoulder here [indicates] and in sign language that's the sign for laughter. So you can modify it onto the arm to make it "laughter", and point to the area of the back if people are laughing on one side of the room. So people, from touch, they don't only get environmental information, they get communication information, they get the emotion of the room*' [24/448-07/10/20] *[…] 'I think for people who have any degree of vision and hearing loss, this is everyday life. Communication through touch, social haptics, are important whether they know it or not'* [24/477-07/10/20]

4.4.3 Pre-pandemic dislike of social touch

All survey respondents were asked: '*Keeping our distance means that we must avoid shaking hands, hugging, or giving comforting touch to each other, such as placing a hand on someone's shoulder. How has that affected you?'* A small proportion of the 464 survey respondents had a pre-existing dislike of social touch. When asked how the forced avoidance of touch had affected them, 46 (9.9%) chose the option: '*I don't mind, I've never liked hugs anyway'*.

Six survey respondents wrote of their dislike of touch, but these comments also specified that the dislike was restricted to uninvited touch from acquaintances rather than the mutually welcomed embrace of loved ones. One respondent, who had a hearing impairment, wrote:

> *'This [i.e. never liking hugs] applies to strangers, but hugging family is good. Some years ago everyone started to hug instead of a nod of acknowledgement. I am glad this has stopped'* [S444-03/10/20]

A visually impaired survey respondent wrote about how they use touch selectively and judiciously to express support, despite their own dislike of being touched:

> *'I am not overly keen on being touched, but if I chose to touch them I would do this as a form of support, if I knew they would be OK with this'* [S304-08/09/20]

The statement: *'I feel safer if no-one touches me'* was chosen by 132 of the 464 survey respondents (28.4%). A hoped-for reduction of work-related assaults was expressed by a hospital worker who wrote: *'There will be less sexual harassment at work (hopefully)'* [S351-17/09/20]. Hypersensitivity could make a hug intolerable for an autistic person, so forced avoidance gave respite as explained in her interview by autism advocate Joyce:

> *'Autistic people don't do hugs, they don't do touching. Not everybody, obviously, but the vast majority of autistic people that come to us would be horrified if you went to touch them without asking them or hug them without asking them'* [03/62-02/09/20]

4.4.4 Normlessness of social behaviours due to distancing

As seen above, touch and proximity have vital social and practical roles in communication. However, the danger of touch was overwhelmingly foregrounded by its role as a potential vector for the spread of Covid. When the 282 survey respondents with a care role were asked: *'How have you managed the need to avoid touch when communicating in your role at work?'*, 58 (20.6%) selected the statement: '*People are now afraid of being touched, touch* *has lost the power to comfort*', while 29 (10.3%) chose: '*The virus has put me off touching people*'. Both statements indicated a behaviour change arising from a shift in the meaning of touch. A sense of grief was expressed by those who felt that a tool for expressing comfort had been corrupted, captured in the survey response of a complementary therapist:

> *'It makes me very sad that touch is now considered dangerous'* [S099-25/08/20]

The danger implied by touch meant that the everyday rituals of touch which form and sustain social bonds were replaced by normlessness. For example, the survey statement: '*It feels impolite to avoid shaking hands'* was chosen by 168 of the 464 survey respondents (36.2%). Some described how uncertainty about the acceptability of touch- and proximity-based social bonding behaviours caused hesitation and awkwardness. A sports massage therapist wrote:

> *'There are many times when a big hug and hello are just the instinctive thing to do, but we now hesitate not knowing if the other person is OK with it or not'* [S292-03/09/20]

Seven survey respondents used open-text responses to write of their concern that this hesitation and awkwardness would be translated by their interlocutor as anger or ill-feeling. One wrote that avoiding touch when communicating *'feels anti-social, a bit stand-offish'* [S328-12/09/20], while a respondent with visual impairment wrote of both sadness and offence from avoiding social touch:

> *'I would hesitate now and not do it. I don't know if people would instantly be offended before remembering it's best not to, which we all might feel sad about'* [S304-08/09/20]

Another survey respondent described their concern that the removal of tactile parting rituals had potential to affect their family relationships:

> *'I miss hugs with friends and family. Saying bye feels awkward without one, it feels like I'm mad at them'* [S461-26/10/20]

A massage therapist described the loss of self through the denial of the everyday giving and receiving of touch:

> *'I do miss it. It's part of me, being very physical when I express affection and I love to receive physical affection too'* [S229-01/09/20]

Avoiding proximity was impossible for some people, which was another source of awkwardness. A visually impaired survey respondent wrote:

> *'I do understand and respect social distancing, but this can be challenging for me as I cannot see if I am close to people and sometimes I rely on these people to help me if I need sighted assistance'* [S226-01/09/20]

People with visual and hearing impairment, such as that of interview participant Charlotte, relied on tactile communication to keep safe while negotiating unfamiliar environments. In her written survey response, Charlotte described the dilemma she experienced by the impossibility of touch avoidance in this situation*:*

> *'When someone tried to guide (help me) because of my poor mobility getting around, I was worried about him and myself for getting the virus' [...] 'I feel safer if no-one touches me only when I do not get the virus, but when I need someone to help me but can't, this means I feel less safe'* [S049-24/08/20]

4.4.5 Emotional labour of forced avoidance of touch and proximity

In their survey response, the manager for a mental health charity wrote of the emotional labour of consciously avoiding instinctive touch:

> *'It still requires an effort to curb instinctive actions, such as hugging my mum, or shaking hands with an interviewee'* [S210-01/09/20]

Tai Chi teacher Noreen spoke of the hurt she felt when suppressing a reflex to touch:

> *'I remember one session, it was in the park, and one of my ladies got out of her car and she fell over. And I went to run to help her up, and one of the other ladies yelled: "Stop!" And I thought: "Oh no, I can't help her up, can I? I'm not allowed". And it was horrible. It was the worst moment'* [19/241-29/09/20]

More than half (51.9%) of all 464 survey respondents chose a statement which described a visceral pain at being denied the ability to give and receive comforting touch from loved ones: *'I ache to hug my friends and family'* was selected by 241 respondents.

4.4.6 Trauma from forced separation from important life events

Pain and distress from forced separation and touch deprivation was described by 16 survey respondents. Social bonding through touch had extra significance where reassurance was needed. A family carer wrote about how the discomfort of touch deprivation was heightened during important life events:

> *'It's hard not to show your feelings by hugging, kissing or touching when someone is dealing with illness or bereavement or even when it is a relative's birthday or other celebration'* [S429-24/09/20]

Interview participants who experienced separation during births and deaths – life-stages normally marked by rites and rituals – vividly described the physicality of their grief and longing. Two colleagues from the self-advocacy group for people with additional needs, Joyce and Lucy, suffered distress from the restrictions on gathering and touching at funerals. Joyce said: *'Our humanness has been taken away from us'* [03/379-02/09/20]. Lucy's description encapsulates the intensity of feeling:

> *'I've had a new grief in the family. We've had grief in our team, we've had genuine moments where you would reach out and you will hug that person or you would*

> *touch them and say, "You're alright". You can't do that. And that is absolutely heartbreaking. It's hard to sit next to someone who's crying, genuinely hurting, and not be able to respond in a human way. You kind of have to go: "I'm not allowed to be a human around you. I'm just going to talk". Words are very powerful, but in certain circumstances they're not powerful enough. Not like human contact. And that's really bad at the minute'* [02/371-02/09/20] *[…] 'Right near the start of this my stepdad passed away. Hadn't seen him for two weeks before lockdown because the care home had decided to put their own lockdown in […] So, he died near the start. It was the worst funeral I've ever been to. We were allowed eight people. My stepdad would have had the whole of [neighbourhood] come see him off, as they say. There would have been standing room only and you would have had to stand outside. Everyone in [neighbourhood] would have come to say goodbye to him. We weren't even really allowed to sit down next to each other, we kind of broke the rules a little bit. It was awful because we got in the car, we went, we came home. Me and [...] my son, my husband and my other son came home and I was like: "This is shit, this is really bad", because we can't grieve properly, because there's no wake. You get together, you share stories, you hug each other, you cry together, you laugh together, you swap tales, and that helps with the grieving process. It makes you feel human and that you're not alone. Even though I had three other members of my family with me when I walked in the house, I've never felt so alone [Lucy is crying]. Because it was like it was as if his life meant nothing. It had meant so much to so many people. Because of this whole situation, all of that was taken away and this is why we have people with mental health issues. It's the inhumanity of this whole situation. It's really crap'* [02/383-02/09/20]

In a separate interview Barbara, the mother of long-term hospital inpatient Carl, equated the devastation caused by the deprivation of touch and proximity to that caused by the virus itself:

> *'People's lives are being destroyed by this pandemic, whether they have it or not. I've lost two friends to it, quite early on, and I've been in a position where I've had to go to a funeral in person where there were eight people. It was the most dreadful thing I've ever been to in my life. I've also watched the funeral of a friend's son (who had cancer, not Covid), and watched that on the computer where normally I would have been in [name of town], taking part. It's got a lot to answer for'* [11/148-14/09/20]

Temporal jeopardy made the denial of touch and proximity particularly poignant for those expecting new family members. Dorah had Motor Neurone Disease, a progressive life-limiting condition. In her survey response, she wrote: *'I am expecting a new great grandchild any day, it will be sad not to be able to hold her'* [S434-23/09/20], while community OT Veronica spoke of her distress at the irretrievable loss of early bonding time with her grandchildren:

> '*You know, I have seven grandchildren, and I haven't seen them. I think my youngest one was on five ounces of milk, and then you get on social media and he's eating mince and dumplings and, do you know what? I was heartbroken. And I thought: "I can't get that time back"'* [18/178-24/09/20]

Mental health therapist Maggie was visibly upset when she described being unable to share in her daughter's pregnancy:

> *'my daughter got pregnant at about April time [...] 'We couldn't see that she had a little bump growing, though we were talking to her all the time [online]. And she was just keeping it secret, thinking: "I'll be able to tell everybody when it opens up again". And, of course, it didn't open up. And then when we did start to, kind of, edge our way back, she's like: "You need to keep your social distance". And we all thought she was being a stickler for social distance, but all the time she was pregnant and hadn't told anybody. So she's six months now'* [12/303-17/09/20]

4.4.7 Adapting to forced avoidance of social touch

For Dave, a GP practice manager and church deacon, adaptation to forced avoidance of proximity evolved in a way which affected and reflected a change in his personality which was accompanied with a sense of sadness and loss. In his 2020 interview, he observed himself and others consciously overriding their usual personal hexis for the purposes of keeping self and others safe:

> *'…that cognitive process, how you actually see people physically responding, moving – people are a lot more mobile. And they're stepping back from people. And if you go into their space, how they quickly move back. The physical space around us, in supermarkets and doctor's waiting areas, we've lived with each other and allowed people to come into our space without question, but now we're getting very protective: "This is my safe zone and don't you dare come into it, cos you might give me some nasty virus". It's amazing how quickly we've adapted, but I think there's something quite sad in there about how we are adapting so easily and readily. And that human touch – I'm a handshaker and a hugger, that's just who I am. I like to stand close to people and talk to them. If we're having a conversation I like to be in close: "It's just us two in the middle of a busy crowd, I'm going to be in close so you think I'm just there for you" sort of thing. That's me. Having to adapt to physical distance, I wonder, what are we going to lose as human beings long-term?'* [13/203-18/09/20]

Dave was severely ill with Covid and was hospitalized for six days in January 2021 [13/4X-04/04/22]. When interviewed again in 2022, Dave described himself as *'a different person'* and observed how his more introverted self was embodied in the way he instinctively avoided proximity and touch:

> *'I think I am a different person. I'm very mindful of distance between myself and others. And I get really uncomfortable when I think people come too close now. Like,*

> *we had to go [shopping] on Saturday afternoon. My wife had to go to Marks and Spencers to get some clothes for her mum who is housebound now – and oh, wow! I hate it! You know, I'm so uncomfortable in spaces like that. Church – if I wasn't, sort of, you know, in my garb, up on the sanctuary, I think I wouldn't be able to cope in the body of the church, even social distancing'* [13/313X-04/04/22]

Habituation to the denial of communicative touch was indicated amongst some of the 464 survey respondents. The statement: *'I am able to live my life just as easily without touching people'* was an option chosen by 78 respondents (16.8%). In their open-ended responses, two survey respondents described the new rituals they had adopted to replace touch-based greetings. The 'elbow bump' was adopted by a respondent who had speech impairment and received domiciliary care due to Motor Neurone Disease [S404-23/09/20] and a mobile sports therapist, who wrote:

> *'It is a bit of fun and just eases the awkward moment when meeting people and new clients'* [S282-02/09/20]

Another survey respondent who had a speech impairment and received domiciliary care wrote that they had adopted another ritual:

> *'I like to greet by folding hands like the Indians do when saying Namaste'* [S405-23/09/20]

A survey respondent (who did not identify as a care giver or receiver) wrote of alternative sources of comforting sensory stimulation and companionship:

> *'I do miss hugs. But I am happy that there are good reasons at the moment for avoiding them. I find doing things outside (swimming, walking) with others gives a different kind of intimacy that I find satisfying'* [S319-11/09/20]

In her interview, hospice therapist Sally said she and a colleague had observed an internal behavioural change to accommodate the forced deprivation of touch, and wondered if this habituation would become permanent:

> *'[My colleague] and I were just mentioning the change within families. Because she said that when her mum left the house, normally she would always give her a kiss and a cuddle. But she's not doing that even though they're in a bubble* [a government-sanctioned arrangement which allowed limited household mixing for support purposes]. *And I'm aware of that with my mum and dad, that we're doing things differently. It'll be interesting to see if that sticks around'* [16/303-22/09/20]

4.5 PROXIMITY AND TOUCH IN CARE PRIOR TO RESTRICTIONS

The effect of forced denial of proximity and touch in the personal and social sphere, as described above, inevitably followed both caregivers and receivers of care into their interactions in the health and care context. To fully appreciate the impact, I will first consider the role of touch and proximity prior to the imposition of restrictions.

4.5.1 Pre-restriction patient care

Survey respondents who worked in health and social care indicated an almost universal use of touch to communicate in their roles. Respondents were asked: *'In your healthcare role, do you normally use touch when you are communicating?'* and 96.5% (272 respondents) selected one of the following responses: *Yes, instinctively'* (47.5%, 134 respondents)*,* or *'Yes, if the situation requires'* (48.9%, 138 respondents).

Appropriate proximity and touch becomes even more important in the health context when emotional factors can be heightened and sensory and/or cognitive factors can be in deficit. Namaste Care (Simard & Volicer, 2010; N. Kendall, 2019) is a specialised multisensory therapy developed for people with dementia. It engages touch, smell, vision, and hearing to create an 'I-thou' connection as expressed by Buber (1986 [1958]). This approach underpins a culture of care which conveys the message 'you are loved', central to Validation Therapy (Feil & de Klerk-Rubin, 2012), an approach where communication meets intervention. With this approach, the practitioner ascertains the level of consciousness through which the individual prefers to connect. This could be through sensory stimuli which trigger memories, or through noticing what happens in the moment. Proximity and touch are useful tools which help the practitioner to 'take the emotional temperature' of a person, which then allows them to amplify their client's positive feelings or to explicitly acknowledge and defuse difficult feelings.

Below is a vignette of an episode of Namaste Care as practised by interview participant Sally, which not only illustrates the centrality of proximity and touch in pre-pandemic patient-carer interaction, but also expresses how being seen to be engaged and empathetic through touch builds and sustains the relationship with the patient's family.

Vignette 2: Sally

Sally calls in on Mary Wilkinson every week. She tries to make it same time, same day, to provide some sort of rhythm for Mary to hold on to – though her dementia has progressed to a point where time is of little consequence, it's Mr Wilkinson who really benefits from the routine. He looks forward to Sally's visits as a lifeline and a comfort, a balm to Mary's moods and a respite from the loneliness of his love which, though unstinting after a lifetime together, has taken on an intensity of a different kind – dependence, confusion, emotional and physical exhaustion. But he refuses to be called Mary's carer. Bob Wilkinson is steadfastly her husband, till death.

Mr Wilkinson opens the door to Sally, who subconsciously scans his face, his posture, to assess the atmosphere and to adjust her own body language and voice accordingly. Sometimes Bob answers the door cheerfully, drying his hands on his apron – he's been getting on with the kitchen chores while his wife sits contentedly in the conservatory, watching the birds. But sometimes he answers the door red-faced, out of breath, tension in his shoulders, arms, and legs: maybe there's been a struggle of wills, maybe Mary has been so afraid of the strangeness of her world

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that she’s defended herself from an imagined threat. Today Bob is smiling, excited to tell Sally of his wife’s delight at a robin’s antics at the bird table. This gives Sally the green light for a heartfelt beaming smile, and an idea for today’s therapy session… Mary loves a particular piece of music which features birdsong, and a hand cream scented with lavender and rose. Maybe after a hand massage there will be time to browse through Mary’s favourite book: The Country Diary of an Edwardian Lady, or to open the box of acorns, conkers and crisp golden autumn leaves she’s brought with her so their colours and textures can be enjoyed.

But she’ll make no assumptions. Piecing together the story of Mary’s life began before their first meeting, and it’s an ongoing process, both as their relationships develop and as the dementia progresses. She always checks in with Bob first, listening carefully to what he has to say with his words, his tone, and his body language. This helps Sally evaluate the needs of both halves of this couple.

Sally walks calmly into the conservatory, making sure she doesn’t startle Mrs Wilkinson. Though Mary rarely verbalises through spoken words anymore, Sally listens with her eyes: she’s learned over time that, for this lady, a lowered head, pale face, stillness and extreme quiet indicates she is in pain; if Mary avoids her gaze, sighing and frowning, it tends to indicate that she’s anxious or angry. Approaching from the front, she softly says: “Hello again Mary, it’s Sally. What a

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beautiful day it is!" Taking her time, watching Mary's face and posture for cues – maybe not of recognition, more of acceptance of a benign presence – Sally gets really close, her soothing voice connecting before her hand does, reaching to rest on Mrs Wilkinson's arm. Up close, in Mary's central vision, foreheads almost touching, Sally's kind eyes gently catch and hold her gaze. They exchange spontaneous smiles.

Drawn from 16/58-22/09/20; 16/65-22/09/20; 16/67-22/09/20; 16/339-22/09/20

The way Sally engages with both Mr and Mrs Wilkinson also includes mirroring (Bastiaansen, Thioux & Keysers, 2009), a universal neurological reflex action whereby seeing the emotions of others recruits regions in the brain involved in experiencing similar emotions. Positive communication outcomes can be achieved when mirroring is integrated with, and modulated by, higher cognitive functions through the application of an understanding of context and intent. Modulated mirroring is part of the hexis of communication which facilitates human relationships and which, in healthcare, is part of the craft of care itself. When cues are limited – for example, when vision, hearing, or speech are impaired – adaptations are made which exploit the senses which remain, such as touch, and alternative languages emerge.

One survey respondent who worked as a massage therapist wrote of the reciprocity of touch interactions: they *received* comfort from *giving* comfort: *'My job [...] also calms and grounds and centres me'* [S173-26/08/20].

Some interview participants chose to give detailed accounts of the centrality of touch in their interactions prior to the imposition of restrictions as a way of illustrating how communication in the care sphere had changed as a result of its denial. Visual impairment charity chairman Eddie, himself completely blind, described the importance of voice and touch when establishing and maintaining relationships, including specifically those with medical professionals:

> *'...you meet somebody for the first time: "Hello Eddie" – I can tell by their voice, I can just hold my hand out and nine times out of 10 I know they're gonna take my hand and shake it. That tells me a heck of a lot about that person and about how we're going to get on, if I'm chatting to them, or whatever I'm doing'* [17/375X-13/04/22] *[...] 'The touch thing is – it's really very, very personal between them two people. You know, I can tell when somebody wants to shake my hand, just by the tone of their voice. I've got this listening skill. It's like a verbal body language'* [17/386X-13/04/22]

A similar observational skill was described by perinatal mental health nurse Beth. She relied on proximity to environmental cues in patients' homes to pick up on essential non-verbal signals which had potentially life-threatening consequences if missed:

> *'...that observation – so just from a risk point of view, in terms of seeing mum and baby together, or from a domestic violence point of view [...] you don't get that atmosphere [if denied home visit]. And as a professional, you can cut that atmosphere with a knife sometimes when you go in that person's home, even if they put on their best face. And even if you never see the partner, or whoever it might be perpetrating that kind of abuse, you could feel it. And you don't get that. You don't get that on video, and you don't get it on the phone'* [23/72-05/10/20]

4.5.2 Pre-restriction inter-professional communication

Of equal importance to patient-carer interactions are those which take place between caregivers. Enactments of professional collegiality sustain both the worker and the service they help to provide (Cribb, Entwhistle & Mitchell, 2022). The significance of informal and taken-for-granted 'catch-ups' between staff has been identified by M. Adams, Robert, and Maben (2013), who describe how good quality of care and good staff morale is linked to the provision of opportunities for staff to informally converse. Perinatal mental health nurse Beth, whose geographical area of practice covered approximately 2,000 square miles [23/253-05/10/20], described in her 2020 interview how informal in-person interactions with other health professionals had been central to patient care and the maintenance of a successful service:

> *'There was a midwife that took a specialist interest in perinatal mental health before our team opened, because our team's three years old at the end of this year, so it's a real baby team when you think about the beast of the NHS. But this midwife laid the groundwork, she laid me a red carpet before I started this job and it made it so much easier. And there is not one other service area that our team covers that matches it'* [23/302-05/10/20] *[...] 'but because that buy-in, and investment, and all of that groundwork had been done before I even joined the job, all I had to do was keep it going. Well, I quite like a chat, so I'm pretty good at networking, and it's kind of been a big part of other jobs that I've done previously. So I've just continued doing that. But it was made easy for me to do that. I didn't have to argue the case for my job. I didn't have to justify why I was taking a 20-minute slot from a health visitors team meeting because they've got a million other things they want to discuss. They wanted me there, and they invited me half the time. [...] One of the senior midwives that I meet regularly with every six weeks, we try and meet just to discuss... we've caught quite a few near misses over the couple of years just by having that time to talk. And it wasn't even a patient I had on my list, or necessarily somebody she thought was*

> *worthy of our team, but just that conversation, bouncing ideas off each other, and that opportunity – which you just wouldn't, you don't, set up a meeting for, do you? "Opportunity of Conversation" – you don't set that meeting up on Teams. You set up a meeting, and then you find out other stuff because you get chatting and you have a cup of tea. That's been invaluable'* [23/311-05/10/20] *[...] 'Just the informality of not having to follow an agenda and just letting your own cogs turn, professionally, and sharing what that means'* [23/334-05/10/20]

In a review of studies of power dynamics in interprofessional healthcare teams, Okpala (2020) identified how direct communication in a receptive and responsive environment attenuates the inevitable power imbalances which result from the orthodox medical hierarchy. Deborah, a GP, described a pre-pandemic lunchtime ritual which brought together everyone who worked at her surgery, without agenda:

> *'One of the things I really liked about my practice was that every day, we used to have a lunchtime coffee, you know, regardless of what else was going on, unless something that really couldn't wait [...] but nine out of 10 of us would all go upstairs at quarter past 12. We'd down tools and go and have 10 minutes'* [33/279-10/11/20]

It can be concluded from these participants' stories that proximity and touch are central to the health and social care communicative landscape. I now consider how rules which prevented and occluded touch affected communication in this sphere.

4.6 TOUCH IN CARE IN THE PRESENCE OF RESTRICTIONS

4.6.1 Impossibility of touch avoidance in care

Before considering the altered nature of care caused by the need to avoid touch, I first consider how the nature of caring means that sometimes it is impossible to avoid physical contact and proximity. Sensory input provides professionals with the knowledge they need to make diagnoses and care for their patients/clients. Survey respondents with diverse roles wrote of the unavoidable physicality of their jobs including a staff nurse in forensic mental health [S198-28/08/20], an adult learning disability supported living worker [S270-02/09/20], a physiotherapist [S420-23/09/20] and a massage therapist [S204-30/08/20].

Participants who worked in health and care often reported that their situation demanded the conscious and justifiable infringement of the rules. Veronica, a community-based specialist Occupational Therapist specialising in older people's mental health, described a situation where she decided that touching a dementia patient was a risk worth taking because of the damage that would have been done by refusing touch:

> *'...if somebody is functioning at a sensory level, it's not about the verbal. It's about touch. They want to touch. I sat the other day with a particular client. I assessed this lady as functioning at a sensory level, and this lady just couldn't get close enough to me. And I'm like: "You know what? I cannot push her away. I know we have the social distancing but if I push this lady away, she's going to disengage, and she won't understand why'. So to me, the risk was worth taking, even though I'm in PPE, but I sat there and this client was just doing that [indicates caress], constantly smiling and touching my hair, and I'm... [indicates reciprocated smile] So how can you not? We've got to have that contact'* [18/264-24/09/20]

4.6.2 Clinical touch as a proxy for social touch

The denial of social touch placed a greater emphasis on those situations where touch could be justified on 'official' grounds. Over a third of the 282 survey respondents who self-identified as health or care workers (41.1%, 116 participants) agreed with the statement: *'A comforting touch means more now than ever'*. The power of comforting touch from a health professional was described by Barbara, who reflected on a message from a friend in Australia who described the emotional release of being touched after prolonged forced avoidance:

> *'She said she'd been to see a chiropractor and when this woman actually physically touched her, she said she burst into tears and couldn't stop. It was the first time since the beginning of lockdown that she'd had any contact, any physical touch'* [11/65-14/09/20]

Specialist pain physiotherapist Vicky described in her interview the powerful comfort of a nurse's touch as she endured a painful and emotionally challenging procedure in the absence of a companion:

> *So, had the mammogram and then went through to see the doctor, there was three of them in there, I think? There was a nurse, and an ultrasonographer, and a doctor. And, basically, they got me on my side, had a look at the mammogram, and said: "There's nothing sinister going on. But you've got about six or seven cysts in there. Some look really old. They've obviously been in there for quite a while but just become reactive". So they said: "Right, we're going to drain them". I was like: "What? Here and now?" "Yeah, best to get it done, especially the fact that it's painful, because they could burst and then they could become septic" and all this kind of stuff. My brain is going: "Phew! Thank God, we can calm down, it's nothing sinister", but at the same time, like: "They're gonna stick needles in my breast!" And oh my gosh, that was uncomfortable. But they were all really good. And*

> *actually, the nurse, who was standing behind me, was kind of holding my hand and rubbing my back, and she had gloves on, and an apron and things. That was so comforting. So I think in those circumstances, it's really needed. She really helped me get through that experience. [That touch], yeah, it meant the world. I think if they hadn't have done that, I think I probably would have felt more uncomfortable. It's just that reassurance, that: "Okay, this is fine. It's okay"'* [25/401-09/10/20]

Survey respondents who had professional touch-based roles described their responsibility for satisfying the public's need for safe comforting touch. A mobile massage therapist described their duty to create a space in which touch could be re-established as a comfort rather than a threat:

> '*As a hands-on therapist I feel it is more important than ever now to continue to touch as I always have. I do not wish to make my clients feel poisonous or toxic and wish to offer them as much comfort as possible'* [S454-16/10/20]

One wrote that, as a wellbeing professional, they were considered as a safe source of needed touch:

> *'I am a massage therapist, so people find this is the only safe way to be touched'* [S445-06/10/20]

This was corroborated by Laura, sole carer for her husband Henry whose Parkinson's deteriorated while they were locked down together. She described how she and her complementary therapist negotiated a mutually agreeable contravention of the rules on the basis of need for tactile relief:

> *'I had acupuncture before we really should have done, because there was a point at which – you know, and she just said: "Are you happy with me doing it? This is what I'm doing". And I said: "Yeah, fine". [...] to be honest, I needed the acupuncture more than... you know...'* [29/509-21/10/20]

An adult learning disabilities supported living worker wrote of how their hugs replaced those of their clients' parents, which carried a weight of responsibility:

> *'The more vulnerable need us to be as 'normal' as possible as they would not understand and cope otherwise. It has been incredibly difficult that their parents are not allowed to hug them, so my hug is essential, however heartbreaking it is'* [S270-02/09/20]

The impact upon the health and care professionals who became proxies for their clients' loved ones, and who were required to interpret the rules when making care decisions, is discussed in the exploration of moral distress in Section 6.3.2.

4.6.3 Quality of touch from a gloved hand

For a notable proportion of the 282 survey respondents who identified as working in care, gloves were worn as part of their PPE: 117 (41.5%) chose the statement: *'I can't avoid touch, so I wear gloves and wash my hands more'*. To ascertain opinions about the quality of touch from a gloved hand, the survey included two opposing statements.

The statement: *'The touch from a gloved hand is not the same as skin-to-skin contact'* was selected by 91 respondents (32.3%). A survey respondent wrote of the different sensation felt from a gloved hand:

> *'I have been massaged both with and without gloves by other therapists and as a client you can feel the therapist's gloves on certain more sensitive body areas such as the legs, and neck, although they are not too distracting'* [S239-01/09/20]

Another complementary therapist wrote that this sensation was off-putting because it changed the perceived intent of touch:

> *'Clients don't want to be massaged in gloves – it feels too clinical, not personal, not comforting, like a medical examination, not relaxing'* [S251-01/09/20]

The dislike of gloved touch extended beyond the context of comfort care, according to a written response from a visually impaired paramedic practitioner in police custody:

> *'People don't want to be touched by a gloved hand'* [S128-25/08/20]

One massage therapist wrote that glove-wearing implied that the wearer considered their client impure or dirty:

> *'Wearing gloves during massage effects the quality of touch and creates a negative emotional response in the client, making them feel "unclean" and that you want to distance yourself from them'* [S047-23/08/20]

The time taken to don gloves was itself a barrier to fluid communication. A hospice-based complementary therapist wrote:

> *'The gloves themselves don't necessarily get in the way of caring touch but sometimes by the time that you find some and put them on the moment for that touch has passed. It has eliminated spontaneity'* [S176-26/08/20]

Deafblind service co-ordinator Charlotte said, for people using hands-on language, the use of gloves prevented a satisfactory transfer of information and also took away the fluidity of communication:

> *'…one client I'm speaking of is a hands-on user […] They liaised with the interpreter they were working with that they would work together during the lockdown period because, of course, without hands-on communication it was going to be difficult. And they agreed they would wear masks and shields as well. And rubber gloves. And when they came to do hands-on communication, the fabric of the gloves just took away from the real human communication […] what they then had to do was remove the gloves, and then use plenty of alcohol gel and sort of gel up 20 minutes before the session just so it was truly effective, and wash hands. And they*

> *really break down communication. The fluidity of "meet, grab, greet, communicate straightaway" had gone, because of all the prep that went into the PPE'*
> [24/110-07/10/20]

Conversely, the statement: *'Gloves don't get in the way of the message conveyed through caring touch'* was chosen by 29 (10.3%). Two therapists – an NHS-based complementary therapist [S034-22/08/20] and a community massage therapist working in palliative care [S277-02/09/20] – described how gloves were not preventing them from giving comfort. The nurse whose touch calmed Natalie during her painful procedure, described in section 4.6.3, was wearing gloves [25/410-09/10/20].

A further nine respondents agreed with both opposing statements: i.e., that gloved touch was unlike skin-to-skin contact, yet also did not get in the way of the message conveyed through caring touch. More than half of the respondents (153, 54.3%) did not select either statement[7].

Twenty-four survey participants used open-ended responses to say they were *not* wearing gloves when touching patients. The reasons for the discrepancy between the rules concerning glove-wearing, the interpretations of those requirements, and the consequences of diverse glove-wearing behaviours, are examined in more detail in Section 5.4.6.

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[7] In Section 7.4 I discuss flaws in survey design and the actions I took to mitigate those flaws.

4.7 DISTANCING IN CARE SETTINGS

4.7.1 In-person care with masks and distancing

Of the 227 survey respondents who indicated that they or someone close to them required care during the pandemic, 116 (51.1%) were seen in person. Of those 116, 75% (87 respondents) were satisfied with their care: 76 (65.5%) indicated that the care they received met their needs, while 11 (9.5%) said it was *'a better experience than before the pandemic'*. Dissatisfaction with the experience was expressed by 29 respondents (25%): 23 (19.8%) said their in-person care only *'partly'* met their needs, three (2.6%) said it was *'better than nothing'* and a further three said care did not meet their needs *'at all'*.

Almost half of the 282 survey respondents who identified as health or care workers indicated that they needed to expend extra energy to avoid touch in their care communications. I analysed the responses to four statements which were offered in response to the question: *'How have you managed the need to avoid touch when communicating in your role at work?'*. Two statements indicated that the respondent felt an extra burden arising from the effort required: 125 respondents (44.3%) selected: *'It is harder to do my job without being free to use caring touch to communicate',* and 54 (19.1%) chose: *'I have forced myself to avoid touching people'*.

Carer support worker Liz, who specialised in learning disabilities, described how the couple who communicated with their daughter through loving touch (described in section 4.4.2) found that gloves and distancing deprived them of their ability to soothe and de-escalate. Liz said:

> *'…when the person couldn't even touch properly, and there wasn't that skin-to-skin touch, I think that became more – because it was the only thing that sometimes would work to bring this person down from where they were, and they weren't being able to do that properly'* [10/201-14/09/20]

Clinical practice was adjusted to adhere to distancing rules and recommendations. This resulted in a different care experience for some patients. A survey respondent wrote that, during an in-person interaction with a doctor, there was *'no physical exam when really there should have been'* [S461-26/10/20].

In her interview, ITU dietician Natalie described the lengths to which she and her colleagues went to avoid proximity when delivering in-person care:

> *'…this is a pure example of how crazy it got at one point – looking through a window that had a half-shut blind on it, trying to see a patient and work out their weight. It was like: "This is just as crazy as it gets, I might as well pull a number out of a hat here!" So what you would do is, if anyone was going in, you'd kind of get on the walkie-talkie, say: "Can you just see if you can maybe have a bit of an estimate of what they weigh?" Then I'd have a little look and go: "You might be right, yeah!"'* [26/463-13/10/20]

Urgent care advanced nurse practitioner Louise also described how she avoided entering the care homes she visited:

> *'…my last encounter was stood at the door, talking to the manager, who was showing me a picture on her phone of the patient's rash so that clarified my diagnosis, and we could go with a treatment that didn't involve me going in'* [34/62-10/12/20]

A benefit of the extreme measures taken to minimise proximity in in-person interactions was the efficiency with which individuals were processed. Nine survey respondents wrote of this efficiency. However, the trade-off was a perceived lack of empathy, exacerbated by the presence of PPE. One survey participant wrote:

> *'A visit to A&E for stomach pain, it was more efficient than previous visits but a dehumanising experience [...] It's not something I wish to experience again and would avoid going at this present time'* [holistic therapist, S089-25/08/20]

4.7.2 Forced separation in medical and care settings

Whilst rules on proximity and in-person interaction fluctuated over time in the general population, there was little change in the way rules were enforced in medical and care settings. Whether due to national laws or the interpretation of guidance by Trusts and social care providers, the effect was that no-one could accompany outpatients attending medical appointments alone, while in-patients were not allowed visitors. The adverse effects on patients and their families were identified in a review by Hugelius, Harada & Marutani (2021): patients' anxiety, pain, nausea, nutrition, and personal hygiene were less well-managed without a visitor on hand, while family members experienced sadness, anger, and guilt at separation. The use of video and telephone calls to replace in-person proximity offered more flexibility and instant accessibility for some, but remote methods of contact were less useful if the patient or their relative found difficulty participating. Relations between family members, and between relatives and staff, suffered because it was harder for families to appreciate the patient's condition and their care environment.

Maggie and her mother experienced the benefits and limitations of remote contact when her father was in an oxygen hood in intensive care with Covid. Whilst the pre-existing connectedness afforded by smartphones and social media made her father as accessible to his friends and family as before he went to hospital, he was less able to contribute to the conversation and he was disconnected from his wife whose dementia meant she was unable to make sense of the image on the screen. Maggie said:

> *'We made FaceTime work with his hood. We couldn't always hear the things that he was saying, but he could make out what we were saying. His grandchildren – they've got six grandchildren who are all grown-ups – they were all FaceTiming him*

> *and keeping his spirits up. Some of his mates were FaceTiming him, and we were FaceTiming him'* [12/198-17/09/20] *[...] 'So my mum's waving, she hasn't got a clue where my dad is, she's going: "Where's he at?"'* [12/208-17/09/20]

For several participants, these issues manifested themselves in maternity care. The non-birthing parent could not attend maternity appointments and was not allowed to be with their partner until labour was fully established, while the wider family could not be part of the life-changing event or step in when things went wrong. Perinatal mental health nurse Beth and her partner, Jack, had been trying for a baby for a year prior to the pandemic, during which time Beth had suffered a miscarriage and an ectopic pregnancy [23/222X-14/04/22]. During her lockdown pregnancy, Beth had gestational diabetes [23/14X-14/04/22], but Jack had not been allowed to attend any of her appointments [23/495-05/10/20]. Care home manager Alex became a mother in March 2021 but, as the non-birthing parent, she was separated from her labouring wife until the final stages:

> *'I was there for the birth'* [14/282X-03/05/22] *[...] 'I had to wait in the carpark until she was on the labour ward. But eventually I was allowed in and, you know, again, face masks. Lovely. That's what you want on your picture. Your first photograph with your child is, you know, chilling out in a load of PPE'* [14/284X-03/05/22]

It was always the intention of carer support worker Paula to be a birthing partner for her daughter, but the hospital only allowed the father to attend when the baby was born in August 2021. When the birth became complicated, the wider family was unable to support the couple:

> *'She was always saying: "Well, you'd have to be there, mum, because Kevin [daughter's partner] would just fall down flat!" You know: "You'll have to be there, mum!" It was always kind of the thing, you know? But that wasn't to be'* [09/374X-12/04/22] *'...for most of the labour he was outside in the car, paying a*

> *fortune in the car park' [09/406X-12/04/22] […] 'she had a very, very bad experience in labour. I don't know all of it, because obviously I wasn't there, so it was just… But they did rush her to theatre'* [09/379X-12/04/22]

The prolonged enforcement of distancing meant Maggie's daughter, who had her baby prematurely in the winter of 2020, experienced similar traumatic isolation in childbirth and postpartum. Maggie said:

> *'…she's got a condition so she had to stay in and be monitored. For all that time, the dad could come in and see the baby, but couldn't come in to see her because of the cross-contamination. So she was in hospital for over a week, and hadn't seen her partner at all, just had to FaceTime him. It was really awful. It was really hard for them…'* [12/348X-08/04/22] *[…] 'It's at a time of their lives where they need that bit of support, don't they? They need somebody with them. It should be happy time. It definitely wasn't. It wasn't. And there was story, after story, after story, of young women having their first babies having a really hard time of it'* [12/367X-08/04/22]

4.7.3 Distancing affects inter-professional interactions

The need to meet colleagues in person was assessed as unnecessary in most circumstances for those participants who worked in health and care. Office-based tasks moved into health and care workers' homes, blurring the boundaries of home and work life. Physiotherapist Gary said:

> *'I think I really see the importance of work now, of actually getting up and going to work rather than just spending my day in my pyjama bottoms'* [30/96-22/10/20]

Online communication methods were adopted for inter-professional conversations, even for those working in the same building. Earlier in this chapter (4.5.2), GP Deborah described how her team's cohesion was fostered by social proximity. In her interview, she went on to explain how this was adversely affected:

> *'…we're just not seeing each other. Work has become so much less fun'* [33/278-10/11/20] *[…] 'now we don't do [lunchtime coffee], because we're not all allowed to gather, social distancing. And that's really sad. Because we just don't talk to each other anymore really. We have a virtual Teams meeting, much like this, but with 10 of us on the screen, which is quite difficult to manage because you can't have the same chat in the same way. It's more – much more – business: of "this needs doing, that needs doing", you know? People who need to speak get to speak, but there's no chat. And I think as a team, we're a lot less cohesive. And you don't get any of that – just that camaraderie'* [33/284-10/11/20]

Remote methods also made it harder to hold challenging conversations with colleagues. Gary said:

> *'I like things to be done properly […] it isn't being done properly, and you cannot go knocking on these office doors for to try and hold them to – you can whinge at them, but you cannot just grab them over the phone'* [30/194-22/10/20]

As time passed and 'work from home' requirements were eased, online meetings were retained by many as a convenient resource-saver. By the time of the second interviews in 2022, the British economy was struggling, not least due to the energy crisis (Bolton, 2024) caused in part by Russia's invasion of Ukraine. A combination of online home working and office hot-desking saved Paula's carer support charity both time and fuel and allowed it to downsize its premises. Paula said the change would mean the team would never be all together in the same space, but that the majority were happy with the arrangement:

> *'So we're never going to all go back in the office in one go any more […] 'we're on two floors. If we condense that down to one floor, and hot desk... And most of the*

> *staff, I think ninety [per cent] – most – were quite happy to continue hotdesking'* [09/26X-12/04/22]

In 2022 therapist Maggie reported a loss of cohesion in her Eating Disorders Team because of permanently distanced inter-professional communication:

> *'I've been working in this team now for two years and I still don't know people in the team. And it's a small team. And that's because we have no face-to-face meetings […] I'm part of the senior leadership team so I should know everybody in the team, but there's been a number of staff that have left and a number of new staff that have come in. And because we're all like ships that pass in the night, some people are at home, some people are at work, and now we're on a rota. And again, when we're in the office, everybody's in masks. So you don't get to know people, you don't gel like a team would gel, just because you haven't got that physicality […] people have been asked on the big team meeting to leave their cameras on – because it's easy to turn the camera off […] just so that people can see who people are'* [12/156X-08/04/22]

The participants' stories make it clear that relationships between colleagues suffered as a consequence of distancing, but it also had a profound effect on the relationships between professionals and patients, which I examine next.

4.8 REMOTE CARE

At the outset of the pandemic, telephone contact became the default method for patients to initiate and conduct healthcare interactions. In-person appointments were reserved for instances where the case had been triaged and the contact was deemed clinically necessary. Video consultations, which had been pioneered prior to the pandemic for people in remote areas, also became more available as the adoption of technology became prioritised.

4.8.1 Telephone consultations

Having the patient in the room provides medical professionals with valuable diagnostic information, even if touch is avoided: the non-verbal behaviours associated with demonstrative suffering give information about symptoms (Heath, 2002), gaze and body orientation at the beginning of a consultation can set the agenda for a the doctor-patient consultation (Robinson, 1998), and non-verbal communication can motivate patients to open up with valuable information about concerns not directly related to the ostensible reason for the consultation (Duggan & Parrott, 2001). The sense of smell provides rich diagnostic cues (Shirasu & Touhara, 2011) and can signal when a person is intoxicated or failing to self-care. Remote medicine – consultation by telephone or video – entirely deprives the clinician of these sensory cues. Eddie, who was blind, described how he imagined a clinician conducting a phone consultation would be ‘working blind’:

> *‘…the thing is, when he’s on the phone to me, talking to me, he’s blind as well’*
>
> [17/41X-13/04/22]

Complex cognitive and communicative skills were required to remotely conduct diagnostic procedures which would normally require touch. Louise’s experience in telephone triage in her work as an urgent care advanced practitioner was established prior to lockdown. In her interview, she described how she and other practitioners conducting a remote consultation would touch their own bodies as a proxy for in-person tactile interaction to satisfy their haptic hexis – a need for sensory cues to place the practitioner 'with' the patient:

> *'…having to talk a parent through remote examining their child's abdomen'* [34/68-10/12/20] *[…] 'It's a good job they can't see us! If I'm describing to a parent how to feel it, I'm touching my own abdomen, explaining it as I go through, because I think we have to feel it to describe it. Or maybe sometimes see it. So things like having something written down, or something in front of you, or watching something, or looking at something before you have a conversation – or actually doing it in reality, even though they can't see you. And we're probably quite animated when we're doing triage, even though no one can see us'* [34/917-10/12/20]

From the perspective of the clinician, telephone consultations could free them from the discomfort of their PPE while patients would not be distracted by the artefacts. *'I prefer to conduct difficult conversations by phone so people are not distracted by the way I look'* was chosen by 37 of the 282 people who identified as health workers (13.1%). However, the discomfort and distraction of PPE would persist if calls were being made in an environment which required them to wear it, as in the case of Natalie, who described an incident in her dietetics clinic:

> *'I had a lady who was Syrian in an outpatient clinic. So I had a translator on the phone [laughs] […] I had my mask on. So I'm trying to shout over the phone to try and get myself heard to this translator, she's kind of trying to translate back, and it was a bit of a nightmare, to be honest'* [26/66X27/04/22] *[…] 'I find telephone calls very difficult with a mask on'* [26/73X-27/04/22]

Of the 227 survey respondents who indicated that they or someone close to them required care during the pandemic, 71 (31.3%) indicated that they received advice over the phone as an alternative to an in-person consultation. Of those 71, the interaction was not satisfactory for 69% (49 respondents): 16 (22.5%) said their needs were only *'partly'* met, 18 (25.4%)

chose the statement *'it was better than nothing'*, and 15 (21.1%) said their needs were not met *'at all'*. Satisfaction was reported by 31% (22 respondents): 17 (23.9%) said the interaction met their needs, and five (7%) said it was *'a better experience than before the pandemic'*.

A survey participant described how reliance on her mother's understated description of symptoms led to a serious problem being missed in a telephone consultation:

> *'Elderly mother, severe sudden pain and swelling in leg, it was hard as doctors not coming out or seeing anyone, spoke to my mum by phone and mum made it sound unimportant [but] it was, ended up going to A&E, turned out to be DVT' […] 'no-one had viewed her condition, only me'* [S249-01/09/20]

The disconnected nature of a telephone-based clinical relationship could be exacerbated by something as simple yet profound as a missed call, as described by this survey respondent:

> *'I missed the phone call of my son's important paediatrician appointment. They gave a five-hour slot but I was at work one hour of it. I hoped they would ring in the other four hours, but I missed call'* [S341-14/09/20]

Clarity of verbal communication was a barrier to telephone care. A hearing-impaired survey respondent wrote:

> *'I can't understand doctor on phone, and as such I'm still awaiting a prescription'* [S147-26/08/20]

A survey respondent who required an urgent outpatient gastroenterology appointment wrote:

> *'I did have a phone appointment, but my consultant did not speak English as his first language, so it was actually harder to understand his accent over the phone. Had we spoken in person then I would have found it easier to communicate and also to show him where the pain was. I also felt rushed for time during later phone appointments,*

> *but I appreciated he was busy. Had we had an in-person appointment, though, I would have felt I was more closely assessed'* [mobile reflexologist, S278-02/09/20]

For some survey respondents, the content of the telephone consultation was sparse:

> *'I could only have a GP telephone appointment and had to diagnose myself and the GP simply agreed as to what I thought my problem is. I may as well have Googled my symptoms'* [S286-02/09/20]

Concerns over the lack of non-verbal communication were exacerbated by issues of confidentiality. A detention centre custody officer who was also a mental health patient wrote in their survey response:

> *'I need regular psych care. All appointments are now over the phone which I find difficult because I can't see the person and I don't know who else is listening'* [S320-11/09/20]

A survey respondent wrote of how their husband could not have a confidential conversation about his bladder problems:

> *'My husband has difficulty speaking on phone so I had to speak on his behalf. A face-to-face appointment would have been better for him'* [S429-24/09/20]

Payne et al. (2023) conducted a study of 95 safety incidents which arose from remote consultations and combined it with an ethnography of 12 GP practices to ascertain the factors which prevented those harms most of the time. Harms occurred when remote consultation was an inappropriate choice for the case, and/or when inappropriate triage algorithms were used. The triage and care pathways were themselves complex, hard to navigate and involved multiple staff – all factors which contributed to reduced safety. Other key factors identified as contributory factors were poor rapport building, inadequate information gathering, limited clinical assessment, and inadequate attention to social circumstances. Those who were most vulnerable to harm were patients with complex pre-existing conditions, cardiac or abdominal emergencies, and/or vague or generalised symptoms. People who had difficulty communicating, those with safeguarding issues, and patients who had failed to respond to previous treatment seemed especially vulnerable. The study identified GP practice resource constraints, understaffing, and high demand as consequential obstacles to staff performance, while patients often owed their safety to individual staff taking initiative, challenging decisions, or personalising solutions. Payne et al. (2023, p.10) provide guidelines for minimising risk in remote consultations, including a recommendation to default to in-person interaction for those with pre-existing communication barriers such as autism, deafness, or the digital divide, and to follow up a remote consultation with a written resource such as a text or a leaflet. They also suggest a checklist for patients and their carers to help them negotiate the consultation, including a list of conditions which are most likely to require in-person attention in the first instance.

Participants also identified positive aspects of telephone consultations, particularly the efficient management of routine issues:

> *'Medication review for hypertension. Chat on the phone. Saved time going to GP surgery'* [S326-11/09/20]

Interview participant Barbara said of remote consultations:

> *'I'm more than happy to have a face-to-face over the internet, or a telephone consultation. I don't have a problem all with that, at all'* [11/335-14/09/20] *[...] 'It saves me time and effort and polluting the atmosphere with my car'* [11/386-14/09/20]

Telephone consultations made experts more accessible, as was the case for this visually impaired asthma patient:

> *'The consultant who I hadn't expected to get attention from so quickly (considering the need for them by others), spent a long time on the phone with me, prescribed me different medication which has worked, they were marvellous'* [S304-08/09/20]

Telephone consultations which were described as successful by participants had in common a sense of being unhurried. Geoff, who was living with Motor Neurone Disease (MND), said in his interview:

> *'Well, our experience through the lockdown has been that instead of the three-monthly clinic for MND, which would be at [major hospital] in [northern city], we've had a three-monthly telephone call with the consultant'* [27/32-19/10/20] *[...] 'The consultations were lengthy, detailed, and in no way time-constrained, you never felt that you were under pressure to finish and let her get on to the next call. And generally, they were 40 to 45 minutes each time. So I always felt happy that we'd covered everything we needed to cover'* [27/32-19/10/20] *[...] 'I think the patient doesn't want to feel that he's imposing on their timetable. You are part of the timetable, but your element of the timetable is as long as you need it to be. And I think that does need to come across. But it has done to me'* [27/403-19/10/20] *[...] 'If I wasn't finished, it wasn't finished'* [27/410-19/10/20]

Physiotherapist Gary, who switched his pain management programme from in-person group meetings to one-to-one telephone consultations, said he was reaching more patients without detriment to outcomes:

> *'The patients prefer it, mind'* [30/155-22/10/20] *[...] 'And there's positives. We've engaged with people who would never have come to a group at all'* [30/157-22/10/20] *[...] 'I think it will change practice moving forward'* [30/169-22/10/20] *[...] 'today, I've done two-monthly follow-ups, and every single one of them's improved. And quite, quite a lot'* [30/173-22/10/20]

The efficiency and effectiveness of remote consultations were identified by K. Campbell et al. (2023) whose systematic review identified them as equally effective as, or more effective than, face-to-face care for the management of certain conditions including mental illness, excessive smoking, and alcohol consumption. They concluded that it could reduce waiting times, and lower patient costs, but they had concerns about socioeconomic equity and the digital divide.

Participants identified factors which affected their remote interactive experience which were specific to audiovisual consultations.

4.8.2 Video consultations

The statement: *'I prefer to conduct difficult conversations online so people can see my face'* was chosen by 58 of the 282 health and care workers (20.6%). Of the 227 survey respondents who indicated that they or someone close to them required care during the pandemic, only five (2.2%) indicated that their interaction took place by video instead of in-person. Of those five, two said the consultation met their needs, one said it was partly successful, one selected the statement *'it was better than nothing'* and one said it did not help *'at all'*.

For one hearing-impaired survey respondent whose reactions to the sight of PPE was extreme enough to make them housebound, they described their video consultation as *'great'*:

> *'I have had a video call follow-up which was great rather than having to sit in traffic for time and pay for parking, so I am pleased that service was newly available where it was not before Covid-19'* [S442-30/09/20]

Laura, who was the sole carer for her husband who had Parkinsons, preferred having counselling online compared to being in-person because it was intimate and allowed for on-screen sharing of materials:

> *'I've had three months of counselling via Zoom and it worked perfectly. In fact, I think personally, it was better, possibly, than being in the room'* [29/117-21/10/20] *[...] 'we were sharing things on the screen, which in some respects was easier [...] And it just seemed so much easier than a bit of paper that you would try to share between you [...] she didn't have to keep printing it out and having a copy and looking at a copy [...] '"Come on", she says: "Because I can see you're getting upset", because we were quite close and your face obviously fills the screen [...] 'And we'd both have a cup of coffee, or a cup of tea'* [29/123-21/10/20*] [...] 'It just seemed to work really well. And I think in some respects as well, I think because possibly you're at a distance you felt a little, I don't know, bit more comfortable'* [29/134-21/10/20]

However, the usefulness of video consultations was limited to those who could fully engage in the interaction. Interview participant Veronica, whose OT role specialised in older people's mental health, described futility of attempting to conduct cognition assessments via smartphone video call:

> *'I've had enough. Trying to do assessments via phone. Occupational Therapists cannot do that. And that's what we were asked to do. How can we do that? You've got an elderly person on their daughter's iPhone or whatever, iPad, and all I got was the top of their head, then the carpet, and then the phone goes off. And then after an hour, I thought: "I can't do this"'* [18/170-24/09/20]

4.8.3 Asynchronous support and self-care

Of the 227 survey respondents who indicated that they or someone close to them required care during the pandemic, 25 (11%) said they did not interact with a care professional. The statement *'I dealt with it myself'* was selected by 19 (8.4%) respondents, while six (2.6%) indicated that they followed advice from an NHS website. Two of the respondents who used the website said it was *'a better experience than before the pandemic',* though one of those went on to describe how the website interaction ultimately resulted in the arrival of paramedics and a hospital admission.

Louise said that, though she and her fellow clinicians were glad that self-care had been adopted, they were afraid that fear, rather than level of need, was the factor which was making patients eschew professional help. They feared that they were not seeing people who required their help:

> *'they [i.e. patients] don't want to go to hosp- they don't want to bring them, because they're scared. So in a way, it's had a benefit but then there's probably some of those that we need to see that we're not seeing. So we're all a little bit worried. That is really difficult'* [34/72-10/12/20]

When asynchronous communication was used, it could be successful. A survey respondent with a speech impairment used text to successfully negotiate a care package which minimised the number of people entering their home. They wrote:

> *'24-hour care needed, so it was a challenge during the lockdown as I wanted minimal people involved in my package. I [...] communicated via text and WhatsApp. All calls were covered without the need of too many care givers'* [S406-23/09/20]

However, technical issues with text-based services could have potentially serious consequences. A survey respondent wrote:

> *'I tried to get a doctor's appointment after feeling continually exhausted. I had to complete a questionnaire that took about half an hour and then wait to hear back. Three weeks later I found an email in my junk mail telling me to ring the surgery'* [S309-11/09/20]

The inability to successfully communicate caused distress, to which I will now turn.

4.9 COMMUNICATION DISTRESS

This chapter has concentrated on the feelings and experiences provoked by presence of PPE and the absence of touch and proximity. I have attempted to draw out and examine those experiences which were an inevitable consequence of the fundamental need to use non-pharmaceutical interventions in a pandemic, to consider the causes and consequences of the sensory stimulation intrinsic in these encounters, and to place them in the cultural context of the relationships between the people involved as they interact in the giving and receiving of care. I conclude this chapter with the descriptions of the distress felt by interlocutors during their health and social care interactions which can be attributed to the inability to successfully express themselves and/or to fully understand because of the presence of PPE and/or distancing. I am describing this experience as ‘communication distress’.

A literature search indicated that the term ‘communication distress’ is not common parlance in research. I could find one example of its use within the context of health and care interactions: by Lum et al. (2020) in their development of a tool to measure the difficulties encountered by *patients* navigating healthcare. My use of the term places equal emphasis on the distress experienced by *all* participants regardless of their roles in the care interaction – it describes how they feel as people trying and failing to connect. By doing so, the complex biocultural experience of health and care interactions in the presence of PPE and distancing becomes apparent.

4.9.1 Communication distress caused by PPE

To ascertain the emotional effect of PPE on health workers’ attempts to communicate, the responses to six survey statements were analysed. Three were negative: *‘I feel frustrated by my inability to communicate in the way I would like’* was chosen by 125 of the 282 health worker respondents (44.3%); *‘I am distracted by the discomfort of wearing PPE’* was selected by 115 (40.8%), and *‘I'm afraid I scare people by the way I look’* was chosen by 75

(26.6%). Statements which indicated positive emotions attached to communicating in PPE were: *'I can communicate just as well as I did without PPE'*, indicating minimal negative affect, chosen by 44 (15.6%); '*I feel safer, so I can express myself naturally'* indicating positive emotion – feeling safe – selected by 41 (14.5%); and *'I've stopped noticing my PPE during conversations'*, indicating habituation and minimal negative affect, chosen by 34 (12.1%). More than half of the healthcare professionals who responded only chose negative responses concerning the act of communicating in PPE (151, 53.5%). Responses which inferred only positive emotions were identified in 46 health workers (16.3%).

When invited to *'add your own comments about the comfort and ease of use of your PPE',* 11 of the 107 written responses (10.3%) from survey respondents who worked in health and care explicitly described the cognitive and visceral discomfort of not understanding or being understood:

> *'Makes me feel very disorientated and confused, particularly if both of us wearing masks'* [aromatherapist, S099-25/08/20]
>
> *'I feel disoriented and not as efficient or effective'* [complementary therapist working from home, S100-25/08/20]

Nurse Louise described how difficult choices between maximising protection or maximising communication made her concerned that she was not conveying a reassuring sense of calm competence:

> *'I knew I was going into a Covid-positive patient, I was trying to get the best as I could with the PPE that I'd got, I had a visor on as well. So I've got a surgical mask, a visor, I wear glasses. I couldn't see absolutely anything' [...] 'I call it the double mist' [...] 'when you first go in you need to be able to see, but you also need to be able to get that interper-[sonal], you know, that communication and reassurance [...] 'The wife was worried. She'd not called the ambulance for ages*

> *because: "Ooh, you are all so busy". I come in and go: "Oh, dear me! We need an ambulance!"' […] It's really hard when you're trying to reassure and look like you're totally competent, and you can't see!'* [34/470X-31/03/22]

Training manager Alex spoke of observing the effort required by her care home staff to resist the instinct to remove a mask to facilitate both verbal and non-verbal communication:

> *'…the staff, so some of them are so kind and you can see that they want to take the mask off because they want to be able to acknowledge that person: "I'm here, I'm human, you know who I am, I'm Alex, I'm going to help you"'* [14/216-21/09/20]

The physical act of attempting to transcend the occlusion caused by PPE was itself a source of discomfort:

> *'The over exaggeration of communicating loudly and with body and eye movements, is exhausting'* [mental health worker, S285-02/09/20]

Communication distress caused by PPE could be detected by the wearer's interlocutor. The most frequently selected statement in the suite of responses concerning the sight of a person in PPE indicated empathy for the wearer: *'I worry about how uncomfortable they must feel'* was chosen by 207 (44.6%) of the 464 survey respondents. An acknowledgement of the difficulty faced by PPE-wearers, and of their conscious adjustments, was also indicated by 152 respondents (32.8%) who chose the statement *'They seem to have to make a lot of effort to be understood'*.

Ultimately, the effort and distress from attempting to communicate can prove too much, resulting in communication failure as described by a social care worker:

> *'You give up bothering to talk to colleagues very easily'* [S442-30/09/20]

4.9.2 Communication distress caused by distancing

Volunteer co-ordinator Alison described how extra effort was required to find alternative non-tactile methods of communication, which could lead to frustration:

> *'I think some people actually struggle because I think there are some people who do that naturally, who are quite tactile [...] 'if your body doesn't instinctively offer something else up that can pass a message on, when you don't have this, it must be quite frustrating'* [20/187-01/10/20]

Communication distress could be further amplified when the interlocutors could only communicate by remote means. Telephone consultations removed all possibility of seeing non-verbal communication cues, and the line's sound quality exacerbated verbal communication barriers. Louise was an urgent care advanced practitioner. Most of her work moved to telephone consultations. She spoke of the distress she felt when dealing with multiple cases where she had no tactile or visual input:

> *'...before, I might only speak to, you know, triage, 10 people a night. Whereas probably now I'm probably triaging, you know, 50-60'* [34/497-10/12/20] *[...] 'It's harder because we're on our computers like this [staring ahead]'* [34/475-10/12/20] *[...] 'you're constantly on the telephone, you can't see your patient, and it's relentless. And that's how it feels. And at, sometimes, even though you've got – you beg for a home visit, even though you've got to do all that PPE'* [34/478-10/12/20] *[...] 'We've switched from one stress – face-to-face – to a virtual stress of going through them'* [34/140X-31/03/22]

Restrictions denied the 'I-thou' reciprocity (Buber, 1986 [1958]) communicated by comfort and satisfaction *gained* by health and care workers from *giving* touch, covered earlier Section 4.5.1. In their survey responses, these diverse health and wellbeing workers described their distress:

> *'I feel sad [to] know I am restricted to help someone'* [mental health worker, S261-01/09/20]

> *'It is particularly difficult if a patient starts to cry in the consulting room or shares something very personal that exposes their vulnerability'* [clinical nurse specialist in chronic pain, S394-22/09/20]

> '*If I cannot comfort someone who is in tears, it makes me cry too – touch is a vital component of humanity'* [complementary therapist, S251-01/09/20]

From the perspective of the person receiving care, receiving difficult news by remote methods served to amplify existing levels of distress. The lack of two-way non-verbal cues prevented clinicians from both perceiving the need for specific empathetic intervention – as would be needed in the absence of a companion for a patient receiving bad news – and the tools with which to deliver it – such as caring touch and sympathetic non-verbal signals:

> *'I was informed of an upsetting diagnosis over the telephone. I became upset during the call and felt that the GP could not pick up on this, possibly due to the more impersonal nature of the telephone call. The call ended with me feeling very upset and distressed. I felt alone after the call as I was in my house by myself and then felt as though I should continue working from home after this'* [CAMHS psychologist, S209-01/09/20]

This chapter has established that the presence of PPE and forced avoidance of touch and proximity in interactions prompted physical and psychological stimuli of sufficient intensity and duration to trigger the neuroendocrine mechanisms of General Adaptation Syndrome (See Section 2.3), and that emotional distress was experienced by participants through suboptimal attempts to communicate in the presence of these artefacts and restrictions.

Although the picture is complex, as I have demonstrated, a key conclusion is that PPE generally caused distress – and there is potential for this to be mitigated by a different approach in the future. Because both PPE and distancing are fundamental infection control practices, such experiences are unavoidable in the presence of a biological threat. However, by providing a better understanding of these lived experiences, my research gives policymakers and planners insight into the intrinsic problems faced by people giving and receiving care when PPE and distancing are required. Such knowledge provides pointers to where interventions can be made to improve product design, adapt protocols and systems, improve communication education and training, and give time and space for recovery to counteract the cumulative effect of GAS.

To that end, the next chapter explores those external factors which ameliorated the participants' adverse experiences of PPE and distancing, and also considers what made their experiences worse.

CHAPTER 5: WHAT LIES BENEATH

This chapter seeks to identify the mediating factors which contributed to participants' intrinsic sensitisation or habituation to PPE and distancing, and the factors which aggravated or ameliorated communication distress in their health and care interactions. I begin by considering whether the participants were influenced by their personal circumstances: whether encountering the artefacts and rules as a caregiver and/or as a receiver of care made a difference, whether the type of care they gave (i.e., conventional or non-conventional) played a part, or whether pre-existing sensory and/or cognitive issues were a factor. I then consider factors concerning the PPE artefacts themselves: differences in their availability, design, and quality, and differences in the way they were thought about and used. I consider the pre-existing factors which affected proximity and the use of PPE. I turn to the ways people attempted to overcome the barriers posed by PPE and distancing and consider how people responded to the need to innovate when in-person interaction was not possible. I conclude the chapter by exploring how people communicated *about* PPE and distancing, and how this influenced the experience of interacting in their presence.

5.1 KEY RESPONDENT CHARACTERISTICS

In the previous chapter I reported how some, but not all, people felt threatened by the sensations they felt from wearing PPE, from the sight of PPE or its absence. I also described how some people felt safer when avoiding proximity and touch, while some were particularly distressed by being unable to be close to others. If a particular kind of person is more or less likely to tolerate the artefacts and rules, we could learn from them. So, before turning to the question of *how* suffering was amplified or mitigated, I first consider the question of *who* was more – or less – habituated to its causes. This question was drawn to my attention by GP Deborah, who described the diverse range of her patients' reactions to in-person consultations and mask-wearing not as falling into two opposing camps but as a 'bell-curve':

> *'...from a polarisation point of view [...] it's a bit more like a bell-shaped curve, that most people sort of sit in the middle somewhere, and kind of go with the majority, and the majority have kind of gone with the: "let's relax things and get back to normal" [...] But we definitely have the cohort at the end, of: "I'm really, really anxious about the risk of catching Covid" [...] And then I have the cohort at the other end of the spectrum who: "Masks are a total nuisance"* [33/112X-09/05/22]

The relatively high response to the survey allowed for statistical analysis to further explore potential demographic patterns and possible distributions of stated feelings, attitudes, and beliefs as expressed in survey responses (and alluded to by Deborah). Initially, the survey was primarily intended as an interview recruitment tool and was not designed with statistical data analysis in mind. Demographic information such as gender, age, ethnicity, socioeconomic status, and region were not gathered. However, each respondent's experiences in the giving and receiving of health and social care provision was categorised via a case-by-case analysis of all open-ended responses, including to the prompt: *'Please* *briefly describe your job, and the type of place where you work'*. A further prompt determined the presence of any pre-existing communication impairment(s).

Tables 2 and 3 report the key characteristics of survey respondents in relation to the contexts in which they interacted in health and care; their pre-existing sensory and/or other differences which impaired communication; and, for those identified as health and social care givers, the roles in which they performed that task.

TABLE 2: Key characteristics of all survey respondents (n=464) in relation to: [a] 'care contexts' and [b] pre-existing communication impairments

Characteristic	Yes n= (%)	No n= (%)
Required care for themselves or someone close to them	227 (49)	236 (51)
Health or social care worker	295 (64)	169 (36)
Respondent care dynamics (all care) *		
Neither gave nor needed care	80 (17)	384 (83)
Needed care only	89 (19)	375 (81)
Gave care only	157 (34)	307 (66)
Both needed and gave care	138 (30)	326 (70)
Care experiences of people with pre-existing communication impairments **		
Pre-existing communication impairment	76 (16)	~
Neither gave nor needed care	18 (24) ***	~
Needed care only	25 (33) ***	~
Gave care only	14 (18) ***	~
Both needed and gave care	19 (25) ***	~
Total responses n = 464		

TABLE 3: The role characteristics of health and social care providers (n=295)		
Characteristic	**Yes n = (%)**	**No n = (%)**
Conventional care-givers	124 (44)	159 (52)
Conventional care-giver roles		
Doctor	8 (3)	~
Nurse	30 (11)	~
Allied health professional *	35 (12)	~
Social care **	32 (11)	~
Service management	19 (6)	~
Indeterminate ***	12 (4)	~
Non-conventional care-giver roles		
CAM #	131 (44)	~
Dual ##	28 (9)	~
Total number of health and social care providers n = 295		

KEY FOR TABLE 2:

*Both professional and unpaid care-giving commitments

** Loss of vision, impaired hearing, dysarthria (difficulty speaking due to neuromuscular problems) and/or ‘other’ issues, such as difficulties reading and/or writing, neurodivergence, conditions which affect information processing, or not being fluent in English.

*** Calculated as % of the 76 respondents who reported pre-existing communication impairments.

KEY FOR TABLE 3:

* Pharmacists, Paramedics, Physiotherapists, Occupational Therapists, and Social Workers and roles statutorily regulated by the Health and Care Professions Council.

** Including those working (paid or voluntarily) in hospices, residential homes, and domiciliary care.

*** Identified as a ‘Health Care Professional’ but provided insufficient information from which to determine further classification.

Complementary and/or alternative therapists (CAM). Practitioners of a specific non-conventional therapy (e.g., ‘aromatherapist’, ‘Bowen therapist’, ‘sports massage’) and also to respondents who self-identified as a non-specific ‘therapist’ who did not otherwise indicate a statutorily regulated role.

Those who practiced non-conventional therapies in conventional settings and/or had two jobs: a conventional role and a non-conventional practise.

5.1.1 The significance of key respondent characteristics

By comparing the characteristics of survey respondents in Table 2 and 3 with the descriptive profiles of the interview participants in Table 1 (Section 3.4), it can be concluded that this thesis is not a study of ‘health workers’, or ‘patients’, nor can it be: these are categories imposed on *people* who can and do experience both identities, sometimes concurrently. For me, this fact emerged as something of the highest significance, and I kept it firmly in mind during analysis.

Those who did give and/or receive care were impelled to do so through proximity in the presence of PPE and/or remote communication. Exposure to PPE and/or distancing may have offered opportunities to become habituated, but this could have been offset by the perception of risk from the virus for which the measures were in place. The risk from Covid was established to be more severe for people whose health was not robust. Therefore, it could be inferred that people who were receivers of care were more likely to experience communication distress in proportion to their vulnerabilities, the frequency and nature of interaction, and/or the greater number of different health and care professionals they encountered. Conversely, it could also be possible that people who had no health or care interaction, and were therefore less likely to be involuntarily exposed, may be less distressed.

Caregivers, whose profession was likely to require multiple exchanges with many patients and colleagues, had even more opportunity to be distressed by their exposure to the sensations and sights of PPE, the performance of distancing, and/or unavoidable transgression of distancing rules, especially as, in August 2020, statistics indicated health and social care workers had an increased risk of dying with Covid compared with the general population[8]. Therefore, it could be presupposed that health and care professionals

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[8] Between 9 March and 20 July 2020, Covid was involved in 30% (2,977) of the deaths of health and social care workers aged 20-65 in England and Wales, compared to 16.6% of the general population of the same age (ONS, 2020).

would be a group likely to experience sensitisation due to the cumulative effect of repeated high-stakes communication distress.

The additional exposure to interaction, coupled with the oscillating relationship dynamics between giving and receiving roles, would support the supposition that the subset of health and care professionals who also needed care were most likely to experience communication distress.

Non-conventional therapies[9] are interventions which are not practised by the medical establishment, usually because they do not meet the evidence criteria required for their use by mainstream practitioners. Moreover, alternative medicine – i.e., the *replacement* of mainstream interventions with non-conventional approaches, as opposed to complementary medicine which uses those approaches to *augment* mainstream care – is connected to the enactment of personal freedoms and of resistance to mandated health interventions such as vaccination programmes. Therefore, it could be conjectured that some respondents who practiced non-conventional therapies would be more resistant to compliance with interventions arising from the scientific establishment, such as PPE-wearing and distancing requirements. It could be assumed that this cohort of survey participants would stand out as having more negative emotional responses to the sight of PPE and distancing, which would exacerbate communication distress.

The survey's proportion of people with communication impairment was less than the estimated proportion of the whole UK population who have communication impairment which, according to the Royal College of Speech and Language Therapists (2022), was approximately 20% (14 million).

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[9] The term non-conventional therapies is used here to denote a myriad of possible wellbeing-related interventions outside mainstream medical use. The decision of a respondent who worked in non-conventional therapies to choose not to identify as a health or care professional could be explained by the respondent considering their role as 'wellness', 'beauty', or 'leisure'.

In the previous chapter I demonstrated that the interaction of PPE with spectacles and hearing devices could exacerbate sensory discomfort and sensory occlusion. The occlusion of the mouth also removed communication strategies for the hearing-impaired while exposing undiagnosed hearing loss, while the denial of proximity and the use of gloves prevented the use of touch as a formal language for the Deafblind and for people with profound learning disabilities. It was also clear that the pre-existing differences to sensory perception experienced by neurodivergent people were exacerbated by the sensation of masks on the face, while some welcomed respite from unwanted hugs. For autistic people, the presence of masks interfered with strategies to cope with aural hypersensitivity, while a predisposition to rule-following and order could have made the sight of a mis-positioned or absent mask the source of extreme anxiety. A higher proportion of respondents with communication impairments were also care-receivers (58% in total of those reporting communication impairments) when compared to those who did not report communication impairments. It is also notable that almost half of the respondents reporting communication impairments also identified as professional health or care workers (n=33). This latter observation challenged the assumed identity of people with sensory or cognitive differences as primarily, or solely, ‘patients’.

5.1.2 Cluster analysis

A hierarchical cluster analysis grouped (clustered) the 464 participants solely on similarity of response to five statements which focused on emotional reactions to touch, to communicating with a person wearing a mask, and to being in the vicinity of a person wearing PPE. Two of the statements which I chose for inclusion in the cluster analysis were offered in response to the prompt: *‘Think about the times when you have been talking with a person who is wearing a face mask’*. The statement: *‘They seem less friendly because I can’t see their facial expressions’* was chosen as it was the most emotive negative statement, and agreement would indicate that the respondent could be negatively emotionally affected by the visual stimulus. It also had the highest response rate for the suite of negative statements about masks. I chose the statement *'I feel more comfortable because their mask is protecting me from the virus'* because it was the most emotive positive statement, and agreement would indicate that the respondent could be positively emotionally affected by the visual stimulus. It also had the highest response rate for the suite of positive statements about masks.

Three of the statements which I chose for inclusion in the cluster analysis were offered in response to the question: *'How [does] being near a person in full PPE make you feel? That is, someone in a mask, visor, gloves, and gown'*. The statement: *'I feel like I'm in the presence of aliens, not humans'* was chosen as it was the most emotive negative statement, and agreement would indicate that the respondent could be negatively emotionally affected by the visual stimulus. *'It's reassuring – they're fighting the virus'* was chosen as it was the most emotive positive statement, and agreement would indicate that the respondent could be positively emotionally affected by the visual stimulus. *'I've stopped noticing, it's becoming normal'* was chosen as it was indicative that a respondent had become habituated.

One of the statements which I chose for inclusion in the cluster analysis was offered in response to the question: '*Keeping our distance means that we must avoid shaking hands, hugging, or giving comforting touch to each other, such as placing a hand on someone's shoulder. How has that affected you?'* I chose the statement: *'I feel safer if no-one touches me'* because it was indicative of a positive emotional reaction to touch-avoidance and an intrinsic acceptance of distancing.

A three-cluster solution provided clusters of roughly equal size and this solution appeared to be the best ecological fit with the data. The three emergent sub-groups of respondents were characterised as being 'habituated' (n=143), 'sensitised' (n=151), and 'conflicted' (170). The responses of the 'Habituated' sub-group appeared to indicate a degree of reconciliation to communication in the presence of masks, PPE and distancing. Those in the 'Sensitised' sub-group were more likely to hold consistently negative thoughts and feelings about the experience of communicating in the presence of masks, PPE and distancing. The responses of the ‘Conflicted’ sub-group were suggestive of contradictory feelings about the experience of communication in the presence of masks, PPE and distancing, perhaps indicating elements of inner turmoil or uncertainty due to normlessness. Appendix J carries full details of the statistical analysis.

There are two key findings from this analysis. Firstly, the experience of communicating in the presence of masks, PPE and distancing was different for respondents who reported communication impairments compared to those who did not. There were notable differences in experience between those who reported having a hearing impairment when compared to those who reported visual impairments.

Secondly, the conjectures outlined above concerning the influence of ‘care contexts’ in relation to potential habituation or sensitisation were *not* supported. Specifically, I could not sustain the assumption that an experience of needing care in the presence of PPE and/or distancing would lead to the formation of a specific outlook concerning masks, PPE or touch which was different from those who did not need care.

Therefore, notwithstanding the circumstances of those with pre-existing communication impairment, I posit that the ‘bell-curve’ of attitudes and beliefs about PPE and distancing was formed by factors extrinsic to personal roles and identities. This chapter seeks to explore these factors.

5.2 EXTRINSIC FACTORS CONCERNING PPE ARTEFACTS

So far, I have considered participants' intrinsic feelings and experiences prompted by exposure to PPE artefacts and distancing rules. However, these objects and imposed distancing behaviours were not generic: there were many extrinsic variables which changed their meanings at different times and in different circumstances. This affected the participants' relationships with PPE items and, subsequently, their relationships with people around them. This section considers the stories surrounding the artefacts, and the participant's responses.

5.2.1 PPE scarcity

When PPE and distancing rules were introduced, participants reported that the artefacts were in short supply and there was no systemic distribution framework. GP practice manager Dave said: *'In the early days, there was just a scramble to get PPE'* [13/455-18/09/20]. Care home training manager Alex described how she and her staff improvised:

> *'I even wore a poncho at one point when I was assisting somebody, because that's all we could get'* [14/56-21/09/20]

A survey respondent who was a care home activities co-ordinator blamed PPE shortages for the spread of the virus:

> *'The PPE given in care homes was inadequate' [...] 'PPE was a joke, so the virus spread to others & carers'* [S033-22/08/20]

Liz and Paula were interviewed together in their roles as carer support workers. They reported PPE scarcity for people being cared for at home by unpaid family members and/or professional domiciliary care workers. The carer organisation itself had difficulty sourcing PPE, and their request to the local Clinical Commissioning Group for help was to no avail. Paula said:

> *'…the carers […] didn't have it [PPE] during most of the lockdown. We were getting called daily for people'* [09/501-14/09/20] […] *'I think the lack of PPE for carers during – was massive'* [09/504-14/09/20] […] *'We could hardly get hold of it. We had to get onto the CCG twice. But then they gave us not hardly anything'* [09/299-14/09/20]

The perceived threats from the consequences of PPE shortage due to a lack of an organisational *'network'* created anxiety for advanced nurse practitioner Louise:

> *'it's the frightening bit about: "Is there enough PPE? How is it going to protect me?" And also: "Is this PPE good enough?" That is often the frightening bit'* [34/600-10/12/20] *[…] '…they were giving it out – rationing it, you know? And I can understand, there wasn't much, it was difficult to get hold of stuff. So therefore, there was a supply issue'* [34/782-10/12/20]

Louise said the fear and paranoia endured beyond the initial shock of scarcity:

> *'I think they'll probably still be organisations and staff that get a little bit twitchy if they're running down. Like if I saw my masks box, and it was down to the last mask, I'd be like: "Oh, my gosh, where's the network? Have we got more masks, have we got more masks?" and going to check that we've got more masks, and we've probably got a little bit – paranoid is probably the word'* [34/790-10/12/20]

Problems with PPE availability changed behaviours which had a direct influence on health and care interactions, both between professional and patient, and between the professionals themselves. In Section 4.7.2, ITU dietitian Natalie described how her practise radically changed to avoid proximity to the patient, offering as an example how she assessed a patient's weight by looking through a window. Whilst she found PPE-wearing physically and psychologically uncomfortable, she asserted that the main motivation for her avoidance of patient contact was the need to preserve PPE stocks, which arose from personal instinct rather than the result of external pressure:

> *'…we have one uniform [laughs] for that day, it meant that you had to plan your day'* [26/38-13/10/20*] […] 'you're very conscious of not wanting to waste any PPE. I think in the early days, when there was a worry about the lack of PPE – and I think that's still at the back of your head, and you kind of think: "I don't want to put it on and then find out the patient's fast asleep and it's a complete waste of time, I'm not even able to speak to them anyway". So part of you is kind of: "Oh, are they awake? Can they communicate to start with? Is there any point in putting this on?" And I think that's kind of at the back your head because you don't want to waste what there is'* [26/383-13/10/20] *[…] 'I think it was probably more an intrinsic thing, to be honest'* [26/407-13/10/20]

Scarcity behaviours, established through fear of running out, continued beyond the initial PPE shortages. Natalie's behaviour changed because she judged her role to be less deserving items still considered to be rare and precious: she thought it should belong to the doctors and nurses:

> *'… there was a point when we did have a shortness of one of the fit test masks, and I was very, very conscious that I did not want to waste any of those. If there was a way around doing it, that I didn't have to put one on, I would take the way around so that they were preserved for the nursing staff and the doctors that needed to be right up and close and personal with a patient'* [26/392-13/10/20] *[…] 'you really wanted to kind of preserve, preserve the stocks. I think it did just kind of – you saw how little there was'* [26/412-13/10/20] *[…] 'yes, I think it is a bit ingrained'* [26/416-13/10/20]

PPE scarcity created boundaries between the haves and the have-nots which could lead to animosity, such as that inferred in a social care worker's survey response which claimed that their greater need was being unmet because of the hierarchical misallocation of resources:

> *'I can't get hold of gloves because someone using it to make a cup of tea when I need it to be protected from poo'* [S127-25/08/20]

Distribution of PPE items could be based on being in the right place at the right time. Louise was off sick for seven weeks in Easter 2020 after being hospitalised with probable Covid, and returned to work to discover she had been forgotten when scrubs had been distributed from a local factory which had repurposed its production line:

> *'So I've seen a few of my colleagues in out-of-hours with scrubs. I said: "Oh, where did you get them?" and they said: "Oh, you missed out!"'* [34/295-10/12/34]

Scarcity led to the over-use or re-use of PPE artefacts beyond their tolerances, which affected functionality, as Louise described:

> *'if you keep taking them [visors] and if you keep cleaning them you can't see out of them, so they don't last very long anyway'* [34/276-10/12/20]

These scarcity behaviours continued beyond the initial shortages and into 2022, as indicated in Louise's second interview:

> *'So they pull out this mask that they bought off the internet, or they've got from their GP when they've been in general practice all day' [...] 'And I said: "You know, I think we're only supposed to use them for a few hours?"'* [34/159X-31/03/22] *[...] 'there's workarounds, which might mean using equipment for longer than it should have been used for'* [34/165X-31/03/22]

Differing personal tolerances for PPE re-use due to shortages led to confrontations between health professionals. Louise described an occluded and distanced argument with a colleague during which she asserted her need for her own visor rather than a shared one, only to be told there were none:

> *'...I said: "Have you got a fresh visor?" And he went: "Oh, it's in there already, the previous clinician's very good". And I went: "Oh well, you know, I need my own". "Oh, no. You just clean them, you just clean them". And I said: "Oh, no, please..." And of course, I'm having to stay two metres away. I've got my mask on. So it's difficult. And I don't think they could comprehend. And I was like: "No". And he said: "Oh, your patient's on his way". I said: "You can't – I'm not having the patient in the building until I've got the right PPE, and I'm not using that visor". And he said: "Well, there's nothing wrong with it [...] it's been cleaned". I said: "No, I need a new one, have you got a new one?" So anyway, in the end, he said that he hadn't got any'* [34/244-10/12/20]

Domiciliary care workers' scarcity behaviours with PPE were reported to carer support workers Paula and Liz by their clients: some families doubted that care workers were using fresh PPE for each visit. Suspicion and perceived threat had a profound effect on care interactions, to the point where some relationships broke down completely:

> Paula said: *'A lot of people cancelled that homecare, didn't they? Because they weren't confident that people were wearing fresh PPE each time they did a home visit'* [09/149-14/09/20]
>
> Liz said: *'Their problem really was: "OK, so they've been to me this morning. Have they changed, having been to our family this morning, are they then changing their PPE for the person who they're going to go and see next?"'* [10/146-14/09/20]

Poor pre-existing management attitudes to staff welfare were alluded to in the description of a domiciliary care worker, who wrote about their employer and the council which commissioned the company's services:

> *'The council have given no thought to the staff in having [PPE] on all day' […] '[Name of organisation] have not considered individuals wearing and coping with it and they are supposed to be advising other companies'* [S207-01/09/20]

There were pre-pandemic PPE shortages which affected behaviours. A social care worker with hearing impairment wrote:

> *'Even before the pandemic we were only allowed one lot of PPE so could not go to lunch or the toilet because it would not be clean afterwards'* [S442-30/09/20]

5.2.2 PPE quality and design

The safety of some participants was at risk of being compromised by poor-quality PPE artefacts. GP practice manager Dave said:

> *'There was a whole load of a particular brand of masks appeared in the country, and then you get a central system alert saying: "Bin them all, they're not safe"'* [13/463-18/09/20]

Advanced nurse practitioner Louise was scared by the quality of her PPE: *"Is this PPE good enough?" That is often the frightening bit'* [34/600-10/12/20]. She described the deteriorating quality of aprons:

> *'…the apron that we've been provided has been shockingly variable in quality. Terrible. And I think that depends on what they've been able to get. So we went from, at the beginning of Covid, we had these really thick, good quality aprons, which were easy to open and to put on'* [34/306-10/12/20] *[…] 'you'd have your pinny over the top and they were quite substantial. Then we noticed that they got worse, and I think it's due to supply. It was what they could get. We were getting some pathetic aprons that were ripped straight away, you were stood outside someone's house, you know, trying desperately hard to get these like – it's like a shopping bag –*

> *open. And then, some of them didn't even cover your waist, this pathetic pinny that you think is not covering my clothes'* [34/312-10/12/20]

Alex said the poor manufacture of surgical masks contributed to the prevalence of skin irritation amongst staff at the care home company where she was training manager:

> *'We've got a lot of spectacle wearers. The whole fogging thing, and the masks not having a good enough metal bar to mould to your nose, and people having it on the end of the nose as opposed to up near their eyelashes, and then getting mad because they end up with a rash'* [14/269-21/09/20]

A massage therapist wrote of how they improvised with tape to compensate for the mask's failure to stay in place when combined with spectacles:

> *'I have to hold the mask in place with tape to stop it slipping as I have glasses. I have a sore face from the tape'* [S204-30/08/20]

ITU dietitian Natalie and her colleagues experienced stocks of poor-fitting FFP3 masks which depended on the integrity of the seal to offer protection:

> *'…we were using one kind of mask and it was coming from America […] I think America just decided they wanted to keep all the stocks for themselves […] there was another one that came out, but unfortunately a lot of people were failing the fit test, it wasn't fitting their faces'* [26/407-13/10/20]

The lack of an appropriate range of PPE to cater for a workforce of different shapes and sizes was also highlighted by survey respondents. A paramedic practitioner wrote: *'I'm 5ft and slim built with a small face... nothing fits'* [S128-25/08/20], while a community mental health nurse wrote: *'Masks don't fit properly, bought as a job lot expecting one size to fit all'* [S182-26/08/20].

The design of some PPE artefacts could exacerbate their inherent irritating properties which were explored in Section 4.1.1. A community health team member wrote:

> *'The visors we were given were unwearable and so could [not] be used'*
> [S369-20/09/20]

Dave commented on the designs available to his GP practice:

> *'…we tried to encourage our staff to wear visors if they wanted. We managed to get something like 500 of them from a company who's providing them. Tried it, and they hate it. They're really uncomfortable and unwieldy to wear, even a couple of designs we got, and it just didn't work. So they've gone back to the masks'*
> [13/189-18/09/20]

Louise said improvised PPE was sometimes better than the official supply:

> *'…I can understand why they were using a bin bag for a pinny: because they ain't got any, or what they had were ridiculously not good enough. And to be fair, if I could have found a bin bag that was long enough to go from my shoulders to my feet, and I could put my arms through it, I would have thought that was a very good idea at the time! Even though it's ridiculous'* [34/816-10/12/20]

Some survey and interview comments were directed at the overall impracticality of standard-design PPE for certain tasks, regardless of whether it met quality standards. A therapist wrote: *'PPE wasn't designed to do a full body massage in, it's ridiculous!* [S089-25/08/20]. Full PPE was required to be worn by staff in the vicinity of aerosol-generating procedures (AGPs), comprising eye protection, sleeved gowns, gloves, and FFP3 masks. Geoff had Motor Neurone Disease (MND) and described how the artefacts were incompatible with the tasks required of his domiciliary carers:

> *'They are obviously wearing a mask, they're having to wear gowns because I wear a respirator at night. So because of the aerosol element, they have to be gowned as well. They are supposed to wear a screen [sic: visor] in the shower as well. But that's impractical. It just completely mists up'* [27/258-19/10/20]

The discomfort of Geoff's carers, and their altered movement from the restricting gowns which was discussed in Section 4.2.3, resulted from a combination of the design of the artefacts, national policy, and the interpretation of that policy by the carers' employer. Geoff's carers had the protective protocol applied to them even though he had been isolating, symptom-free, and was more at risk of catching the virus from the carers than vice-versa. Meanwhile, Louise and her colleagues, who were attending critically ill Covid patients in the community, were told by government bodies to wear, as protection, surgical masks designed for the purpose of source control. This was because they asserted that, unless a respiratory aerosol was provoked by a medical intervention, Covid was not airborne and the droplet-repellent coating on surgical masks was sufficient protection for the wearer.

The dissonance between official directives about virus threat and the perception of those in working in its potential presence led to deep distrust of the functionality of the prescribed PPE's design, which was eventually proved to be justified.

5.2.3 Appropriateness of official PPE

From the outset of the pandemic, there had been a debate involving the World Health Organisation about whether Covid-19 was transmitted by aerosol as well as droplet (Baraniuk, 2021). By the time of my second interview with Louise, there was conclusive evidence that transmission of Covid commonly occurred through inhalation of the airborne virus carried on an infected person's out-breath (Tang, Marr, Li, & Dancer, 2021). On 14 October 2021, the UK Health Security Agency (UKHSA) – the successor to Public Health England – accepted that the virus was airborne, the conditions within the homes of Covid sufferers were most likely to create the conditions for transmission, and that surgical masks were likely to offer inferior protection:

> *'…long distance airborne transmission (beyond 2 metres) is possible and that when it happens, it is usually in poorly ventilated indoor settings where the index cases and potential infected cases stayed for an extended duration of time'*
>
> (UKHSA, 2021, p.15)

> *'…evidence suggests that N95 [i.e., FFP3] respirators might be effective in reducing infection risks in healthcare settings, the results are less clear for surgical masks'*
>
> (UKHSA, 2021, p.20)

However, when I spoke to Louise in March 2022, she and her community colleagues were still being told to use surgical masks and had no access to the appropriate FFP3 design. The communication behaviours of Louise and many of her colleagues, already altered by the presence of surgical masks and distancing, were further distorted by a heightened sense of danger and threat. Here I offer a vignette of Louise's description of a night shift, focussing on the details she gave of an interaction with a patient and his wife. It is an illustration of her cumulative embodied actions, sensations, and emotions prompted by the quality, availability, and specification of her PPE, the practicality of using it in a real-life community nursing context, and the subsequent profound effect it had on her interactions with the patient and his wife. It also describes the creative measures Louise and her colleagues put in place in response to the uncertainties and discomforts of the practical implementation of PPE and distancing rules.

Vignette 3: Louise

It’s winter 2021. Derek, Louise’s driver, pulls the car up outside the house. Derek backs up towards a wall to provide Louise with some shelter from the wind and rain. The wind tugs on the door as Louise steps out and goes to the back of the car. She opens the hatchback which casts a feeble light upon the kit which Derek had laid out for her. Now, in the wet, cold, and dark, *under cover of the boot,* Louise takes off her coat.

She bought this coat just for work. She chose it because it washes and dries well. She’s *washed that coat more times than anything now*. At the beginning of Covid the weather was better, and it was still light at the start of her night shift. She never had a coat to worry about then. But with the onset of winter, what do you do with your coat? She doesn’t want to wear it into multiple people’s houses, because that’s high risk, Instead, she wears layers of clothes, knowing that she’s able to strip all those layers off. For a visit she takes a different top, undresses, puts a different top on, pinny over the top, and ready to go. It’s her own way of doing everything she can to minimise risk. But on this bitter night, she draws the line at stripping down to her strappy T-shirt. This tunic will have to do until she gets back to base. She feels guilty for compromising her self-imposed rule.

Early on in the pandemic, there’d been a link circulated to NHS training videos showing how to don and doff. Useful, but only to a point: it was filmed in a well-lit,

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well-stocked, spotless clinical room with a handwashing sink and hot running water – not what she and her colleagues in the community are faced with on an average shift. Then one night she'd gone into work and waiting for her had been a laminated flowchart containing all the information on new procedures, but in a way that relates to a community setting*, saying: 'This is how you don, this is how you doff, and this is the new system: when you go to someone's house, you have to have a yellow bag…'* Louise had said to Derek: "*Someone's really thought about this, they've been really good. They've sent us all the information, I love this. I'm so happy".*

Shivering, she reaches for one of the bags Derek has prepared for her to try to make the process easier. "*Bless him, he's so organised",* Louise thinks*. He has it all ready in a little individual bag: pinny, gloves….* When this all started, Derek had talked her through the laminated flowchart until it had become routine. *He was like: "Okay, so you have to take a yellow bag, and leave the yellow bag outside the door of the building you're going in, because when you get out, you have to take it all off at the door. And then you have to have another bag, which is to put your equipment in. And then you come to the car, and then you clean your equipment".* Louise had noticed *the community nurses were doing the same thing. They'd had the same laminate.* You can tell on her patch when a home is being visited – on the

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front step there's *a yellow bag with a bottle of hand gel on top to stop it flying away.* That laminate, *it's the one thing that's worked really well.*

She cleans her hands and puts on the apron. *The pinnies have gone back to being ridiculously rubbish.* As she ties it, it tears. Louise fumbles for what looks like a roll of pedal bin liners. *At the beginning of Covid,* they *had these really thick, good quality aprons, which were easy to open and to put on,* but now, they're *shockingly variable in quality. Terrible. It depends on what they've been able to get. They'd actually had some really good ones last week, and doctors and nurses* were *getting excited about the quality of the apron because that's the most important thing! Every morning at cross over, they talk about PPE, which* Louise *never thought they'd ever do.*

But quality aprons are not on offer tonight. Taking an apron off this roll is as tricky as unpicking the start of a roll of Sellotape. Once free, it catches in the wind *like a shopping bag.* Louise has *gone through three* before she has an apron which is still intact. She ties it around her waist and contemplates how much of her clothing and body are still exposed: "*This pathetic pinny is not covering my clothes".*

She puts on a fresh mask. It's standard Type IIR surgical one, not a Level 3 filtering face piece which the Health and Safety Executive says is what any worker needs around airborne hazards, regardless of whether their job is in health,

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manufacturing, whatever. But she and her colleagues on the community have *only ever had access to surgical masks, never had any access to fit testing, never had any access for respiratory protective* equipment. Many of her hospital-based colleagues have been through fit-testing, but not those on community. Initially, she *thought that was absolutely fine*. But months later, what the RCN *knows now is that, actually, that's not good enough. England is an outlier, globally, for guidance on PPE, particularly about masks.* But it's no good just asking for a stock of FFP3 masks. *You can't just put them in a cupboard, because you've got to have the fit testing.* The wrong sized mask doesn't provide the necessary seal. Between reading the medical journals and spending many hours in the stuffy bedrooms of people who are clearly in the throes of the kind of respiratory distress caused by Covid, it's always on her mind. When she's up close to her patients the thought makes her turn her head away.

Louise puts on her visor. And this visor is definitely hers. She's had to stand her ground on that. Despite supply being a bit more reliable now, the culture of scarcity seems to have embedded itself, so the idea that visors should be cleaned and shared between clinicians is *like a myth that sort of carried on*. But Louise had checked with the RCN and was given the infection control facts: Y*ou should not be cleaning them* to share them, *they've got foam on them.* So, she carries her visor with her so she can be sure no-one else uses it. She spots another box-fresh visor,

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still in its wrapper, which Derek put in the boot to give her peace of mind in case they run out again.

With her medical bag in one hand, and the two waste bags and gel in the other, Louise heads for the house of Mr Grainger, who has respiratory distress, confirmed Covid. His wife answers the door as she places the gel on top of the yellow bag on the front step, and Louise steps into the hallway. The stifling air of the overheated house condenses both on her cold visor and the spectacles she wears – double layer steam. She goes back to the door, acclimatizes, demists herself, before going back in.

It's clear that Mr Grainger needs to go to hospital, but at this moment Mrs Grainger is more concerned about Louise’s comfort: ‘Oh, you poor thing! You must be freezing!’ It’s a struggle to be heard through the mask and the visor, but Louise perseveres, projecting her voice as loudly as she can, just short of full-on shouting, enunciating her words as clearly as possible. Though it’s a skill she’s developed over these long months of PPE-wearing, her diaphragm still aches from the effort, especially when using her usual communication tactics: getting down to the same level as the bedbound man, twisting her body to make eye contact, then turning to look up to Mrs Grainger hovering above. The flimsy plastic apron rustles and rips.

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Her glasses and visor steam up again, like the silvering on the back of a mirror, as her breath is funnelled upwards by the surgical mask. ‘Not much chance of Mrs Grainger seeing the smile in my eyes through this’, Louise thinks. Indeed, all Mrs Grainger can see is her own distorted reflection on the visor’s plastic surface.

Louise’s effort is emotional and psychological as well as physical, as the couple are not convinced that hospital is the safest place for Mr Grainger. He caught Covid at a funeral, and the family’s loss is still raw. They do not want to be parted. But this is an emergency, and they allow Louise to call an ambulance. And the next phase begins: the wait. She’s told to *expect it in an hour*. And all the while, Louise is calculating risk. Mr Grainger has a *desperate need for oxygen*, and the cylinder only holds 40 minutes’ worth. She realises she must *ration the oxygen* she has. She puts the oxygen mask on his face, takes it off, repeats the process. A reflex action, born from knowing her mask does not protect her, makes her turn her face away from the scared eyes of the coughing man.

There’s another risk assessment going on which means she can’t do what her instinct tells her to do. In all probability, this man is *dying in front of her eyes*. She would have sat by his side, sounded his chest, took his pulse, held his hand, soothed his brow. Actions rather than just words, a comfort to both her patient and his wife. But a voice in her head is saying: *‘I haven’t got good enough PPE. It’s no good me listening to this person’s chest, because they’re going to hospital and the*

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ambulance is coming. That would mean putting me at extra risk. There's no benefit, I'm not gonna do anything different, and I'll know if I need to do CPR'. Louise tries to stand back while she observes Mr Grainger's vital signs, hovering in the hallway whenever she feels able to step away, just to limit her exposure, for the sake of her next patient, for the sake of her own family. '*An hour is a long time*, when you're *thinking of exposure. I'm trying to be a swan! I can't go up and say to them: "I haven't got the right PPE on"*'.

When the ambulance comes, Louise runs *out into the driveway*. Approaching the paramedics, she says: *'Give us your oxygen while you don your gear. He's definitely Covid. You need to get kitted up'. In the beginning they were in spacesuits,* but the tall one says: *'What do you mean by kitted up? This is all we have – surgical masks. And we've dealt with nothing but Covid all night. This is the way it is now'*.

She does a handover for the paramedics who take Mr Grainger away, leaving his wife behind. Mrs Grainger is inconsolable. Louise tries her best, and fails, to express empathy. No amount of exaggerated body language and muffled words of sympathy can do the work of the hug she longs to give. But if she could offer it, would it be welcome? She has just witnessed Louise treating her husband in the most detached, functional way. They say goodbye at the front step, but as Louise

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peels off her layers and wrangles them into the wind-blown yellow waste bag, she can hear Mrs Grainger's sobs through the closed door.

Derek opens the car's passenger door as shivering Louise rubs another shot of alcohol gel into her hands. 'How are you doing? Do you need a minute?' says Derek. 'Not good, mate. What's next?'. The rest of the shift is a blur, and Louise heads home in the weak morning light. Now comes another doffing routine, a parody of her professional practice. This time it's for the protection of her own family – and quite a few of her colleagues have confessed that they're doing the same when they get home.

Louise, *like so many other nurses*, has re-instated her homecoming ritual from the spring of 2020. Back then, it was a response to knowing too little about the virus; now, maybe, they know too much. This time they know they haven't got the right PPE. She leaves her shoes outside, strips naked at the front door, and runs upstairs to the shower.

Drawn from 10/12/20 interview: 34/202; 34/274; 34/301; 34/306; 34/348; 34/600; 34/909. 31/03/22 interview: 34/33X; 34/51X; 34/57X; 34/69X; 34/144X; 34/148X; 34/287X; 34/292X; 34/306X; 34/310X; 34/318X; 34/335X; 34/339X; 34/345X; 34/353X; 34/413X; 34/430X; 34/455X; 34/473X; 34/491X; 34/846X; 34/968X

Louise’s communication behaviours were radically altered because she was sensitised to the perceived threat from her inadequate PPE artefacts: she had reduced eye contact, her body recoiled from proximity, and she minimised touch – all communicators of dislike and a lack of empathy, regardless of intent. For Mrs Grainger, the salience of this pivotal life event – perhaps the last time she would ever see her husband – could have imprinted this perceived distain in her consciousness, exacerbating her pre-existing distress and contributing to the establishment of a visceral negative impression of Louise as a person, of the out-of-hours urgent care service she represented, and of the wider nursing profession of which she was a member. The consequences of this fracture of patient-professional relations are explored in detail in Sections 6.3 and 6.4. The causes of this fracture inflicted their own toll on Louise: the denial of access to FFP3 masks, the rationing of oxygen due to the extended wait for an ambulance, and the privations Louise suffered through her self-imposed home-time infection control regime to compensate for the failures of PPE provision and protocol are forms of structural violence (Section 6.2), resulting in moral distress (Section 6.3).

5.2.4 Variety of PPE appearance

Consistency lends itself to habituation: repeated exposure to an identical stimulus allows the person experiencing it to evaluate and downgrade its saliency. However, the experience of seeing a person in PPE was ever-changing: the rules changed for different environments; other people’s adherence to the rules varied; and, as seen above, the availability, quality, and design of PPE meant that artefacts were not uniform in appearance. Some items were handmade by members of the public, as described by Louise [34/293-10/12/20]. Some were repurposed items, such as the lab equipment donated to Dave by a local school [13/466-18/09/20], or the rain ponchos used at Alex’s care home [14/56-21/09/20]. Official PPE could also be seen to be unfit for purpose, such as Louise’s aprons which visibly did not cover her clothes [34/312-10/12/20], or the visors clouded by repeated cleaning [34/276-10/12/20]. The sight of a clinician wearing soiled, ill-fitting, low-quality, or improvised items would evoke different emotions to the sight of them wearing fresh, well-fitting PPE made of quality materials.

PPE design could vary widely depending on the supplier. This could lead to the sight of clinicians in the same environment wearing different-looking combinations of PPE artefacts. Figures 13 and 14 (Cree, 2020a; Cree, 2020b) are an illustration of how two clinicians in identical roles, on the same ward, wearing PPE intended to afford identical protection, could look substantially different: note the variation in colours, quality of fabric, and the number of overlapping items. They have different levels of facial occlusion, so the observer's access to their non-verbal communication cues is also substantially different.

FIGURE 13 (left) and FIGURE 14: Dr Nicky Cree (left) and Dr Richard Cree, both Intensive Care consultants on the same unit, pictured wearing the same level of protection. Both images reproduced with permission © Richard Cree, 2020 (Cree, 2020a; 2020b)

The diversity of combinations of PPE artefacts was illustrated in the survey's responses. The 282 survey participants who had self-identified as health workers were offered a list of nine

PPE items (hair covering, goggles, visor, mask, respirator, gloves, apron, gown with sleeves, full body suit) and were asked to indicate all those items which they wore as part of their role. A case-by-case analysis of each of the 260 respondents who reported wearing one or more items identified 30 different combinations of PPE.

5.2.5 Clear masks: expectation and experience

A window which gives access to facial features can help the wearer convey their emotions and personality, as seen from the smiling face of Dr Cree in Figure 14. In both the survey and interviews, the most frequently posited solution to communication barriers was the adoption of masks with clear windows, as pictured in Figures 9 and 10, Section 2.12. Despite a government statement in September 2020 that 250,000 such masks had been distributed (DHSC, 2020b), the open-ended survey responses by diverse respondents suggested that these masks had not yet reached all those who needed them, as they mostly contained requests for the items rather than experiences of using them. Those requesting clear masks included a prison mental health team member [S153-26/08/20] and a respondent who had hearing and visual impairment [S464-26/10/20], while Veronica's interview included repeated statements that her role in older people's mental health would benefit from clear masks to facilitate facial recognition which is central to rapport-building, as well as allowing lipreading and communication by facial expression [18/282,286,301,522,526-24/09/20].

Some participants felt that, rather than reserving clear masks for people with identified hearing loss, it would be more practical and respectful to communication if they were universally adopted. In-patient Carl said that an appropriate design which made the mouth visible would '*be very useful to people who are to any degree relying on lip reading, but also just as a means of paying due respect to human communication*' [32/318-29/10/20]. Therapist Sally, who had a hearing impairment, pointed to the widespread presence of hearing loss amongst health workers as a reason to prioritise universal adoption of clear masks:

> *'…if I'm struggling, I need it for me as well as for our patients. It's no good just me wearing a [clear] mask to help the patients, I need my colleagues who might be wearing masks to also be wearing these clear masks. I do think that would help'* [16/115-22/09/20]

However, GP Deborah said that the adoption of clear masks would be resisted due to their *'odd'* aesthetic and the likelihood that they would steam up [33/214-10/11/20].

The two participants who did use windowed masks both confirmed the problem with steam. Care home training manager Alex said: *'You can get the plastic ones [masks] with the clear inset, but then they steam up. That's why I'm only recommending it for short periods, just to diffuse distress'* [14/254-21/09/20]. Charlotte, who was Deaf and had severe visual impairment, described in her survey response *'wearing clear mask and visor but they were cloudy / misty / steamy'*. When Charlotte subsequently spoke to me via a BSL interpreter, she went on to describe how the adapted masks still distorted facial expression and introduced the obstacle of reflected light:

> *'…because of the line of fabric over the nose, a lot of the facial expression is distorted. And if it's only like a postage-stamp size – well, bigger than a postage stamp, a couple of inches just around the mouth – it takes away a lot of the image of the face to be able to read the face and read the lip patterns. Another problem is reflection as well, because whenever you have clear plastic, then there's going to be a reflection of light. So it's not a case of just everything being see-through and transparent'* [24/119-07/10/20]

5.3 INTERVENTIONS AFFECTING PPE AND DISTANCING

PPE objects and distancing were experienced in the context of time and place. The government-specified levels of PPE and proximity-avoidance changed repeatedly over time. Rules became behaviours at the human interface, where PPE-wearing and distancing were interpreted in real life. Top-down interpretations were made by those with local responsibility for enforcement, and bottom-up interpretations occurred when individuals observed each other's actions and copied them.

5.3.1 Inconsistency of rules

Depending on which regulations were in place at the time, clinicians and the public were required to wear different combinations of PPE and practice different levels of proximity-avoidance for the same type of interaction. The fluidity of regulations was so labile that part-timer Natalie would be disoriented from one ITU shift to the next. She said:

> *'I was coming in on a Thursday and finding that everything had changed'* [26/28-13/10/20] *[...] 'And that in itself, I think, kind of – it did put you on edge a little bit because you kind of thought: "Right, what am I going into this week?"'* [26/109-13/10/20]

NHS CAMHS therapist Maggie described similar confusion at what she considered to be an illogical interpretation of distancing rules imposed on her son-in-law when her daughter and newborn grandchild were kept in hospital:

> *'He could go in to see the baby, but he couldn't see her because of cross contamination. So he couldn't go into the ward, because no partners are allowed into the ward. But he could go in and see the baby until he took him home'* [12/379X-08/04/22] *[...] 'the baby was taken to a place where dad could come in and see them, and then the baby's taken back to mum'* [12/383X-08/04/22] *[...] 'It doesn't make any sense, does it?'* [12/387X-08/04/22]

Differences in environment required different protocols: masks and distancing were strictly enforced on one side of a hospital door while staff and public mingled without face-coverings on the other side. These contrasting sights could create a sensitising dissonance in an observer, especially if their expectations of careful mask and distancing observance had been instilled by the same staff whose bare faces now passed close by. This was the experience of in-patient Carl and his mother Barbara. I interviewed them separately and present their combined recollections of the incident as a vignette.

Vignette 4: Barbara and Carl (part 1)

Saturday 6 September 2020. Barbara was anxious. She'd been phoning the spinal injuries unit since breakfast, *ringing them and ringing them, four or five times, trying to find out* if her planned visit to Carl was still on, but she *couldn't get through, they just weren't answering*. She couldn't face yet another last-minute cancellation: they'd only started allowing visiting a month ago and she'd been put off more times than she'd been. *It's likely to change on a day-to-day basis.* Any chance of a Covid case and it's full lockdown.

She'd only seen him three times since March – five hours in seven months. It didn't feel right. Carl might well be a fiercely independent 46-year-old grown man, but he was still her boy, and he'd been through the mill. Since the accident when he was 17, he'd not let his paralysis stop him living his life – he didn't miss out on the partying at uni, and still came away with a Psychology degree that set him up for a

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successful career. He loved teaching computers to people with learning needs, dementia, visual impairment – he really clicked with folks who needed that extra support. He had his own home, he was driving, he had a new Jag that he loved. He was out and about and getting on with his life. But then, in 2016, the cervical dystonia kicked in, and the driving had to stop. His muscles just didn’t seem to work when he called on them to transfer from wheelchair to bed. Then things just spiralled: the skin damage from those struggles got infected, then there was osteomyelitis, a blocked femoral artery. His leg had to be amputated in 2018 but that wasn’t the end of it: sepsis meant it was touch and go for a while, and the dystonia was keeping him in bed. Four years in one hospital or another, or waiting to go in. He’d been in this one since before Christmas.

She wanted to see him. She put up with the strict rules. You had *to make a booking and you get an hour of time, one person to one person, and you’ve got your full PPE stuff: your gloves, your pinny, a mask – everything*. Where, and for how long, was strictly controlled: *outdoors, in a corridor, or in a different room*. The staff called the shots, and woe betide if you broke the rules: Katie, Carl’s sister, had been upset last week when she’d come over after seeing him. She’d gone *to look for somebody to come and take him back to bed because his leg will only stay in comfort for so*

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long. So she began to walk into the unit and they'd yelled at her: "You can't come in here!"

But Katie said *she'd seen two visitors with one patient*, and Barbara was desperate to find out if her husband, Bill, could come too. Tired of calling the ward, Barbara gave Carl a call on his mobile. Carl sounded in great spirits:

> "Hi mum! The botox seems to have done the trick. I got into my chair and *I'm actually sitting outside! I'll be at the front entrance of the unit. And I'll meet you there. Perhaps we could go to the café* in the foyer if it's open?"

Barbara and Bill put on their surgical masks as they spotted Carl, also masked, at the entrance of the massive hospital – *32 miles of corridor*, according to Carl. Together they made their way through the automatic doors to the main thoroughfare, where the open-plan café served as a place to pause while people bustled by. They weren't the only ones wearing masks, but there were plenty of people who weren't – including *the security guards*. Barbara *had never seen so many security guards as* she did *that day, and not one of them was saying a word to anybody.*

Barbara pumped one of the two hand sanitizers on the table at the threshold of the café, then the other, but *both were completely empty, and the table was a mess*.

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There were *no positive directions as to what you needed to do.* They each bought a tea, took a seat at one of the spaced-out tables, removed their masks and sipped their drinks. As they talked, they observed the comings and goings of the staff and the handful of visitors. *There were people crossing by, you could touch them.* Their eyes were drawn to the faces, some with fully visible mouths, smiling, frowning, talking, chewing… The café staff pulled down the shutters, but the tables continued to be occupied by a procession of people taking a break and moving on.

Barbara said:

> *“Nobody seems to think there’s a problem here. People are wandering about and nobody seems to be bothering. You know, I’ve no idea what the culture call here is. There are no positive directions, nobody telling you what to do. Nobody informing you as to what the protocol* is*. I’m feeling very confused. One has to assume, I suppose, that it’s up to you whether you do or whether you don’t, whether you feel comfortable, or you don’t feel comfortable*.”

One young man came and sat at the next table, in surgical scrubs – doctor, nurse, physio? – and for the next half hour sat maskless, eating the packed lunch he’d brought, talking on his phone.

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Carl switched his gaze to his own mask, set next to his paper cup:

> *“I wonder if I should put this back on?”*

He looked across the concourse to the corridor which led directly to his unit, to the different world, the world of PPE and “you can’t come in here!”. The corridor was locked as a pandemic infection control measure. Carl said:

> ‘It’s *curious how confined and limited – restricted, the – our – my – movement is inside* the *unit in comparison with the rest of the hospital*. It feels like there’s *almost security controlling your movement* in there. But here, *travelling in through the* main *entrance, it’s very clear there* isn’t.
>
> “And I reckon”, said Carl, “It’s like the restrictions depend on how well you can move. I reckon it’s the same distance to go out of the unit, round the outside, and into this cafe as it is to go down that corridor. I’ve *wandered in* here a*nd there was nothing at all* to *stop me*. *The only people in* the unit *who would* be *prevented from doing that would be the people who were bed bound and, I suppose, the people who weren’t in a position to physically to push themselves round*.”

The three sat in silence for a while, looking around, looking at each other’s faces. The lack of masks only served to give full view of their worried expressions.

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> "OK then," said Barbara, *"If somebody says: 'Put your mask on', we'll put our masks on quite happily"*.

But for the *three hours* that they nursed their cold cups as an excuse for keeping their seats, nobody did. All the while, the ball of confusion was growing in Barbara's chest. *Where was the logic?*

[Drawn from interview with Barbara on 14/09/20: 11/34-54; 11/60-93; 11/106; 11/158-171; 11/178-9; 11/199-219; 11/227-8; 11/234-248; 11/264-5; and interview with Carl on 29/10/20: 32/23-34; 32/41-45; 32/189; 32/217; 32/299; 32/357; 32/420-424]

Barbara and Carl's experience illustrates how the normlessness of the rules as they stood at any given time gave a space for individual and collective (mis)interpretation and adaptation. The next sections consider how people coped with the communication challenges posed by PPE and distancing.

5.3.2 Behaviours aimed at mitigating in-person communication barriers

Carl observed the demeanour of the staff who cared for him and reflected that staff-patient communication in masks was *'about an awful lot more than just the words that we use. It's a full-on kind of interaction. It's in the eyes as much as the tone of voice. We're very, very responsive to all sorts of subtle things'* [32/404-29/10/20] such as posture [32/418-29/10/20]. Carl said these factors seem to be instinctive or, as Carl put it: *'animal'* [32/417-29/10/20]. Carl admired *'the experience and practice of the staff here in communicating often quite complex things in the most effective way that they can'* [32/211-29/10/20] through non-verbal communication or *'semaphore'* [32/210-29/10/20]. Carl noticed how staff approached people *'with a smile on their face: even though we can't see their faces you can tell that's what they're doing'* [32/431-29/10/20]. They also modulated the tone of their voices to aid communication [32/430-29/10/20].

Extended and repeated experiences over the years as a hospital in-patient gave Carl ample opportunity to observe how teams of staff in different hospitals communicated, both with patients and between each other, and in the absence and presence of PPE and physical distancing. Carl said that his experience in the unit from which he spoke to me was *'incomparably better'* [32/74-29/10/20] than his recollection of time spent in similar wards of other hospitals prior to the pandemic where there was no interaction between patients and staff except to facilitate medical tasks [32/260-29/10/20]. Carl warned of the *'dehumanising potential [...] if [staff] see their patients as either objects or customers'* [32/399-29/10/20]. Carl said:

> *'I'm certain my mental health would be in a vastly more brittle place than it is now had I been basically anywhere other than here, or somewhere filled with staff like the staff are here, because they do put the time and the effort into having relationships with the inmates'* [32/247-29/10/20*] [...] 'the capacity of the staff here particularly to serve as a surrogate family is a good reflection of quite how cohesive the staff here are, by how well they all get on with each other'* [32/54-29/10/20]

Carl said that the communication skills and positive working atmosphere which he observed ought to be explicitly taught [32/433-29/10/20], but only one survey respondent, a staff nurse on a respiratory ward, reported receiving *'training from the psychology team'* about communication techniques [S426-24/09/20]. Two interview participants, senior nurse Louise and care home training manager Alex, described their own efforts to plan and deliver training and guidance. Louise's national role involved interpreting and disseminating authoritative and constructive advice. She said her clinical practice informed her advisory work:

> *'…that's why I love my two roles, my different combination of roles, because you see what it is in reality'* [34/151-10/12/20]

Alex described the complexity of designing training which both reinforced compliance and facilitated communication:

> *'I've been doing top tips for mask wearing and then top tips for communicating with residents wearing a mask […] I've been trying to upskill staff in that area because people have been not wearing them, or wearing them wrong, or putting them on their head, or taking them off to talk to somebody and then putting them back on again. So I wanted to raise awareness around why we wear the mask and also how to communicate better with the mask on'* [14/16-21/09/20] *[…] 'There are so many things that I say to people every day that I think that they should be doing differently. But, the excuses... It all to boils down to being educated'* [14/200-21/09/20]

Survey respondents were invited to describe *'any particular methods or techniques [you have used] to get around the barriers to communication caused by your PPE and/or distancing'*, and to describe the outcome. Both survey respondents and interviewees specified altered speech and/or movement in their descriptions of the strategies they used to overcome communication barriers.

In April 2020 a learning resource on coping with PPE, including ways to improve communication while wearing it, was published by *Performing Medicine* (2020), an arts-based initiative to support the wellbeing of health professionals. It drew from the experiences of speech and movement experts with relevant experience: performers who worked inside restrictive masks, prosthetics, and costumes such as the life-size puppets in the theatre production of Michael Morpurgo's *War Horse*. English Unlocked, a training organisation originally created to promote techniques which clarify communication with non-English speakers, also published a resource in July 2020 to teach people how to be better understood while wearing a mask (Purchon, 2020). Both survey and interview respondents described some behaviours which matched the resources' advice on verbal and non-verbal communication – and some behaviours which did not.

Performing Medicine advised facing one's interlocutor, because *'eye contact is paramount'*. The accompanying advice to *'engage and enliven'* the eyes. This is consequential when considering a prison psychologist's written survey response, which described how *'eye contact has become more intense and sustained'* [S177-26/08/20], illustrating the potential harms of misinterpreting engagement as confrontation. Purchon's advice is to *'smile all the more' […] 'to put your conversation partner at ease' […] 'if they are able to relax, they are more able to do the hard cognitive work of attending'*.

A Duchenne smile (Ekman, Davidson & Friesen, 1990), named after French neurologist Guillaume Duchenne, engages the muscles around the eye to create what Carl observed in his carers as *'that sort of slight crease in your face'* [32/415-29/10/20]. The difference between a Duchenne and non-Duchenne smile is apparent above a mask, as demonstrated by communication trainer Shelley Purchon in Figure 15 (Purchon, 2020).

FIGURE 15: Duchenne smile (left) and non-Duchenne smile (right).
Image: © Shelley Purchon (2020), reproduced with permission

Dorah, who was living with primary lateral sclerosis (PLS), a form of Motor Neurone Disease, said:

> *'…smile with your eyes. That communicates the world, you know. Encouraging, isn't it? It is, smiling at you is actually encouraging. And you can see that, even with the mask'* [31/420-26/10/20]

Alex described how in her training she emphasised the need to smile:

> *'I say this constantly to people – that your eyes give everything away. So smile. It's a really cheesy thing to say, but yeah'* [14/204-21/09/20]

A chronic pain clinical nurse specialist wrote of how they combined techniques:

> *'When wearing PPE I smile more – I know as a consequence of feedback from others – that smiling shows in my eyes; I enunciate more clearly; I adjust my position so that I face the patient squarely'* [S394-22/09/20]

However, a physical therapist's survey response suggested a sense of futility in the act:

> *'I smile but know they can't see it'* [S125-25/08/20]

Louise suspected that there had been a loss of faith in the ability to convey a smile from behind a mask, and even the loss of the habit of smiling during interactions, both of which would need correcting:

> *'…as a student nurse, I had to learn that as part of our training: "Keep the poker face on! Smile!" And I just think it's gonna be interesting for people, especially who are only coming into healthcare this last couple of years, that they are going to be sitting there looking like that: [pulls face] and not keeping their face straight'* [34/717X-31/03/22] *[…] 'I think we'll need some education on how to come from behind the mask! [Laughs]'* [34/731X-31/03/22]

Verbal contextualisation and reinforcement was required, as advised by Purchon (2020):

> *'Give context' [...] 'make sure your conversation partner has all the contextual information they need and* ***after that*** *begin your message' [...] 'Before you rephrase something, try repeating it slowly in the exact same words'*

Occupational therapist Veronica, who worked with people with dementia, agreed that the meaning of non-verbal expressions from the eyes required verbal augmentation to prevent misunderstanding:

> *'I think you've got to verbalise it sometimes: "Yes, I am listening to you. Yes, I am feeling your pain"'* [18/318-24/09/20]

Physiotherapist Vicky concurred:

> *'You know, we say to each other in the corridor now: "I'm smiling behind this!" and things like that, because you can't see it, obviously'* [25/216-09/10/20]

A GP working in urgent care wrote:

> *'Explanation about my facial expression behind my mask: e.g., "I'm smiling at you behind my mask, are you smiling at me?" can be a helpful way to engage children in conversation and reduce the barrier of the mask, or "I'm sorry that you can't see my facial expression clearly but I want you to know that I feel concerned about you right now". I have found the methods above have helped in consultations'*
> [S389-14/09/20]

Listening and contextualising were features of the written response of a learning disabilities support worker:

> *'Speaking more clearly and checking that others have understood me'*
> [S166-26/08/20]

The survey response from a visually impaired respondent alluded to the energy required to listen and express oneself mindfully:

> *‘I make an effort to be more friendly and polite verbally’* [S304-08/08/20]

Nurse Louise also described the exhausting reality of engaging in repetitious vocal reassurance to compensate for the loss of facial and tactile expression:

> *‘...you have to talk more, talk and reassure, rather than rely on touch, and keep reassuring and reassuring and reassuring. Which is really hard when you’re waiting an hour for an ambulance. It is tricky. And also it’s uncomfortable’*
> [34/491X-31/03/22]

Issues of burnout are considered in Section 6.4.1.

The resource created by *Performing Medicine* (2020) advised PPE-wearers to *‘acknowledge and accept what you look like’*, advice which Alex shared with her care home staff:

> *‘…explain what it is you’re doing and why you’ve got a mask on, because a lot of people we look after and support have got cognitive impairment, they might not have the capacity to be able to understand why I’m stood in front of them the mask on. I see a lot of people going gung-ho, like: “We’re going in, we’re going to assist this person”. I’m like: “Whoa, whoa! Take a step back, have a conversation, talk to the person. Acknowledge the mask, talk to the person about the mask. If you want, encourage them to wear a mask – that might make them feel more at ease”. They kind of look at me like I’m a bit daft when I say things like this. But you’re trying to build that relationship and that trust with that person. You’re about to go into their personal space and you’re about to touch them, you’re about to assist them, you’re about to be really close to them with a mask on looking completely alien to them’*
> [14/205-21/09/20]

The *Performing Medicine* resource advised interlocutors in PPE to *'use humour'*. A sports therapist wrote of using an alternative to a handshake as a fun 'icebreaker' which acknowledges the difficult circumstances in a light-hearted way:

> *'I have been using an "elbow bump" to those I would normally shake hands with. It is a bit of fun and just eases the awkward moment when meeting people and new clients'* [S282-02/09/20]

Carl praised his carers on the spinal injuries unit for their appropriate use of humour which facilitated an easy rapport which both acknowledged and transcended the masks:

> *'…we have amusing conversations'* [32/277-29/10/20] *[…] 'Very often there's the sound of laughter coming either from the staff or from the patients'* [32/60-29/10/20] *[…] 'I suppose one of the key things that I remember about that time [the initial introduction of PPE and distancing] was that it immediately became a running joke'* [32/82-29/10/20] […] *'there is always a joke just around the corner. There is always a laughing at the madness of it all, laughing at the dark side of things, you know?'* [32/251-29/10/20]

Perinatal mental health nurse Beth connected with her client by sharing a joke about her visor:

> *'So I would take my plastic visor, which the mum equally called "riot gear" so we could have a bit of banter about that'* [23/225-05/10/20]

However, Beth said that, as someone who had used bluntness and humour to communicate prior to Covid, she had adjusted what she said because she could not provide the non-verbal context required for its meaning to be accurately received:

> '*I'd worked with [a patient] about seven months prior to the pandemic, the banter, the straight talking, the bluntness and everything – all the delights that I bring to a working relationship, I could do with her because she knew that it comes from a*

> *place of real care and passion for the job. Whereas the usual tactics that I might use, with somebody who's never met me [without PPE], they could probably say: "Ooh! You're a bit of a knob", in terms of being a bit too blunt'* [23/178-05/10/20]

By 2022, this inhibition of Beth's tendency to incorporate humour in her clinical communication style had endured beyond the relaxation of mask-wearing:

> *'I still feel there's an element of being a bit more measured'* [23/201X-14/04/22] *[...] 'I guess it's not fully back to how it was. And there are still some markers that we have – that I have to hold in mind. But yeah, it doesn't feel as big a hindrance as it was before, but it's not gone. It's still there'* [23/205X-14/04/22]

The use of *'gestures and props'* were recommended by Purchon, but with the caveat: *'Be wary of overusing'*, while *Performing Medicine*'s guidance suggests:

> '*…developing a shared physical language with those you communicate with regularly. Agree basic signals. Keep your movements assertive'*

Three of the 12 survey respondents who described using body language and gestures to facilitate communication described using formal 'sign language'. A health care assistant for people with complex needs [S456-19/10/20] and a respondent who worked in hospital/home support services [S457-20/10/20] both described 'signing', while a speech and language therapist who worked on an adult learning disability team specified their use of Makaton [S190-27/08/20], system developed in the 1970s to communicate with people with learning disabilities (M. Walker, 1976). Unlike a language for the hearing impaired such as BSL with its own grammar and syntax, Makaton is used by people who have no hearing deficit. Signs are used with speech, in spoken word order, to provide extra clues about what someone is saying. Makaton's use has extended into mainstream early years education and communication with people who have English as an additional language.

A survey respondent who was not a care professional noted the positive impact of attention to diction and tone:

> *'[When responding to] people with expressive voices I rely less on visual cues'* [S310-11/09/20]

Performing Medicine gave comprehensive advice on speaking in a mask:

> *'Instead of raising your voice and speaking in higher pitch to be heard, try to speak low. Let your voice drop down – a lower voice can cut through and be more resonant and soothing to others. Don't trail off at the end of sentences – get to the end of the thought. Annunciate. Articulating consonants of words improves clarity'*

This advice was complemented by Purchon's guidance to go for a slower pace rather than louder volume, and to '*put a gap between every word.* ***The wrong way*** *is to extend the length of each word.'* Dorah's speech was affected by her Primary Lateral Sclerosis (PLS). When I interviewed her by video, I noticed she was engaging in both sets of strategies. Her dysarthia and limited vocal power was minimised, and the conversation flowed easily.

In contrast, the strategies described in survey responses occasionally emphasised volume over enunciation. For example, a hospice complementary therapist described talking *'louder and clearer'* [S244-01/09/20], while the strategies described by a staff nurse in forensic mental health met most, but not all, of the recommendations:

> *'Increasing voice volume, gesticulating more, encouraging patients to give eye contact'* [S198-28/08/20]

Both *Performing Medicine* and Purchon advised self-care and vocal exercises to protect the voice. These factors were notably absent from participants' responses. *Performing Medicine* advised:

> *'When wearing restrictive gear and PPE it is essential to take regular breaks to rest, even if it is an effort to change' […] 'Create rest stations out of the way of the action. Have water, rehydration pouches, chairs, even a fan. Have a person whose job it is to look after the staff in your shift. Maybe create a rota amongst yourselves'*

Performing Medicine strongly advised against *'pushing through',* however, as seen in Section 4.1.3 and 5.2.1, this was a habit reported by a notable number of participants who, due to PPE shortages, did not have fresh gear to change into. While ITU dietician Natalie was grateful that she had *'somewhere to go, take the masks off, have a break, have a drink or whatever, and then go back on the wards or whatever. So we have got an area to do that in'* [26/565-13/09/20], Louise said that she and her colleagues did not [34/298-10/12/20]. The lack of changing rooms and rest areas occurred despite them being a requirement of Standard 13 of the RCN's Nursing Workforce Standards (RCN, 2021, p.27), as described by Louise [282X-31/03/22]. This structural violence will be explored in more detail in Chapter 6.

The altered behaviours described by respondents in their attempts to overcome the communication barriers created by PPE and distancing are very similar to those described as 'Third Circle' by theatre voice and movement coach Patsy Rodenburg (2008, pp.17-19): projecting *'bluff and force'* which can result in others *'experienc[ing] you as insensitive, arrogant, and overbearing'*. In-person communication in PPE can be contextualised using Rosenburg's descriptors: the need for PPE means you have no choice but to *'wear clothes that get you noticed';* observing the two-metre distancing rule, particularly when considered alongside perceived threat of infection, would lead to '*people withdrawing from you or making space for you'* and you would *'find yourself taking up more space than you need'*; occlusion of the visual field would make it hard to *'really notice the people you are speaking to or the room you are in'*; the occlusion of the mouth would make you *'breathe with noise'* and speak at a volume that would be *'too loud'* in usual circumstances; the need to exaggerate gestures and facial expressions would mean you *'feel that you have to inject energy into every social event at any price to yourself and others'*; and the occlusion of your interlocutor's mouth and facial cues, combined with the noise and aural occlusion afforded by the PPE, could force you to *'take command of a discussion even if you have only heard a fragment of what is being discussed, so that you are accused of interrupting others'*. Consequently, a subliminal, often contradictory, message can be conveyed by the very behaviours being engaged with the intent of overtly expressing connection and care: a 'double bind' (Bateson, Jackson, Haley, & Weakland, 1956), which creates a disturbing normlessness.

For example, a double bind could arise from the *'intense and sustained'* eye contact described by the prison psychologist [S177-26/08/20], particularly in such a high-stakes setting. Such intensity could be difficult to interpret as empathy if not accompanied by an exquisite attention to what is said, especially as other non-verbal clues are denied, such as a smile or a gentle touch. Respondents described an awareness of a potential 'double bind'. Specialist pain physiotherapist Vicky spoke of uncertainty caused by closed-off or distorted subtle facial expressions:

> *'…even speaking with my colleagues, you know, even though you know them, you still feel like you can't get your expression across'* [25/215-09/10/20] *[…] 'when you kind of open your mouth and your eyebrows go up, if you're just doing the eyebrows it completely can change the connotations of what that might mean. So, yeah, I suppose it makes you feel a little bit unsure'* [25/218-09/10/20]

The most frequently reported behaviour to reduce in-person barriers to communication was the 'distanced doff', where the PPE-wearer took their mask off to communicate outdoors and/or with as much space between themselves and their interlocutor as possible. This tactic was reported by 15 (16.3%) of the 92 survey participants who gave free-text responses. Participants reporting this behaviour worked in a range of disciplines and included a GP

[S389-21/09/20], a domiciliary carer [S207-01/09/20], a community palliative care complementary therapist [S277-02/09/20] a hospital-based learning disabilities support worker [S166-26/08/20] and a sports massage therapist [S077-25/08/20]. Care home training manager Alex described a typical ‘distanced doff’ and its effects:

> *‘I deal a lot with people who have behaviours that challenge, and somebody rang me and said: “We’ve got a problem. There’s a guy that won’t let go of somebody”. We quickly realised he was absolutely frightened to death. So I stood at a distance from him, took my mask off, and smiled at him. He soon let go’* [14/231-21/09/20]

However, there was a perception amongst some participants that managerial culture sought to blame and punish staff for non-compliance without valuing the complex experience-based risk/benefit analysis which underpinned the practitioner’s decision to diverge from protocol. Perinatal mental health nurse Beth anticipated conflict:

> *‘I’ve always persevered and tried, but yeah, much to my manager’s delight I’m sure, I’ve had to take it off or wear a visor’* [23/222-05/10/20] *[...] ‘only for that particular baby have I deviated from that plan because I couldn’t sit there and actively put him in distress, it just – Yeah, the chief exec can argue with me on that on another day, that’s fine’* [23/435-05/10/20]

This perception of a blame culture in the healthcare profession reached the public consciousness. In her survey response Charlotte, who was Deaf and visually impaired, described how her GP’s distanced doff made her fear that he could be reprimanded:

> *‘I was worried when the doctor removed his mask for communication. I was more worried about his wellbeing because of his ethics’* [S049-24/08/20]

5.3.3 Artefacts aimed at mitigating in-person communication barriers

Staff in the intensive care unit caring for the father of children’s therapist Maggie adjusted their PPE by writing their names on it to identify themselves [12/232-17/09/20], while a hospital worker described in their survey response how they and their colleagues attached a *'photo of our face on gown'* [S351-17/09/20]. This PPE Portrait, as described in Section 2.11, was also alluded to by a nursing home manager [S381-21/09/20] and a physiotherapist [S378-21/09/20], while a different adaptation of their own portraits was reported by two other respondents. Care home training manager Alex wore a *'"my name is…" badge with a picture of me with no mask hung around my neck'* [S050-24/08/20], while a care home admissions manager described how they had created a suite of communicative picture cards:

> *'We have used picture cards: our faces and various facial expressions on those cards to indicate to individuals who we are, how we are feeling and why we are there for reassurance'* [S382-21/09/20]

The use of objects with visual symbols or images upon them were also mentioned as communicative tools by four survey respondents including a community dementia nurse specialist [S022-19/08/20], a nurse with visual impairment [S027-20/08/20], and a deputy manager of a care home [S380-21/09/20]. They were used *'for people to point at'*, as described by a complementary therapist who used them while working in an NHS hospital setting [S427-24/09/20].

Pen and paper, to replace or augment the spoken word during in-person interactions, were also mentioned by the community dementia nurse specialist [S022-19/08/20] and the physiotherapist who engaged with images as described above [S378-21/09/20]. A hospital hearing implant technician, who was themselves hearing-impaired, used their tablet computer rather than paper to communicate in writing [S388-21/09/20]. An NHS mental health therapist *'ask[ed] clients to write down what we discuss'* [S460-24/10/20]. However, pen and paper was considered unsatisfactory by the owner of a therapy centre who wrote:

> *'Sometimes I have to write things down, which isn't good'* [S095-25/08/20]

By August 2020, when the survey was circulated, there were portable audiovisual resources available such as Cardmedic (Grimaldi, 2020) – an app for smartphones and tablets which provided audiovisual augmentation for in-person healthcare conversations which was developed in response to the challenges of pandemic-related PPE-wearing and distancing – but such innovations were not specifically described in survey or interview responses, suggesting that there was no widespread adoption of the product amongst the respondents.

Two massage therapists [S040-22/08/20 and S041-22/08/20] reported changing clothes between each client to avoid the need to wear a disposable apron. Dementia care therapist Sally also used a separate set of clothes as a replacement for PPE for the client who was disturbed by the sight of her tunic and the distracting sound and texture of her apron:

> '*…for the lady that I visit who thinks I'm going to take her away to the workhouse, I wear a white polo shirt, she seems okay with that. She doesn't freak out when she sees me. If I turn up in my blue tunic, she identifies me as something nursey, I think, and just doesn't like it'* [16/433-21/09/20]

Two survey participants wrote of items which reduced the distraction of the discomfort caused by their PPE. A health clinic therapist wrote of a *'gadget which sits like a headband so I can attach [my] mask so [it] doesn't mess with my varifocal glasses'* [S249-01/09/20], while the care manager of a sight loss home for over 65s wrote of an item which prevented mask elastic rubbing behind the ears [S446-13/10/20].

5.3.4 Engaging remotely by choice

The interpretation and application of distancing rules by their employers or other authorities meant many health and wellbeing practitioners, such as massage therapists, were prevented from any in-person contact with their clients. Even when in-person interactions were allowable, some practitioners abandoned attempts to work in-person due to the barriers posed by PPE. Instead, they either moved their practice online or withdrew some or all their services entirely, as did a social care support worker who wrote:

> *'I've stopped communicating, I refuse to be part of this nonsense'* [S143-26/08/20]

Some participants saw clients in-person, but also engaged in remote interaction to minimise time in physical proximity. Twenty-five of the survey respondents who delivered hands-on therapy used phone, video, and email for pre-treatment assessments and after-care advice. One massage therapist with a hearing impairment wrote that this *'work[s] really well and adds to the therapeutic alliance'* [S121-25/08/20], but another complementary therapist said:

> *'...this does not seem to work – with clients needing to talk as much as ever during their time with me in person!'* [S195-27/08/20]

Another massage therapist said the process *'makes everything a lot longer [...] and is not financially viable'* [S249-01/09/20], whilst another reported more non-attendance [S273-02/09/20].

Switching to video calls had *'varying degrees of success'* for an NHS clinical psychologist working with adults with learning disabilities, not least because it introduced *'lots of technical issues for people'* [S353-18/09/20]. This respondent also *'tried phone calls but ha[d] not been able to progress therapy this way'*.

5.3.5 Distancing as an impetus for innovation

Charlotte, who was Deafblind, described in Section 4.4.2 how people with severe sensory impairment had a history of using creative approaches to develop effective communicative languages. At the onset of forced deprivation of proximity, similar creative innovation was displayed by the participants I interviewed. The fact that I was able to interview Charlotte remotely was a testament to such innovation. She had a laptop in front of her carrying my audio-visual feed, above which was a 27-inch screen carrying the image of her BSL interpreter [24/21-07/10/20] who had two cameras transmitting his face-on and side-on images [24/224-07/10/20]. The interpreter, who was at different venue, was in front of a green background wearing a plain white shirt to maximise the sharpness of the image which Charlotte could perceive. I was able to see and hear both Charlotte and the interpreter, and from this I could see a warmth in their relationship which contributed to the fluency and accuracy of the interpretation. Charlotte described how Covid restrictions were an impetus for innovation:

> *'In terms of before Covid, let's say, I think I'd used Zoom a couple of times. I do a fair amount of international work [...] I have colleagues all around the world who I meet with. And I would say pre-Covid, I wasn't especially confident. Since lockdown started, it was a case of: "We have to learn, there is no choice". And that sort of impetus has you put on a great learning curve'* [24/229-07/10/20]

In 2020/21, people aged 65-74 were the most likely age group to formally volunteer their unpaid time to groups, clubs, organisations, or individuals to whom they are not related (Tabassum, 2023). The vulnerability of older people to the virus added impetus to the need for innovative approaches which facilitated distancing. At the onset of lockdown in March 2020 Noreen, a lady in her 70s who taught Tai Chi in care homes, began offering twice-weekly live sessions online via Zoom and on Facebook for free [19/41-29/09/20], and produced a DVD for staff to play in the locked-down care homes [19/171-29/09/20]. Her previous knowledge of online communication was from keeping in touch with family overseas via Zoom [19/221-29/09/20].

This section has illustrated how the people who engaged in occluded and distanced health and care interactions did so with perseverance and creativity. I now turn to the influence of people in power (i.e., individuals who, singly or collectively, due to their position or perceived status, have the capacity to lead, influence, dominate or impact upon the actions of others), whose presence in those interactions was manifested through their policies, messaging, and behaviours.

5.4 COMMUNICATION *ABOUT* PPE AND DISTANCING

So far, I have examined how thoughts and feelings arising from the embodied sensations of *being in the presence of* PPE and distancing had an influence on health and care interactions. In this section, I consider the explicit and tacit communications which took place *about* PPE and distancing. I consider how these interactions affected people's behaviours and their personal beliefs about the *role* of PPE and distancing, which in turn fed back into their health and care interactions *in the presence (or absence) of* those artefacts and behaviours. Explicit and implicit communication about PPE and distancing took place on macro, meso, and micro levels – the government's imposition of rules and policies; the way organisations and groups interpreted those instructions; the words and behaviours of individuals.

5.4.1 Government messaging on PPE

As discussed in Section 2.4, the specifications and purposes of different designs of masks had been established by the HSE before the pandemic (Gawn, Clayton, Makison, & Crook, 2008; HSE, 2013). However, in communication during the pandemic, the blanket term 'mask' was applied to non-medical face-coverings and medical-grade artefacts alike, obfuscating the differences between 'source control' and 'wearer protection'. The World Health Organisation's January 2020 advice discouraging mask-wearing in community settings (WHO, 2020a) was criticised by professionals and academics for amplifying confusion, making unfounded statements, and ignoring or misrepresenting existing evidence (Chan, Leung, Lam, & Cheng, 2020). The WHO updated this guidance twice (WHO, 2020c, 2020d) and it was translated into English policymaking in a selective and piecemeal manner: the UK Government's official health and safety procedures relating to Covid-19 infection prevention and control in the NHS were updated 51 times between their publication on 10 January 2020 and when they were withdrawn on 27 May 2022 (UKHSA, 2022a).

Here I critically analyse an example of government messaging in the context of the experiences and beliefs of this study's respondents.

A Public Health England press release on 2 April 2020 launched new guidance for the use of PPE in the NHS (PHE, 2020c). Some elements of the guidance ran counter to the instincts of some people who were aware of the established knowledge and regulations and whose professional decision-making around their use of PPE instinctively incorporated a 'precautionary principle' (Martuzzi & Tickner, 2004) which focussed on limiting transmission of the virus rather than conserving stock. The press release stated: '*this guidance will protect stock levels from unnecessary use',* inferring that scarcity was a key factor behind the levels of protection being prescribed. Since 1992 there have been workplace directives which stipulate the need to always minimise risk by choosing and using the appropriate PPE, replacing it as soon as it reaches the end of its protective life (HSE, 2022), but the April 2020 announcement specified behaviours which had the effect of reducing the number of PPE artefacts being used:

> *'PPE, particularly masks and eye protection which is there to protect the health and care worker can be worn for an entire session and doesn't need to be changed between patients'* (PHE, 2020c)

This relaxed approach to the tolerances of PPE were accompanied with the caveat that whole-session use of PPE was only appropriate *'in some circumstances'* and only *'as long as it is safe to do so'* which transferred the burden of decision-making to the wearer and/or their managers. Moreover, the unspecific wording of the advice missed the opportunity to reinforce the guidance in donning videos, posters and official documents which stated: *'gloves and apron should be changed between patients'* (PHE, 2020c). For one survey respondent, this room for doubt became translated into an instruction to nurses. A member of a community healthcare team wrote:

> *'I was horrified that nurses that have contact with patients were being told to wear [gloves] the whole session with different patients. No wonder infection spread'* [S369-20/09/20]

The consequences of diverse beliefs on the use of gloves are examined in Section 5.4.7.

Despite the PHE 2 April press release initially stating that *'WHO had confirmed the guidelines were consistent with their recommendations'*, it later explained that it diverged from WHO's recommendation for *'full arm gowns when seeing any suspected or confirmed case of Covid-19'*. Instead, the PHE guidance reserved *'full arm gowns [for] high risk procedures and aprons for other procedures'* and advised *'thoroughly washing forearms if there is a risk of exposure to droplets'* due to the lack of a gown.

The press release acknowledged that '*coronavirus is now widespread in the community, meaning clinicians are more likely to see patients with the virus, some of whom may have minimal or no symptoms'*. However, the instructions about when to wear PPE did not apply the logical consequence of this statement, which would be to assume infection was present unless proven otherwise. Instead, PPE was reserved for *'within 2 metres of a suspected or confirmed coronavirus Covid-19 patient'.* This guidance, which was superseded various times between its publication and the time of data collection from August 2020, influenced the scepticism of some participants' statements about the need for distancing and PPE in health and care contexts which did not deal specifically with the care of Covid patients.

Having trust in the actors within one's environment contributes to habituation. However, some statements, presented in the press release as facts, were questionable from the evidence and experiences of survey and interview respondents both at the time of its publication and in the months that followed. The press release statement *'Covid-19 is not airborne, it is transmitted through droplets and surfaces'*, which justified more modest levels of protection, was offered as a settled truth. However, as seen from Louise's evidence-gathering in Section 5.2.2, such confidence was premature and ultimately misplaced; while the claim that *'there is good stock of FFP3 masks in the UK'* was not the experience of respondents who suffered shortages and quality issues, as explored in Section 5.2.1 and 5.2.2. On a macro level of communication, a challenge to the veracity of government's 2 April press release was reported in the coverage of a statement by the chief executive of NHS Providers, who said the government could not be trusted on promptness, quality, or quantity of deliveries:

> *'Bitter experience in recent weeks has shown that promised consignments of gowns cannot be relied on until they come, are checked and found to contain the right kit' […] 'For example, a consignment of 200,000 gowns that arrived from China last week actually contained only 20,000 gowns. This follows previous instances of consignments of gowns being mislabelled and failing safety tests'*
>
> Chris Hopson, Chief executive of NHS Providers, *The Guardian,* 19 April
> (D. Campbell, 2020)

The personal behaviours of parliamentarians and officials were also forms of communication which contributed to the conflicting and opaque interpretations of the rules. The political fault lines on mask biographies were visible when the House of Commons reconvened in September 2021 for their first exclusively in-person sitting since the 'stay at home' instruction of March 2020: the Government benches were filled with uncovered faces, whilst staff and opposition MPs wore coverings, contributing to the perception that mask-wearing behaviours signified an aspect of political affiliation and societal values. For much of the previous decade, the House had been the epicentre of the 'Brexit' debate about independence from the European Union, and the masked/unmasked faces offered a binary visual statement which correlated with the Brexit-related concepts of primacy of independence and freedom, and the individual over the social group. It is notable that non-clinical face coverings are 'source control' artefacts. If an observer is aware of this, their use would communicate a culture of collective responsibility as opposed to the expression of individual freedom, i.e., 'I wear my mask to protect others'. The perceived properties and purpose of a face-covering is considered in Section 5.4.5.

5.4.2 Community disaster response

These explicit and tacit messages from government which established its casual approach to protection were seen by many participants as a statement about the low esteem in which the government held health and social care workers and the people they cared for. There was a sense that the government had abdicated responsibility for the protection of its vulnerable citizens, increasing the seriousness and scale of the disruption caused to participants and their communities. The United Nations Office for Disaster Risk Reduction defines a disaster as:

> *'A serious disruption of the functioning of a community or a society at any scale due to hazardous events interacting with conditions of exposure, vulnerability, and capacity'* (UNDRR, n.d.)

So far, I have comprehensively described participants' exposure to hazard, their vulnerability, and the limits of their capacity: this is a story about disaster. However, it was Dave's description of how he and his colleagues *responded* which made me see their experiences through this lens. Dave became part of an ad-hoc local network which filled the organisational void, drawing upon pre-existing good relationships with the local community and colleagues to source and equitably allocate scarce PPE stocks:

> *'I got a local school ringing me up, saying: "Would you like some goggles and visors?" I got four big boxes. Then there was a registrar with us at the time, had a friend who worked at a company in [name of city] who, whatever they did, they changed their production line to just making visors. And he said: "I can get them for nothing. Would you want four boxes?" At that stage: "Just get them and I'll distribute them afterwards". I think I got about 2,000 in total. I got in touch with the CCG and said: "I've got these. I'm keeping 500 for us, and I've offered some to the practice at [name of town]. A few have gone out, but I've got about 1,000 just sitting there". They came and took them, and they were going to give them to dentists.*

> *You'd have managers, you'd kind of know them but they were in [names of various places], and suddenly an email from them would pop in your inbox saying: "Oh, I've heard such-and-such a company's got alcohol gel on sale today, get in quick!" And it was how we'd each try and support each other: "I've ordered extra masks. Does anybody need any?" So we managed to keep the thing going'*
> [13/466-18/09/20]

The social bonds created and sustained during this experience had deep personal significance for Dave in later months when he and his wife caught Covid. While Dave was seriously ill in hospital, and admission was also being contemplated for his wife, one of his colleagues set up a WhatsApp group to support his family. Dave said:

> *'…he was calling my kids just to make sure they were alright' […] 'He just was there for them. And I didn't know this was going on. He just did it'* [239X-04/04/22] *[…] 'the humanity of people was amazing, you know? That really touched me, and it kind of moves me still'* [247X-04/04/22]

Dave and his colleagues' acts were a disaster response of the type described by Aldrich and Meyer (2014), who highlight the critical role of social capital and networks in disaster survival and recovery. Hanifan (1916) first identified social capital as mutual sympathy, fellowship, goodwill, and social intercourse among the people who make up a social unit. Bourdieu (1986) expanded on that definition to describe social capital as the combined actual or potential resources linked to possession of a durable network of relationships of mutual acquaintance or recognition. Such a network of relationships placed social capital in the centre of the disaster response described by care home training manager Alex. Her organisation avoided the shortages caused by the incompetence of orthodoxy through the goodwill of pre-existing networks unconnected with any structures likely to be involved in official emergency preparedness. Alex said:

> *'So our chief nursing officer looks after and fosters young children from China. They come to be educated in this country, and then they go. She looks after two or three at a time, these Chinese girls. They'd come back at Christmas and said: "There's this awful virus going on. And the people are wearing more masks than they did do before and people are dying from it. It's awful". So, this pricks my manager's ears up. So that was January time. And then February came and the rumblings got stronger. And at that point, they decided that they were going to start stockpiling, and making contact with the people that they needed to for masks and gloves and things. And a couple of the relatives of the girls in China sent us a lot of stuff – masks, gloves, everything you could have thought of'* [14/491-21/09/20] *[...] 'And then as soon as March hit, and we were like: "Yeah, we're using masks", we had contingency'* [14/507-21/09/20]

The bottom-up community response to the disaster occurred across the country. In response to the scarcity of PPE items, a groundswell of volunteers made PPE by hand. For example, TV 'Sewing Bee' celebrity Patrick Grant co-ordinated a national campaign to sew scrubs and non-surgical face coverings at home for distribution to health professionals as well as the public (Grant, 2020), while schools and business repurposed equipment to make items such as visors (Chaudhari, 2020). Such items were used in Louise's practice. She said:

> *'...most people that were not in uniform had scrubs, but those scrubs were donated by the public, and people made them'* [34/293-10/12/20]

These are all examples of 'positive deviance' (Pascale, Sternin & Sternin, 2010; Singhal, 2014) and 'distributed leadership' (Grint, 2000). Positive deviance is based on the observation that in every community there are certain individuals or groups whose uncommon behaviours and strategies enable them to find better solutions to problems than their peers, while having access to the same resources and facing similar or worse challenges. Distributed leadership describes the circumstance when large numbers of 'ordinary people' with unique skills take up leadership roles and responsibilities as and when necessary, operating within a heterarchy (a flexible structure that retains the necessary degree of coherence and coordination). When the task requiring their leadership is completed, they revert to a non-leader position.

Aldrich and Meyer (2014) recommend that official disaster planning and response should embrace and value positive deviance and distributed leadership, while social capital should be nurtured outside these times as a form of preparedness to enhance the social cohesion and trust within and between communities which facilitates the power of ordinary people. However, the participants' testimonies contained little evidence of such engagement by authorities, and plenty to indicate that the opposite was the case. For example, care home training manager Alex developed a 'Smile kit' of artefacts to enable staff to communicate with distressed residents. She explained:

> *'So I've put together a "Smile pack", which has a clear mask that they use for someone that's in distress. [...] 'it's in its own little jelly bag on the back of the door in the office. And there's three or four of these per community. And if somebody is in distress, somebody has maybe behaved in a way that has been considered challenging, and they need to defuse that situation, or they might need to administer medication to calm that person down, then they go and grab the "Smile" mask. They put it on so they can see their smile through the mask, and then they go in and deliver intervention, whatever that may be' [...] 'That's my plan, and I'm trialling it next week on one of the communities'* [14/219-21/09/20]

However, Alex's Positive Deviance was frowned upon by the authorities who regulated her practice. When interviewed again in 2022, she reported that her Smile kit had been vetoed:

> *'It got kiboshed, really, by the local authority. I was really keen on it. I thought it was a really important part of caring for people with dementia, and it was just a*

> *straight: "No, you can't do it. You've got to use these surgical face masks, to this standard, in order to be able to protect those people from Covid". And that was it. There was no case to argue, there was no: "Yes, Alex, fantastic". No, no. It just was: "No, absolutely not, you're not doing it"'* [14/175X-03/05/22]

As can be seen by Alex's disappointment, the interface between innovative community response and the orthodoxy of authority is an area which requires sensitive handling which would benefit from positive pre-existing relationships. Louise was aware of this, as seen in the way she described her discomfort while writing guidance which instructed nurses to decline some home-made PPE items due to quality control issues:

> *'…we were having to say: "Actually, yes, it's nice that they're making you a mask, but that's not – you shouldn't really be using that mask, because it's not good enough. And it's lovely that they're giving you a uniform bag to put your uniform stuff in, but actually, that's not good, you should have changing facilities at the hospital' […] 'So then you look a bit harsh, because you're saying: "Thanks, but no thanks"'* [34/804-10/12/20]

Now I have identified the mismatch between the community-generated constructive and collaborative disaster response, and the top-down resistance and denial contained in the government's explicit and tacit messaging, I can look afresh at how official communication about PPE and distancing affected the depth and nature of the disaster as it was experienced by this study's participants.

5.4.3 Information failures about PPE and distancing

Official communication from the UK government included the use of signage (Figure 16) displayed on the lectern during Downing Street press conferences. Under Health and Safety Executive regulations (HSE, 2015, p.12), there are standardised and enforceable specific meanings to colours used on signage: Red is a prohibition signal or danger alarm with the attendant messages ‘dangerous behaviour’, ‘stop’, ‘evacuate’; yellow is a warning signal which conveys the messages ‘be careful’, ‘take precautions’; and blue signage indicates that the attendant behaviour or action is mandatory. Green indicates ‘no danger – return to normal’ and identifies escape routes. The slogan: *‘Stay home. Protect the NHS. Save lives.’* became familiar on the Downing Street lectern, displayed in black type on a yellow background with red stripes. The slogan was used from the imposition of ‘lockdown’ until 10 May 2020, when it was replaced by: *‘Stay alert. Control the virus. Save lives.’* and the red stripes were replaced by green. These signs were interspersed with the use of the blue and white *‘Hands, Face, Space’* slogan illustrated with simple graphics. The red and yellow *‘Stay home’* sign returned to the lectern during subsequent national lockdowns. The confusion and ‘opaque’ quality of messaging was discussed in an ITV news item one year on from the initial lockdown (Evans, 2021).

FIGURE 16: Downing Street lectern signs. © The Board of Trustees of the Science Museum. Released under a Creative Commons Attribution - Non Commercial - Share Alike 4.0 Licence: https://creativecommons.org/licenses/by-nc-sa/4.0 (Science Museum Group, 2020)

When the UK government on 10 May 2020 changed the instructions to the English public from *‘Stay home’* to *‘Stay alert’*, this was at odds with Wales, Northern Ireland, and Scotland whose First Minister, Nicola Sturgeon, called the messaging ‘vague and imprecise’ (Mason & Siddique, 2020). The green and yellow *‘Stay alert. Control the virus. Save lives.’* sign exhorted the public to adopt undefined behaviours while delivering a dissonant subliminal message within conflated colour-coded signals of safety and warning. It drew ridicule in a conversation between two members of the self-advocacy team, who were angry at the nebulous message and normlessness resulting from the government's failure to establish and reinforce expected behaviours at the earliest stage. Lucy said:

> *'If we had public service announcements from the beginning, rather than for us going: "do this, you do that, you don't do this, you* ***do*** *do that, oh, wait a minute, you do it this way, but you don't do it this way…" Instead of having that muppet [i.e., Prime Minister Boris Johnson] telling us stuff, I think had we had proper public service announcements about... "Stay alert"? What does that mean? What am I staying alert for?'*
>
> Joyce: *'What is "alert"?*
>
> Lucy: '*What am I staying alert for? I don't understand' […] 'You've got loads of people not entirely sure what's right. There's a lot of conflicting information. If they'd just from the start had gone, some public service announcement: "this is what rules are", it would have been a lot better'*
>
> Joyce: *'Do you think it's not too late now, Lucy? Because I think it is'*
>
> [02/511-02/09/20]

The theory that behaviours adopted in the earliest stages were hard to change is supported by Joyce's opinion that the opportunity to bring clarity to messaging had passed.

As a GP practice manager, Dave had a high level of responsibility for interpreting and acting upon instructions about PPE and distancing. In his reflections in 2022, he said information vacuums and ineffective, inappropriate, and complex messaging from leaders preoccupied with their political image created confusion and discouraged adherence to PPE/distancing rules in the general population. Dave said:

> *'…right throughout the whole two years, I think communication, at so many different levels in society, has been wanting at times. And the crystal clarity. You know, I*

> *mean, I think the websites – the government websites are useful, but you've got to be computer literate, and actually, I think they have a very high degree of literacy, you've got to be English, your first language'* [13/528X-04/04/22] *[…] 'a prime minister, bless him, who is not the greatest orator in the world at the best of times, and politicians who I think have maybe been too cognizant of their political image, and not just giving us simple clarity and truth at times. […] 'There have been plenty of gaps we've had to fill in ourselves. […] 'we've never been in this before, we are making this up as we go along. But they're* ***all*** *making it up as they go along, in silo. Down here, where we see the vast majority of the contact in the NHS in primary care on a daily basis across the country, we're just like: "Oh, God, here they go again"'* [13/570X-04/04/22]

This backdrop of complex, incomplete and conflicting implicit and explicit communication *about* distancing and the use of PPE manifested itself as a normlessness in behaviour *in their presence.* Vignette 4 in Section 5.3.1, describing Barbara's visit to her son Carl in hospital, illustrates such normlessness.

5.4.4 The 'culture call'

Barbara and her family had become accustomed to close observation of strict PPE and distancing rules which were imparted by the words and behaviours of the staff on Carl's ward, but the relaxed protocols in the hospital thoroughfare were even more disconcerting due to a lack of explanation through written or verbal communication, or consistency in behaviours. Consequently, Barbara was unsure of what she described as *'the culture call'* [11/193-14/09/20]: the behaviours she should adopt to demonstrate her compliance with the norm. This normlessness was exacerbated when Barbara looked on as the protocols she had expected to be in place were openly contradicted by staff whose colleagues had been so strict with her family.

In any given place in England during between 2020 and 2022 – for example, on public transport, in shops, in care homes, in a person's private residence, or in hospital – the PPE and distancing behaviours of that environment's dominant group at that moment became the norm. A person entering that space would make their 'culture call'. Their compliance with the prevailing culture would depend on their interpretation of which behaviours were required to comply, whether they had the resources to comply, whether those behaviours were sympathetic to that person's own beliefs and, if not, whether they had the power and autonomy to act in contravention of the prevailing behaviours. Central to this process was the level of understanding of what the PPE and distancing measures were, what they were meant to do, and how successful they would be. That understanding was shaped, in the main, by the content and quality of official communications about PPE and distancing – which participants have described as lacking.

Louise's description of her confrontation with a colleague over visors in Section 5.2.1 is an example of this complex interplay: communication *about* the artefact was made worse because of *the presence of* PPE:

> *'I'm having to stay two metres away. I've got my mask on [...] and I don't think they could comprehend'* [34/249-10/12/20]

As described in Section 4.2.6, Louise usual non-verbal communication techniques were occluded, making it harder to de-escalate the discussion and leaving both parties open to misinterpretation while she challenged the cultural norms of her workplace in their handling and use of PPE. This was an example of a micro-communication *about* PPE and distancing: mutual observance of distancing and mask-wearing implicitly established an agreed set of behaviours, but this message was confounded by the overt verbal content which revealed where their beliefs diverged:

> *'"I'm not using that visor". And he said: "Well, there's nothing wrong with it"'* [34/252-10/12/20]

Natalie’s experience as a part-timer in ITU, described Section 5.2.4, illustrated how ever-changing and complex instructions about her required behaviours created a labile and unpredictable culture of PPE and distancing, resulting in sensitisation:

> *‘…it did put you on edge a little bit because you kind of thought: “Right, what am I going into this week?”’* [26/109-13/10/20]

This sensitisation had a negative effect on Natalie’s interactions *in the presence of* PPE and distancing:

> *‘…it got to the point where you just go on a ward and say: “Right, what do you want me to do on here? Because I can’t keep track of what I’m meant to be doing”’* [26/49-13/10/20]

Disagreements and uncertainties extended beyond behavioural expectations. There was also conflict over differing understandings about the nature and purpose of PPE artefacts.

5.4.5 Diverse artefact biographies

In Section 4.3, I offered respondents’ examples of their PPE and related items acting as communicative artefacts, and I introduced the concept of artefact ‘biographies’. Here, I consider how diverse biographies were constructed through different understandings of the purpose and function of the artefacts. An example of diverse mask biographies occurred when NHS children’s mental health worker Maggie assumed that I had the same perception of what a mask meant. When she was offered an alternative mask biography, she admitted she had not considered it.

> Maggie: *‘“If they’ve got a mask on, they mustn’t have Covid”: that’s what we assume, isn't it? That they’re safe if they’ve got a mask on? Of course they’re not safe! They’re no safer than anybody else, but we make that assumption’*

> Andrea: ‘*do you think we’ve moved into the space now that a mask on a face equals an infection behind the mask? That the only reason why a person would be wearing a mask is because they’ve got a cough? Is it that?’*
>
> Maggie: *‘Actually, I’ve never thought of that, but people might think that’*
> [12/473X-08/04/22]

If a mask could ‘speak’ its ‘own’ truth in accordance with its specified manufacturing standards, a ‘source control’ design might say: ‘my wearer wants to protect you’, while a vented mask would say: ‘my wearer is prioritising their own self-protection and comfort’. An unvented FFP mask could say that its wearer was concerned for their own and (probably) other people’s wellbeing. However, artefacts cannot speak for themselves. They speak through the filter of interpretation – hence the term ‘biography’ rather than ‘autobiography’. Each interlocutor has their own biographical understanding of the artefact, written from the standpoint of their own knowledge, beliefs, and experiences, their understanding of the environment, and the level of perceived risk in which the artefact is situated. These understandings of the purpose and functions of artefacts are established through the transfer of (or absence of) authoritative information and knowledge. Therefore, opacity from the sources to whom professionals and the public looked for authoritative information can, in part, explain the diversity of beliefs and feelings amongst participants.

While some study respondents indicated that they understood the concepts of ‘source control’ and ‘wearer protection’, the responses of other participants indicated that they did not know the differences. A detention centre custody officer described mask-wearing as a source control activity, asserted their willingness to protect others by wearing a mask, and expressed gratitude to those who wore masks for source control:

> *‘I hate wearing masks but I still do it’ [...] ‘I’d still rather people wore masks coz feeling uncomfortable for a bit is better than getting corona’* [S320-11/09/20]

A massage therapist and reflexologist used their survey response to frame mask-wearing as an altruistic act of source control, and described the sense of safety which came from the cumulative self-protective effect of mutual source control:

> *'I feel so much safer if we both have masks' [...] 'I feel they [who are wearing PPE] are doing everything they can to keep us safe. I do the same when I am working' [...] 'I feel safer doing everything I can to limit transmission'* [S265-01/09/20]

A senior operating department practitioner's survey response indicated faith in their PPE, but emphasised self-protection rather than source control:

> *'It is for my own safety and has become second nature to wear'* [S001-15/08/20]

A mobile reflexologist wrote about their methodical and objective approach to their understanding of infection control artefacts and behaviours:

> *'I have done a Covid prevention course and a thorough risk assessment of my practices'* [S278-02/09/20]

As in Vignette 3 in Section 5.2.3, describing nurse Louise's visit to a Covid patient, some respondents did not trust their PPE to protect them. This understanding was shared by a community mental health nurse, who wrote:

> *'[PPE] seems futile... the virus can land on my arms, hair, wearing a plastic apron is going to do nothing'* [S191-27/08/20]

The biography of Louise's mask, as she 'read' it through the lens of her in-depth knowledge gleaned from critical analysis of the available evidence, was the story of an artefact which offered little protection against a big threat. This understanding of her mask's biography altered her body language and decision-making, contributing to the unsatisfactory quality of her communication with her patient and his wife.

In her national role, it was Louise's job to navigate official materials which changed constantly, and to translate it into a digestible form in response to queries from health professionals, the public, and the press. Louise said:

> *'…we were working day and night, you know? Just before I was off sick, we were working from eight in the morning to 11 o'clock at night. […] We needed to be that responsive'* [34/823-10/12/20]

However, most people did not have the time, ability, access, and/or inclination to stay up to date. Louise's guidance was added to a diverse pool of conflicting and ever-changing messages populated by government broadcasts, TV, radio and print media, workplace interactions, the unregulated environment of social media, communications from health providers, conversations with family and friends. For the most part, the population (i.e., both givers and/or receivers of care, and those who did not have experience of a care interaction) passively received information through this myriad of channels. The conclusions they drew from what they selected from that information supply, and how they interpreted it, was coloured by their pre-existing circumstances, experiences, and beliefs.

There were some respondents who did not consider the virus to be a great threat, so in their opinion PPE artefacts were superfluous and intrusive. A massage therapist wrote in their survey response:

> *'I am not convinced it [PPE] is completely necessary in a non-clinical environment'* [S061-25/08/20]

A social carer pointed to the dissonance between the precautions being prescribed, the initial rationale used to discourage public mask-wearing, and the failure of experts to provide a clear and authoritative message, as reasons to conclude that Covid was *'fake'*:

> *'Why wearing something [i.e. mask] which doesn't help? Where are all professors? Medical experts?' […] 'it's an illusion. Fake and not true. If it was about health the precautions would have been different'* [S127-25/08/20]

Some respondents who believed the threat to be small also considered the presence of PPE artefacts to do more harm than good, i.e., creating those barriers to communication described in Chapter 4. A survey respondent who encountered PPE at their orthotics out-patient appointment wrote:

> *'It [PPE] can instil an unnecessary sense of fear in situations where the real "risks" to individuals are incredibly small'* [S281-02/09/20]

There is a dissonance in the survey response below: the respondent argues that masks were unnecessary yet also refers to a *'false sense of security',* which suggests they believed a threat did exist. While the disparate opinions and understandings *between* people are evident, this confused response suggests an *internal* normlessness:

> *'Masks are a[n] unnecessary evil. I don't see the sciences to back up such a deconion [sic] measure' […] 'In a scientific or medical setting it is a necessity carrying out some procedures but in a shop, school, office etc... there is no benefit [from PPE] apart from giving some people a false sense of security...'* [massage therapist, S089-25/08/20]

The failure to access and absorb the developing evidence-base about the risks from Covid and the mechanisms of protection afforded by PPE was illustrated in the comments of NHS CAMHS therapist Maggie, whose opinions were gathered over the space of 20 months. In her survey response in August 2020, she wrote:

> *'I don't understand PPE when there is no physical contact with a person, it seems a nonsense'* [S161-26/08/20]

When interviewed in September 2020, she said:

> *‘We know that the masks don’t work, but we've created a safety behaviour so people only feel safe now when they’ve got a mask on. And that’s going to take a lot of shifting’* [12/248-17/09/20]

In April 2022, despite the evidence that had been established during 2021 (outlined in Section 5.2.3), Maggie reiterated her belief:

> *‘But the masks, again, there’s not a lot of evidence that the masks are any more protective, so…’* [12/136X-08/04/22]

Though the World Health Organisation discouraged the use of valved FFP3 masks (WHO, 2020e), it could not be assumed that even those traditionally considered to be the most well-informed held the best understanding of an artefact’s properties. In August 2021 a National Patient Safety Alert (NHS England, 2021) withdrew valved FFP3 masks from stockrooms supplying surgical teams because, since March 2020, there had been potentially fatal infections caused by condensation dripping from the exhalation valve into the sterile field, including ‘*a cerebral abscess involving an oral bacterium linked to the use of a valved FFP3 respirator during brain surgery’*.

However, while the inappropriate mask-wearing behaviours of the surgical teams which prompted the safety alert could have been the result of the wearer failing to understand the implications of an artefact’s properties, and/or having no regard for their patient’s health, there could have been other factors in play: did the wearers have complete autonomy over the decision that the inappropriate mask should be worn? If not, who or what was shaping the decision?

One survey response conveyed a low perception of threat from the virus when compared to the harms done by failing to address wider social determinants of ill health which also resulted in high mortality and morbidity. Moreover, the respondent expressed anger at the inequity of prioritising one threat over another:

> *'I feel angry that the whole world has gone mad, fighting a virus that has killed a tiny percentage of the world population compared to the millions that die of chronic health conditions like diabetes which the system perpetuates because nobody tackles the poor food system that perpetuates it... but keeps a few people very rich'* [S099-25/08/20]

The lack of consistent and clear communication on a macro level allowed space for conspiracy theories to take hold, as seen in this deliberately unfinished survey response hinting at a sinister ulterior motive behind mask-wearing rules:

> *'…there is a sense of depersonalisation, even preparedness, bit by bit, for…….'* [S097-25/08/20]

A combination of the salience of enforced touch deprivation, the perceived lack of consensus amongst scientists, reports of the success of a non-interventionist approach in another country all featured in the written survey response of a practitioner of non-conventional therapies which concluded in an allusion to a conspiracy theory:

> *'…none of the so-called scientists have a clue if they [masks] work or don't. They are just covering themselves in case they are wrong. Sweden's had no problem' […] 'I'm an holistic healer, you need touch or else we'll all end up as zombies, it's a way of keeping people down'* [S294-03/09/20]

When the mask biographies of those involved in an interaction were diverse, conflict could arise if the presence or absence of the mask was interpreted as a threat to one's own safety or as a performative challenge to an interlocutor's own world view. This is explored in Section 6.1.3.

The Sunflower lanyard (Section 4.3.7) was an artefact invented with the purpose of explaining the biography of a *missing* mask: it asked the observer to show understanding for its wearer whose hidden disability made it difficult for them to comply with mask-wearing. However, as with the masks, different interpretations of its purpose were constructed by its user and its observers, and these biographies were shaped by their (sometimes absent or incomplete) awareness of the artefact's purpose, as well as their diverse beliefs and values.

Participants reported that dissemination of such information to the public had been insufficient. In the self-advocates' group discussion, Lucy, who was autistic, said that when the lanyard's significance was not recognised the artefact had no saliency, so its implied appeal for leniency went unheard. Lucy said:

> *'…in a lot of places, you still get challenged'* [02/240-02/09/20] *[…] 'some supermarkets have signed up to the Sunflower scheme. Not everybody's aware what it is. So you still have to explain why you're wearing a lanyard so it's why you'd need the exemption card anyway. Because just wearing a lanyard, people don't know what it is'* [02/243-02/09/20]

The saliency of Sunflower-branded artefacts was also disrupted by the Government's directive:

> *'…you do not need to seek advice or request a letter from a medical professional about your reason for not wearing a face covering. However, some people may feel more comfortable showing something that says they do not have to wear a face covering. This could be in the form of an exemption card, badge or even a home-made sign. Carrying an exemption card or badge is a personal choice and is not required by law'* (Department of Health and Social Care/Cabinet Office, 2020)

Confirmation that authentication of the right to wear a lanyard was not required, the official endorsement of optional self-made facsimile, and failure to reference the Sunflower scheme itself, denied the Sunflower its status an authoritative symbol of hidden disability. Consequently, Sunflower lanyards, cards, and badges were sometimes deceitfully used by non-disabled people who simply did not want to wear a mask. Lucy said:

> *'I actually know people who've got one who do not have a disability, they just don't want to wear a mask and I think it's a bit naff. They're like, "Oh, we can get these lanyards"* [02/240-02/09/20]

GP Deborah confirmed Lucy's assertion:

> *'I've had quite a lot of interesting conversations with patients who want exemption forms and – which don't exist – and basically for me to say that they can not wear one, because they don't want to. Which is interesting, because clinically, there's very, very, very, very, very few people who actually would physically be unable to wear a mask'* [33/189-10/11/20]

Autism services director Joyce blamed the abuse of Sunflower artefacts on the government's advice:

> *'People are abusing the lanyard, without a doubt, and if you look at the government website, it says you can make your own [exemption card] and show it. So, what on earth are we at here?'* [03/328-02/09/20]

Differences in opinion about the purpose of a mask occurred amongst colleagues who otherwise shared strong bonds: there was a disagreement within the self-advocacy group representing people with autism and/or learning disabilities during their group discussion. Siblings Fran and Pete, both sessional workers for the group, shared the understanding that mask-wearing was a source control intervention imbued with social responsibility and were angered by the disrespect shown in transgression. Fran was her brother's carer, and interpreted his speech which was affected by cerebral palsy. Fran said:

> *'…they're not wearing masks and you're thinking: "why am I protecting you if you don't give a damn what you're doing to me?" Pete says it does his head in, he feels like kicking them'* [07/344-02/09/20]

But in the same meeting, Joyce, the Director of Services for an autism organisation, and autistic self-advocacy worker Lucy, said that masks had no infection control purpose and had been mandated as a performative measure to soothe anxiety:

> Lucy: *'I personally don't think they [masks] make any difference whatsoever'*
>
> Joyce: *'I'm with you'* [02/538-02/09/20]

By standing '*with'* Lucy's mask biography, Joyce implied that she stood *'against'* people who expressed other interpretations, creating room for division along lines of identity politics in which assumptions were made about the internal dialogues and personal values of others based on whether they wore a mask in a public place.

Gloves were another PPE item about which participants reported conflict due to diverse artefact biographies.

5.4.6 Gloves: Protocol versus perception

Twenty-four survey participants used their open-ended responses to explicitly state they were not wearing gloves when touching patients. For complementary therapists, this was allowable within the official guidance published by their regulator (Complementary and Natural Healthcare Council, 2020) and their leading professional body (Federation of Holistic Therapists, 2020).

For NHS workers, the guidance on gloves was opaque. The government press release on 2 April 2020, launching new PPE guidance for NHS teams (PHE, 2020c) stated: *'The advice therefore is bare below the elbows and you scrub your hands, your wrists and your forearms',* but posters and demonstration videos explicitly showed that gloves should be worn. Louise, who needed to be fully informed of regulations as part of her national role, knew that people giving injections were advised *not* to wear gloves due to the loss of sensation:

> *'Public Health England have written guidance, and it says they don't need to wear a pair of gloves. They have a mask on, but they don't need a pinny and they don't need a pair of gloves when they're vaccinating'* [34/580-10/12/20] *[...] 'the rationale is, it's more risky. There's more risk of a sharp injury'* [34/590-10/12/20]

Disquiet about protocols was increased when they ran counter to a respondent's understanding of risk. Physiotherapist Vicky said:

> *'...there are certain circumstances where you see that [ungloved touch] happening and your hackles go up, almost: "That shouldn't be happening!"'* [25/422-09/10/20]

Similar levels of distress resulted from the opposite sight, through understanding of infection risk. A survey respondent in a community healthcare team wrote:

> *'I was horrified that nurses that have contact with patients were being told to wear them the whole session with different patients' [...] 'We were told to wear gloves but these actually increase infection risk to patients because you can't clean your hands in them'* [S369-20/09/20]

Namaste Care co-ordinator Sally described in her interview how a risk assessment by her hospice employers resulted in the decision that she and her team should wear gloves, despite the absence of compulsion in the official guidance and the effect of gloves on quality of touch:

> *'We've taken the view that some contact, even with gloves on, is better than none'* [16/67-22/09/20] *[...] 'but if you look at the FHT guidance for massage, they're not telling you to wear gloves when you do a massage, as long as you have really good*

> *hand hygiene before and after. So maybe we're being overly cautious with that'* [16/341-22/09/20]

The cautiousness of Sally's hospice management could have been, in part, due to the performative aspect of PPE-wearing, as discussed in Section 4.3.7: that glove-wearing conveyed the message: 'I care for you because am placing a safety barrier between us'.

The recommendation about when gloves were not appropriate was not universally assimilated by health professionals. The first Covid vaccination in the UK was given on 8 December 2020 (*BBC News*, 2020c), and I first spoke to Louise two days later. She had been intervening on social media threads in which other nurses had criticised their colleague who had been filmed wearing the appropriate PPE to administer that historic first vaccine: without gloves or apron, but with a surgical mask:

> *'…we're so harsh at criticising each other on social media. And so, I've spent yesterday and the day before, commenting on social media, where they're slating the nurse'* [34/577-10/12/20] *[…] 'about not having her PPE'* [34/579-10/12/20]

When Louise and I spoke again 15 months later, the dissonance between the *guidance* and the *perception* of correct procedure had become entrenched: the conflict between nurses had continued on social media despite the efforts of official bodies to normalise recommended glove protocol through opportunist multimedia exposure.

> *'We say: "Look, whenever there's a TV thing about having a vaccination, please have a picture with somebody without gloves on". And when you have got someone without gloves, we get no end, on social media, criticising: "Well, they weren't wearing the gloves! Did you see them on the news? They weren't wearing the gloves!" And we're going: "Because they don't need to wear the gloves"'* [34/800X-31/03/22]

Louise, as a private citizen, received her vaccination from staff wearing gloves but no mask. She said they framed their decision in terms of ‘personal choice’ – a concept which was central to the government’s strategy for the country’s disengagement from the use of PPE and distancing. However, Louise described how, when probed at greater depth, one vaccinator said he had bowed to the ‘culture call’ and wore gloves to avoid conflict. Louise said:

> *‘He said: “Look, I know I don’t have to wear gloves, but people keep criticising me if I haven’t got gloves on”’* [34/794X-31/03/22]

This chapter has established the external influences which diminished or worsened participants’ intrinsic visceral effects of PPE-wearing and distancing. In this examination, it became clear to me that participants were describing a disaster: the functioning of their communities was seriously disrupted due to hazardous events interacting with conditions of exposure, vulnerability, and reduced capacity. I have demonstrated how participants suffered an amplification of their distress through normlessness prompted by failures in communication about PPE and distancing, central to which were the acts and omissions of organisations and individuals in positions of power. Where participants were situated in communities which drew upon their pre-existing social capital and engaged in positive deviance and distributed leadership, adverse effects could be mitigated. The next chapter considers the landscape upon which PPE and distancing were imposed upon participants, and consequences of the acts and omissions of people in power.

CHAPTER 6: THE CONSEQUENCES

My reflections on the previous chapters led me to consider three new key themes which have valency in characterising the experiences of my respondents. These are structural violence, epistemic injustice, and moral injury. They did not figure in my initial literature review but are critical to an understanding and interpretation of these results. This chapter therefore draws upon additional material to provide analysis through these three lenses.

I begin by considering the participants' experiences in the context of structural violence inflicted directly through the presence of PPE and distancing. I then consider how pre-pandemic circumstances of structural violence were exacerbated when PPE and distancing were superimposed and consider the extent to which its presence or absence amplified or mitigated their distress. Then I turn to examples of epistemic injustice, in which the knowledge through experience gained by the participants' multifaceted, fluid, and sometimes unacknowledged identities was overlooked and/or undermined by those in charge of PPE and distancing policies, and its value depreciated by 'Clap for Carers': a distanced rhetoric of heroism which obscured the personhood of those whom it was meant to celebrate. I then consider how the normlessness described in previous chapters contributed to a wider societal 'anomie' in which a moral uncertainty took hold, resulting in conflict and confrontation over PPE and distancing. Ultimately, I consider these examples in the context of the participants' moral constraints and moral dilemmas, evaluating the participants' stories as potentially morally injurious experiences (PMIEs), and contemplating the breadth and depth of moral distress and moral injury experienced by those participants. To conclude, I explore the consequences of moral distress and injury for those participants in terms of cognitive and visceral effects, and the actions taken by the participants in response to those consequences. In other words, I am following the advice of Paul Farmer (1996, p.272):

> *'To explain suffering, one must embed individual biography in the larger matrix of culture, history, and political economy'*

6.1 STRUCTURAL VIOLENCE

Johan Galtung, who coined the term ‘structural violence’, considered violence to be present ‘*when human beings are influenced so that their actual somatic and mental realisations are below their potential realizations’* (Galtung, 1969, p.168). Therefore, violence is not committed in a terrible situation caused by unavoidable factors for which every mitigation is applied. However, it *is* present if there are ways to reduce the body-mind suffering of that situation but they are not pursued, or if measures are introduced which add to suffering. This differentiation between avoidable and unavoidable harms is at the heart of this thesis: Chapter 4 identified participants’ intrinsic body-mind sensitisation and habituation to the unavoidable presence of PPE and distancing, while Chapter 5 identified how the commissions and omissions of acts by others added to, or reduced, their suffering.

Galtung considered violence to be present when resources are unevenly distributed, and when the power to decide the distribution of those resources is also unevenly distributed. He also considered the presence of a sense of threat to be an act of violence. He specified that, in contrast to ‘personal’ violence, where a person or persons directly commit the offence on another, ‘structural’ violence had no such human present. However, Farmer (1996) argued that specific humans could indeed be implicated in the perpetration of structural violence: decisions involving those acts of commission or omission were made by *people* who comprised and/or influenced the authoritative bodies in whose name those acts were perpetrated:

> *‘These afflictions were not the result of accident or of force majeure; they were the consequence, direct or indirect, of human agency’* (p.271) *‘Extreme suffering [...] is seldom divorced from the actions of the powerful’* (p.274)

Using Galtung’s definition and Farmer’s observations, an overwhelming number of the participants’ experiences described in the previous chapter qualify as incidences of structural violence perpetrated by people in power: those individuals whose official positions or perceived status imbued them with the capacity to lead, influence, dominate or impact upon others, and whose interventions, or lack thereof, led to sensitisation, anomie, and conflict.

6.1.1 The violence of inadequate PPE

Participants who were aware of the inadequacy of their PPE experienced a sense of danger and had to live with the consequences of their behaviours, which often changed when exposed to hazard. The fear and shame this triggered were a form of structural violence which stimulated the visceral neuroendocrine responses which constitute General Adaptation Syndrome (GAS). An example of such structural violence is described in Vignette 3 in Section 5.2.3. Nurse Louise spent an hour with a coughing Covid patient in his stuffy bedroom with only a surgical mask and visor for protection, even though the UKHSA had concluded months earlier that the environment she was entering had a combination of factors which made her most vulnerable to the airborne transmission of the virus. The UKSHA knew FFP3 masks were more effective than her surgical mask, for which there was little evidence of efficacy, but senior officials had decided not to change the policy in response to the review. This structural violence inflicted upon Louise exposed her to an avoidable level of harm from the virus and made her fear for her own health and that of all those with whom she would subsequently interact – both patients and her own loved ones. It polluted her non-verbal communication behaviours which in turn caused further pain and distress: the sick man's wife observed Louise turning her head away from his pleading eyes, standing in the doorway rather than holding his hand, even failing to perform the basic diagnostic acts expected of her role. Moreover, Louise had insight into how her compromised behaviour could cause pain, thus exposing her to moral shame: she knew her behaviour violated her normal standards despite it being the justifiable result of a compassionate and measured risk/benefit analysis based on years of professional knowledge and experience. The structural violence of failing to change mask policy in response to scientific findings on virus transmission led to Louise experiencing a potentially morally injurious event (PMIE), a concept which will be explored in Section 6.3.4.

I now turn to how historical acts of structural violence intensified the harms done in the context of communication in the presence of PPE and distancing.

6.1.2 Ableist deprivation of advocacy and communication support

Experiences of pre-existing failures of communication support in health and care interactions for people with additional communication needs led to fear, suffering, and forfeiture of essential healthcare when PPE and distancing were introduced. Fran was a personal assistant to her brother Pete, whose cerebral palsy meant his mobility and speech were severely affected. She said pre-Covid experiences, where she needed to intervene to prevent harm to her brother, made her fearful for his safety in healthcare settings which imposed distancing rules which deprived him of her essential advocacy:

> *'…if Pete went into A&E I wouldn't let them take them in unless I was with him. Because of his communication, I would say that it was his human right to have somebody there that could speak up for him'* [04/82-02/09/20] *[…] 'Pete's been in hospital before, and it takes me to stand there and say: "You're not doing that" […] I have come across nurses saying: "Well, we're gonna do this", and they want to put cannulas in his arm where it bends, but Pete's arms are behind his back, and they want to take his blood pressure with his arm rather than his leg, and stuff like that, and they don't listen to Pete, they listen to me. And there's no way I would leave Pete in A&E and walk away. It would destroy me, and it would destroy him. There's no way there's anybody trained enough to listen to Pete, probably. And they're too busy looking after other poorly people. So I always said that if I left Pete that I would... that he wouldn't come back out of hospital. And it sounds a bit dramatic. But it's the truth'* [04/161-02/09/20]

Eddie, who was totally blind, resisted a hospital admission for a serious infection in September 2020 because his wife, Dot, would not be allowed to accompany him. The reason for his resistance was accidents and omission of care which occurred when he was in hospital prior to Covid, which taught him that his wife was a vital safeguard in the presence of the structural violence inflicted through the failure to embed blindness awareness in the staff cohort:

> *'I said I didn't want to go in because it was bad enough without Covid. The reason I was saying that is because if Dot wasn't allowed to visit me, I'm going to struggle because I've lost my communication link'* [17/199-23/09/20] *[...] 'my first stay in hospital as a totally blind person with no perception, registered blind, when I went in, my wife informed them that I was totally blind and I would need several things doing, but it seemed as though the information wasn't getting passed on to the next shift'* [17/28-23/09/20] *[...] 'it took three weeks before I got through to the different shift patterns about my needs'* [17/39-23/09/20] *[...] 'It started on the morning when they said: "Right, there's your breakfast". I said: "I need to know where everything is". "Oh, your toast's on the trolley with your cup of tea". And I said: "Well, I'll try, but I normally can't do this". And I knocked the cup of tea all over myself'* [17/34-23/09/20] *[...] 'somebody said: "Are you not going to eat your breakfast?" I didn't even know it was there'* [17/61-23/09/20] *[...] 'Dot brought in my DAISY [Digital Accessible Information System] CD talking book player. But I couldn't charge it up because "it would have to be checked, it was an issue for health and safety"'* [17/226-23/09/20] *[...] 'I said: "What about all the mobile phones in here, are you going to PAT-test all of them?"'* [17/231-23/09/20]

A failure of staff to listen to Eddie's appeals to consider his blindness had led to his urine being spilled across the floor when the nurses were dealing with his catheter:

> *'…the bottle was left on the floor beside the bed. And of course, you can imagine what happened. I knocked it over and it went all over'* [17/80-23/09/20]

Charlotte, who was Deafblind, suffered structural violence when, prior to the pandemic, she was repeatedly denied access to appropriate interpreters when she needed a course of eye surgery because the hospital deemed it financially *'not worth it'*:

> *'It turned out they hadn't booked an interpreter. There was a bit of a panic. So that task got put to me to book and provide the interpreter […] I need an interpreter who is not just a sign language interpreter, but somebody who understands Deafblindness and all its versions […] We had to work out haptic cues, and had the wrong interpreter come […] there would have been no communication during the procedure, I wouldn't have known what the surgeon was saying or doing. […] The hospital was very reluctant, and they said: "An interpreter is just an interpreter, it's just word for word". But in fact, it wasn't. It was "word for touch" […] all of which, not understood by the medical professionals. Also, the added complexity that the hospital said that they didn't want to pay for an interpreter because they didn't think it was worth it'* [24/486-07/10/20] *[…] And having done the operation a few weeks earlier, they didn't provide an interpreter for the follow-up appointment when I had lasers shot into my eye to kill the debris, so to speak. So, it was down to me to bring my own interpreter because they couldn't and wouldn't provide what my need was'* [24/514-07/10/20] *[…] 'I had to go into, you know, a very frightening experience with lots of potential outcomes, one of which could render me completely blind, which would then change my life massively. And of course, I had to hold on to all those emotions and all those thoughts, and then get all the communication back through different channels, some being touch, some being vision'* [24/539-07/10/20] *[…] 'that experience was huge, was huge. The shock of that was, was, you know, it was a terrible experience'* [24/547-07/10/20]

The imposition of distancing exposed pre-existing reliance on family members for healthcare communication. Lucy described how a ban on her sister, Sarah, from accompanying her Deaf Spanish husband to A&E resulted in him refusing essential care:

> *'My sister and her husband are Deaf. Her husband's first language is Spanish and not English, so she technically is his carer and interpreter. […] He was in agonising pain […] they were told that they could send an ambulance and he could go to hospital, but Sarah was under – no way she could get in that ambulance with him. […] He actually didn't go, which made him ill for a few more days because he was frightened. He was terrified of going in that ambulance by himself. […] She was like: "You don't understand, I have to communicate for him". And they're like: "Well, we'll write on pen and paper" and she's like: "His first language is Spanish!"'* [02/116-02/09/20]

In terms of official communication, the UK government stood out in contrast to the devolved governments in that it did not include a BSL interpreter in its broadcasts and press conferences about PPE and distancing. Deafblind campaigner Charlotte said:

> *'…in Wales, Scotland, and Northern Ireland, they always brought in British Sign Language interpreters to stand next to the politicians. But in England, there was a huge campaign to make that information accessible. It was a campaign called #WhereIsTheInterpreter? The government said: "No, we're not doing it"'* [24/337-07/10/20] *[…] '…it was obviously not a priority to the government. But the government was also speaking about vulnerable people sheltering, so of course you need to reach out to make it meaningful for disabled vulnerable people'* [24/349-07/10/20]

6.1.3 Conflict and hate crime

The reliance on unpaid family carers to provide support through advocacy was exposed when distancing rules were imposed without consideration of its implications. Those responsible for setting and maintaining standards of training failed to fulfil the 'reasonable adjustment' requirements of the Disability Discrimination Act both prior to and during the pandemic period.

Some people with additional needs felt that they had been abused through the denial of advocacy. Autism service director Joyce described how the attitude of staff to two autistic people had the effect of an assault:

> *'The biggest issue in health care settings, for autistic people, is the fact that they're not allowed to have somebody with them. So, we've had two incidents in accident and emergency, in the past two weeks, where, for whatever reason, somebody's had to present there, not being allowed to have anybody to go in with them, and to be with them. And it's kind of like having a communicator with you, somebody that can assist meaningful communication and effective communication' [...] 'A couple of our people were verbally abused. Or they felt that they've been verbally abused [...] by staff [...] 'because they asked for somebody to go in with them. And they're like: "I don't care if you're autistic, this is the rule"'* [03/65-02/09/20]

Joyce described a different occasion where the failure of GP surgery staff to accommodate the communication needs of one of her autistic clients was exacerbated by a distancing policy which ruled out in-person appointments. When the patient, who had severe health anxiety, predictably reacted with a 'meltdown', the staff compounded their failure due to a lack of awareness of de-escalation techniques. Instead, they called the police. Joyce said:

> *'Most [autistic people] are highly verbal. And that's misinterpreted as being able to communicate effectively. And so that anxiety is not being factored in at all, and what*

> *it's doing to them. In the early days getting an appointment was impossible. We've got a lot of guys have got health anxiety, and it's been absolutely escalated by Covid. So, some of these people have wanted to get doctor's appointments to be reassured. And, again, the doctors and the receptionists have been quite... I mean, one of our ladies, the police were called because she had a meltdown'* [03/86-02/09/20]

Eddie, chair of an advocacy group for blind people, said the unsympathetic incidents within healthcare were a symptom of the general hostile environment for people with disabilities which was encouraged by media outlets, such as radio talk shows (17/434X-23/09/22), which gave exposure to narratives which drew links between benefit fraud and disability:

> *'When the present government changed over to Personal Independence Payment from Disabled Living Allowance, it was portrayed on the radio that, you know, people with disability, a lot of them were fraudsters'* [17/416X-23/09/22] *[...] 'But that caused a lot of problems for disabled people. You found that, when you're out and about, people didn't have the same friendly, sort of, gestures or whatever towards you, because they were taken in by what's been put out on the media'* [17/419X-23/09/22] *[...] 'There was a notable increase of harassment of disabled people and, sometimes, discrimination as well'* [17/433X-23/09/22]

In a separate interview, autism service director Joyce reported an incident of harassment over her autistic client's inability to comply with mask-wearing:

> *'One of our people was verbally abused and stopped short of being physically attacked in one of our supermarkets recently'* [03/326-02/09/20]

Statistics from the Home Office (2022) stated that incidences of disability hate crimes in England and Wales rose 43% between the year ending March 31 2021 and the same date in 2022, from 9,945 to 14,242. Deafblind service manager Charlotte spoke of a case which was reported to her charity in which two sisters were verbally attacked on a train when one lifted her mask to communicate with her Deafblind sibling [10] [24/146-07/10/20], while self-advocacy group co-ordinator Des described how an autistic man was verbally assaulted by the driver and passengers on a bus, which prompted the autism charity Dimensions[11] to produce their own public information campaign in the absence of government intervention in response to mask-related hate crimes [01/318-02/09/20].

Charlotte said government messaging which failed to be clear about mask exemptions created a gap in knowledge which fuelled antipathy towards people who removed their mask to communicate due to disabilities:

> *'And, of course, people have been exempt – people with asthma, people with disabilities or a need to communicate being exempted – but that wasn't absolutely clear, because that's a very small part of the message that you have to wear a mask. So, because the communication was aimed at the main population, they go with the main message' […] 'There are ways that you can put this communication, but I don't think the initial advice was inclusive enough to cover everybody'* [24/373-07/10/20]

Health and care workers also experienced verbal assaults and the threat of violence, encouraged by press coverage which promoted the perception of 'lazy doctors' using pandemic restrictions as 'an excuse' not to see patients in-person (cf. *The Telegraph*, 2020). In 2022, Deborah had made a career shift away from general practice but she still did occasional GP shifts due to shortages in her locality, where a fellow GP had died from Covid in 2020. Deborah described the threat she felt from a patient's verbal assault:

> *'I was with a patient and I could hear the next patient in the waiting room talking very loudly to my receptionist about how poor the service was, and how he had had to wait too long to see a GP, and how it's been rubbish for the last however many*

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[10] https://www.theguardian.com/society/2020/jul/24/deafblind-woman-and-sister-verbally-abused-for-lifting-mask-on-train (*The Guardian*, 2020)

[11] https://dimensions-uk.org/icantwearamask-think-twice-kind/ (Dimensions, 2020)

> *months and every time you ring up, you can't get through and then you spend an hour on... And all I could hear was him shouting away, and I'm trying to concentrate the patient in front of me. And it was just so distracting. Yeah. [pause] It makes it very difficult to focus when all you know is that the next person to come in is going to bring all that with them'* [33/252X-09/05/22]

6.1.4 Institutional distancing

Many participants reported the withdrawal of essential health and/or social care services. The absence of structures to compensate for this loss led to a disconnection between people and their care providers. I call this form of structural violence 'institutional distancing'. It took two forms: pre-existing – the consequence of longer-term attrition of resources and governmental policies which situated care responsibilities with the individual rather than the state – and pandemic-related – the consequence of a reactive shift in allocation of resources in direct response to the crisis. GP Deborah said a reliance on remote methods led to her practice losing connections with people who required proactive in-person care for chronic problems. She said:

> *'...I'm struggling with [...] my mental health patients, because we're trying to do a lot more of those remotely. In fact, loads of them I haven't seen, people I would normally see once a month or, you know, my regulars, I just haven't seen them. Some of them I've spoken on the phone, some I haven't had any contact at all from, so there's a few that I'm quite worried about'* [33/95-10/11/20]

The withdrawal of the duty of care was formalised within the Coronavirus Act 2020, which temporarily provided 'easements' to local authority responsibilities contained in the Care Act 2014 (DHSC, 2021). The suspension of essential social care day services resulted in crises for the families of people with complex needs, as described by carer support workers Liz and Paula. Liz said:

> *'…about six weeks into the pandemic – and of course day services had all been closed […] we were having families where there were crises'* [10/143-14/09/20] *[…] 'An example: I support a carer whose son, before Covid, would be five days at day service. He also had, through Direct Payments, one and a half days [paid carer attending]. This lad has behaviour problems, autism, learning disabilities, quite a lot going on. And also, he would also have respite at […] an overnight respite place. Obviously he's not getting the overnight respite […] so mum now has him at home, every day, every night'* [10/425-14/09/20]

Paula said families were struggling to cope alone, particularly because the restrictions on movement and/or the desire to avoid infection risks removed access to simple activities outside the home which could give structure to the day, such as taking a walk or going to a café. The ban on mixing of households prevented other friends and family coming to offer additional unpaid support to compensate for the absence of official services. Paula said she received '*lots of phone calls from people that were caring for someone with dementia' […] 'that were finding it absolutely impossible to get through it'* [09/244-14/09/20].

Isolation and separation unconnected to the pandemic was already familiar to family carers. Dowling (2021) describes how the heightened emphasis on resilience and personal responsibility for care is promoted as a socioeconomic expectation, while Tronto (1993) identifies that society considers the act of caring to be a private matter. People who have a family member with care needs suffer the structural violence of 'responsibilised commoditisation' (Higgins & O'Leary, 2023, p.23) in which the government benefits fiscally from the savings it makes from the unpaid labour of those who assume responsibility – or who have it thrust upon them – in the absence of a care infrastructure. Petrillo & M. Bennett (2023) estimated that, in 2021, the economic value of the contributions made by unpaid carers in England and Wales was estimated to be roughly equivalent to the budget for NHS health service spending, with unpaid carers saving the public purse £18.6 million per hour.

Parkinson’s UK support volunteer Audrey, whose husband Eric died of the condition in 2017, described how she had internalized being ‘responsibilised’ and consequently became desperately isolated behind a façade of coping:

> *‘…when we went out, I always put on this: “Oh, yeah, yeah, we’re fine” and that you’re like Tigger, almost. But it doesn’t matter what people say to you. When you’re at home, those curtains are closed and that door is locked, you’re on your own. That’s when your shoulders go down. And then the sadness comes’*
>
> [22/113-21/10/20]

While Audrey acknowledged her ‘Tigger-like’ collusion in this form of institutional distancing, she also described how the state withdrew and disconnected from her family’s care needs. She described how in the 2010s she and Eric lost their professional network, and she had subsequently watched the service deteriorate further for the people she supported on the Parkinson’s UK telephone helpline thereafter:

> *‘Eric was under a consultant to […] a well-known hospital. He had the deep brain operation […] at that stage he was still at home, but the operation didn’t work. And the appointments with the consultant were getting further and further apart. And I know a couple of our members were saying: “I haven’t seen a consultant for two years, I haven’t seen one for 18 months”. And we used to see a consultant, perhaps once every six months. But we’d see a Parkinson’s nurse once every six months, so we did see somebody every three months. And they were also on the end of the phone. But gradually that got worse. There was one day I was at work and my husband rang me very, very distressed. And he said: “Ring Lesley, ring Lesley!” and that was the Parkinson’s nurse […] And when I rang, it was an answering machine and it said: “This service is no longer being provided. Please contact the consultant’s secretary”. So I rang the consultant’s secretary, who told me that none of the services were being provided, including the consultant, because the funding*

> *had been stopped and they were all – all neurologists – were being transferred to [name of hospital in a different area]. And to get to see anybody, we had to go back to our GP to be re-referred'* [22/435-01/10/20] *[...] 'And this was after the deep brain hadn't worked, and you can imagine he was very stressed, I was very stressed, who the hell do you go to? And also, we had a fantastic support worker [...] but they were cutting back on them as well, Parkinson's [charity] were cutting back on the support workers. And she was having to move and take over, she was covering [four cities] instead of just [city with major hospital] area. So we never saw her much again, neither. And you just – you really start feeling you're on your own'* [22/451-01/10/20] *[...] 'Is there enough medical support out there? It seems there isn't, because the nurses are disappearing'* [22/434-01/10/20] *[...] '...the NHS has been wracked to bits and we're losing people left, right and centre. And the only person out there is you supporting – or that's how it feels, you're on your own in this one, big time. And all I can say is I'm glad Eric's not here now because it's a hell of a lot worse now than it was then'* [22/463-01/10/20]

Laura, the chair of Audrey's local branch of Parkinson's UK, was also sole carer for her husband who had the condition. Laura's description of an incident in December 2019 described the consequences of being a responsibilised relative. In effect, the system assumed Laura was coping unless she explicitly told someone otherwise. Laura's health was only addressed when crisis point was reached, and Henry was admitted to a neuropsychiatric unit. Laura said:

> *'...we had to call an ambulance one night, because I'd had enough, and the ambulance guy got in touch with social services for me. And as it turns out, they sort of almost took him in to get me a break, sort of'* [29/226-21/10/20] *[...] 'everything just came to a head and I'd managed, and managed, and managed'*
> [29/150-21/10/20]

This pre-existing situation was exacerbated by the imposition of distancing. Laura described how a similar incident during lockdown experienced by a fellow Parkinson's group member placed the woman in a physically vulnerable position through the eagerness of services to limit in-person interactions and discharge patients at the earliest opportunity. Laura said:

> *'…another friend who goes to the group, her partner, he had a diagnosis of dementia starting. But he has really bad reactions – she ended up having to call the police, they did ultimately end up him being sectioned'* [29/266-21/10/20] *[…] 'he was being violent and going for her. And they got him into a ward and they said: "Oh, he's fine, he's coming home", then he turned around and went for one of the nurses'* [29/266-21/10/20] *[…] 'but he's back at home again'* [29/280-21/10/20]

Unpaid carers face severe financial disadvantage in the face of derisory state support. Claiming Carer's Allowance can disqualify the carer or the person they care for from receiving other benefits, but if one meets the complex eligibility criteria and chooses to apply, at 2023/24 rates (DWP, 2023) the payment is £76.75 a week. That amounts to 46p an hour if the claimant needs to be available to tend to their loved ones 24/7, as were many of Paula and Liz's clients locked down with family members who had day care and respite services withdrawn. Responsibility for sourcing and paying for the PPE to be worn by professional and family carers in private homes was handed over to the individual in most circumstances. Liz said:

> *'…a lot of people have had to pay for their own PPE, a lot of carers had to actually go out and source their own PPE […] some places where they've had a private health care provider […] the provider has said: "Oh, we can't buy that or we can't source it, you're gonna have to source it"'* [10/288-14/09/20]

In England, professional social care services, including domiciliary social care, is accessed via a complex system of needs assessments and financial evaluations to establish whether a person in need of care is eligible for funding and, if so, what specific tasks should be performed, at what cost, and whether the money is provided through NHS Continuing Care payments or means-tested local authority-funded Personal Budgets (NHS, 2021, 2022a, 2022b). Families who received funding for professional care services can exercise some autonomy by choosing to receive their budget directly and employing the staff themselves.

Liz described how some domiciliary care clients and their families felt vulnerable to Covid because they were aware of the multiple contacts the care workers were having, both through their job and/or their social lives. When Direct Payments were controlled by the client and/or their family, the care workers funded by those payments were their employees and the client had human resources responsibilities for those workers. The client or their family had to evaluate the threat posed to them by this exposure and balance it against the necessity of the support those workers provided. They then had to decide whether to attempt to negotiate with the care workers about their PPE and distancing behaviours, or even tell their paid carers to stop attending – which could be construed as a suspension or sacking. The families Liz supported who were receiving Direct Payments had no decisive government guidance in these difficult negotiations – an example of responsibilised commoditisation. Liz described the sense of abandonment and its damaging effects:

> *'Within social care, I think we're being left with far too much of: "well, it's your decision. You're the adult. It's what you want to do. It's how you feel about that person" [...] somebody has to take some responsibility. It can't just be left to the carer to deal with it, because what's happening is that carer therefore is not getting a break, that carer is not being supported. If you're being told: "well, you're an adult, you need to sort this out, you're the employer..." No. That person needs some understanding from somebody up high, they need some direction from somebody'* [10/403-14/09/20] *[...] 'I think we've got an awful lot of more vulnerable carers out there, and who possibly feel unsupported by the powers-that-be because there's not*

> *direct guidelines for them. It's very much: "You're the decision maker on this'* [10/414-14/09/20]

For those whose care needs were new, or needed reassessment, the suspension of NHS Continuing Healthcare assessments to provide funded care for people with long-term complex conditions led to client distress: some people had missed out on funding to which they were entitled while concurrently performing demanding tasks which would have been assessed as requiring professional carers.

> Paula: *'I know that some of those that had Continuing Healthcare that perhaps had an end date – they've given it to them for three months, then they're going to review – those reviews haven't happened […] Perhaps someone that's paying for care might not have had to be paying those big amounts if they could have had a Continuing Healthcare assessment'* [09/488-14/09/20]

> Liz: *'…those people who probably were going to go through an assessment, that was stopped, so they were having to up their caring role'* [10/306-14/09/20]

When I spoke to Paula again in 2022, the disconnect between unpaid family carers and any former support infrastructure had a feeling of permanence. She said the logjam in the assessment of needs in existing and new cases, and the provision of appropriate care to meet those needs, was still unresolved. This left the financial burden and/or the practical caring tasks to be met by unpaid family carers. Many services continued to be suspended or reduced, some people lost their permanent placements, and some services no longer existed. Paula said:

> *'It still isn't back to normal […] the adult group with learning difficulties and autism, their services haven't fully resumed. They're not going back to what they were assessed as needing pre-Covid. They are finding it extremely difficult to get those services back. Maybe some of those services no longer exist. Most of the*

> *parents that I've spoken to at support groups are still finding that the services for that particular group are not back as it was pre-Covid times'* [09/176X-12/04/22] *[...] 'Those that thought they had permanent placements, and then discovered when things were reopening that they didn't have that permanent place, it has been difficult for them'* [09/185X-12/04/22]

By 2022, there was a shortage of health and social care workers resulting from Brexit and workforce burnout (Perkins & Repper, 2021). Paula said that people who had asked their care workers to stay away to reduce the risk of contracting the virus were *'finding it difficult to get back on to where they were pre-Covid because, again, there isn't the agencies and the staff out there with the capacity that they used to have'* [09/417X-12/04/22]. They had effectively locked themselves out of the care system by their earlier decision to shoulder the care burden themselves to protect their loved ones.

The level of disintegration of the care infrastructure had directly impacted the charity which employed Paula. She said it would normally have the capacity to act as safety net when care provision broke down, but *'finding agencies that can do it for us, that we can purchase it from, is nigh on impossible'* [09/187X-12/04/22].

Paula also described an experience which embodied the extent of institutional distancing experienced by unpaid carers. They were invisible to the state: there was no list of eligible people when it was decided that unpaid carers were a priority for the Covid vaccine. Paula said:

> *'...the NHS was caught with their pants down in a way because to invite carers in, they had to know who they were'* [09/278X-12/04/22] *[...] 'Surgeries, because we'd been asking them about their carers register, it wasn't important when they had their CQC [Care Quality Commission] inspection, it only comes to such a small amount*

> *of points that they never really bothered […] So the GP surgeries couldn't invite carers in'* [09/279X-12/04/22]

Because of the eligibility issues and hidden costs of Carer's Allowance, a list of people who received that benefit would only identify a small proportion of people who did unpaid caring, so health managers called upon Paula's charity to approach all the members on its contact list. This diverted Paula's resources to a task for which the state had abdicated responsibility:

> *'…so this became my life for three months. February and March, weekends, you name it. Because what we did was we contacted all 23,000 with a little form, saying it needed to be signed for consent to go back to the GP surgery so that they could be called for their vaccine'* [09/293X-12/04/22]

6.1.5 Socioeconomic factors

Galtung stated that structural violence is aggravated further if the victims are low on income, education, health, and power (1969, p.171). The influence of pre-existing socioeconomic circumstances and healthcare resources on structural violence can be seen in the juxtaposition of the experiences of two participants with identical professional roles. Gary and Vicky both worked as NHS specialist pain management physiotherapists, using psychologically informed interdisciplinary methods. They reported contrasting experiences of delivering healthcare in the presence of PPE and distancing so, for an insight into the underlying causes of the diverse narratives, I considered the demographics of the two populations with whom they worked using Office for National Statistics (ONS) census statistics from 21 March 2021, five months after the interviews (ONS, 2023b, 2023c) (Appendix K). Using the Integrated Care Board (ICB) catchment areas in which they were employed, I compared Gary's population in Northern England, and Vicky's in the South. Gary's catchment area contained 247.3% more people, of whom a higher proportion (21.77% versus 16.84%) considered their health to be less than good. In the North ICB, 9.16% of the population had never worked or were involuntarily unemployed, compared to 5.76% in the South ICB.

Gary was working remotely by telephone rather than video, in part due to the lack of internet connectivity and devices – the digital divide (Sections 2.14 and 6.1.7) – caused by his patients' socioeconomic deprivation. The day before we spoke, he had had two patients who disclosed despairing or suicidal thoughts. Because he could not monitor them in-person, nor observe them remotely by video, the urgency of intervention was intensified. However, the emergency mental health infrastructure failed both Gary and his patients due to a pre-existing lack of resources which had created a form of institutional distancing. When he spoke to me the following day, he described his and his patients' intense distress from the combination of forced avoidance of proximity and structural violence. Gary said:

> *'So yesterday, there was a woman who had problems, previously a very high flier, all of a sudden, hit a downturn, life turned upside down with pain, etcetera. Consequently, her mental health and her world just fell apart. And this is the word she used: she feels abandoned. Everyone's abandoned her, the district nurses have stopped going, the social worker's put a note through the door to instruct her how to use some of her supportive aids – and she's doubly incontinent as well'* [30/19-22/10/20] *[...] 'She's only on lower rate of disability, so she can only afford carers twice a week. She's got to empty her own commode, which is obviously horrendous, but she's really struggling to wash. So, it's a bit of a shitshow for her, really'* [30/27-22/10/20] *[...] 'I asked about her situation, she had a social worker, she hadn't been in touch. So I phoned the social worker, couldn't get through to her, so I spoke to someone else. They said basically: "Oh, we'll get in touch". I said: "Well, she said you haven't been trying to get in touch". [The social worker] checked the number [that they had for the patient], and it's the wrong mobile number. Anyway, I pushed, got her a welfare check and, hopefully, a reassessment, which they've promised. But*

> *she hasn't been assessed for two years and her circumstances have changed. So, she's been fucking abandoned, basically. I did push that. So, another one, completely fucking suicidal, significant issues again, former intensive care nurse, her world fell apart with pain and real significant problems mentally, had a stay in hospital because of the mental health side. Got passed to me, thought I could make some headway to try and get her physically moving. And she's just basically had a breakdown on the phone, said she'll kill herself. And so I had to phone the crisis team. The crisis team said it wasn't appropriate for them,'* [30/34-22/10/20] *[...] 'she was under secondary care so obviously she has a CPN [community psychiatric nurse], a psychotherapist. So, I was directed towards them. Their nurse basically said: "Oh, I'll have a word with her psychotherapist when he comes in". So I said: "Well, this is a bit of an emergency". And her words were: "We're not an emergency service". So, I basically said: "What is meant to happen to this woman who is suicidal and the crisis team don't think it's appropriate?" She went: "Oh, right. I'll see if he's in". Found out he was in. She said: "I'll get him to phone her now". So I obviously document that, phoned the GP, got in touch with the GP, advised them. The GP was going to phone as well. Liaised with my manager, who's a psychologist, and they said I'd covered all bases. But that's the fucking state we're in'* [30/49-22/10/20]

Gary said pre-existing socioeconomic precarity had exacerbated the distress caused by distancing when it came, because rules preventing social gatherings prevented patients from having access to mental health coping mechanisms while self-isolation often meant the loss of income:

> *'...people are really affected by it now. Lifelines have been taken away, you know?'* [30/79-22/10/20] *[...] 'the popping up to your mate's, or whatever'* [30/82-22/10/20] *[...] 'these people struggle with mental illness on the day-to-day. And a lot of people*

> *who haven't, and have been completely fine throughout their life, have suddenly realised what depression and anxiety is actually like to live with. Waking up the next day, thinking: "Have I got a job?"* [30/84-22/10/20]

Gary said purposeful planned healthcare was stifled by disparity of resources because top-down centralised planning did not account for the Inverse Care Law (Tudor Hart, 1971): the people most in need of care are the least likely to receive it:

> *'…we're constantly fire-fighting, the NHS. That's what we concentrate on: the now, not long-term strategies, which we're meant to be with this five-year plan. And I think we should have resources devolved [to the local level]'* [30/288-22/10/20] *[…] 'how the funding calculation is done, it doesn't take deprivation into account...'* [30/297-22/10/20] *[…] 'Is this levelling up? Well, it's not, is it, you know what I mean?'* [30/304-22/10/20]

In terms of structural violence, Gary believed that there was an intent in the harms done by the funding structure*:*

> *'I believe a lot of this is purposeful'* [30/302-22/10/20]

He noted how resources and infrastructure had deteriorated, rather than improved, after the first acute lockdown period between March and May 2020. Gary alluded to the government's prioritisation of business over both the physical dangers from the virus and the mental despair caused by living with austerity in isolation. Gary spoke to me a week after the introduction of the multi-tiered local lockdown restrictions which prevented many of his patients from meeting indoors. In response to the question: 'And is it getting more like a typical day [i.e., two mental health emergencies]?' he said:

> *'It's much worse this time than last time'* [30/59-22/10/20] *[…] 'I think so. I think it's ramped up, definitely. That's just my feeling. I think the first time it was new, it was novel. You know, we'd got it under control, I would say, fairly quickly last time,*

> *because of the intensity of the restrictions. This time, it seems as though we pretty much went: "Ah, well. All of these fucking dead people are worth saving the economy for". But we have to remember, you know, the Tory government are in charge, and the ensuing austerity from this is depressing as fuck. And austerity kills people as well'* [30/71-22/10/20] *[...] '[Covid is] the straw that broke the camel's back'* [30/79-22/10/20]

While providing the identical physiotherapy pain management service in Southern England, Vicky coped with distancing by expanding her pre-existing use of video consultations. Her account of remote working lacked reports of crisis, and contained examples of patients who had resources with which she could work:

> *'…we're lucky enough to have got an excellent practice that we are under now, and we can do online consultations. And they've been doing that for a long time anyway'* [25/293-09/10/20] *[...] 'we got hold of Attend Anywhere, the NHS one that was trialled up in Scotland initially. And we managed to get it up and running. So we started doing virtual clinics, which was better, because obviously, you have that face-to-face sort of contact still, and you can see people's expressions'* [25/58-09/10/20] *[...] 'in some ways, I think that's a good way because you see them in their home environment. You know, you get to see what that environment looks like. It's helped me to kind of assess people in their own environment a little bit better as well, and see exactly what they've got in terms of their setup if they're struggling with specific things'* [25/151-09/10/20] *[...] 'You can have a look and give some ideas on how to adapt it to suit them better, like raising up the laptop and things like that, rather than being kind of hunched over'* [25/174-09/10/20]

Despite higher levels of affluence compared to Gary's patients, Vicky did report that some of her clients could not take part in video calls due to lack of equipment or familiarity with the technology:

> *'…we were offering people either telephone or virtual. And there were some people that just weren't comfortable doing this [indicates video conversation] because they weren't used to it. Or there are those that don't have the available equipment to do it'* [25/477-09/10/20] *[...] 'Lots of people just said: "I just don't have a computer, I don't have a smartphone" [...] not everybody has the modern-day equipment. And we have to accept that that is the case'* [25/487-09/10/20]

However, Vicky considered that due to the affluence in her area, only a small proportion of patients who did not use video consultations would have been hampered by poverty:

> *'...maybe 5, 10 percent will only have limited resources to be able to have the equipment'* [25/506-09/10/20] *[...] 'It's not [a big problem] for our area, no. I imagine that might be different – I suppose [name of town] is seen as a bit of an affluent area. I think there is quite a bit of money in the area. And I do see a lot of people with chronic pain that do still work and do well for themselves, even though they're living with it'* [25/510-09/10/20]

6.1.6 Gifting as a form of insult

Gifts are a form of communication (Mauss, 2016 [1925]). In 2022, they were used by some organisations as a way of marking the 'end' of the Covid crisis. Some gifts expressed the esteem in which they held their staff for their efforts made during the time of PPE and distancing. Perinatal mental nurse specialist Beth considered the gift from her employers was commensurate and she appreciated it:

> *'…our organisation in the last financial year gave everybody an extra day of annual leave, which I thought was nice. And this – I mean, it hasn't reached my bank account yet, but I'm assuming it's going to, because they've put it almost in the public domain, that they're giving – the Board of Trustees is giving everybody £200 as a sort of recognition of what, yeah, working in this time has been. So yeah, that's*

> *nice'* [23/447-14/04/22] *[...] 'it's a nice token. It's a gesture that they didn't have to make'* [23/447-14/04/22]

However, Beth noted how the wrong kind of gift could be interpreted as being insultingly disproportionate to the sacrifice made:

> *'I guess when it's a thoughtless one, then it's just a bit like: "Oh, bugger off". But yeah, you know, you're not talking about a £5 Asda voucher. Like, if they did like a £5 fuel voucher, I think you could shove that up your arse'* [23/461-14/04/22]

Beth described how these gifts could exacerbate the structural violence of the socioeconomic divide. The benefits system acted against those of her colleagues who needed Universal Credit (UC) to bring their income to subsistence level. They would have to declare the gift and, consequently, their benefits would be reduced, thus cancelling out the gift and causing jeopardy for future payments:

> *'...people on Universal Credit – means-tested benefits or whatever – that £200 is going to affect what that means. And I hadn't thought about that. They had to send round an email that: "Actually, for those people that it does affect, if they want to opt out of the payment, then please do". And I thought: "Oh shit. Well, that's really crap, then"* [23/468-14/04/22] *[...] 'I feel like there needs to be something else for them really, because it's a bit of a kick in the teeth: "Here's £200, but actually it's gonna affect your payments, so you're not having it"'* [23/482-14/04/22]

NHS CAMHS therapist Maggie was insulted by a low-value gift from her employer, given belatedly and under pressure. She highlighted the normlessness of gift-giving messaging by contrasting the begrudging nature of her employer's offering with the sense of worth conveyed in the spontaneous and generous gifts which her sister received from her employer. Maggie said:

'My sister, who works in a GP surgery, they've all been rewarded beautifully. Christmas parties paid for, and lovely Christmas presents, and bonuses, they've been really valued in that surgery. And then you get a Trust like ours who do nothing' [12/319X-08/04/22] *[...] 'I think [a decent salary is] the only way nowadays that people can feel valued. Towards the end of the pandemic, when things were getting back to normal, there was some Trusts who were rewarding their workers with an extra day's holiday, or they were rewarding them with things like £500 bonuses in their salaries and stuff. And we were hearing about that. And we got an email from our Trust that said: "I know you've heard that, that other trusts are doing a, b, and c to reward their workers. We're not doing that. But we want you to know that we still appreciate everything that you do". And I just thought: "What a kick in the teeth that is". And there was no reward. And I think people kicked off a little bit, and then we ended up getting this notebook with a thank you note in it: "For everything that you've done"'*

Andrea: '*Are we talking about, like, an Apple notebook or a – '*

Maggie: *'Yeah. like a – No! Not an Apple notebook. Like a write-in notebook'*

Andrea: *'Paper?'*

Maggie: *'Yeah! Yeah'*

Andrea: *'So, not a piece of technology that you could flog to pay the gas bill?'*

Maggie: *'No. Nothing like that. No pay rise. That kind of stuff's hacked people off'* [12/314X-08/04/22]

6.1.7 Experiences of the digital divide

Another element of structural violence with socioeconomic aspects was the exclusion of some members of the population from the online world, as described in Sections 2.14 and 6.1.5. The digital divide was a pre-pandemic problem. Self-advocacy group co-ordinator Des acknowledged a skills/competency deficit experienced by some people with a learning disability, but emphasised how the key problem was a lack of resources and access:

> *'...a massive barrier for people with learning disability has been lack of access to technology'* [01/111-02/09/20] *[...] 'there are lots of people that don't have access to a smartphone or a computer'* [01/113-02/09/20]. *[...] 'We found lots of people when we made these phone calls that weren't connected to Wi Fi or didn't have smartphones'* [01/471-02/09/20]

Lack of access to technological resources became problematic if non-technological alternative routes of communication were not maintained. Des said:

> *'...as long as the video consultations are part of different ways that people can communicate, including face-to-face, that's fine, but if you're moving towards a "one size fits all" – "We're all going to do our hospital appointments online" – then you're gonna increase health inequalities for people with a learning disability in particular'* [01/473-02/09/20]

Des reported pre-pandemic difficulties accessing repeat medication following changes which meant it could only be ordered through an app [01/112-02/09/20], while colleague Fran described a health provider's failure to offer non-technological alternatives:

> *'I have a neighbour [...]. She's in her eighties and she has no phone. Before Covid I rang up to say that she wasn't very well and couldn't make surgery and they said:*

> *"Right-ho, we'll give her a ring back", and I went: "What will you give her a ring back on? She hasn't got a phone!"'* [04/99-02/09/20]

Parkinson's support volunteer Audrey warned of the pre-existing need to diversify provision of information and support for carers beyond websites:

> *'…not everybody's computer literate. A lot of people diagnosed with Parkinson's – now I know a lot are younger these days, but a lot of people who are older wouldn't know how to switch a computer on, let alone search for something. So what do they do? Where do they look?*' [22/536-21/10/20]

Parkinsons UK branch chair Laura said her committee's discomfort with online communication, and their knowledge of the digital skills of their members, was the reason for deciding not to move group meetings online:

> *'…you get people on Zoom meetings or things like this, that they're not used to doing it. I mean, I've been on a couple of Parkinson's UK ones, and they're making a noise all the time'* [29/23-21/10/20] *[…] 'It wouldn't work on a group system because of issues like the fact that you need a meeting etiquette, you know, a "hands up" or something like that. Because if folk barge in, everything all goes pear shaped'* [29/138-21/10/20].

Rural infrastructure was also a barrier to accessing digital resources. Barbara was interviewed by telephone after she was unable to secure the Teams link due to unstable internet connectivity. She said it would cost *'£30,000 per person'* [11/271-14/09/20] to get fibre broadband in her village:

> *'We are right in between areas where the broadband has been provided. There are absolutely no plans to give it to us and we're as far away from the main connection where we need to be. Seven miles over fields, they would all have to come up for them to put it in for us, and we'd just have to pay them to do it'* [11/271-14/09/20]

These diverse aspects of structural violence experienced by participants were accompanied by another specific form of violence – the kind which is inflicted through belittling or ignoring a person’s knowledge and/or capacity to know and be heard. ‘Epistemic violence’, first described by Spivak (1998), is a form of injustice which was meted out to many participants, and it is to this which I now turn.

6.2 EPISTEMIC INJUSTICE

Fricker (2007, p.1) defines epistemic injustice as *'a wrong done to someone specifically in their capacity as a knower'* and describes two kinds of epistemic injustice: testimonial and hermeneutical. Hermeneutical injustice occurs when someone's experiences are not well understood, by themselves or by others. Testimonial injustice occurs when prejudice causes a hearer to give a deflated level of credibility to a speaker's word. Both forms of epistemic injustice are acts of *'prejudicial exclusion from participation in the spread of knowledge'* (Fricker, 2007, p.162), and both concern matters about the speaker's identity and characteristics.

6.2.1 Unrecognised identity of unpaid carers

The institutional distancing inflicted on families needing social care, described in Section 6.1.4, was a form of testimonial epistemic injustice: authorities disengaged from dialogue with unpaid carers and the people they cared for to the point where their existence went unregistered through lack of accurate records. There was a failure to acknowledge their needs and/or the value of the work that they do. In public discourse, the term 'carer' was used to describe the people who were in the 'front line' of the pandemic response. It was usually accompanied by images of paid health and social care staff, but most frequently nurses and doctors. This amounted to a testimonial form of epistemic injustice upon unpaid carers, whose labour was considered as merely a fulfilment of familial duty rather than a contribution to the nation's care effort. Carer support worker Paula said:

> *'"Carers" – they always get that term muddled, especially during the crisis, because you would hear on the media: "it's about carers". But they weren't talking about carers, they were talking about care* **workers**. *They never talked about carers, and it muddied the water even more. Because we've always struggled with this: the difference between a carer and a care worker, and I think Covid muddied it all up even worse than before. As a movement, we don't consider there are formal and*

> *informal carers. For us, it's only carers and care workers. So, we've lost ground on that, trying to persuade about that definition. During Covid I don't think the family carer did get much of a mention at all, and they were providing a lot more care than anybody else'* [09/469-14/09/20]

Parkinson's UK support volunteer Audrey said that the invisibility of carers had exacerbated a tendency towards allocation of resources based on self-interest rather than need:

> *'I think a lot of people are quite ignorant to what carers put up with, what carers have to do. They like to wash their hands of it. If it doesn't happen to them, they're not interested, effectively. It was bad enough before Covid and I can't imagine that it's got any better [...] the last thing on the list will be: "What can we do for carers?"*' [22/408-01/10/20]

Participants also reported a form of hermeneutical epistemic injustice: many people had not even considered themselves to be carers. GP practice manager Dave said that his surgery's efforts to connect unpaid family carers to services struggled to transcend the pre-existing reluctance of carers to self-identify with that role, considering it disrespectful to their spousal identity:

> *'...you use the words "self-identifying as carers", and that's the biggest challenge. You've got Jack and Jill who've been married 65 years. He has dementia now, she's having an absolute torrid time dealing with him. And we suggest to her: "Well, actually, you're his carer, can we record you as a carer and this might open some doors of support for you?" "I'm not his carer, I'm his wife! I'm just doing what – ". I'd never realised that depth of feeling until I came to be a practice manager about 12 years ago. [...] 'In each practice I've been in, the struggle and the challenge to get, particularly elderly, people to see themselves as a carer... "No, I'm just:*

> *'Sickness and health till death do us part'" They just see it as part of that. And they refuse to be [identified as a carer]. We have to respect it'* [13/235-18/09/20]

Dave said forced separation had led unpaid family carers to become conscious of, and consequently fiercely protective of, their caring role:

> *'That younger generation, what's been fascinating is that they've never seen themselves a carer until they're not allowed to do it. Covid has placed some kind of restriction on them, and then they become suddenly quite militant'*
> [13/244-18/09/20]

This opinion concurred with Paula's experience in her work supporting unpaid carers:

> *'...grown children may have been doing things like the shopping or something, dropping into mum on Sundays or whatever, and probably having a bit of a caring role but they never considered it. It was just a fact: they popped in and they helped here and there. And then when they couldn't get out to do those things – to do mum and dad's shopping, or drop by to help dad with his socks or whatever – I think then hit the realisation: "I am a carer", for mum, or dad, or both. I think that's where the biggest group was, was people realising they were actually caring for their parents when they hadn't realised – it was just part of their normal routine'*
> [09/319-14/09/20]

Linda, whose husband James had Parkinson's, said the lockdown had made her feel a frightening shift in her identity, from wife to carer:

> *'I've upped my game now, to actually being a proper carer. And it's feeling quite scary'* [21/484-01/10/20] *[...] 'I wondered in the beginning, when does a carer become a carer? I thought: "Oh you silly fool, you're caring all the time", but to*

> *actually start caring. And this is what I'm finding that's really scaring me these last few months, because now I'm feeling my role is changing…'* [21/473-01/10/20]

Maggie, a high intensity CBT therapist in NHS children's services, had the role of family carer thrust suddenly upon her. Her father was one of the first Covid patients in his hospital's intensive care unit [12/240-17/09/20] in the second week of March 2020 [12/180-17/09/20]. Maggie's mother had dementia, so Maggie suddenly became a locked-down live-in carer for her mother. She described the moment her carer identity manifested: as she arrived at her parents' home as the paramedic took her father into hospital, leaving her mother behind:

> *'[The paramedic] said: "You're the only person that can stay. You can't let anybody else in the house". And your head's racing with work and with: "How am I going to manage this? How are we going to get food? And what's going to happen to my dad? And am I going to be able to cope with all this? Am I going to be able to manage my mum?" And your head's just racing so you're only taking in bits that they're telling you. […] And he just said: "After every single thing that you do, wash your hands", and he stressed that: "You are the only person that can do this". And so, it felt like a huge weight of responsibility'* [12/132-17/09/20]

Maggie continued to provide live-in care for both parents on her father's discharge [12/67-17/09/20] and, after moving back home to her husband, she continued to share the daily care of her parents with her sister, arriving at 7.30am every morning to get her mother out of bed [12/76-17/09/20]. This arrangement was still in place when she we spoke again in April 2022 [12/19X-08/04/22] – and by then she was also caring for her new grandson two days a week [12/30X-08/04/22].

Paula and Liz described how some clients of their support charity were forced to confront their identity as a carer when they were expected to resume a working life, which was no longer possible due to the unpaid responsibilities they'd had to assume – and were still required to perform due to the continued and entrenched absence of other support:

> Paula: *'…before being locked down had completely finished their employers were asking them back in, and they were saying they couldn't come in because they were caring for someone. There was the problem. They could only remain at home if they were sick, not that they were looking after someone that was unwell. And we had a lot – a* ***lot*** *– of issues and calls around that'* [09/339-14/09/20]

> Liz: '*We had to really do research to find out how we could support somebody like that. And of course, GPs – well, they couldn't do a letter because that person was "not fit for work", that person* **was** *fit for work, it was just that person now had a caring role. So there's a lot of people that have had to really consider their employment – how they work,* **can** *they actually work? – because of the role that they've now inherited due to Covid. There's still a lot of families who aren't happy about their son or their daughter going back to school, going back to a day service, mum or dad going back to a day service. And of course, because services have been cut down to accommodate everybody, so that everybody gets a turn who wants a turn, those packages that were in place before have had to be reduced for that person. So that's had a knock-on effect on employment as well'* [10/344-14/09/20]

By 2022, Paula had noticed a shift in identities: people either expanded their identity to include 'carer' alongside their other tasks and personae, or they had left a paid role to assume the family carer role full-time. Paula expected that the number of people becoming conscious of their carer role would be reflected in the responses to the self-identification question in the 2021 census:

> *'…we say there's 60,000 [carers in the county] because that's from the 2011 census. The 2021 census, we've not had any feedback yet. But, though we don't think there's*

> *any more carers in the county, we feel that a lot more identify with the term. So we think that those ticking that question: "I am a carer", will increase because, in 2020-21, we were still in the Covid, sort of. So I think that kind of turned on to people: "Oh, I am a carer for mum and dad", or, "I am – "So we think that that number will be vastly increased from that 60,000'* [09/285X-12/04/22]

In contrast to people's tendency to resist self-identification as carers, authorities habitually over-identified people as carers, often without their informed consent. Paula described how the healthcare Trust in her area resisted the carer support charity's attempts to ensure that family members who were about to have patients discharged into their care had the capacity to cope with medically recovered relatives who were still in need of intensive support for basic activities of daily living. This pre-existing institutional eagerness to infer 'carer' identity on families was exacerbated in 2022 by the fragility of the formal social care infrastructure. The ensuing family crises led to an increase in emergency re-admissions. Paula said:

> *'…they're not having [social care] beds available'* [09/247X-12/04/22] *[…] 'I think this has always been the case, but it's probably even worse now. So they're very much dependent on the carer saying they can come home'* [09/2487X-12/04/22] *[…] '…no one's assessing them at the right time to know if they can cope with that. So I know, pre-Covid days, 25% of readmissions was down to carer breakdown'* [09/250X-12/04/22] *[…] 'Where we need to be, is at the point when someone's being discharged from hospital, and talk to carers at that time'* [09/233X-12/04/22] *[…] "…but in 22 years of doing this job, we still can't get into any of the Trusts for discharge'* [09/236X-12/04/22]

The epistemic injustice experienced by unpaid carers meant that when the role was assumed, by choice or necessity, the carer's personhood was affected, as if they had been rendered invisible. Conversely, it was a very public display of identity that adversely affected the personhood of their paid counterparts, whose work was lauded on the nation's doorsteps at 8pm every Thursday night between 26 March and 28 May 2020.

6.2.2 'Clap for Carers' and its effect on personhood

Rhetoric is defined by W. Booth (2004, p.10) as '*the whole range of arts not only for persuasion but also of producing or reducing misunderstanding'*. 'Clap for Carers' (CfC) was a distanced form of sonic rhetoric. The minute-long round of applause and other noises, such as pot-banging, whistle-blowing, cheering, and singing, was initiated via social media by Dutch yoga teacher Annemarie Plas and performed by an estimated 69% of the public across the UK at least once at some point in its 10-week existence (YouGov, 2020). The symbolic act was intended to be a sign of appreciation for NHS and social care staff for delivering care in the presence of PPE and distancing, yet some academics at the time noted the dissonance between the intended signal and its context:

> *'…at the same time that it is being rhetorically lauded, [care labour] is also being directly exploited by the wealthiest of society'* (Wood & Skeggs, 2020, p.647)

Care home training manager Alex said CfC was a form of communication which had a uniting anti-hierarchical effect and provided a moment of respite for her traumatised care workers:

> *'We did a tour of all five homes when they were doing the Clap for Carers thing. I pulled together every senior manager within the company, and anyone I could really gather, and we travelled the homes every week. For the five weeks, we went to each of them and we did a clap for that home. If you go on the homes' Facebook pages, you'll be able to see there's a video for every clap. And they're fantastic. It was the most amazing thing I've ever been involved in. And that's just probably about this much [indicates tiny amount] of the stuff we did throughout it all, but it was probably one of the best things we did. I know people berate the clap and think it's a*

> *load of rubbish, but I know for a fact that those care staff took a lot away from that moment of, just, serenity, where everything was just calm, and we were all clapping for them regardless of job role, regardless of where our stance is within the company, we were all there for the same reason. We had relatives come and clap with us. We had some researchers come and clap with us. We had old staff coming, relatives were outside, residents, everyone. So, it was kind of a real humbling moment, in a really horrendous place. But yeah, we did that in every single home, our five homes had their own clap'* [14/591-21/09/20] *[...] 'And I mean, I know it gets some stick. And other people have said it went on for too long. But I won't forget the feeling of the first one. It was when me and [my wife] were here, at home, because we weren't working late at night, and we had the patio doors open and just the roar and eruption of the whole housing estate where we live, it was just phenomenal. It was amazing'* [14/606-21/09/20]

Alex's uplifting description of the embodied experience of *being involved in* clapping – as opposed to being the recipient – is in line with the findings of a study of health and social care workers' reactions which exposed the possibility that the clappers may have benefitted more than the clapped-for (Manthorpe et al., 2022). In contrast to Alex's account, other participants, unprompted, raised the subject to express their ambivalence or outright dislike of CfC. GP practice manager Dave considered it to be a political manipulation of public opinion to distract from the pre-existing health and care crisis:

> *'I never went out and clapped, not once, in our street [...] and there were doctors and nurses who felt exactly the same, never joined one of these weekly claps because we were just doing our job. And, you know, we didn't need the thanks. It's nice to be thanked and for people to be grateful for the service we do, but in terms of protecting the NHS, I cringed at it because I thought that was a – and I probably will be political here – I thought that was politicians trying to redress a situation*

> *that they'd caused in the first place, particularly with general practice: prolonged underfunding of general practice. You know, we used to have 12.8% of the NHS cake, we now have 6.8% or something. So, actually, we've been asked to do more and more with less than less'* [13/368-18/009/20]

The CfC augmented a damaging narrative of health workers being parts of an invincible machine, a baselessly asserted trope which was established on 3 March 2020 by Boris Johnson when he told a press conference: *'We have a fantastic health service and it is well capable of handling the most tremendous pressures, as everyone knows'* (Clarke, 2021, p.58). By setting up health professionals as 'heroes', their personhood was diminished, undermining their ability to be seen and heard as vulnerable individuals. Meanwhile, the public's performative sounding and listening served as *'little more than the tools of a trite kind of "folk politics" that closes its ears to structural crisis'* (Mackay, 2021, p.217). This view was echoed by perinatal mental health nurse Beth:

> *'It [the NHS] is not supported properly. If people want to get out there eight o'clock on a Thursday and give it a good old clap it makes themselves feel better, but –'* [23/550-08/10/20] *[...] 'after about three weeks, I kind of just stopped because – what does my dad say? He said: "The day that you wake up and you just think the bad guys have won, you might as well finish it". Because there is a lot of good in the world but, I don't know, the people that seem to make these decisions really, really aren't getting it'* [23/553-05/10/20]

Even Alex, who championed the cause of CfC, said she had *'a real big problem'* with *'conversations around: "Oh, you're heroes" and all that kind of thing'* [14/590-21/09/20]. According to Whitham (2021), CfC promoted a discourse of war, heroism, and sacrifice which framed the lives of key workers as already forfeited, as described in concept of the 'ungrievable life' (Butler, 2009). Rather than being an act of reciprocal recognition, CfC was an example of:

> *'a specific exploitation of targeted populations, of lives that are not quite lives[...] When such lives are lost they are not grieveable since in the tpwisted logic that rationalises their death, the loss of such populations is deemed necessary to protect the lives of "the living"'* (Butler, 2009, p.31)

The consequences of this dehumanisation and 'othering' of healthcare workers by the public was reported by participants in 2022: those previously lauded as 'heroes' were now being subjected to verbal and physical violence. NHS children's mental health therapist Maggie said:

> '*We went from being the best thing since sliced bread' [...] to now being the devil's advocate' [...] 'It's soul destroying'* [12/270X-08/04/22] *[...] 'People are screaming at us. You know, during Covid everybody wanted to – you know, they were clapping for the NHS. Now they just want to knock you out because they can't get an appointment'* [12/47X-08/04/22]

Intensive Care Unit dietician Natalie described how her husband, a respiratory ward manager, predicted at the time of the CfC that there would be a backlash. Natalie said:

> *'...my husband, at the time, went: "This [Clap for Carers] is a load of old rubbish" [laughs]. He is very black and white, my husband. And he said: "It's all well and good them doing this now, but give it six months and they'll be back to the complaints, and the moaning, and the usual thing, and blaming us for everything". And I was like: "Okay!" And do you know, he's been right. He's right'* [26/354X-29/04/22]

Nurse Louise referred to the CfC and subsequent antagonistic behaviours displayed towards her profession by some members of the public, and explained that the slogan to rally support for the nurses' campaign for improved pay and conditions challenged the public to reflect on the rhetoric in which they had indulged:

> *'I think sometimes, of the public as well, they're not very nice sometimes. And I think, you know, you see some quite nasty stuff put on social media now'* [34/592-10/12/20] *[...] 'while as before you got: "Oh, thank you for being a nurse", that respect, seemed to – it didn't last very long. [...] I mean, our saying for our pay is: "You clapped us, now back us"'* [34/597-10/12/20]

A theme of those participants who reflected on CfC was the ease with which events were forgotten – a phenomenon which requires further examination.

6.2.3 Active forgetting

ITU dietician Natalie said antagonism towards health and care professionals was fuelled by a societal forgetting:

> *'...it's the fallout of it now. I think everyone's kind of forgotten the clapping and: "Oh, you're amazing"'* [26/374X-29/04/22] *[...] 'going from that to what it is now, I think people have very short memories, to be honest'* [26/387X-29/04/22]

Several participants commented about how their temporal perception of the previous months was confused and vague, some struggled to recall the correct order of events, and some described unresolved and ongoing situations in the past tense. The ability to control unwanted memories is critical for maintaining cognitive function and mental health (Hu, Bergstrom, Gagnepain, & Anderson, 2017), and active forgetting adapts memory to be aligned with cognitive and emotional goals (Anderson & Hulbert, 2021, p.27).

Anthropologically, Connerton (2008) describes multiple forms of forgetting, some of which are deliberate attempts to protect people – sometimes from pain, sometimes from retribution. 'Forgetting as humiliated silence' is a covert coping mechanism in response to shame, often motivated by political expediency. 'Repressive erasure' is a deliberate elimination of the memory of people, events, or ways of being. It can be employed by states '*to deny the fact of* *a historical rupture as well as to bring about a historical break'* (Connerton, 2008, p.60). The denial of humiliating facts was a central feature of Boris Johnson's insistence that the country should *'move on'* from the Partygate scandal (Merrick, 2022; House of Commons Committee on Privileges, 2023), discussed further in Section 6.3.1. 'Structural amnesia' results from a tendency for memories to atrophy if they lack saliency for the society which carries them. If that society practises epistemic injustice against its members who carry those memories, they are more likely to atrophy. This is problematic when those who suffer epistemic injustice are also those who carry the main burden of memory, as I will explore in Section 6.2.4. Conversely, 'forgetting as annulment' arises from having a superabundance of memories, and their deliberate jettisoning is a response to the resultant *'cultural nausea'* (Connerton, 2008, p.64).

GP practice manager Dave acknowledged the necessity for coping mechanisms, saying the lived experience of the pandemic had been *'overpowering and overwhelming for people, and we can't process it as quickly and as efficiently as maybe we need to, in order to survive'* [13/352X-04/04/22] *[...] as people, we've still got a lot of processing to do'* [13/361X-04/04/22]

The cumulative testimonies of the participants indicated that, by Spring 2022, England's health and care systems had moved into a chronic phase of severe precarity. However, the outbreak of war in Ukraine facilitated active forgetting: the depth of the crisis warranted extensive coverage and, through the mechanisms of Agenda Setting Theory (McCombs & Shaw, 1972, 1976), the audience not only learned about the intensity of the unfolding events from the rolling media coverage, but they also learned how much importance to attach to that issue. Coverage of the conflict reduced the available airtime for other issues and contributed to the perception that issues other than the war (such as the consequences of the pandemic) were less significant. Agenda Louise described participating in high-level emergency meetings to discuss *'all the health and social care, it's not functioning'* but said:

> '*The problem is, nothing's gonna get on the news'* [34/210X-31/03/22]

For those who required action to be taken based on those experiences which were being actively forgotten, this was a form of testimonial epistemic injustice. For example, in the previous chapter Dave described how he and other practice managers collaborated to source and distribute PPE. However, he was sceptical that senior executives with the responsibility for culture and policy change would want to learn from their experiences and consider them in the future planning of PPE design and supply:

> *'I think people are listening, but are they actually hearing what we're saying? And even if they are, I think, with the best intention, people have what they think is a solution for going forward, and they're in positions of authority and responsibility where they can make things happen. And you kind of think: "Well, whose vision are you trying to bring to life here? Yours, his, hers, theirs, or ours?"* [13/497-18/09/20]

NHS CAMHS therapist Maggie concurred that the weight of a practitioner's opinion had been culturally devalued. She said: *'...it's a culturally social thing. I think people have just stopped valuing public service workers'* [12/264X-08/04/22]

Similarly, in the previous chapter Louise recounted her national efforts to influence PPE and distancing policy through evidence-based publicity campaigns and lobbying, but in 2022 she was frustrated by active forgetting by government, society and even her own family, which was a painful form of testimonial injustice for her:

> *'...from the last conversation, I feel like we haven't really come that much further with the state of the world. The world thinks we have, but you know, we haven't in reality. I think that's more stressful: that we know things that the public are just thinking: "Well, it's all gone away, it's fine"'* [34/7X-31/03/22] *[...] 'I mean, even my family say to me: "Don't, oh, we're fed up of hearing it, Louise, fed up of hearing it, don't want to hear anymore. Nobody wants to know". I'm thinking: "But it's..!"*

> *Because we know what we know'* [34/124X-31/03/22] *[...] 'now we all say: "We are just fed up of hearing about Covid". But it's not going away'* [34/913X-31/03/22] *[...] 'Why isn't it on the news? That's what we can't understand. And it's because the government probably know the fact the public can't cope with thinking about Covid again. They think it's gone away. They just can't cope with thinking about it again'* [34/957X-31/03/22]

The depth of active forgetting may have been a reason why so many participants expressed gratitude for my attempts to research the experience of health and care communication in the presence of PPE and distancing: they could not forget, and they wanted practical learning to arise from their experiences.

In 2020, GP practice manager Dave predicted a return to old ways, despite hoping that the upheaval of prolonged exposure to the frustrations of communicating in the presence of PPE and distancing would prompt a re-evaluation of priorities. He said:

> *'…we get back into work and you fall back into the same routines and ruts. But I think time will tell, and I hope that society does emerge from this a little bit different'* [13/444-18/09/20]

By 2022, Dave's prediction had been realised, to his regret:

> *'...we've got to come out of this as a society, as people, differently. But we don't seem to be doing that. We seem to have reverted back to type, and going back to normal. And I just think, maybe, you know, in a digital age where everything is so instantaneous, and whether it's news or coffee, or food, we just want it there and we want it now. Maybe we've lost the ability to be patient, to look at things in a longer-term perspective, to actually think about the various trajectories in life [...] Maybe we have lost a sense of humanity, of anthropology and sociology, you know? What is*

> *it to be human, you know? Maybe we need to sort of step back and look at that again'* [13/670X-04/04/22].

Similarly, NHS CAMHS therapist Maggie agreed that people had moved on from considering the experience of PPE and distancing as an opportunity to learn:

> *'I think I've learned how fickle people are'* [12/546X-08/04/22] *[...] 'People were saying to me: "This will change everything, won't it, for people? It'll change everything forever". And I was going: "No, people will go back to doing exactly what they were doing before the pandemic". And they have'* [12/549X-08/04/22]

6.2.4 Unlikely victims of epistemic injustice

The Independent Scientific Advisory Group for Emergencies identified nine key areas where UK government actions diverged from scientific advice (Independent SAGE, 2021). Instances included: delaying the implementation of requirements to wear face coverings; failing to avoid confusion and contradiction in messaging and communications; setting out a 'road map' to the ending of mask-wearing and distancing based on fixed dates (while talking about 'data not dates'); and using 'personal responsibility' messaging instead of implementing an evidence-based risk-management strategy. This large-scale testimonial epistemic injustice silenced some of the most respected scientific voices, especially those in government positions who were bound by protocol which prevented them publicly contradicting their leaders. Moreover, it was compounded by the structural violence inflicted via false claims by senior politicians that their actions were 'following the science'.

Research into epistemic injustice in health and care interactions has overwhelmingly been conducted with the assumption that power rests with those in professional positions while patients face an uphill struggle to be heard. This dynamic has been challenged (if not inverted) at the hands of neoliberal (i.e., anti-intervention, anti-regulation) politicians, and media outlets sympathetic to their agenda, such as the TV and radio channel *GB News*, and the newspaper *The Daily Telegraph*, which provide comment platforms for right-wing politicians and commentators. The narratives given space by these media outlets, also disseminated via social media, include challenges to scientific consensus.

Participants noticed a switch in dynamic between professional care-givers and the public. GP Deborah explained how testimonial epistemic injustice gave precedence to the neoliberal narrative over the voices of health workers. In 2020 Deborah said:

> *'…obviously you see all the press about: "Oh, you can't get an appointment with a GP, my GP won't see you" and we* ***are*** *bringing in people, I promise you, we* ***are*** *bringing in people who need to be seen'* [33/314-10/11/20]

In 2022, Deborah said:

> *'I think that's got worse. There's been an incredible amount of GP-bashing in the media. And politicians haven't helped with that, saying, you know: "We are going to ensure that you can see your GP" and dict[ated]: "You must have face-to-face appointments available" So there's all the rhetoric at the start of it about how wonderful the NHS was, that's being sort of handily forgotten about and replaced with: "No, it's all the doctors fault, it's all the GPs fault, they're all not accessible, and..." Yeah. [laughs] They neglect the actual facts'* [33/213X-09/05/22] *[…] 'The amount of activity we've done is hugely more than average, but all you hear is: "We're not accessible enough", and that's from the media as well. But the thing is, patients hear that'* [33/222X-09/05/22]

Some participants found comfort from me listening to them actively as part of this research. Deborah said:

> *'I have to say, it's been very therapeutic, being able to just, sort of, think through all this, hmm'* [33/389-10/11/20] *[...] 'Yeah, so I'm very – I'm a bit more relaxed with you, talking about it'* [33/244X-09/05/22]

Deborah's comment draws attention to a vulnerability, emotional pain, and a sense of harm done by epistemic injustice. This, combined with the other themes of violence considered in this chapter, point to the need to explore the anomie, moral distress, and moral injury suffered by participants as a consequence of lives lived in the presence of PPE and distancing.

6.3 ANOMIE, MORAL DISTRESS, MORAL INJURY

To understand the effects and consequences of visceral-emotional assaults on the participants' body-minds, I now consider them through the lens of anomie, moral distress, moral injury, and the factors which constitute a morally injurious event.

6.3.1 Anomie

The participants' testimonies offer multiple examples of normlessness – the state that exists when the expectations of behaviour are unclear and the system which establishes those expectations has broken down. Normlessness is a feature of 'anomie', Durkheim's theory (described in Section 2.9) to describe the consequences of the societal loss of shared ethical norms, moral values, and social standards which had previously kept people united. These consequences come in the form of feelings of frustration, anxiety and despair, and behaviours which can be harmful to self and/or others.

In the final weeks of 2021, four months after laws on masks and distancing had been lifted for the final time, the concept of shared ethical norms was damaged when journalists began to expose systematic flouting of lockdown laws by the Prime Minister and Downing Street staff during the height of the pandemic (House of Commons Committee on Privileges, 2023). The scandal, which became known as 'Partygate', had the Prime Minister's contempt for the truth at its centre. In April 2022, GP practice manager Dave noted *'we've had the highest absence rate at the minute that we've had for the past two years'* [13/112X-04/04/22] and believed that Partygate, not science, was driving policy which had led to high circulation of the virus:

> *'…given the political events around parties and lockdowns, I think releasing the country a little bit earlier than maybe had been anticipated from some of the stricter measures was probably a very politically savvy thing for the Prime Minister and the*

> *government to do. He's always said he would adhere to the science. I'm not sure he has'* [13/122X-04/04/22]

Participants' descriptions of their interactions in the presence of PPE and/or distancing revealed a divergence of social behaviours, loss of trust, societal withdrawal, conflict, and confrontation, much of which arose from normless communication *about* these artefacts and measures emanating from people assigned with the task of developing and implementing policy in organisations and in local and national government. What had occurred was 'social distancing' in its true sense, as defined in Section 2.8: there had been a breakdown in *'the degree of sympathetic understanding that functions between person and person, between person and group, and between groups'* (Bogardus, 1959, p.7).

By 2022, the consequences of anomie were becoming apparent. Children's mental health therapist Maggie said:

> '*... people abuse you for – I mean, I don't get abused personally, but I know staff who do – because they can't get what they need from services*' [12/50X-08/04/22] *[...] 'My sister manages all the reception staff in a really big GP surgery, and she says the same. She said: "The front line, Maggie, honestly, those poor girls, what they have to put up with, nobody can pay them enough for what they have to put up with on a daily basis"* [12/211X-08/04/22] *[...] 'Her reception staff take all the phone calls. And because people are unwell, and people are angry, and they're trying to get a service, you get all that expressed emotion, don't you? And the frontliners get it all. And [the receptionists are] trying to triage you. They're trying to get you the best service. And they're trained to do that. But [the patients] don't know that, they just think they're being nosy. And she said: "The abuse that people get. We used to be able to say: "If you speak to us like that, we'll strike you off"' But she said: "There's so many people now, we can't strike them off anymore!"'* [12/216X-08/04/22] *[...] 'She says the receptionists are crying because of the way*

> *that people speak to them'* [12/224X-08/04/22] *[...] 'And I guess – people are unwell. And something else has changed as well, I think people are less patient, or I think maybe they've just ran out of being patient'* [12/227X-08/04/22] *[...] 'I just think maybe it's just a bit of burnout'* [12/284X-08/04/22]

In 2022, Dave described how the temporary structures put in place at his surgery to facilitate safe in-person distancing were being made permanent to protect the staff from assault, a symptom of what Dave suspected was a permanent social disconnection:

> *'…the doors are open, they have been for quite some time. We're still asking people coming in to – as they do in every health setting – to wear a mask. And there's tensions there, more regularly now than ever before. We – like a lot of practices – we put up a spit screen on reception. And actually, we've taken down the temporary screen and we've erected a permanent one. So it's interesting how it has changed. We have created a barrier between us and the patients now. A protective from an infection control point of view – around virus issues, you could say – and from a safety perspective of the aggressiveness of patients wanting to lean over the counter and invade the staff members' space. We've had to say: "No, actually, that's not going to happen". We've got a sort of a curved, wavy reception counter, which means that the Perspex screens have had to be built in three sections. They look horrible. And again, for elderly people who may be slightly hard of hearing, for example, it's causing problems there. You've got to speak up in a way you didn't before. So it's interesting how we've changed our long-term strategy in response to things that we did during the pandemic'* [13/457X-04/04/22] *[...] 'I would love the day when we could maybe get rid of these screens. But, you know, I can't see that happening. I mean, I've got 10 years left, and I can't see that happening before I retire' [...] 'from a staff safety point of view, unless there's a massive change in*

> *patient behaviour, I'll not be taking down those screens. I've got to protect my staff'* [13/472X-04/04/22]

When listening to participants' stories of anomie, I was moved by their distress: circumstances were making them do things, and/or tolerate things, which were morally unacceptable to them.

6.3.2 Moral distress

Jameton (1984, p.6) first defined moral distress as the psychological response which arises when *'one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action'*. Specialist OT Veronica expressed her distress at knowing she was failing to connect with her patients, but that mask-wearing was an institutional constraint which she could not override. The experience led to feelings of inadequacy:

> *'It is about getting beyond the mask. But sometimes I don't feel I can get beyond the mask, depending on who my client is. It's very important to get beyond the mask, but I can't always do it. And that's when I walk away and I'm shaking my head, thinking: "This is not good". And I don't like it'* [18/660-24/09/20] *[...] 'there's nothing worse than when I come back into office, and I don't think I've done a good job. And I think, since we've been back out there, I'm still not happy, because I just think I can do better'* [18/514-24/09/20]

Similarly, GP Deborah described a sense of failure, despite investing large amounts of energy into non-verbal communication techniques to de-escalate confrontations. The effort, combined with the awareness that it seemed to be in vain, lead to exhaustion:

> *'I can hear, and see, my body language has gone all to pot, but I'm actually very conscious of that with people. I try not to let – I* ***have to*** *not let – my frustration*

> *show when I'm having, for the 10th time in a row, somebody say that they can't see a GP. I maintain my relaxed, open posture. Very, very conscious of it. And with my smile behind my mask, so my eyes are smiling, to de-escalate it. I actively de-escalate it before I start, I have to just maintain my composure, and I work at that. But it is a frequent thing, that every single time you go around that little: "Let's de-escalate and then move on"'* [33/244X-09/05/22] *[...] 'I start off my clinics being very positive and very open and relaxed and very, like: "I'll just accept this, I'll let it wash over me". But by the end of the clinic, I do feel my shoulders beginning to droop. Because it's very wearing'* [33/269X-09/05/22]

Moral distress is linked to the presence of some kind of constraint on the sufferer's *'moral agency'* (McCarthy & Gastmans, 2015, p.131). Epstein & Hamric (2009, p.2) give an example of an institutional constraint as the pressure to preserve resources, and there are examples in Section 5.2 of participants changing their care communication behaviours because they were required to eke out scarce PPE stocks.

Another example of an external moral constraint given by Epstein & Hamric is when *'policies and priorities conflict with care needs'*. Some interview participants expressed their distress at the moral dissonance between a suite of policies which encouraged proximity and socialisation between strangers in hospitality venues while forcing separation from loved ones in health and care settings. The UK Government scheme 'Eat Out To Help Out' (HMRC, 2020) paid hospitality establishments to give 50% discount on food or non-alcoholic drinks which were consumed inside restaurants, cafés, bars or pubs. The discount, up to a maximum of £10 discount per diner, applied at participating venues every Monday, Tuesday, and Wednesday in August 2020 (see Appendix A for timeline of events). Perinatal mental health nurse Beth said the government's prioritisation of hospitality over parenting exacerbated the spread of the virus, and explicitly attributed that decision-making to the masculine and misogynist culture of the Cabinet Office described in the proceedings of the UK Covid-19 Inquiry (2023a, pp.217-222; 2023b, pp.69-73). She said the relaxed distancing culture of ‘Eat Out To Help Out’ compared to maternity unit rules sent a message to new fathers about expected gender roles which unravelled years of work on inclusion and bonding in fatherhood, one of Beth’s core moral values. Beth, who herself gave birth in December 2020 under PPE and distancing regulations, said:

> *‘…my own experience is my partner hasn’t been able to attend one maternity appointment, but he can go to Wetherspoons and get pissed. And I’m just like: “Please tell me how that makes sense”’* [23/494-05/10/20] *[…] ‘you’re talking to mums, and they’re like: “Why can’t partners come to these appointments? Why can’t he do this and why can’t he do that?” and you’ve just got no real answer for them. And it’s just the logic seems to be very, very missing’* [23/567-05/10/20] *[…] ‘even I can see: “Eat Out to Help Out”, and now we’re back in a shit state again’* [23/516-05/10/20] *[…] ‘The message of what that is sending is just phenomenal, in the sense that: “You women can just deal with it on your own because you’re mothers and that’s what you should do, you fathers still can’t, you're just not really quite up there, really, in terms of priority to be there”. And when you just think about the history of parenting and how they display those different roles in the media, I just feel like we’ve gone back to square one. Any of the campaigns, anything to try and have a sense of equality in life, it’s just shone brightly as to how far we haven’t come, in terms of the decisions that have been made by seven men [i.e. members of the government and their advisers], that are just so far removed from life’* [23/496-05/10/20]

Autistic self-advocate Lucy suffered from arthritis and needed blood tests, but her GP surgery had put in place a distancing protocol that re-directed patients to the hospital for such procedures. The dissonance between the surgery policy and that applied to the hospitality industry was compounded by the loss of moral agency over her choice to avoid public transport, thus minimising the need to wear her mask. Lucy was angry and anxious about being forced to endure the heightened sensory experience, and she was bewildered at the normlessness created by the contrasting distancing cultures:

> *'I can go to a pub, I can go to my restaurant over the road from my house but I can't go to my GP for my health care. Why? Also, I'm now going to have to travel on public transport, which I haven't been doing since the start of this really. Why can we do certain things but we can't do other things? It's very confusing, and it's frustrating. And it's causing me huge anxiety over something else now. I have anxiety over other things. This has added to my list'* [02/290-02/09/20]

In their definition of moral constraints, Epstein & Hamric (2009, p.2) differentiate between the institutional, as described above, and those they describe as internal or 'personal', such as '*lack of understanding of the full situation'*, *'perceived powerlessness'*, or a '*socialisation to follow orders'*. Care home training manager Alex described how a lack of understanding on the part of a resident's daughter, who was distressed at being unable to enter the home, led to a confrontation in the street. However, an external factor – the policy which prioritised the hospitality economy over care – exacerbated the distress of both parties. The daughter had been eating in a restaurant and had spotted Alex through the window:

> *'In Pizza Express was a relative of somebody I look after. And she ran out to see me because, obviously, she's not seen me [during the home's lockdown]'* [14/303-21/09/20] *[...] And she went: "I think it's disgusting. I can't see my dad", and all this kind of stuff. And I stood and I tried to explain and talk to her and tell her the reasons why she can't see Dad, that we had suspected cases, and what if she came in and she caught it, and then she took it home? And it dawned on her in the middle of that conversation that she'd never thought about it like that. She thought that* ***we*** *were the ones stopping her from seeing Dad'* [14/310-21/09/20]

An added complexity to this scenario is the moral distress Alex had experienced in her personal life: she had been prevented from being with her pregnant wife for antenatal appointments and during most of her labour, and she had had to stop visiting her own grandmother [14/37-21/09/20].

The respondents' experiences illustrate how 'personal' constraints on moral agency can be influenced by acts of commission or omission by external influences, an example of which can be seen in the description of the hospital café meeting between mother and son Barbara and Carl, described in the Vignette 4 in Section 5.3.1. Barbara's use of the term 'culture call' is a neat description of Epstein & Hamric's *'socialisation to follow orders'*. Barbara and her family wanted to practise mask-wearing and distancing – they had been socialised to follow the orders given to them on Carl's ward. However, when they went to the café, their resolve was undermined by a new set of external forces: firstly, the proportion of non-mask wearers moving closely around them were interpreting the hospital concourse as an 'off-duty' space where the culture, if not the actual policy, of the hospitality sector applied rather than that of an 'on-duty' medical space which required stricter compliance; secondly, there was the absence of any explicit 'orders' from the hospital management to do otherwise.

6.3.3 Moral dilemmas

Another contributing factor to moral distress, according to Jameton, is the *'moral dilemma'*. This arises *'when two (or more) clear moral principles apply, but they support mutually inconsistent courses of action'* (Jameton, 1984, p.6). In Vignette 5 I resume the story of Barbara and Carl's experience as an example of a moral dilemma. While they sit in the café on the hospital concourse, Barbara is torn between her responsibility towards protecting the visiting public from Covid-19 and the need to protect her son and his ward mates from extreme restriction of association.

Vignette 5: Barbara and Carl (part 2)

Barbara was a regular at this hospital café, before the pandemic, both as a mother and as a health professional. It had been normal for Barbara and Carl to sit here on visits. When she was an advocate for service users, she’d also meet her clients here to support their visits to the hospital. And that’s what really troubled her: what would health professional Barbara do? As she played with her empty paper cup, she voiced her unease to Carl and Bill:

> “Who else could have walked in off the street today*? If I’d been working, if I’d had a client in here, I would probably ask to speak to a manager. But, when it’s personal, and I’m thinking about* you, *son,* if *I make a fuss about this, we will be virtually saying to the patients in the spinal injuries unit: “You can no longer go to the café”. It’s a very double-edged sword for me*. Carl, I don’t want them to stop us doing this again. *I don’t want them saying to* you: *‘Well, this is your fault, you went up there and had a cup of coffee’*.”

It took Barbara *until Tuesday to decide to ring PALS,* the Patient Advice and Liaison Service. She was afraid of an executive’s *knee jerk reaction that would stop Carl going out*, because she suspected that it was *the only thing keeping him going at the moment*. Her identity as a mother was bone-deep and she knew she needed to keep communicating for the rapidly approaching day of his discharge home. He would need complex support if it was to succeed, but Barbara had a delicate path

(continued on next page)

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to tread which would somehow navigate her role as his carer in a way which protected his dignity and autonomy as a grown man. However, she couldn't shake off the sense of responsibility to the public which she'd developed over her professional life. Over breakfast that morning, she said to Bill:

> *"I can't not do something about it. I have to do something. I have to point out that there was nothing there to tell you what you needed to do. No hand sanitizer."*

She made the call. The voice on the other end said:

> *"I think somebody further up the chain may wish to discuss this with you."*

A week later, she was still waiting for a response. And by then Carl was struggling to transfer again, confined to bed. *Back to meeting in the corridor with the full PPE.* The café was out of reach: immobility was back in charge of infection control.

Drawn from interview with Barbara on 14/09/20: 11/34-54; 11/60-93; 11/106; 11/158-171; 11/178-9; 11/199-219; 11/227-8; 11/234-248; 11/264-5;
Interview with Carl on 29/10/20: 32/23-34; 32/41-45; 32/189; 32/217; 32/299; 32/357; 32/420-424]

By picking up the phone, Barbara converted a moral dilemma into what she feared would be a deliberate act of betrayal. The reason Barbara hesitated was her awareness that, in doing so, she jeopardised her relationship with her son on two fronts: not only would a rule-tightening restrict their ability to meet freely when Carl was able to self-propel again, perhaps demotivating Carl after his setback, but they would both know that it was she who triggered that separation. When I spoke to Barbara, she had not heard whether this was the consequence, but I could tell she was deeply troubled.

In Section 6.2.1, carer support worker Paula described how hospital discharge managers relied on family members to assume responsibility for medically recovered but otherwise frail patients, and in Section 6.1.4, both Paula and Liz described the realities of 'responsibilised commoditisation' – the transfer of the cost and duty of care for those in need of social care from state to unpaid family carers. The allocation of the 'carer' identity, whether willingly accepted or imposed without consent, can be a source of moral dilemma and moral distress. Often, the role of unpaid family carer occurs through accident of kinship and/or proximity. To refuse or resist the role is a morally complex process which firstly requires one to identify one's actual or potential caring role, then to navigate the emotional labour and practical landscape of asserting one's own needs against those of a vulnerable person for whom it is assumed one holds unconditional positive regard. This assumption of an untroubled and emotionally beneficial relationship is reinforced by the ubiquitous use of the term 'loved ones' in health and care interactions concerning relatives who give and receive practical care.

Care home training manager Alex's moral dilemma was even more complex: her need to foreground her professional carer identity meant she had to stop visiting her grandmother for whom she performed essential personal care – yet she used self-critical language when she spoke of the double-bind in which she and her colleagues were caught: she said it was 'selfish' to have fears for the safety of one's own family as well as the people in one's professional care:

> *'I look after my grandma and I go and give her a shower maybe once or twice a week, sometimes maybe even three. It was when it hit really bad at the homes [prior to the imposition of 'stay at home' rules] when I thought: "Well, hang on a minute, I'm going to have to stop going to see my grandma here, I'm going to have to*

> *literally tell her I can't come and assist her"'* [14/37-01/09/20] *[...] I was frightened for my own family, which I found really selfish. I think a lot of people were'* [14/67-01/09/20]

When we spoke again in 2022, Alex's grandmother had died three weeks' previously. She described the trauma, tension, and conflict of the high-stakes moral dilemma suffered by her family who had promised to be at her hospital bedside, and the staff who were under instruction to prevent this from happening. She described how she used her knowledge and experience of distancing regulations to challenge staff, and highlighted the potential inequities which could occur due to that privilege:

> *'...it was in a hospital setting and that was a really awful scenario, some of the red tape that still exists'* [14/90X-03/05/22] *[...] 'you've got to know your systems, you've got to be able to play your cards. If you if you don't know those things, you're going to be left with your loved one having an awful death'* [14/96X-03/05/22] *[...] 'we had to fight for it. You know, and that shouldn't be the case [...] The frontline staff wanted us to be there, but they kept saying their hands were tied'* [14/107X-03/05/22]

GP practice manager Dave described a moral dilemma which led to decision-making on PPE procurement which ran counter to usual ethical finance and quality control practices:

> *'I think if all my back orders actually get fulfilled, I'll probably bankrupt the surgery, paying extortionate prices for stuff. Simple supply and demand. People put their prices up astronomically in some cases. It was an absolute struggle, daily at one stage, having to just go on websites, hunt around, find what you can get – it's eased a bit now – even to the extent of using Amazon. All the corporate tax responsibilities and moral issues there, I had to set them aside and just think: "Actually, I need this PPE for my staff, so I have to get it off Amazon"'* [13/455-18/09/20]

6.3.4 Potentially morally injurious experiences (PMIEs)

The emotionally charged dilemmas described above are ‘potentially morally injurious experiences’ or PMIEs, first identified by Shay (1992). PMIEs are defined by Litz et al. (2009, p.697) as *‘perpetrating, failing to prevent, or bearing witness to acts that transgress deeply held moral beliefs and expectations’* and by Shay (2014, p.183) as *‘a betrayal of what’s right, by someone who holds legitimate authority, in a high-stakes situation’.*

People who experience PMIEs can be their perpetrator or their victim. Perpetration can be identified in Dave paying *‘extortionate’* prices on Amazon to secure PPE for his staff, potentially making the medical practice *‘bankrupt’*; Barbara making a phone call exposing her son to potential confinement by hospital staff; Alex choosing the people in her professional care over her grandmother – but each suffers the pain and trauma of being forced to transgress moral boundaries. When bearing witness to a transgression has the effect of a moral assault, it places the witness in the role of victim. An example of this was described by autistic self-advocate Lucy. Her nurse betrayed her moral determination to abide by mask-wearing rules despite her extreme discomfort:

> *‘I went to the hospital to get blood tests [...] I realise I’m wearing [my mask] for other people. I find it really hard to wear it [...] I start to breathe heavily. I get really anxious, I feel sick [...] I had to wear it that in really warm hospital. I was already anxious about people, I was already anxious about having a blood test [...] and when I went in the nurse who did my blood test was not wearing a mask. And I was like: “Why?”’* [02/223-02/09/20]

The diversity of perspectives gleaned from interviewing a range of participants allowed me to consider a PMIE incident from the perspective of both victim and perpetrator. Parkinson’s UK volunteer Laura described how the ban on in-person visits had prevented a friend’s husband from being given an official dementia diagnosis, thus barring him from receiving the necessary related medical and social care intervention:

> *'…her partner's sort of been semi-diagnosed with dementia […] he's been diagnosed over the screen, but the problem is that they won't do anything until they actually see him in person. They won't give them any medication'* [29/255-21/10/20]

Veronica was a health professional who had been on the other end of video calls just like that described by Laura's friend, and her communication distress was described in Section 4.8.2. To Veronica, such a delay could be considered a 'harm done':

> *'…new referrals coming are much more impaired than they would have been prior to lockdown. […] I want to get out to see somebody in the early stages so that we can get treatment interventions in to slow this down'* [18/355-24/09/20] *[…] 'if you've got dementia, you can't get that time back. I mean, time is limited for these people to begin with […] Talking to members of staff, I think this kept coming up in supervision, this need to go out and see these people. I think staff are so frustrated. And I think we were all willing to take the risk […] as long as we were in full PPE. We had the equipment, but we weren't allowed to'* [18/182-24/09/20]

Carer support workers Paula and Liz described how their clients had been morally betrayed by the country's highest authority. Litz et al. (2009) consider PMIEs to include learning about an inhumane, cruel, or immoral act after the event. Hearing about the flagrant breach of distancing by Prime Minister Boris Johnson's special adviser Dominic Cummings (described in Section 2.10) was a deeply morally injurious event for family carers, as identified by Shale (2020): Johnson's description of this transgression as responsible and appropriate care behaviour suddenly reframed law-abiding family carers as perpetrators of a morally injurious betrayal. He was effectively telling them that they had unnecessarily abandoned their loved ones. I interviewed carer support workers Paula and Liz on September 14 2020, the day people in England were once again legally prohibited from meeting more than six people socially. They described how their clients demonstrated the

'Cummings effect' (Fancourt, Steptoe, & Wright, 2020, p.12): behaviours and emotions indicating a disintegration of trust in the rules and the people who imposed them.

> Paula: *'I had a call from a family where the son, just before lockdown, had come up from London to be with his parents. And so he, like yourself, moved back in with his parents [...]. Anyway, he went down with the virus. And he couldn't get anything. It was a real crisis trying to get something in place for mum and dad, because he [hadn't been] going anywhere. His daughter was down in London, she couldn't come up either because of the distance, and so we had a lot of carers that were unwell. And then that left the person they were caring for in a vulnerable position'*
>
> Andrea: *Of course, you weren't supposed to travel then, were you?*
>
> Paula: *'No, unless your name was Cummings'*
>
> Liz: *'All right, Paula, all right, all right!' [Laughter]*
>
> Paula: *[Laughter]*
>
> Andrea: *That was a turning point for people, do you think?*
>
> Liz: *'Oh, I think so. Yeah, I think for some people I think it was. Yeah, definitely'*
>
> Paula: *'Because they were saying, "We haven't been to see our parents, and they need us. But he can do it. So bugger it"'*
>
> Liz: *'I think as well, I think we've got a little bit of a militant attitude going on at the moment because of this 'group of six' thing now, you know, and families are feeling that they've looked after themselves and because of the idiots that are out there, you know, they're being penalised for it'* [09/355-14/09/20]

Litz et al. (2009, p.697) also consider PMIEs to include *'bearing witness to the aftermath of violence and human carnage'*. Care home training manager Alex witnessed an intensive loss of life in her workplace in the time between the staff expressing their wish to wear PPE and the adoption of it in the home in accordance with government PPE and distancing measures. Alex described how the experience transgressed her deepest moral values, and how the memory of it caused her to *'freeze'*:

> *'I work across five care facilities and was hit particularly hard in the beginning. Before the restrictions around PPE we must have lost 13 or 14 – one day, I saw about seven people out of the building. In a day. It was awful'* [14/44-21/09/20] *[...] 'I was involved in quite a few of the deaths. Which reflecting on, if I sit and think about it, can be quite emotional. But at the time, or if I'm talking to somebody about it, I'm just quite: "Yes, this is what happened", and fine. But if someone asks me questions about it, I kind of freeze, and I'm thinking: "Well, how should I be reacting to that?" Because it was awful'* [14/73-21/09/20] *[...] 'all of my focus, and goals, and my history, and my past, is all about making sure that people are comfortable at the end of their life. And I'm seeing people now dying in the most horrendous way. And you think: "How can this be happening?" It's like you're in some sort of horrible film. Yeah, it was pretty crap'* [14/79-21/09/20]

Dave, the GP practice manager who was also a church deacon, was visibly upset by the memory of how, while seriously ill himself, he prayed as he watched a fellow Covid patient die in the next bed:

> *'I said: "Is he actually dying?" And she went: "Well, yeah, he is, actually". Because his wife and son had come in, which I knew they weren't allowing on a Covid ward unless... you know. So I said: "Okay", and then they pulled the curtains round and all that kind of stuff. And I just said to her, I said: "Look, I'm a deacon" and I explained briefly what it was, and I said: "I can't do anything, but all I can do is just, sort of, offer some prayers across the ward". So I just remember that afternoon, as I'm drifting away myself, and on cloud cuckoo land myself, just praying for this*

> *guy opposite, and for his wife and for his son, and the rest of the family. And that was a really odd afternoon. I mean, I've been present when somebody has actually died before, a family member, but this was a completely, completely different sort of death. It was rather uncomfortable'* [13/182X-04/04/22]

As I listened to my interlocutors, observed their distress, and felt their pain, I realised that they had suffered moral injury. This is a concept which has two contrasting models.

6.3.5 Moral injury

In the Prescriptive Cognition model of moral injury, posited by Farnsworth, Drescher, Evans, and Walser (2017, p.392) the moral injury is the not the damage associated with the triggering event, or even from the moral pain which ensues. Farnsworth and colleagues consider moral injury occurs only when the PMIE is accompanied by two other factors: firstly, the sufferer adopts inaccurate moral emotions which condemn themselves and/or others, then they attempt *'costly or unworkable attempts to manage, control, or cope with the experience of moral pain'*. The moral injury is the manifestation of '*maladaptive behaviours [...] such as self-handicapping, substance use, behavioural avoidance, and social isolation [...] '[which] may affect the number and quality of an individual's relationships and their ability to find meaning in activities of community living (e.g., work, school, religious traditions).*

Finding meaning from his religious activities was, indeed, problematic for church deacon and GP practice manager Dave. He described in detail his changed relationship with his faith, his work, and the world in general in the aftermath of the PMIEs he had experienced over the previous year:

> *'Reflecting back, I've really struggled, you know, in the aftermath. People say I'm different, that I have changed. And I agree with that, I have. My wife, my kids, my work colleagues, they all say I'm different. I have never been a person to suffer fools*

> *gladly. I don't even suffer them at all now! There's another member of staff in here who had a similar sort of experience, she was really poorly early on as well. And we were talking about it. There's a newfound appreciation of time. You know, our life is so short here. And time is so precious. I've got no time for time-wasters now. And maybe I will change again, and soften up as time passes and memories fade and such like, but it's still quite raw. So yeah, I look at the world differently. As a person of faith, and an ordained person, it's made me question a few things, and – Oh! Is my faith weaker or stronger? I'm not quite sure at the minute'* [13/227X-04/04/22] *[…] 'I think I'm still processing everything, I am not out of the tunnel yet. I wouldn't say I've experienced depression, but probably not far off it. Whether it's church, work, faith, whatever – that sense of being lost. It's quite liberating, in one sense. I view the church with different eyes, I see my faith differently. I view work differently. Maybe the scales have fallen – my idealism and my naivety, in terms of scales – have fallen from my eyes a little bit, maybe. Maybe I'm just a bit more jaded and cynical, possibly. But I look at things differently. And I want things to be different.* ***I*** *want to be different'* [13/663X-04/04/22]

Nash (2019, p.469) points out that the cognition model can only apply to humans with the mental capacity to accurately appraise the challenges they face. Consequently, this model fails in the face of PMIEs experienced by people with limited cognitive capacity – a cohort most likely to engage in healthcare interactions. The Stress Injury Model of moral injury offers an alternative explanation which is more compatible with the biocultural experience.

General Adaptation Syndrome (GAS), explored in Section 2.3, is central to the Stress Injury Model of moral injury. According to this model, the cascade of hormones and neurotransmitters provoked by a PMIE inflict *'a literal wound to the mind, brain, body, and spirit'* (Nash, 2019, p.468), but whilst the body's homeostatic rebalancing response is functioning correctly, the strain is reversible and within the bounds of normal life stressors.

However, when distress or alterations in functioning persist despite adequate rest, *'irreversible (but possibly repairable)'* moral injury has occurred. One can see how the body-mind response to a PMIE can traverse through the three phases of GAS, through alarm and adaptation to the exhaustion stage, especially if exposure is extreme and/or if repeated exposure results in sensitisation rather than habituation, as described in Section 2.2.

Though acute moral distress decreases after the situation passes, some painful feelings can linger. Epstein & Hamric (2009, p.3) call this *'moral residue',* which serves as a new, more sensitised, base line for the next episode of moral distress. In a theory which they call the *'crescendo effect'*, they describe how, over time, as repeated crescendos of moral distress are experienced, the baseline of the moral residue itself increases to its own crescendo, making the sufferer sensitised to any future episode. The exquisitely biocultural experiences of being with PPE and forced avoidance of touch, and the prolonged period under which the objects and behaviours were salient, makes the Stress Injury model a particularly relevant way to interpret my participants' moral injuries.

The physical and emotional pathologies of GAS, including forgetfulness, emotional lability (e.g., tearfulness, anger), and physical fatigue, were reported by many participants regardless of whether they explicitly described being morally injured by their experiences. This lack of cognitive awareness of their moral violation would disqualify their pain as being moral injury according to Litz et al. (2009, p.700), who states that for moral injury to have occurred, the person's reaction to their exposure to PMIEs must be far enough along the scale for the individual to '*be (or become) aware of the discrepancy between his or her morals and the experience'*. However, Shay (2011) states that it is enough only to experience a potentially morally injurious event for a moral injury to be imprinted upon the body-mind. In his assertion, Shay (2011, p.186) reiterates his definition of a PMIE – *'a betrayal of what's right, by someone who holds legitimate authority in a high-stakes situation'* – and continues:

> *'When all three are present, moral injury is present and the body codes it in much the same way it codes physical attack'* (p.183) *[…] '"The body keeps the score," as traumatologist Bessel van der Kolk (2014) has so resonantly said. The body codes moral injury as physical attack and reacts with the same massive mobilization […] your heart rate and guts will respond. We are just one critter: brain/body, mind, social actor, and culture inhabitant at every instant. None of these has ontological priority'*

In Section 2.3, when I introduced GAS, I considered the biocultural explanation of the factors which can both cause and heal trauma (van der Kolk, 2014, p.38). A key factor identified by van der Kolk which connected the physiological to the cultural was the critical contribution of relationships and community to a person's wellbeing. The participants' testimonies have given an insight into how PPE and distancing created barriers in their relationships with families, peers, and communities, and how their self-motivated community-based disaster response had a healing effect, such as that experienced by Dave (Section 5.4.2). The power of language and communication was also identified by van der Kolk as factor which could wound or heal. My research has focussed on the effects of PPE and distancing on communication, and in so doing has revealed that communication *about* these artefacts and behaviours is as influential to interpersonal relations as their occluding presence. Communication in all its forms provoked strong negative emotional responses – which are essentially the neuroendocrine cascades which contribute to GAS. I now consider the consequences of the effects of GAS and moral injury on the lives of the participants, and the subsequent implications.

6.4 CONSEQUENCES OF MORAL INJURY

The combination of Shay's visceral 'scorecard' interpretation of moral injury, Epstein & Hamric's crescendo effect, and van der Kolk's biocultural contributors to trauma has profound implications for both this study's participants and the wider population, especially when one acknowledges that the events experienced during this time qualify as a disaster. The diverse backgrounds and experiences of this study's participants are united by key factors which were replicated throughout the country's population: over many months, they experienced frequent adverse body-mind sensations from the presence of PPE and distancing, and all the while these experiences were overlaid by structural violence and normlessness. The consequences of the resultant moral injury were evident in the participants' testimonies in 2020, and even more so in 2022.

6.4.1 Exhaustion

The universal despair of exhaustion was described by GP practice manager Dave:

> *'…two years down the line, we're all bone-weary with it all and we want the world to get back to normal. I don't think it ever will, in one sense'* [13/338X-04/04/22]

The emotional toll of isolation, both in personal life and in conducting advocacy work remotely, was articulated by Des, the co-ordinator of the self-advocacy group for people with learning disabilities and autism:

> *'There's not one person in this [virtual] room […] that hasn't been in tears over the last few weeks'* [01/405-02/09/20]

Exhaustion was commonly identified theme by respondents who had been exposed to PMIEs, even when their testimony did not indicate that they had consciously identified a specific event which they would consider injurious. Veronica's mental health deteriorated because she felt isolated from her personal family life, guilty for compromising her professional practice to accommodate remote methods, and angry at being expected to do so. Veronica described an incident where her moral injury from attempting and failing to carry out dementia assessments online (described in Section 6.3.4) manifested itself in an emotional crisis:

> *'I hate to admit this but, do you know, I'm getting really teary all the time. I feel really teary. And it was a bit of a shock to myself because I'm not like that. Normally I deal with things really well, so it was actually quite a surprise to me that I felt I was struggling'* [18/423-24/09/20] *[...] I actually took two weeks off, because I've just needed to shut down'* [18/169-24/09/20] *[...] 'I've been trying to support a couple of colleagues [...] but actually I was struggling as well – not seeing my grandchildren amongst the most other things – and then I just got to the point where I thought: "I don't think I can cope now, I need to go off". So I did'* [18/431-24/09/20] *[...] 'I felt mentally exhausted. But angry. I felt angry that I wanted to do things, and what they were asking us to do – I didn't feel it was working. And I felt as if I kept shouting: "Look, OT is about face-to-face. That's what I do, I observe behaviour! How can I do that over the phone?" And I felt like they were making me do things that I was totally against. And then I'm doing it, and then I'm going into supervision [...]and go: "Look, I'm sorry. I did it. It was absolute rubbish. I felt Joe Bloggs off the street could have done a better job than I did there. I felt as if I did absolute rubbish, and I feel terrible"'* [18/437-24/09/20] *[...] "That was the day that I actually got to breaking point myself. It was in the OT Teams meeting'* [18/454-24/09/20] *[...] 'after the OT Teams meeting, [my clinical manager] messaged me and I answered her: "I can't talk to you!" And that's when I think the tears started to flow. And I knocked her off. [...] I really felt like throwing the towel in. And I think I can remember I went home that day and I cried all the way home. [...] I absolutely sobbed. I pulled on my drive, and I sat for 20 minutes on the drive trying to control myself before I dared to walk in the house. I thought:*

> *"That's wrong. That is really, really wrong". Because I think I was in brain overload. Yeah, it was just too much. My brain couldn't take anymore. […] I felt guilty. I felt they were paying me and I wasn't doing my job'* [18/492-24/09/20]

In 2022, Paula described the 'burnout' of a bereavement worker with whom she had worked closely:

> *'Amanda was on complete burnout by the time of the end of the two years, because I remember asking her about Christmas, and she'd spent all day Christmas Day in the bath in her flat on her own'* [09/464X-12/04/22]

Once participants reached this level of despair, they had to find a way out.

6.4.2 Moral repair

Veronica's admission of her mental health difficulties prompted her dementia specialist OT colleagues to open up to each other about their own struggles. Veronica said:

> *'And then […] a couple of others have said: "I had a meltdown". So it was only because I'd opened up about it […] that others started to talk about it'* [18/427-24/09/20] *[…] '[a colleague] said: "The patient rang me up and said to me: 'I feel worse now than I did before'. And that's just not acceptable"'* [18/448-24/09/20]

Veronica was comforted when her managers and peers were open about their own struggles with moral distress:

> *'I can't praise them [clinical lead and team manager] enough for being as supportive as they were. My clinical lead, I know how supportive she is. The team manager, I didn't know so much, but I did find I was in tears in supervision with him, and I thought: "Oh!" But I got a shock, actually, at how supportive he was […] I'll always remember, he actually said to me: "Don't think I haven't been the same". […] 'You know, I really needed to hear that'* [18/699-24/09/20].

Veronica’s road to recovery can be seen in the recommendations of Greenberg & Tracy (2020), who advocate a preventive approach to supporting staff at risk of occupational moral injury, by reinforcing social bonds between colleagues and supervisors, meeting basic staff needs, being alert to early signs of distress and avoiding the ‘medicalisation’ of reactions to traumatic experiences. Veronica felt the support of her peers and managers and was pleasantly surprised when they shared their own vulnerabilities rather than medicalising hers.

Shale (2020) supports this approach, but goes further by specifying seven acts of acknowledgement as process for moral repair. She describes acknowledgement as *‘a combination of deep listening, altered understanding and mutually agreed reparative action’* (Shale, 2020, p.226). The seven acts are: to acknowledge the injured party as a moral equal, because healing is not possible if they are considered to have less right to define the situation than those in authority; to acknowledge the authority of shared norms; to acknowledge that injury has occurred and listen to the testimony of those affected; to ensure responsibility is acknowledged by the person or institution who caused the harm by contravening the shared norms; to acknowledge that remedy is due, and that the injured party should define what is owed; to acknowledge righteous anger, or other negative feelings, rather than being in a hurry to ‘move on’; and to acknowledge that in injuring another, the perpetrator should experience sorrow and regret. This process is focussed on the reestablishment of a sense of moral equilibrium within individuals and between people, restoring trust, confidence, and hope. In the government’s post-pandemic policies, these acts have been conspicuous by their absence.

While Veronica’s story contained hope of moral repair, she and other participants were more prepared to remove themselves from their morally injurious environments in an act of self-compassion.

6.4.3 Self-compassionate disconnection

Farnsworth et al. (2017) consider moral pain to be a potentially beneficial phenomenon which '*creates an opportunity at the moment of awareness to take actions that are values consistent'* (2017, p.392). Some participants who worked in healthcare, and had the autonomy to do so, used this moment of awareness to make career moves away from the roles in which their experience of PPE and distancing had caused them distress. Of the nine participants re-interviewed in 2022, four had radically changed their professional role: GP Deborah had left her practice to lead a Long Covid clinic and a private life-coaching practice; Alex had moved jobs twice and was the manager of a small family-run care home; Natalie had moved from ITU to a bariatric outpatient clinic; Maggie had retired and had temporarily returned part-time to an eating disorders team while completing a qualification to set up in private practice which worked around her responsibilities as a family carer. Veronica stayed in her role, but expressed self-compassion by giving herself permission to step back from her job before reaching those levels of injury again:

> *'I've learned that I don't cope as well as I thought I did. But I won't be as frightened, either, to speak up if I'm starting to feel that way. I think I would recognise now, more, when I've had enough and I need to maybe take a step back. […] I would do something about it before it got to the point where I was absolutely in floods of tears. I couldn't do that again, I cannot go back there, because that was terrible. And I wouldn't, I wouldn't'* [18/681-24/09/20]

There were adverse consequences from self-compassionate disconnection in the paid health and social care workforce. Carer support worker Paula, whose colleague Liz (interviewed in 2020) had left the charity for a job with more secure prospects, described a crisis in services:

> *'…care homes […] haven't got the staff that they had pre-Covid times, because probably people have decided to do something else, or whatever'*
> [09/246X-12/04/22]

Advanced nurse specialist Louise concurred:

> *'…care homes haven't got a staff, they've got empty beds […] their staff are fed up with it, they can go and work down the road for a lot more money doing something not as emotionally draining'* [34/998-31/03/22]

One in nine NHS nurses in England left active service in the year to June 2022 (40,365 nurses), and on 15 December 2022 those remaining in the profession took action in an attempt to create a more self-compassionate working environment when RCN members went on strike for the first time in UK history over pay and conditions. Louise explained how self-compassionate disconnection was the main reason for the attrition of staff:

> *'…the second wave was horrendous, and that wore everyone out, and then the other waves. But now, it's like: "Oh, gosh, we just really can't do it again". We've got all the pressures, the NHS is expected to do all the catch-ups for elective everything. They're all falling on their knees'* [34/347X-31/03/22] *[…] '…we are losing a lot of nurses and healthcare professionals who are coming up to retirement and just think: "I just can't cope with it any more. There's no end to it. I've done my bit. I've stayed and worked through". And these aren't old people, you know? Anyone 55-ish onwards. And they're also quite anxious about what's the next thing around the corner'* [34/560X-31/03/22]

When health professionals suffering moral injury coped through self-compassionate disconnection, the cumulative effect added pressure on already-weakened care systems. Time passed, and Covid became an endemic disease no longer requiring PPE and distancing. But, instead of respite, repair, and recovery, the participants reported that their experience of care was worse than it had ever been.

6.4.4 Compromised health and care systems

When I re-interviewed participants in 2022, the protective mechanisms of ‘active forgetting’ were taking hold in the general population with the lifting of distancing and public face-covering restrictions on 24 February 2022, and the end of health and care PPE requirements on 1 April. However, some health and care services had still not been restored and some participants’ symptoms of moral injury were reaching a crescendo, with some using metaphors of visceral pain and collapse to describe their colleagues’ and their own mental despair and exhaustion. This is illustrated by comparing GP practice manager Dave’s comments from 2020 and 2022. In 2020, between the first and second lockdowns, Dave described how pre-existing unaddressed systemic deficiencies and unfairness exacerbated the exhaustion of primary care staff:

> *‘There’s definitely a feeling within general practice, up and down the country, that we are certainly playing second fiddle to the foundation hospital trusts. We’ve always known that and it always has been, but I think this has just really brought it to the fore. That shift from secondary to primary care and dumping work on us. I think there’s an increasing apathy amongst general practice that actually, you know, we can’t take much more’* [13/491-18/09/20] *[...] ‘The doctors are on their knees – all the staff are – but the doctors and nurses are at the core of the business. I worry about the coming winter because I think that they’re worn out already’* [13/276-18/09/20]

But rather than experiencing recovery, on 4 April 2022 Dave described further deterioration:

> *‘...we’re bone-weary now’* [13/97X-04/04/22] *[...] ‘staff are saying, that, actually, this last month or so was probably the more stressful period in the past two plus years, and the most stressful period that some have ever experienced’* [13/106X-04/04/22]

Similarly in 2022, Maggie described despair in her Eating Disorders Team, exacerbated by a failure to tackle morale through improved pay and conditions:

> *'…nothing's got any better in the NHS. It's got worse, in fact. We have half teams, we have triple referral rates since Covid. And the teams are on their knees. There were no rewards for the NHS at all. And the staff are on their knees, and they're just falling – they're buckling like flies. We have no staff'* [12/42X-08/04/22] *[…] 'because people are overworked and undervalued, and they've given their all – honestly, the NHS staff have given everything that they could – and now they're all burnt out. The staff can't do anymore. They're burnt out, and they're going off sick. […] And a backlog from before Covid. The NHS was already struggling for staff before Covid. The money is there for staff but we can't recruit. And that's right across the board, we can't recruit. I mean, who would want to come and do this?'* [12/99X-08/04/22]

Louise described how the ongoing emergency caused by a lack of health and care provision, with waits of an hour for an ambulance to attend a heart attack or stroke [34/336X-31/03/22] which then decanted patients into '*tents, and sheds, and portacabins and things outside their main A&E entrance'* [34/351X-31/03/22]:

> *'The hospitals are full of patients that need to be in nursing homes. All the patients that need to be in the hospital are outside in the car park, either in an ambulance, in a tent, or in a shed, waiting to get in the hospital'* [34/995-31/03/22]

Autonomy to practise self-compassionate disconnection was dependent on financial security and a moral reconciliation with detaching from care responsibilities. The former was less of a dilemma for many health and social care workers: as explained by Louise, experienced staff were more likely to be able to access their pensions [34/560X-31/03/22], while the government's refusal to address pay and conditions meant that jobs in retail and other non-care industries would pay a similar wage for less responsibility and moral distress [34/998X-31/03/22].

While these conditions persisted in the UK, a life as a care professional abroad looked ever more attractive: 4,843 doctors left the UK to work abroad between May 2021 and May 2022 (GMC, 2022). While the UK government failed to acknowledge the moral injury suffered by its health workers, other governments were not afraid to use their awareness of this oversight to attract workers to their shores by explicitly referencing the effects of moral injury in their recruitment campaigns, as seen in this poster advertising careers in British Columbia, Canada (Figure 17).

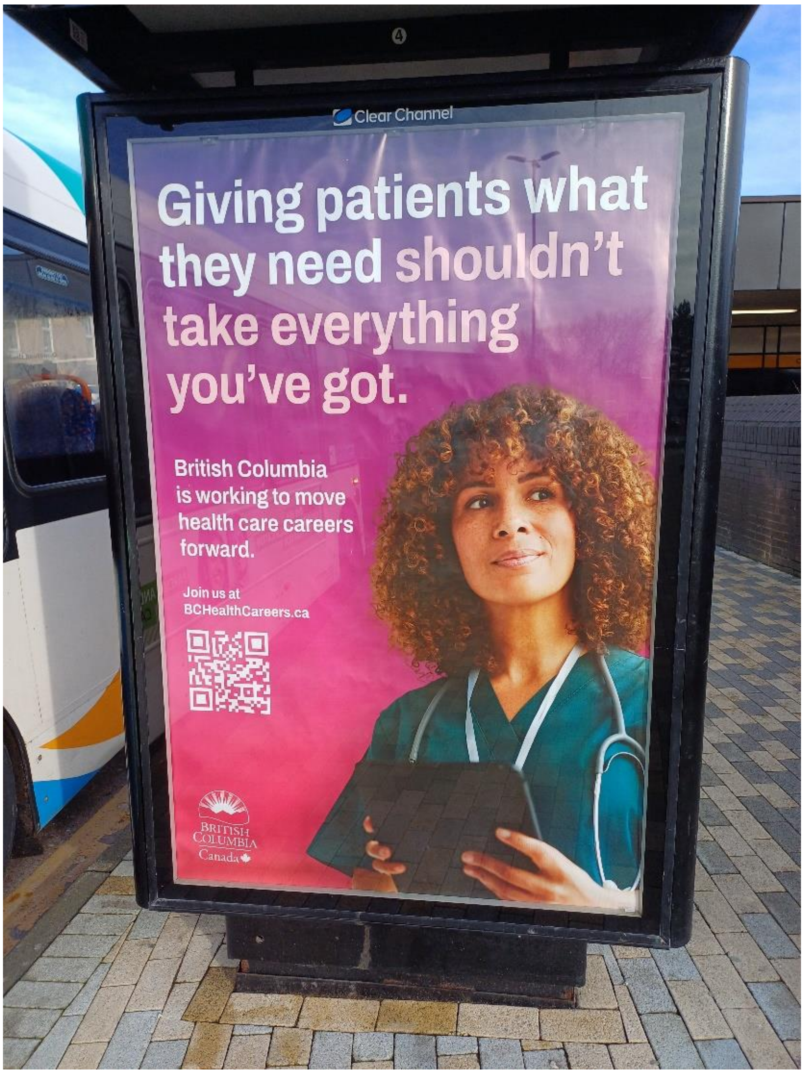

FIGURE 17: An advert for health care careers in British Columbia, Canada, at a bus stop in South Shields, Tyne and Wear, February 19, 2024 (Lambell, 2024g)

However, detaching from the people who needed you was challenging, both morally and practically. For many family carers, self-compassionate disconnection was impossible: putting an ailing parent in a home was not an option if there were no places, stepping away from the daily routines of toileting, showering, cooking, and cleaning for frail family members could not happen if there were no domiciliary carers to take over. And, as Paula described [09/236X-12/04/22], the insidious and incessant pressure upon family members to assume responsibility continued: more and more people were less and less able to perform paid work as they assumed essential but unpaid care roles. This further depleted the health workforce when those giving up paid care for unpaid were health professionals like Maggie – an essential carer for her parents and her grandchild.

But a combination of active forgetting and the prolonged, gradual nature of the disaster meant the population became inured to '*tents, and sheds, and portacabins and things outside their main A&E entrance'* [34/351X-31/03/22]. They were drawn to new horrors, such as war in Ukraine. Hence Louise's observation:

> '*…all the health and social care, it's not functioning' […] 'The problem is, nothing's gonna get on the news'* [34/210X-31/03/22]

It can be concluded that a disaster was still unfolding from the consequences of moral injury suffered by people who experienced health and social care interactions in a time of PPE and distancing, but the world was dreaming otherwise.

CHAPTER 7:

FROM PANDEMIC TO SYNDEMIC:

A SLOW DISASTER THAT CONTINUES TO UNFOLD

I begin this chapter with a summary of my key findings, then move to an exploration of the implications of my research and the insights it contributes. After a consideration of the strengths and limitations of my work, I conclude with recommendations for action, and ideas for future research.

7.1 KEY FINDINGS

The aims and objectives of this thesis were to identify the barriers and facilitators to health and care communication in the presence of PPE and distancing, to identify the wider determinants affecting these interactions, and to consider the consequences of these experiences and their moderating determinants on the lives of those who participate in health and social care interactions. The process of exploring these objectives has revealed insights which can inform how people could be reconciled with the physical, emotional, and societal effects of their exposure to PPE and distancing. These insights can also contribute to policymaking which would prepare for subsequent circumstances requiring the use of PPE and distancing in health and care interactions.

It was clear from the participants' descriptions of interacting while using and seeing PPE, and being forced to avoid touch and proximity, that theirs was a biocultural experience. They were frustrated and distressed by physiological and psychological sensations provoked by the artefacts, the occlusion of facial and body expression, and the loss of important non-verbal information when using remote methods of communication. Mechanisms of sensitisation and habituation (Thompson & Spencer, 1966) moderated the visceral and psychological perception of the sensory stimuli elicited by exposure to PPE and distancing:

sensitisation fed into the neuroendocrine mechanisms of General Adaptation Syndrome. The centrality of communication to sociocultural wellbeing meant that interlocutors experienced distress when these physical and emotional barriers meant they failed to interact effectively. I have called this condition ‘communication distress’. The discovery that communication could be so traumatic for participants was an unexpected finding which made it important to explore the sociocultural origins of that trauma. By conducting a cluster analysis of the statistical survey data, I deduced that the diverse range of beliefs, experiences, and emotions were not due to identifiable demographic factors other than pre-existing impairments affecting communication (such as hearing loss). This indicated that external influences could sensitise or aid habituation – a finding which guided me in my analysis of the participants’ stories.

The necessity to switch to remote communication methods during the Covid-19 pandemic led to the rapid adoption of technologies for which there had been previous resistance in healthcare settings. Those with pre-existing technical skills and resources adapted better than those without, widening the digital divide (ONS, 2019). While some people preferred the ‘detached intimacy’ of the close-up face on screen, others were morally distressed by their futile attempts at remote clinical interactions. Remote working practices were judged to be preferable for a range of routine meetings and consultations and have been permanently adopted for some circumstances since distancing rules were relaxed. However, practitioners and patients alike were concerned that the focus on efficiency in the face of staff shortages and increased demand would result in a failure to offer a range of communication options appropriate to the task and feared a permanent loss of opportunities to interact in person.

Participants’ experiences of PPE and distancing were profoundly affected by what was said and done by people in power. The lack of clarity and consistency in their directives caused confusion and normlessness. The contradictions between what they claimed to be true about the availability and suitability of PPE, and the reality of the shortages and inappropriateness of those objects, led to a loss of trust. The emotional and physical labour of persevering with occluded interaction was intensified if one or more parties could not trust that the PPE was both effective and necessary.

Vague and contradictory information about PPE and distancing combined with fluid rules which contributed to the construction of sometimes contradictory understandings about the purpose and functions of PPE artefacts and distancing behaviours. Where interlocutors held different understandings, conflict could arise. Distancing rules denied patients their visitors, prevented them from being accompanied by a companion or advocate, and closed some health and care services altogether while concurrently encouraging proximity in hospitality and commerce for economic reasons. This projected a disdain for the givers and receivers of care, which was amplified when the behaviours of leaders contradicted the rules they had imposed. This conflict and normlessness developed into societal anomie (Durkheim 1960 [1897]), contributed to potentially morally injurious events, moral distress, and moral injury (Shay, 1992, 2014; Litz et al., 2009).

Distress could have been reduced if the politicians and officials with the responsibility to do so had ensured the provision of a timely and plentiful supply of good-quality PPE artefacts, a clear rationale for their use, clear information about how to use them, and an environment which gave its wearers time and space to safely remove it and rest. If health and social care practitioners had been trusted to make wise decisions based on their knowledge and experience, distress in health and care interactions could have been reduced. Their situational risk-assessed application of alternative safety measures (e.g., the ‘distanced doff’ or outdoor consultations) could have reduced the harms done through communication distress caused by PPE and distancing, but they feared reprisals for breaking protocol.

The failure of people in positions of authority to mindfully manage PPE and distancing, both in their official roles and in their own personal behaviours, exacerbated pre-existing structural violence in the form of ableism, socioeconomic inequity, the digital divide, and the ‘responsibilised commoditisation’ of unpaid family carers (Higgins & O’Leary, 2023, p.23). Epistemic injustice was also exacerbated, including that caused by the lionisation of healthcare workers via the sonic rhetoric of the ‘Clap for Carers’ (Mackay, 2021), framing them as ‘superhumans’ who had willingly forfeited themselves and were therefore ‘ungrievable’ (Whitham, 2021). This dehumanisation facilitated the subsequent demonisation of the same workers, encouraged by the neoliberal narrative, when health and care workers’ adherence to PPE-wearing and distancing in the face of depleted staff numbers and increased demand coincided with forms of active forgetting (Connerton, 2008) in a societal eagerness to discard bad memories and construct a post-Covid identity.

As the effects of anomie and moral injury became embedded, and their resultant exhaustion and despair became widespread, the need for moral repair (Shale, 2020, p.226) became more urgent. However, the required deep listening, altered understanding and mutually agreed reparative action on the part of those who perpetrated those harms was not forthcoming. In its absence, people in health and care roles practised self-compassionate disconnection as their own attempt at moral repair, leaving their roles or radically adapting them to distance themselves from triggering circumstances. By Spring 2022, the cumulative effect of the consequences of moral injury, attempts at moral repair, and state-supported active forgetting had led to severe and unabated deterioration in the health and care infrastructure. The consequence is that responsibility for care is increasingly being transferred from the state to unpaid carers.

7.2 INTERPRETATIONS

The passage of time between the two phases of data-generation and the period of analysis has allowed me to reflect on my findings with the benefit of a longitudinal perspective. This has helped me to consider the participants' diverse experiences of PPE and distancing in different contexts – in short, I know what happened next. This extra knowledge, and the benefit of hindsight, prompts me to introduce the concept of the syndemic – a lens through which the disaster of Covid and the role of communication distress and moral injury through PPE and distancing takes on new significance.

Singer (1996) coined the term 'syndemic' to describe population-level clustering of social and health problems. According to Singer, Bulled, Ostrach & Mendenhall (2017, p.946), syndemics emerge due to a range of shifting circumstances, including a change in political and economic conditions, social behaviours, rapidly developing technology and/or breakdown of public health protective measures.

I begin by explaining how the concept of a syndemic applies to my participants' experiences, then I reflect on the missed opportunities to tackle communication distress, and conclude by considering the implications for the gradual, and still-unfolding, disaster of Covid and its attendant harms.

7.2.1 Experiences of a syndemic

I found that all the people I interviewed suffered various degrees of damage to their welfare. Some witnessed death first hand, while others grieved for those unseen and unreachable. All experienced the physical and/or mental ill-health of themselves and/or others, and the application of distancing rules and the redirection of resources led to the curtailment and cessation of their health and care infrastructures. But their stories also tell of how Covid collided with non-communicable disease, pre-existing sensory and cognitive differences, and embedded socioeconomic inequities. Their testimony frames Covid, and their experiences of the PPE and distancing that came with it, as part of a syndemic. Calcaterra et al. (2022) and the editor-in-chief of *The Lancet* (Horton, 2020) were amongst the voices who called on Covid to be seen through the anthropological lens of the syndemic. Here I consider how participants' stories meet the conditions of a syndemic (Singer et al., 2017, p.942).

Covid combined with pre-existing health conditions, and those which arose concurrently – not least those associated with experiences of PPE and distancing, which are described in detail throughout this thesis. There was a consequential adverse interaction of factors, including the self-compassionate disconnection practised by health and care professionals attempting moral repair. This increased the health burden of a population struggling to address an ever-growing backlog of demand with fewer resources. This backlog was exacerbated by the lack of an appropriate response by the government: it did not seek to rebuild trust through moral repair by taking the reconciliatory steps described by Shale (2020). Instead, authorities responded to the moral injury inflicted upon health and care professions with gifting which was sometimes was interpreted as a form of insult, and by criticising health workers who took industrial action. This unprecedented and (at the time of writing) ongoing dispute began when the Royal College of Nursing first took strike action in December 2022 and was followed by days of action by paramedics, physiotherapists, radiographers, doctors, consultants, and others, most latterly in February 2024 with four days of action by British Medical Association junior doctors (Garratt, 2024). Despite this action, concerns for the precarity of health and social care became submerged by active forgetting and a rising tide of new horrors and preoccupations: the cost-of-living crisis and wars in Ukraine and the Middle East. The world was dreaming otherwise, but they were nightmares. The strikes slipped out of the news cycle, becoming normalised in the face of an unresponsive government.

A key condition of a syndemic is the interaction of all the contextual and social factors at play which moderate the experiences of the people at its centre. I have highlighted the direct links between the participants' pre-existing socioeconomic and cultural conditions and the depth of distress they experienced. To do this, I contrasted the experiences of physiotherapists from two ends of the country with identical roles whose communities were at opposite ends of the socioeconomic scale.

The breakdown of public health protective measures is another central feature of a syndemic. Many participants – particularly those with sensory impairments and those who understood the lived experience of neurodivergence – drew my attention to pre-existing vulnerabilities in health and care communication and the loss of capacity in the health and social care system prior to the pandemic. However, the cardinal factor in this syndemic – central to this thesis – was the absence of a PPE stockpile. This is the most basic public health protective measure, and its lack led to artefact-sparing, contact-avoiding behaviour change. This persisted even when supplies became more reliable.

Syndemics have political, social, and economic change at their core. The official withdrawal of the UK from the European Union took place on 31 January 2020, the same day as the country's first Covid-19 case was confirmed (Industrial Injuries Advisory Council, 2022). The communications climate, established by influential actors with vested interests whose focus was on politics rather than pandemic preparedness, was confused, weak, and contradictory. In this climate, care workers and the public alike reacted to their exposure to hazard by applying their own diverse interpretations of the precautionary principle: some foregrounded the virus and wanted to wear specific PPE artefacts that were unavailable to them; others foregrounded the visceral and psychological discomforts from wearing and seeing PPE artefacts and the dangers posed by forced avoidance of proximity and touch. Many were conflicted by the two competing threats. The conflict resulting from this diversity, explained through the concept of artefact biographies, was temporally and spatially fluid as scientific, political, and public understandings of the risks fluctuated at different times, in different environments, and within and between different communities.

As part of the temporal unfolding, societal anomie was fuelled by revelations of 'leader exceptionalism' and the hypocrisy of decision-makers flouting the laws they had imposed on their population. This illustrates how a lack of preparedness and irresponsible leadership contributed to the intensity of the distress in England experienced during the period of exposure to the uncertainties and hazards of a novel Coronavirus.

The participants' stories, and my reflections on them, support the claim that they have experienced a syndemic. Their testimony also holds clues about how to cope with the challenges to communication.

7.2.2 Tackling communication distress

Participants with pre-existing additional communication needs adopted and adapted remote technologies in ways which allowed them to fully participate: it seemed as if the presence of PPE and distancing was just another barrier to be overcome using their well-flexed muscles of persistence and co-operation. Their levels of inventiveness and perseverance indicated knowledge that would be of benefit to anyone looking at ways to reduce communication distress, regardless of the presence of absence of sensory or cognitive difference. However, whilst I had identified quality educational resources to support those interacting remotely and/or in PPE (Parry, 2020; Parry, Mannix, & Pattison, 2020; *Performing Medicine*, 2020; Purchon, 2020; Whittaker et al., 2020) one factor notable by its absence was a lack of any descriptions by the participants of a systemic and proactive programme to disseminate training in communication techniques for people interacting in the presence of PPE and/or distancing. The diverse participants discovered their techniques for themselves, and had a wealth of impartable knowledge which could have been shared more systemically. The value of collaboration was illustrated by the self-advocacy group's timely intervention when a health Trust asked for their feedback on images they intended to use for a publicity campaign (Section 4.3.4), but this was an exception. In one case, a health professional whose job it was to train her care home staff described how officials thwarted her efforts to address complex communication issues with cognitively impaired residents (Section 5.4.2).

Predictions of a permanency about the violent disrespect of health staff (Section 6.3.1) seem to have been borne out and, rather than exploring ways to remove barriers to communication, the interventions that were introduced by management were reactive to the aggression that arose when communication failed. In 2023, the Health and Safety Executive reported that violent and aggressive incidents were the third biggest source of injury reports from the health and social care sector (HSE 2023). To combat this, the adoption of body cameras by health staff was becoming widespread. The cameras allow the wearer to record audio and video of healthcare interactions as a deterrent and to gather evidence of assaults. These were new communicative artefacts which spoke of a cultural distancing, feeding into a deepening of anomie, and a study warned that the ethical and practical considerations of bodycams could *'create even greater distance between patients and staff'* (Foye et al., 2024, p.10). The RCN's position paper on bodycams (RCN, 2023), while supporting their use where justified, warned that the nursing workforce had emotive, conflicted, and diverse views on the devices and their potential adverse effects on ethics and trust.

The unaddressed consequences of PPE and distancing on communication, the ramifications for the future of health and social care, and the framing of these experiences as aspects of a syndemic, presents a new perspective when considering events through the lens of a disaster.

7.2.3 Experiences of an unacknowledged slow disaster

The experiences described to me unequivocally fit the United Nations definition of a disaster, as I first stated in Section 5.4.2:

> *'A serious disruption of the functioning of a community or a society at any scale due to hazardous events interacting with conditions of exposure, vulnerability, and capacity'* (UNDRR, n.d.)

I am dismayed by the length of time it took for me to perceive that what the participants were describing was, definitively, a ‘disaster’. But perhaps this is an illustration of how power was applied through the language used by those who wielded it – including the words that were deliberately *avoided*. This disaster is particularly dangerous because it is deliberately unacknowledged by the government – i.e., the people in charge of disaster management.

Lucy Easthope, a member of the Cabinet Office National Risk Assessment Behavioural Science Expert Group, was explicitly told not to use the word ‘disaster’ by the government figures she advised. Easthope’s experience of her limited, and limiting, interactions with government officials illustrate how the spectrum of people who became unlikely victims of epistemic injustice (as discussed in Section 6.2.4) even extended to the government’s own experts. Easthope wrote:

> *‘The requests for help I received from government [during the pandemic] were sporadic and disconnected. […] The most frequent refrain was “this will be over soon” and silence when I posited gently that this would take much longer than that. I was also asked not to use the word “disaster” because this wasn’t one […] I was concerned about the way it would dissolve the glue of society’s fabric […] the damage to the National Health Service…’* (Easthope, 2022, pp.262-263)

Easthope’s fears for the *‘glue of society’s fabric’* reflects the academic consensus on the defining feature of disasters. In a review of the academic body of work on the concept, Perry (2017, p.17) concluded:

> *‘…most researchers currently view social disruption as the key defining feature or essential dimension’* (Perry, 2017, p.17)

However, the UK’s Civil Contingencies Act 2004 does not refer to ‘disaster’. Instead, it uses the term ‘emergency’, the definition of which includes:

> *'an event or situation which threatens serious damage to human welfare in a place in the United Kingdom […] only if it involves, causes or may cause […] 'loss of human life, human illness or injury, homelessness, damage to property, disruption of a supply of money, food, water, energy or fuel, disruption of a system of communication, disruption of facilities for transport, or disruption of services relating to health'*
>
> (Civil Contingencies Act 2004, Section 1)

According to the UNDRR, an 'emergency' *'can also relate to hazardous events that do not result in the serious disruption of the functioning of a community or society'*. What makes a disaster is its disruptive effect on people's lives. Using these definitions – and bearing in mind that the terms 'disaster' and 'emergency' are often used interchangeably (UNDRR, n.d.) – this thesis offers the evidence to conclude that a disaster has occurred and was still ongoing during, and after, the second round of interviews in 2022. It reinforces a pre-existing body of evidence that supports the argument that disaster is inherently anthropogenic, even when apparently arising from naturally occurring phenomena, and that it is non-linear, i.e., is cyclical and messy rather than contained within an identifiable beginning, middle, and end. This is illustrated by the crescendo of distress described by the participants in 2022, the events thereafter, and the mechanisms of syndemics which brought their seemingly unconnected circumstances together to create a storm.

Yamori & Goltz (2021) describe the Covid pandemic as a gradual onset disaster. This differentiation from the more identifiable rapid-onset disaster, such as a hurricane or earthquake, is characterised by the *'very diffused events'* (Quarantelli, 2005, p.335) which are features of a pandemic or climate change. Key features of a slow disaster are its gradual and unacknowledged nature, and its traumatising effect on how we communicate with each other. In his seminal work on the nature of disaster, Erikson (1994) defined collective trauma as:

> *'…a blow to the basic tissues of social life that damages the bonds attaching people together and impairs the prevailing sense of communality. The collective trauma works its way slowly and even insidiously into the awareness of those who suffer from it, so it does not have the quality of suddenness normally associated with 'trauma'. But it is a form of shock all the same, a gradual realization that the community no longer exists as an effective source of support and that an important part of the self has disappeared'* (Erikson, 1994, p.235)

The loss of informal sources of support was officially mandated through forced avoidance of proximity: births, deaths, and funerals were solitary and traumatic (Section 4.4.5), advocacy was denied (Section 6.1.2) and the supportive bonds between health and care professionals fell apart (Section 4.7.3). Unpaid carers could no longer call upon friends and neighbours when they left to cope alone as services evaporated due to 'institutional distancing' (Section 6.1.4). The separation became more, not less, entrenched over time (Section 6.4.4) and people's identities were profoundly – yet insidiously – changed as it took away their capacity to continue in the workplace or foreground their place as wife, husband, son, or daughter (Section 6.2.1). Erikson describes trauma in terms which reflect the concepts of sensitisation (discussed in Section 4.1.4), anomie and moral injury (Section 6.3), and self-compassionate disconnection (Section 6.4.3):

> *'The classical feelings of trauma range from feelings of restlessness and agitation at one end of the emotional scale to feelings of numbness and bleakness at the other. Traumatised people often scan the surrounding world anxiously for signs of danger, breaking into explosive rages and reacting with a start to ordinary sights and sounds, but at the same time all that nervous activity takes place against a numbed gray background of depression, feelings of helplessness, and a general closing off of the spirit as the mind tries to insulate itself from further harm'*
>
> (Erikson, 1994, p.228)

The low salience, or even an outright lack of recognition, of the Covid pandemic and its consequences as a gradual-onset disaster lies in the persistence of the concept of a disaster as a rapid-onset event. Yet Erikson's description of the gradual onset of the effects of a disaster illustrates how 'slow' does not mean 'mild': the shocks caused by slow disasters hit hard and without warning. This apparent contradiction also lurks in rapid-onset disasters such as hurricanes, where the roots of a catastrophic few minutes can be traced back to decades of climate change and societal unpreparedness.

Hsu (2017) supports Erikson by arguing that the temporal typology of disasters should be expanded to include everyday structural occurrences, and to frame disasters as *processes* rather than discrete events with an identifiable beginning, middle, and end. In their exploration of the effects of the Covid pandemic on militant violence, Pape & Price (2024) place slow disasters at a distinct position on a temporal spectrum, with acute onset events at one extreme and generational catastrophes (such as climate change) on the other. Acute onset disasters have front-loaded costs, obvious in the first days and weeks; the costs of slow disasters start low and mount incrementally at an uncertain rate over months or years; generational disasters have recurring rapid onset events repeated at changing rates over decades. The defining feature of a slow disaster, according to Pape & Price, is bounded uncertainty: its enormity is unknown due to a lack of awareness across a range of factors such as the lethality of the shock and the political, social, and economic capacity for meaningful mitigation. This means that the aetiology of disaster is complex: This thesis provides some insight into those factors, most notably the decimated capacity of the health and social care system, the damage done to the people who interact within it, and the loss of trust caused by the deliberate refusal by government to acknowledge the situation as a disaster.

My observations about the pernicious harms arising from the ever-evolving cumulative effect of PPE and distancing on health and care communication – caused by factors both intrinsic (Section 4) and extrinsic (Section 5) – align with Erikson's assertion that the breadth and depth of traumatic experience can be more complex than the 'short, sharp shock' of a discrete event:

> *'it makes sense to insist that trauma can issue from a sustained exposure in battle as well as from a moment of numbing shock, from a continuing pattern of abuse as well as from a single searing assault, from a period of severe attenuation and erosion as well as from a sudden flash of fear'* (Erikson, 1994, p.230)

The continuing and open-ended unfolding of traumatic events and experiences described in Section 6.4 is a key characteristic of disaster identified by scholars of the phenomenon. Five years after Hurricane Katrina, '*the storm is not over'* was a phrase used by both Erikson (2010, p.xviii) and Bevc, Nicholls, & Picou (2010, p.156) in a comprehensive study of its aftermath. The continuing storm has its roots in historical acts of structural violence and epistemic injustice, such as those described in Section 6.1 and 6.2. These pre-existing concepts are incorporated into the understanding of individual and collective trauma. Erikson places trauma in the context of pre-existing circumstances:

> *'"trauma" has to be understood as resulting from a **constellation of life experiences** as well as from a discrete happening, from a **persisting condition** as well as from an acute event'* (Erikson, 1994, p.229, emphasis as original)

This forwards-backwards temporal continuum was confirmed by a study by Fothergill & Peek (2015), who followed the lives of children for seven years after they had lived through Katrina. They found that post-disaster life trajectories were shaped by pre-disaster circumstances. Structural disadvantages – not individual or personal factors – mattered most in determining a child's downward trajectory, while a child whose parents had pre-existing cultural capital was more likely to find equilibrium. This finding is reflected in Section 6.1.5: in comparing the experiences of two physiotherapists who served communities with contrasting socioeconomic demographics, the participant and his patients in the more deprived community were clearly more distressed.

Picou, Brunsma & Overfelt (2010) describe a ‘corrosive social cycle’ of collective pathology – with the resonance of a syndemic (Section 7.2.1) – which emerges in the phase following the initial disaster:

> *‘This dynamic process involves recurring threats, warnings, and secondary disaster impacts. Because most of the corrosive social processes that occur have anthropogenic causes, with survivors assigning blame to various responsible parties, this pattern of blame results in loss of trust in traditional institutions’*
>
> (Picou, Brunsma & Overfelt, 2010, p.14)

Social scientists have identified the role of official structures and actors in the exacerbation of slow disasters. The failure to prepare, the failure to respond, and the failure to rebuild are identified by Lotke and Borosage (2006) as the three major failings of human institutions, leading to the conclusion that no disasters are entirely ‘natural’. N. Smith (2012) identifies human influence at all points of the disaster cycle:

> *‘In every phase and aspect of a disaster – causes, vulnerability, preparedness, results and response, and reconstruction – the contours of disaster and the difference between who lives and who dies is to a greater or lesser extent a social calculus’* (N. Smith 2012)

The malevolent influence of official actors can go beyond a failure to acknowledge the significance of the ‘social calculus’ to a calculated exploitation of people. Rajan (1999) documents the implicit and explicit calculated risks which led to the 1984 Bhopal chemical catastrophe in India – both the event itself and its still-unfolding consequences for the physical, psychological, and societal health of that population.

The cultural and social construction of vulnerability to catastrophe exists in the most advanced communities: Bolin & Stanford (1999) compare four separate communities in the aftermath of the Northridge earthquake in ostensibly affluent Southern California. Economic stability, home ownership, education and employment drastically affected the differing responses and the ultimate viability of the communities. By focussing on the English experience, this thesis adds to the body of work which highlights socially constructed vulnerabilities in the so-called First World (i.e. wealthy, technologically advanced, democratic countries).

Previous examples of disasters in the UK, and the state's failure to respond appropriately, are examined by McLean & Johnes (2000). Focussing on the 1966 Aberfan disaster, in which 116 children and 28 adults died when a colliery slag heap collapsed on the village school, they identify similarities with other disasters: issues of empowerment, access to information, the weakness of regulation, and the role of class – particularly the fact that risk takers are usually different from risk bearers. These are themes which are replicated throughout this thesis. McLean & Johnes also find common themes which have relevance beyond the temporal scope of this thesis which provide a warning: instances of failure associated with to conduct effective inquiries, to bring appropriate prosecutions, or to provide justice for the bereaved and the injured.

The failure of UK authorities to acknowledge the unintended consequences of biosecurity measures has precedent. Mort et al. (2005) described how the extensive culling of animals and severe curtailment of free movement in Cumbria during the 2001 foot-and-mouth livestock epidemic contributed to an unaddressed human disaster in rural communities, culminating in mental ill health and a loss of trust in authority similar to that described by participants in this thesis. Similarly, the limitations of official responses From their five-year observation of a working-class Doncaster community after a flood, Easthope & Mort (2014) identified that official responses to disaster, incorporating 'technologies' such as checklists, templates, and guidance documents, are potentially useless when not transformed by situated and localised experiences and practices with the involvement of those affected.

In the aftermath of the onset of the 2020 pandemic, the consideration of the need for formalised disaster recovery was stifled by the perception of disaster as a place-based and sudden-onset event. This was exacerbated by 'active forgetting' (Section 6.2.3) on the part of the government and sections of society. What 'technologies' existed were aimed at reaching a point where PPE-wearing and distancing could be consigned to the past, rather than dealing with the complex social and psychological effects described in this thesis. Tools took the form of complicated tier systems for lockdowns and a time-bound *'roadmap'* (HM Government, 2021) for a return to pre-pandemic behaviours, which diverged from the approach of the devolved governments of Scotland and Wales. These tools led to conflict and anxiety (Section 5.4), or incorporated promises which were not kept, such as the failure to reinstate care services (Section 6.1.4). In contrast, the permanent societal shifts, the moral injury, and the structural violence reported by participants was unacknowledged and unaddressed. The testimony of participants in this thesis provides evidence of a failure to identify these core aspects of the unfolding disaster, let alone any engagement with the affected communities to tailor such disaster recovery processes. On the contrary: the government's failure to enter meaningful dialogue with healthcare professionals resulted in unprecedented strikes (Section 7.2.1).

Beyond the wilful neglect and structural violence inherent in disasters is 'disaster capitalism' (Klein 2008): the use of crises to establish questionable free market policies in which private interests descend on destabilising events for the purposes of tactical and strategic extraction of profit. As part of the UK's response to the Covid pandemic, PPE suppliers referred by government ministers, MPs and other senior officials were unlawfully afforded favourable treatment in procurement processes worth tens of millions of pounds by being allocated to a so-called 'VIP lane' (R [on the application of Good Law Project Ltd & Everydoctor] v. The

Secretary of State for Health and Social Care, 2022), while PPE scarcity could be traced back to the abandonment of stockpiling in favour of cost-conscious ‘just in time delivery’ strategies (Section 2.10). My thesis documents how this preoccupation with profit had profound consequences for communication and, in turn, trust and social cohesion: in-person behaviours were affected by PPE scarcity (Section 5.2.1), the poor quality and design of PPE artefacts which did reach participants (Section 5.2.2), and the realisation that PPE standards had been dictated by supply rather than appropriateness (Section 5.2.3), while participants suffered moral injury as a consequence of the Treasury’s ‘Eat Out To Help Out’ scheme which encouraged people to socialise to spend money in pubs and restaurants at the same time as they were being prevented from being with loved ones who were struggling alone in their day-to-day lives, giving birth, dying, and grieving (Section 6.3.2).

By drawing from the literature on disaster, most notably Erikson’s assertion about the multifaceted nature of trauma and Klein’s concept of disaster capitalism, I posit that the circumstances which cause moral injury can, and do, go beyond the kind of discrete, linear, individual event implied in the term ‘Potentially Morally Injurious Experience’. The circular, persistent, messy, insidious nature of collective trauma, the often-malevolent contribution of official structures and actors to this trauma, and the toxicity inherent in the failure to acknowledge gradual disaster, are indicative of a ‘Potentially Morally Injurious ***Culture***’ – a ‘PMIC’ – from which moral injury can and does arise, as illustrated in this thesis.

The consequences of a ‘PMIC’ are manifold. The withdrawal from their work roles, described by some participants, was replicated across the country. In October to December 2023, there were 9.28 million people aged 16-64 in the UK who were not in work, nor actively looking for work. The proportion of the population aged 16-64 who were economically inactive was 21.9% (Francis-Devine, Buchanan & Powell, 2024). Described as the ‘great resignation’ (Ocean & Meyer, 2023) the loss of health and social care professionals from the workforce – along with people with the skills, knowledge, and experience of all other professions – has consequences for UK emergency preparedness. I have established that the threshold for a disaster is crossed when a society or community lacks the capacity to respond to challenging circumstances. Attrition of the health and care workforce is alarming, because it lowers the threshold for disaster to be made manifest. Their absence contributes to high levels of long-term sickness due to the long waiting lists, and it reduces workforce capacity in all professions as people withdraw from the workforce to take on their family members' social care in an unpaid capacity. This makes the population less able to respond to a diverse range of natural and man-made challenges.

The 2021 census (ONS, 2023) identified that there were 4.7 million unpaid carers in England – 8.9% of the whole population aged five years and over. The proportion of unpaid carers in the population had a direct correlation with deprivation, rising from 8.1% in the least economically deprived areas to 10.1% at the other end of the scale. Moreover, the oldest people were most likely to be providing the most care. But, despite the prediction of carer support worker Paula that the 2021 census would show an *increase* in people self-identifying as carers, it was reported that there was a substantial *decrease* compared to the 2011 census (which reported that in England and Wales combined, 11.4% were unpaid carers).

The Office for National Statistics (ONS, 2023a) said the pandemic's forced separation and distancing contributed to the reduction of self-identified carers because it severed care relationships and concentrated more tasks amongst fewer people. Another major confounding factor was a change in the census question. In 2011 respondents were asked: *'Do you look after, or give any help or support to family members, friends, neighbours or others?'* but the question posed in 2021 was more specific and medicalised: *'Do you look after, or give any help or support to, anyone because they have long-term physical or mental health conditions or illnesses, or problems related to old age?'* My research has identified an innate reluctance for family carers to identify themselves as such – they simply see a social need, and no-one else is doing it. The 2011 census question was more inclusive of those subtle yet essential social interventions, but the substantial reframing in 2021 could have further discouraged people from self-identifying as carers by formalising and problematising the act of social care. By overlooking these factors and interpreting this statistical evidence as a reduction in activity and need, there is a danger that the unpaid care landscape could be underestimated by policymakers.

7.3 IMPLICATIONS AND RECOMMENDATIONS

My thesis illustrates how the health and care system is made up of humans who possess complex and valuable skills and experience, and who also have their own vulnerabilities and support needs. It also exposes how the public *is* – or *must become* – the health and care system which, like an iceberg, consists of many more hidden unpaid carers than those in paid work. With this in mind, my findings show that the presence of PPE and distancing in health and care, particularly in the context of the way the pandemic was managed in the UK, has had consequences which leave its citizens with little capacity to cope with the next challenge, whatever form it may take – and this vulnerability is even more dangerous because it is hidden and unacknowledged.

Remembering and forgetting have a strong influence on risk perception and hence on the willingness and ability of society to adopt informed preparedness measures (Monteil, Barclay & Hicks, 2020, p.297). In one respect, this thesis is an act of remembering: I captured and learned from the experiences of people as they lived through a critical period of history. My findings become increasingly relevant as the effects of active forgetting take hold, as discussed in Section 6.2.3, and the attention of policymakers and the public shifts to other crises. In their work on the aftermath of volcanic eruptions, Monteil et al. (2020) noted how an active disaster-forgetting process was in place at the national level to encourage psychological recovery and economic development. Such disaster-forgetting was evident in the testimony of the participants in this thesis, which has subsequent adverse effects for those who cannot forget and who worry that there will be no learning from their experiences.

The need to raise awareness of the findings of this thesis, particularly in the context of syndemics and slow disasters, is particularly relevant because, unlike previous editions, the 2023 version of the UK National Risk Register (NRR) (Cabinet Office, 2023, p.6) does not address chronic risks, which it defines as *'long-term challenges that gradually erode our economy, community, way of life, and/or national security'*. By excluding chronic risk *'to* *make the NRR most usable by resilience practitioners',* the register directs those practitioners to focus solely on acute risks, defined as *'discrete events requiring an emergency response'.* This tacitly frames a disaster as linear, having an identifiable start, middle, and end, despite a body of evidence which acknowledges that a disaster is not only cyclical, but its turns are also unique, complex, and messy (Sawalha, 2020). The linear approach also diverts attention from those pre-existing elements which make a disaster as defined by the UNDRR: '*exposure, vulnerability, and capacity'.* It may have the effect of discouraging planners from thinking holistically and strategically. I offer insights which can help to redress the balance. I highlight the critical role of trust, openness and consistency in communication *about* the measures taken to mitigate a disaster, and I foreground the importance of reducing epistemic injustice by seeking out and listening to the voices of experience, recognising the multifaceted and fluid roles and responsibilities of people who give and receive care in disasters, both in overtly tackling acute moments of crisis and in performing the concurrent routine and unseen socially essential acts of care.

While it is clear that the UK's health and social care infrastructure is vulnerable to a spectrum of shocks including floods, heatwaves and economic failure, the lessons in this thesis are particularly relevant when one considers the high likelihood of another pandemic. The NRR reasonable worst-case scenario assessment predicts a 5%-25% likelihood of another 'catastrophic' pandemic in the next five years (Cabinet Office, 2023, pp.161-162). Therefore, the creation of a robust emergency preparedness plan which places social cohesion at its core is a matter of urgency. By offering practical insights into the embodied experience of giving and receiving care in the presence of PPE and forced avoidance of touch and proximity, this thesis can inform such planning. Participants found their own ways of facilitating communication while wearing PPE or when restricted to remote methods, but this was not explicitly taught despite the existence of such knowledge and training materials. My findings demonstrate how there is untapped knowledge about communication in adversity, particularly held by those whose 'otherness' makes overcoming communication barriers a daily occurrence, from whom organisations could learn and which should be widely taught.

This thesis reinforces the importance of holding and maintaining a plentiful stock of good-quality, better designed, appropriate PPE artefacts at all times; ensuring manufacture, supply and distribution arrangements are pre-arranged, and will be robust and reliable in times of stress and high demand; and that there is consistent and transparent information about their use – and familiarity even before the items are needed.

My exploration of the consequences of communication distress, the exacerbation of the digital divide, and institutional distancing in the form of the abandonment of those whose routine health and social care services were withdrawn illustrates the need to establish and maintain robust relationships between services and people through a wide-ranging choice of communication systems which do not exclusively rely on digital connectivity. It also illustrates the need to ensure digital resources, training, and connectivity are available to the widest population. This observation is similar to that identified in the ethnography of Ebola conducted by H. Brown & Marí-Sáez (2020, pp.24-25): that *'effective disease control is likely to be as concerned with providing spaces for reconfigured forms of closeness as it is with separating people to keep them safe'*.

H. Brown & Marí-Sáez (2020, pp.24-25) also recommend that disaster management practices and systems will be best identified if public health policymakers found *'new ways of incorporating publics and their concerns within epidemic response'*. By illustrating the complexity of a pandemic as a syndemic and a gradual-onset disaster, I would argue that such integration needs to occur outwith the acute phase of the disaster cycle, particularly because the public *is* – or *has to become* – the care system. The forced avoidance of proximity exposed the extent to which the interdependency of family and friends underpins the social care infrastructure in England. It also exposed how the boundaries between 'formal' and 'informal' care, and 'essential' and 'non-essential' care, are spurious at best.

Strathern’s dividualism (1988) is all around and within us in England, regardless of the political structures which inflict structural violence through policies which attempt to assert individualism. This thesis sheds light on the moral dilemmas and injuries faced by people whose multifaceted personae included the role of unpaid family carer and, in turn, exposes the limits of the Western concept of the individual: inequitable benefits systems which ignore the value and demands of unpaid care work, inflexible employment conditions, and wages incommensurate with the value of the role for those whose caring is done as paid work. Redressing these inequities would be an important disaster recovery and preparedness intervention. The state should recognise the contribution of unpaid carers and create a sustainable support system which supports rather than penalises their labour, and which, in times of crisis, is given the status of an essential service by emergency planners.

In addition to making clear the importance of operational factors, the thesis highlights the profound, often unintended, effects of the (ostensibly) ‘small’ things done by people in influential roles: consistency, transparency, the tacit reinforcement of explicit rules by ‘practicing what you preach’; listening to voices of experience, including those from overlooked communities; taking seriously the importance of trust; actively seeking out the voices of those who are silent rather than caving into the wants of those who shout the loudest. These ‘soft skills’ ought to be incorporated into all stages of the disaster management cycle.

7.4 STRENGTHS AND LIMITATIONS

The poem with which I introduced this thesis, *'We Wear the Mask'* (Dunbar, 1895), was written by the son of enslaved people. Not only does the poem take on new meanings in the context of the experience of mask-wearing in 21st Century pandemic times, it also serves to draw attention to the disproportionately severe effect of the pandemic on ethnically minoritized groups (Cook, Kursumovic & Lennane, 2020; Haque, Becares & Treloar, 2020; Marmot et al., 2020). The lived experience of PPE and distancing for this population is not addressed in this thesis and demands its own investigation.

While the survey and my online promotion of the study identified a diverse range of people who had given and/or received care in a wide range of contexts under pandemic infection control measures, this diversity did not extend to the inclusion in the interview stage of migrants or people of colour. This was not deliberate, as the survey did not collect demographics on ethnicity, and the people who responded to the invitation to be interviewed were all White British. This apparent weakness could be repurposed as a strength – the study could be a useful comparator to an exploration of the experiences of ethnically minoritized people. It would also be useful to investigate the reasons why migrants and people of colour did not come forward to participate in this study: its findings would inform recruitment methods and data-generation tools.

The dissemination of the survey and recruitment of participants (described in Section 3.4) had its limitations – not least due to the forced avoidance of proximity which was the subject of the study. Due to pandemic regulations, I was unable to meet anyone in person to discuss the project. Consequently, survey recruitment was limited to people who were able to interact remotely, either with the emails disseminated across my varied network of contacts, or through the websites of organisations who were supportive of the project. Because the survey was exclusively online, those who were unable to access it were excluded. Similarly, because interviews could only take place via video or telephone, I could only be exposed to the beliefs and experiences of people who were able to interact in this way. I tried to mitigate for these barriers by providing a link to a printable version (although no paper submissions were received), and by not making the completion of the survey a prerequisite for interview for those participants with communication disabilities who were reached via my presentations at online meetings. When recruiting for the interview phase, in contrast to the snowball method used to disseminate the survey, I used purposive selection by triaging participants on the demographic and experiential content of their open-ended survey responses.

Opportunities, as well as barriers, emerged from the necessity to recruit participants in a way which did not need National Health Service Health Research Authority (NHSHRA) ethics approval, and which allowed for research to take place under pandemic restrictions. Such benefits and drawbacks are described by Johnson (2022), who recounts how a participant for her study of chronic pain stated categorically that they would not have taken part had they been approached through conventional channels: negative experiences involving NHS structures had made them wary of disclosing personal information. The decoupling of my research from the need for formal NHS approval meant that the range of people I could recruit was distorted by the reach of my own (albeit varied) personal networks. However, by approaching participants as private individuals, they had reason to feel able to speak freely as human beings rather than representatives of a profession, thus removing factors which could elicit self-editing. In my analysis, where participants are presented as representatives of specific professions, this has arisen not from any formal arrangement but from a tendency of those participants to speak of their profession as part of their identity. They spoke of an intrinsic set of values, mores, and behaviours as factors which they also recognised in the characters of their colleagues.

The study was not designed to be a quantitative project. Because I had not anticipated a need for a survey analysis strategy, I did not design the survey with statistical analysis in mind, so its flaws were exposed when the size of the response offered an unplanned opportunity for adjuvant statistical analysis and presented a need to select interview participants.

Firstly, an assumption that it would attract a small response, thus allowing me to gather demographic data from each of the respondents who came forward for interview, meant I did not include questions on ethnicity, age, socioeconomic, gender, and geographical area. This was a missed opportunity, which would have helped to provide insights on the extent to which the dissemination of the survey reflected the population it intended to reach. Secondly, because it was an interview recruitment tool rather than the primary data-generation method, there were limitations in the way the questions were generated and validated. The survey was designed and piloted as a provocation (i.e. to cause the respondent to reflect on the topics contained within, and to motivate them to share their experiences and beliefs at interview) rather than as a tool to measure specific variables concerning those experiences and beliefs. Consequently, there was little attention paid to statistical parameters of validity, i.e., that the survey measured what it was supposed to measure, and it was not subjected to formal tests of reliability, such as Cronbach's alpha (Cronbach, 1951).

Thirdly, I did not make the questions compulsory because I did not want to force participants into taking a stance over something about which they felt neutral. This problem would have been mitigated by using a Likert scale to indicate a *level* of agreement to the statements I had offered. Moreover, my failure to offer respondents a Likert scale meant post coding (i.e., the coding of open questions from the completed questionnaire) was required to prepare the data for inferential analysis. Such categorisation of responses is not equivalent to Likert scales, so the inferences made are not as statistically robust as those which can be made from data in which Likert scales are used in the original data generation.

I mitigated for these flaws by using the statistical analysis as an informative adjunct rather than a basis for conclusions. I have also applied the lessons learned from my reflections on the limitations of this survey's design on subsequent research projects.

CONCLUSION

This thesis contributes to the UK Health Security Agency's request for research '*to improve knowledge on how face coverings are used by different population subgroups and in different community settings'* (UKHSA, 2021, p.27). In 2022, the UKHSA said observational studies into respiratory PPE efficacy needed to *'consider whether factors other than the intervention may impact the results'* including the impact of *'behavioural factors'* and *'communication issues'* (UKHSA, 2022b, p.25). By shedding light on the direct links between what people feel and do *in the presence of* PPE and distancing, and the explicit and tacit communication *about* those artefacts and specified behaviours, this thesis informs future research by signposting those profound and far-reaching *'factors other than the intervention'*.

My findings align with the call by *The Lancet*'s editor-in-chief Richard Horton to respond to the slow disaster of the Covid syndemic with a preparedness plan which addresses the structural violence seen in the participants' testimonies:

> *'Nothing less than national revival is needed. Approaching Covid-19 as a syndemic will invite a larger vision, one encompassing education, employment, housing, food, and environment. Viewing Covid-19 only as a pandemic excludes such a broader but necessary prospectus'* (Horton, 2020, p.874)

Therefore, I conclude this thesis with a call to action. Policymakers and professionals must urgently recognise the existence of the gradual-onset syndemic disaster which, as I write, is still unfolding as people who work in health and care leave their professions, exacerbating the hidden burden of abandoned unpaid carers. The disaster must be addressed with the greatest urgency, because there is a high possibility that there will soon be a need for the wholesale adoption of PPE and distancing again. When it comes, it will inevitably be a different experience because each pandemic has its own unique presentation. But for those who experienced PPE and distancing in health and care interactions, the body keeps the score, no matter how comprehensive the effect of active forgetting. Those who remember the body-mind sensations of donning and distancing under opaque and ever-changing rules, who felt exposed by insufficient and/or substandard artefacts, who struggled as services melted away, who were kept apart from loved ones in pain whilst being encouraged to ‘Eat Out to Help Out’, who agonised over impossible moral choices between caring for family *or* patients, who compromised their deeply-held standards and beliefs about care communication at the behest of people in authority who betrayed their trust, whose exhaustion and vulnerability was overlooked because it did not fit the ‘heroes’ narrative – these people are likely to remember on an all-pervasive cellular level. According to the theories of moral injury, their previous exposure to betrayal of trust will embed a lowered threshold for visceral sensitisation. If this is the case, then I wonder if the population will trust those who lead the disaster response, or will their actions reflect Veronica’s words?

> *‘I cannot go back there, because that was terrible. And I wouldn’t, I wouldn’t.’*
>
> [18/688-24/09/20]

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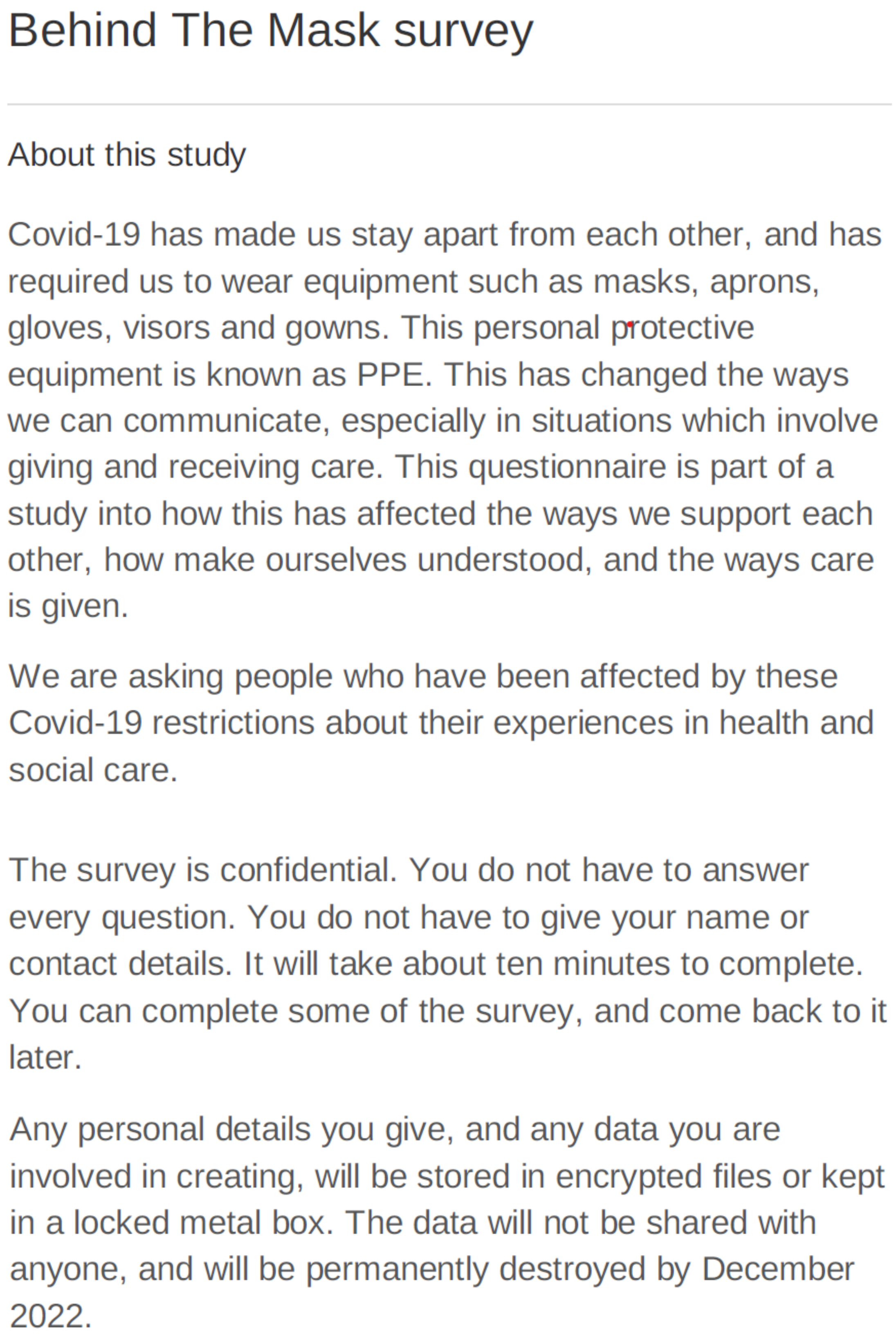
APPENDIX A: PANDEMIC TIMELINE

TABLE 4: Timeline of pandemic-related events		**Page 1**
Date:	**Event**	**Source:**
2020:		
25 Feb	PHE states it is ‘*very unlikely that people receiving care in a care home or the community will become infected*’. Staff told they need not wear masks because *‘they do not provide protection from respiratory viruses’*	(PHE, 2020a)
25 Mar	First UK national lockdown begins. Two-metre distancing rule imposed. NHS bans visitors to inpatient and outpatient settings until further notice. One person may be allowed if they are a woman in labour's birthing partner, or the patient is their child, or the patient is at end of life	(PM’s Office 2020a) (The Health Foundation, 2020)
26 Mar	First ‘Clap for Carers’	(Mackay, 2021)
29 Mar	First confirmed Covid death of UK health worker	(Weaver, 2020)
2 Apr	DHSC tells care homes to admit patients with Covid PHE advises care homes to ban visitors except next of kin at end of life PPE requirements downgraded. Only to be used ‘*within 2 metres of a suspected or confirmed coronavirus Covid-19 patient*’, *‘doesn’t need to be changed between patients’*. FFP3 masks and full-arm gowns reserved *‘for high-risk procedures’*	(Public Accounts Committee, 2020) (PHE, 2020c)
4 Apr	Deputy Chief Medical Officer Jonathan Van Tam: *‘we do not recommend face masks for general wearing by the public’*	(*BBC News*, 2020a)
19 Apr	NHS Providers Chief Executive reports inadequate quantities of PPE, mislabelling, and safety test failures	(D. Campbell, 2020)
10 May	Prime Minister Boris Johnson switches messaging from ‘stay at home’ to ‘stay alert’	(PM's Office, 2020b)
11 May	Government advises to wear face coverings in public places	(DHSC, 2020b)
13 May	Individual households allowed to socialise outside	(J. Brown & Kirk-Wade, 2021)
24 May	Johnson praises special adviser Dominic Cummings for travelling 250+ miles with family while symptomatic during lockdown	(*BBC News*, 2020b)

TABLE 4: Timeline of pandemic-related events		Page 2
Date:	**Date:**	**Date:**
2020 (continued):		
28 May	Final ‘Clap for Carers’	(Mackay, 2021)
1 Jun	People from different households allowed meet outside in groups of up to six	(J. Brown & Kirk-Wade, 2021)
5 Jun	Suspension of hospital visiting lifted in England, replaced with local discretion of NHS Trusts	(Kulakiewicz, Foster, Powell & Loft, 2020)
15 Jun	Masks become compulsory in English hospitals	(PHE, 2020d)
4 Jul	Most lockdown restrictions lifted. Hairdressers, pubs, and restaurants reopen under ‘Covid Secure’ guidance	(DBEIS, 2020)
24 Jul	Face coverings become compulsory in shops and on public transport in England	(DHSC, 2020c)
31 Jul	‘Hands. Face. Space.’ slogan launched	(PM's Office, 2020c)
3 Aug	Month-long ‘Eat Out to Help Out’ scheme begins	(HMRC, 2020)
8 Sep	NHS publishes framework to assist reintroduction of rules allowing a birthing partner to accompany patients accessing maternity services	(NHS, 2020c)
5 Nov	Second UK lockdown begins	(PM’s Office, 2020d)
2 Dec	Second lockdown ends, replaced by tier system	(DHSC, 2020e)
8 Dec	First UK citizen receives Covid vaccine	(*BBC News*, 2020c)
2021		
5 Jan	Third UK lockdown begins	(PM's Office, 2021)
21 Jan	Pandemic’s highest total UK Covid-19 deaths in a single day (1,370)	(Gagliardi, 2023)
8 Mar	‘Roadmap’ out of lockdown begins. Care home residents are allowed one visitor	(Cabinet Office, 2021)
19 Jul	Final lockdown laws revoked in England: face coverings in indoor settings or on public transport no longer required	(Barber, J. Brown & Ferguson, 2022)
30 Nov	First news report on ‘Partygate’: Downing Street held parties during lockdowns which broke mask and distancing laws	(Crerar, 2021)

APPENDIX B: BEHIND THE MASK SURVEY



Behind The Mask survey

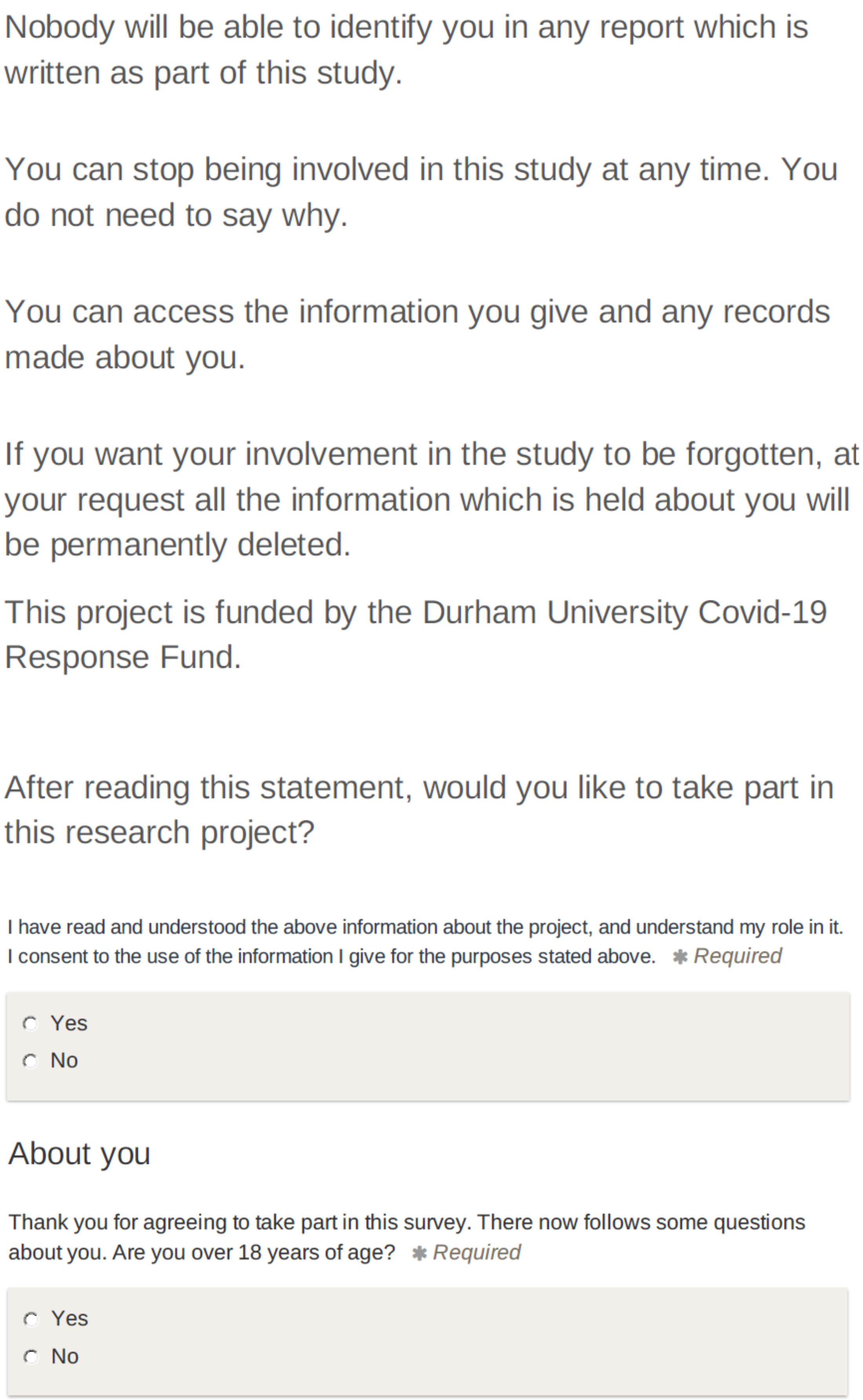
About this study

Covid-19 has made us stay apart from each other, and has required us to wear equipment such as masks, aprons, gloves, visors and gowns. This personal protective equipment is known as PPE. This has changed the ways we can communicate, especially in situations which involve giving and receiving care. This questionnaire is part of a study into how this has affected the ways we support each other, how make ourselves understood, and the ways care is given.

We are asking people who have been affected by these Covid-19 restrictions about their experiences in health and social care.

The survey is confidential. You do not have to answer every question. You do not have to give your name or contact details. It will take about ten minutes to complete. You can complete some of the survey, and come back to it later.

Any personal details you give, and any data you are involved in creating, will be stored in encrypted files or kept in a locked metal box. The data will not be shared with anyone, and will be permanently destroyed by December 2022.



Nobody will be able to identify you in any report which is written as part of this study.

You can stop being involved in this study at any time. You do not need to say why.

You can access the information you give and any records made about you.

If you want your involvement in the study to be forgotten, at your request all the information which is held about you will be permanently deleted.

This project is funded by the Durham University Covid-19 Response Fund.

After reading this statement, would you like to take part in this research project?

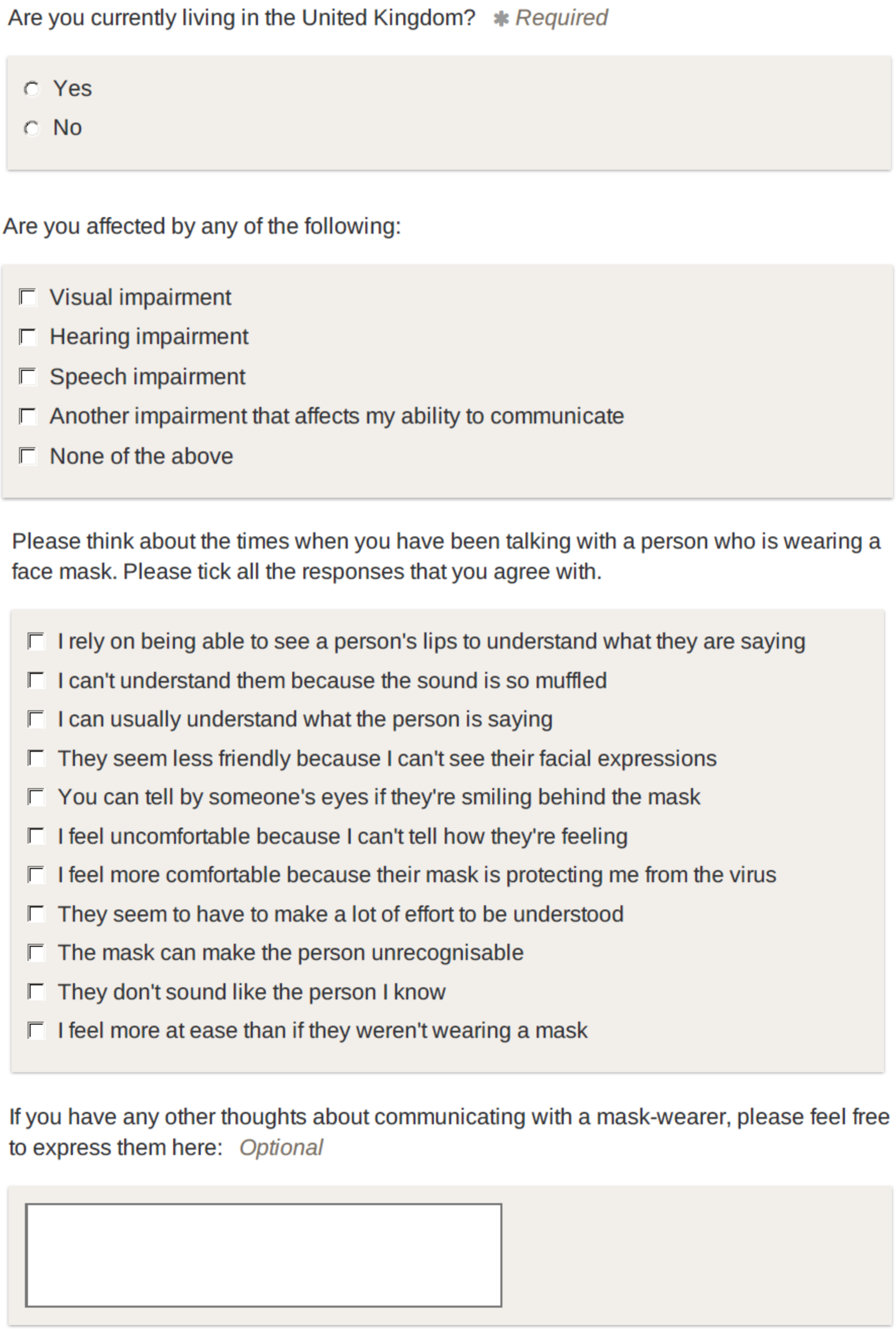
I have read and understood the above information about the project, and understand my role in it. I consent to the use of the information I give for the purposes stated above. ✱ *Required*

○ Yes
○ No

About you

Thank you for agreeing to take part in this survey. There now follows some questions about you. Are you over 18 years of age? ✱ *Required*

○ Yes
○ No



Are you currently living in the United Kingdom? ✱ *Required*

○ Yes
○ No

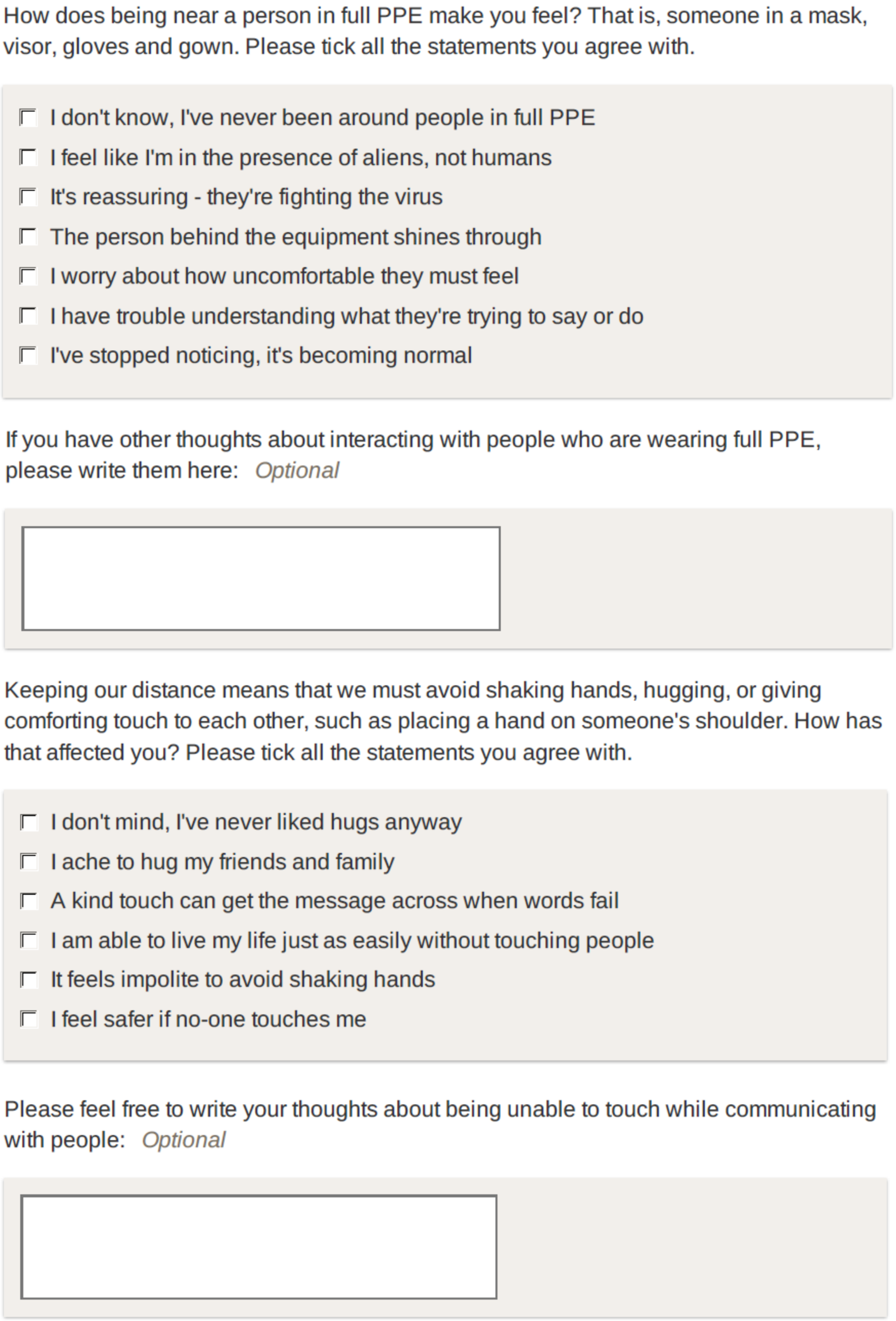
Are you affected by any of the following:

☐ Visual impairment
☐ Hearing impairment
☐ Speech impairment
☐ Another impairment that affects my ability to communicate
☐ None of the above

Please think about the times when you have been talking with a person who is wearing a face mask. Please tick all the responses that you agree with.

☐ I rely on being able to see a person's lips to understand what they are saying
☐ I can't understand them because the sound is so muffled
☐ I can usually understand what the person is saying
☐ They seem less friendly because I can't see their facial expressions
☐ You can tell by someone's eyes if they're smiling behind the mask
☐ I feel uncomfortable because I can't tell how they're feeling
☐ I feel more comfortable because their mask is protecting me from the virus
☐ They seem to have to make a lot of effort to be understood
☐ The mask can make the person unrecognisable
☐ They don't sound like the person I know
☐ I feel more at ease than if they weren't wearing a mask

If you have any other thoughts about communicating with a mask-wearer, please feel free to express them here: *Optional*



How does being near a person in full PPE make you feel? That is, someone in a mask, visor, gloves and gown. Please tick all the statements you agree with.

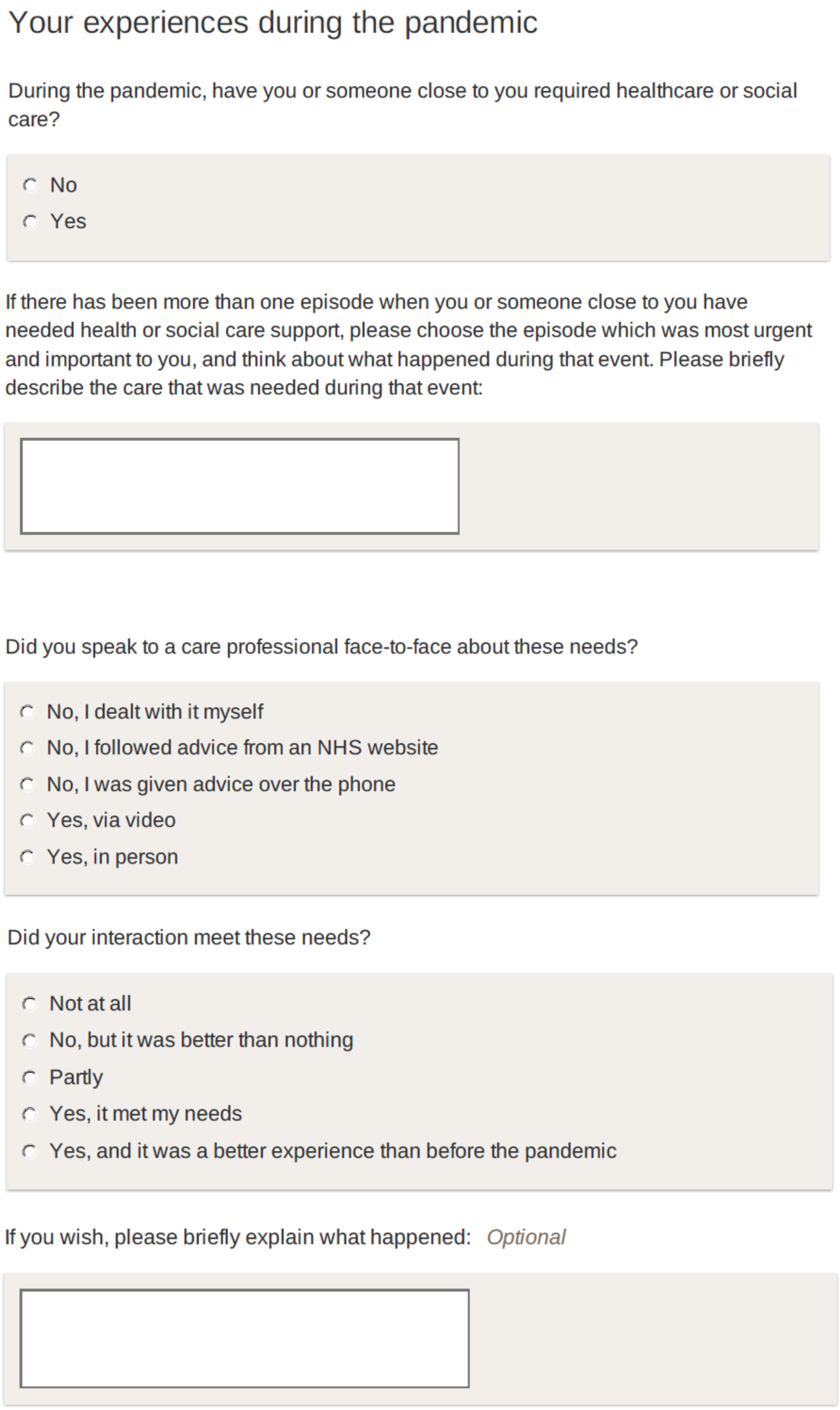
☐ I don't know, I've never been around people in full PPE
☐ I feel like I'm in the presence of aliens, not humans
☐ It's reassuring - they're fighting the virus
☐ The person behind the equipment shines through
☐ I worry about how uncomfortable they must feel
☐ I have trouble understanding what they're trying to say or do
☐ I've stopped noticing, it's becoming normal

If you have other thoughts about interacting with people who are wearing full PPE, please write them here: *Optional*

Keeping our distance means that we must avoid shaking hands, hugging, or giving comforting touch to each other, such as placing a hand on someone's shoulder. How has that affected you? Please tick all the statements you agree with.

☐ I don't mind, I've never liked hugs anyway
☐ I ache to hug my friends and family
☐ A kind touch can get the message across when words fail
☐ I am able to live my life just as easily without touching people
☐ It feels impolite to avoid shaking hands
☐ I feel safer if no-one touches me

Please feel free to write your thoughts about being unable to touch while communicating with people: *Optional*



Your experiences during the pandemic

During the pandemic, have you or someone close to you required healthcare or social care?

○ No
○ Yes

If there has been more than one episode when you or someone close to you have needed health or social care support, please choose the episode which was most urgent and important to you, and think about what happened during that event. Please briefly describe the care that was needed during that event:

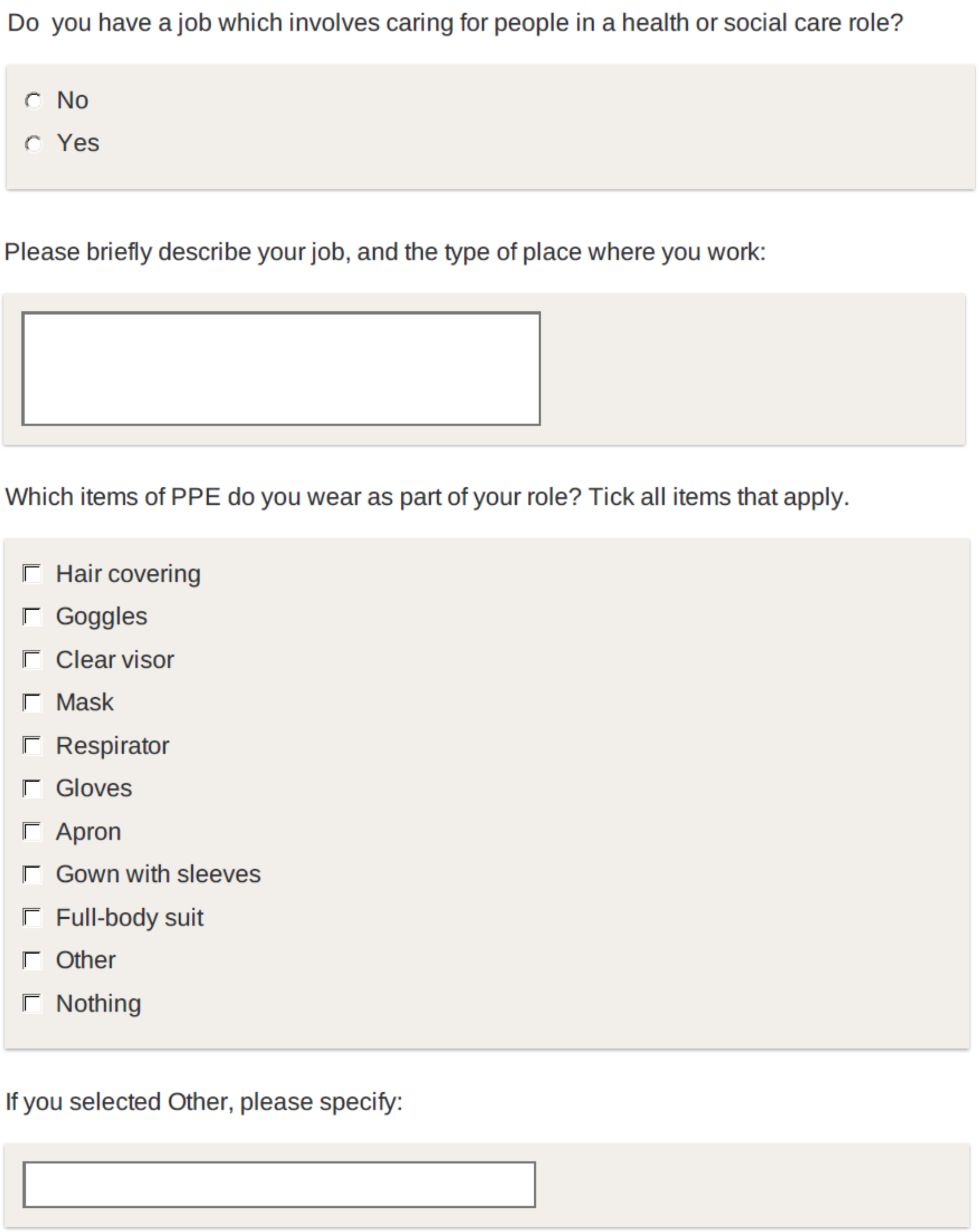
Did you speak to a care professional face-to-face about these needs?

○ No, I dealt with it myself
○ No, I followed advice from an NHS website
○ No, I was given advice over the phone
○ Yes, via video
○ Yes, in person

Did your interaction meet these needs?

○ Not at all
○ No, but it was better than nothing
○ Partly
○ Yes, it met my needs
○ Yes, and it was a better experience than before the pandemic

If you wish, please briefly explain what happened: *Optional*



Do you have a job which involves caring for people in a health or social care role?

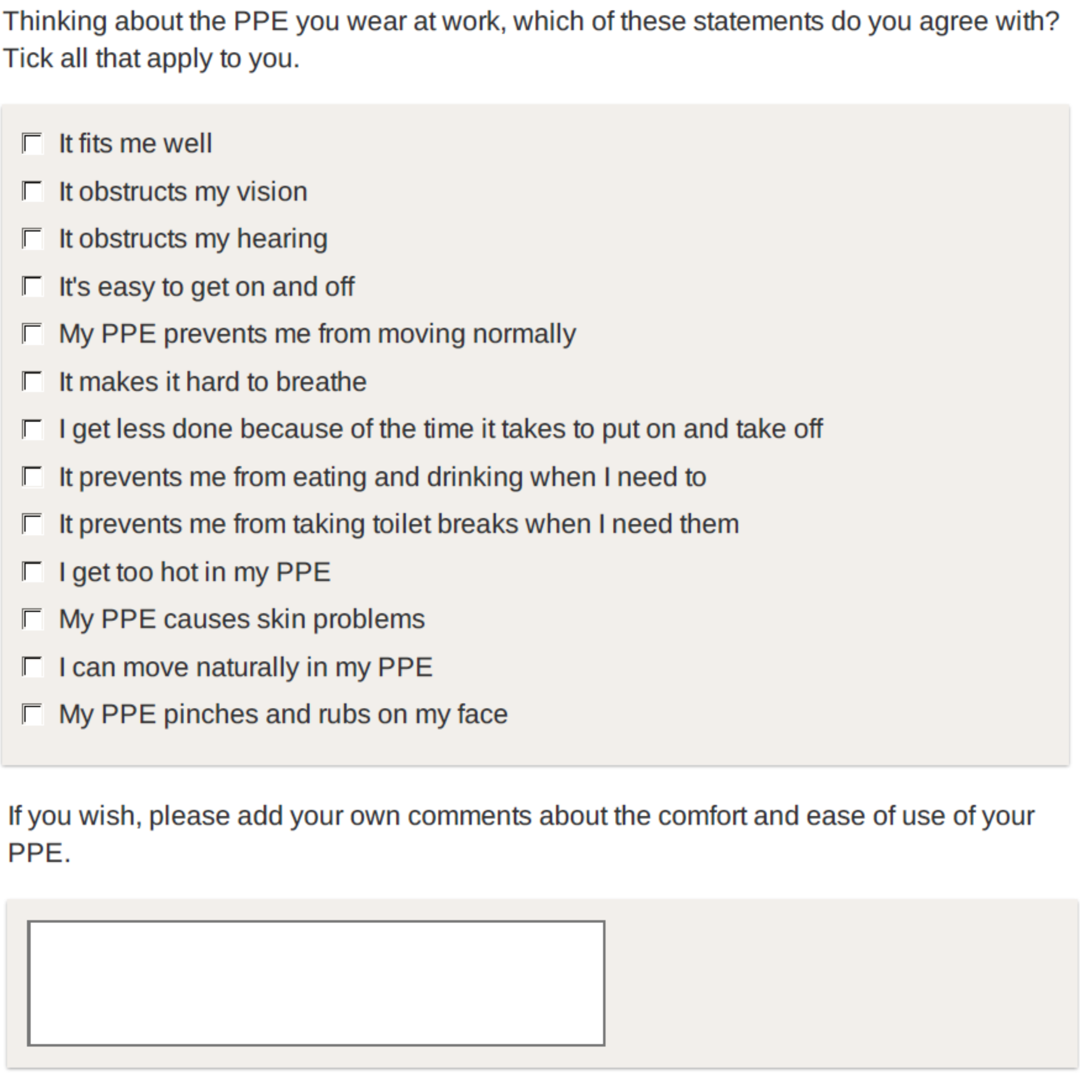
○ No
○ Yes

Please briefly describe your job, and the type of place where you work:

Which items of PPE do you wear as part of your role? Tick all items that apply.

☐ Hair covering
☐ Goggles
☐ Clear visor
☐ Mask
☐ Respirator
☐ Gloves
☐ Apron
☐ Gown with sleeves
☐ Full-body suit
☐ Other
☐ Nothing

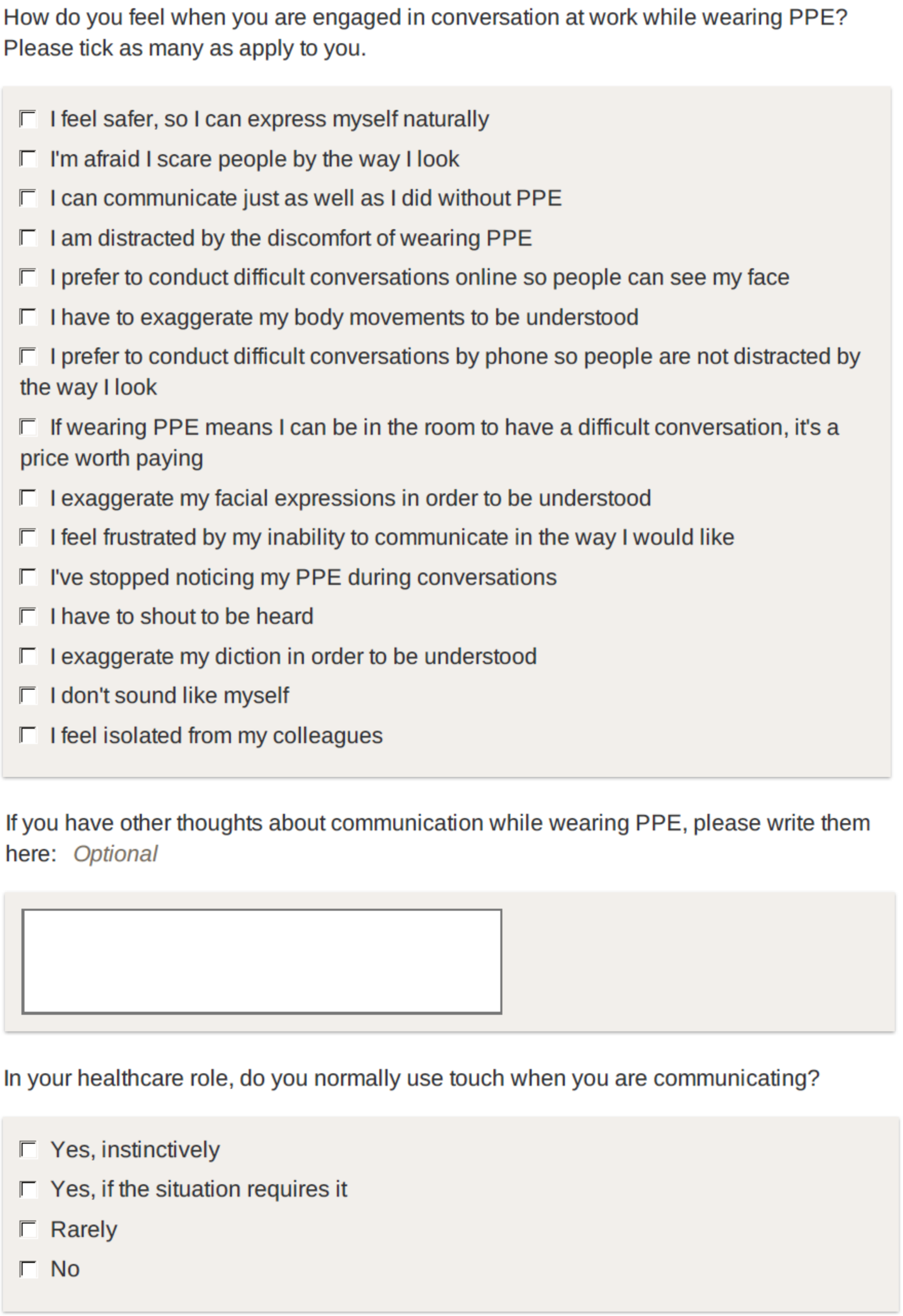
If you selected Other, please specify:



Thinking about the PPE you wear at work, which of these statements do you agree with? Tick all that apply to you.

- ☐ It fits me well
- ☐ It obstructs my vision
- ☐ It obstructs my hearing
- ☐ It's easy to get on and off
- ☐ My PPE prevents me from moving normally
- ☐ It makes it hard to breathe
- ☐ I get less done because of the time it takes to put on and take off
- ☐ It prevents me from eating and drinking when I need to
- ☐ It prevents me from taking toilet breaks when I need them
- ☐ I get too hot in my PPE
- ☐ My PPE causes skin problems
- ☐ I can move naturally in my PPE
- ☐ My PPE pinches and rubs on my face

If you wish, please add your own comments about the comfort and ease of use of your PPE.



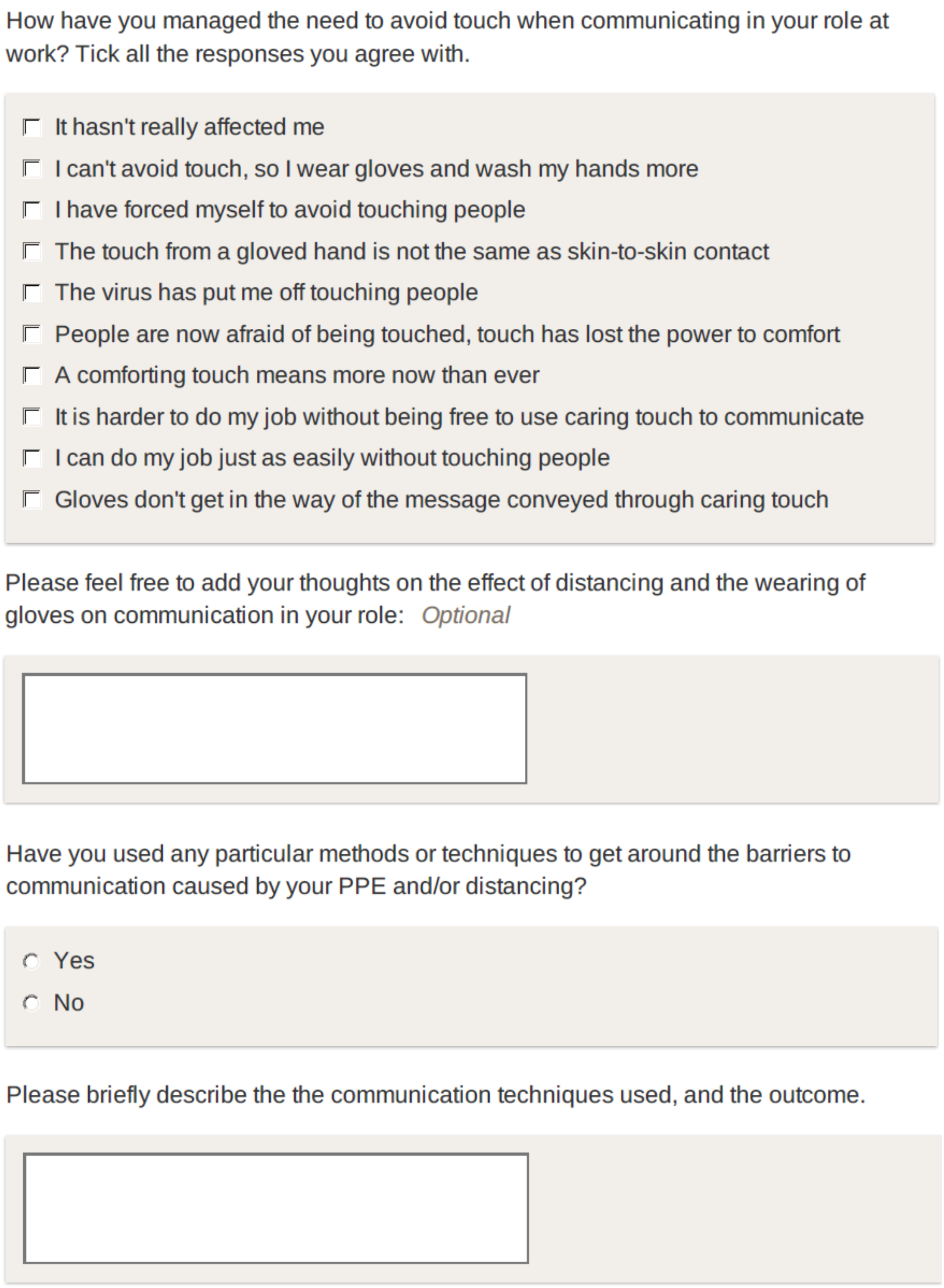
How do you feel when you are engaged in conversation at work while wearing PPE? Please tick as many as apply to you.

- ☐ I feel safer, so I can express myself naturally
- ☐ I'm afraid I scare people by the way I look
- ☐ I can communicate just as well as I did without PPE
- ☐ I am distracted by the discomfort of wearing PPE
- ☐ I prefer to conduct difficult conversations online so people can see my face
- ☐ I have to exaggerate my body movements to be understood
- ☐ I prefer to conduct difficult conversations by phone so people are not distracted by the way I look
- ☐ If wearing PPE means I can be in the room to have a difficult conversation, it's a price worth paying
- ☐ I exaggerate my facial expressions in order to be understood
- ☐ I feel frustrated by my inability to communicate in the way I would like
- ☐ I've stopped noticing my PPE during conversations
- ☐ I have to shout to be heard
- ☐ I exaggerate my diction in order to be understood
- ☐ I don't sound like myself
- ☐ I feel isolated from my colleagues

If you have other thoughts about communication while wearing PPE, please write them here: *Optional*

In your healthcare role, do you normally use touch when you are communicating?

- ☐ Yes, instinctively
- ☐ Yes, if the situation requires it
- ☐ Rarely
- ☐ No



How have you managed the need to avoid touch when communicating in your role at work? Tick all the responses you agree with.

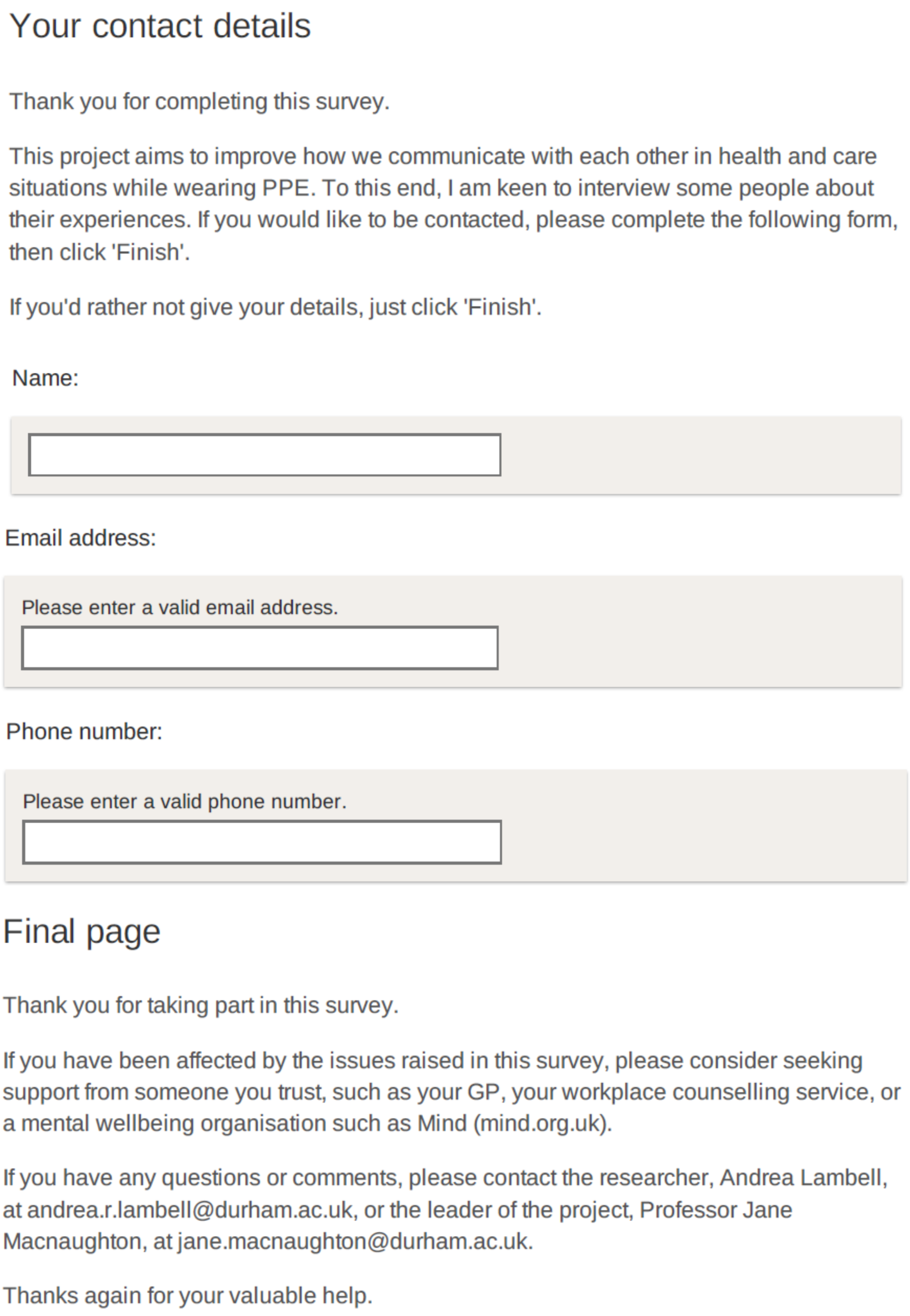
☐ It hasn't really affected me
☐ I can't avoid touch, so I wear gloves and wash my hands more
☐ I have forced myself to avoid touching people
☐ The touch from a gloved hand is not the same as skin-to-skin contact
☐ The virus has put me off touching people
☐ People are now afraid of being touched, touch has lost the power to comfort
☐ A comforting touch means more now than ever
☐ It is harder to do my job without being free to use caring touch to communicate
☐ I can do my job just as easily without touching people
☐ Gloves don't get in the way of the message conveyed through caring touch

Please feel free to add your thoughts on the effect of distancing and the wearing of gloves on communication in your role: *Optional*

Have you used any particular methods or techniques to get around the barriers to communication caused by your PPE and/or distancing?

○ Yes
○ No

Please briefly describe the the communication techniques used, and the outcome.



Your contact details

Thank you for completing this survey.

This project aims to improve how we communicate with each other in health and care situations while wearing PPE. To this end, I am keen to interview some people about their experiences. If you would like to be contacted, please complete the following form, then click 'Finish'.

If you'd rather not give your details, just click 'Finish'.

Name:

Email address:

Please enter a valid email address.

Phone number:

Please enter a valid phone number.

Final page

Thank you for taking part in this survey.

If you have been affected by the issues raised in this survey, please consider seeking support from someone you trust, such as your GP, your workplace counselling service, or a mental wellbeing organisation such as Mind (mind.org.uk).

If you have any questions or comments, please contact the researcher, Andrea Lambell, at andrea.r.lambell@durham.ac.uk, or the leader of the project, Professor Jane Macnaughton, at jane.macnaughton@durham.ac.uk.

Thanks again for your valuable help.

APPENDIX C: EXAMPLE TRANSCRIPT

01 October SECOND meeting

PARTICIPANT 21 ‘Linda’: Parkinson's activist/support volunteer, husband ‘James’ has Parkinson's

PARTICIPANT 22 ‘Audrey’: Parkinson's activist/support volunteer, husband ‘Eric’ had Parkinson's but died prior to pandemic

ANDREA: There's the message that says we're recording. So you have both had a look at the consent form, and is there anything on that consent form that you sort of think: 'Well, I'd like to have that option?' Is there something on the consent form you'd like to opt out of, Linda?

21 ‘Linda’: I can't remember now, because I did it days ago. [...] At the time we were trying to print it off. And I just said to you that we couldn't, so...

ANDREA: So really, there are different elements to the consent form. The first one is that you're okay with me talking to you about the issues surrounding how the use of the masks, the PPE, the distancing, is affecting your health and social care communications in your lives, not just in your lives as carers, but as possibly patients yourself, or, the givers of care, that sort of thing. So that's one element to it. The next element is to record it. And the next bit is to use the transcript of the recording, as part of my data gathering, and come up with themes and theories, and then write it down and use possibly quotes from yourselves in the final documents that I will create. And to let you know that you will be anonymized, you won't be identifiable, because this is a wide study, you could be living anywhere in the country, really. And you'll just be identified as a person who is caring for somebody who has Parkinson's, or has experienced of being that person in the past. So that's the state of play. So if you are happy with that - oh, the other thing is, if you change your mind at any point, you can withdraw. You can withdraw your permission right to the moment it's published.

21 ‘Linda’: Okay.

ANDREA: So you're happy with that, Audrey?

22 ‘Audrey’: Yes, that's fine.

ANDREA: Champion. That's grand. So we've made it! What a journey! And the thing is, it was so lovely that you were initially motivated to help me with this study, you know, to do to help by sharing your experiences of being in the lives of people with Parkinson's. And what that means now, when, you know, it's difficult enough at times to get those communication links going with health and social care providers, isn't it? Difficult at the best of times, and now you throw in masks, and not being able to be in the same room with somebody, that's an extra layer. So what I'm interested in is your experiences, particularly since COVID.

22 ‘Audrey’: Well, I'll start straightaway by saying, I'm not caring for anybody with Parkinson's now. I lost my husband three years ago, so I haven't got any of that issue.

ANDREA: But you are very actively involved in the Parkinson's group now. So you are bringing your experiences and your expertise and your knowledge to help the people around you.

22 ‘Audrey’: Hopefully, yeah.

ANDREA: And also to draw some strength from your experience as well.

22 ‘Audrey’: Yeah.

ANDREA: And one of the things, [22 ‘Audrey’], that I've particularly noticed in the work that I've done so far, is the pre-existing structures that we've got with regard to health and social care - how things were before - have a big influence on how things are now with the extra obstacles thrown in. So good experiences in the past, or bad experiences in the past, have a knock-on effect to now when we have the isolation and we have the masks and PPE. So, you know, what, what your experiences have been do have a knock-on effect?

22 ‘Audrey’: Right.

ANDREA: And for you, Linda, how are things now?

21 ‘Linda’: Maybe a bit a bit calmer. We were starting to sort of go out and have little trips, and now James has got a scooter, we can go somewhere we can actually walk - well, I’ll walk, and he'll scoot. But now - well, things were starting to get a little bit better but his mobility is still really bad. And now where we're confined again, and we can't even see our family, because we'll be seven. And we can't isolate in the house, so we would usually sit in the garden. So we can't even do that now. James started this online video course and it's been a disaster because we didn't have internet last night, as I said, for hours and then he found out that there'd been a lesson. And although he's behind, he's still trying to do a painting that's a pen and ink. And then the guy, in fact, himself - the teacher - is having problems videoing it and sending it. And it's Venice in four parts. And James has only got three. But this morning, he couldn't keep up. So he's doing it in his own time. And then he couldn't get the lessons that the guy had already allegedly done. So it's been a bit difficult for him. But I've taken pictures of the picture on my iPad, so he can be doing that now, instead of being on the computer. And then we're hoping to do some gym on a video call as well. We're just waiting for that, to do some exercises and things. I think it was [name of physio] who said there's this gym in [name of city]. But since we've spoken to the guy I'm worried about them coming to the house now because things have got worse, because they bring equipment for you and work out a plan for you. And then I was I saw someone - because I was going to the chemist yesterday - and I saw someone from our old Pilates class. And she says: 'Well, why don't you come along?' But I said: 'Well, we've been a bit

nervous'. And James has lost his confidence. So I thought I would phone the gym anyway and see - I know he can't have as many in his class as he used to, and he's very popular. And so in that respect, things feel as if maybe we will be getting, you know, a little bit more stimulus and incentive. But, you know, apart from that, you can't - we can't - go out. It is difficult because James can't walk, he can say: ‘Oh, we’ll go somewhere’, but he can't actually walk. So it's going to be a scooter or a walker, which prevents you from going to certain places.

ANDREA: [...] Fewer numbers in the in-person meetings [...] That kind of sifting, and that kind of 'eeny, meeny, miney, moe' situation, is actually happening in day-to-day life. [...] And these continuing bonds that are very important in our lives - like for yourself, Audrey, I mean, technically, you're no longer a carer but it's part of your life. You've still got the continuing bonds with the people who you identify with because you've got a shared experience - barriers are getting put in left, right and centre, aren't they?

22 ‘Audrey’: Yeah, they are. It's certainly been a struggle, trying to sort things. Yeah.

ANDREA: And here's the thing about carers past and present: how's your health?

22 ‘Audrey’: Good!

ANDREA: Fantastic.

21 ‘Linda’: Mine isn't so - I think it's just wearing... it's been wearing me down as well. everything that's happening, and I have just been diagnosed - well, I haven't got diabetes, but I'm pre-diabetic, I've had blood tests and I have to do a WeightWatchers nine-month course to try and get the numbers down. And that's sort of taxing in itself, because I don't feel ill with that. But I could be if I carry on, sort of being at home, and we're baking and eating and, you know, cakes and things that probably aren't very good for us. But there's not always time - I mean, at this moment, and I can prove it, I have a crispbread! [shows plate]

ANDREA: Oh, well done!

21 ‘Linda’: It's very boring. But it's, um, I've got to stop and think about me as well. And also with my shoulders, I pulled muscles and I had a call from the physio this morning. And all I would need is a good massage. [link interrupted] put me on painkillers and I can't actually take painkillers all the time because if I have to drive - because James is not driving - so if I've got to drive anywhere. But I had a nice chat with her, she's a nice lady. But I said: 'You know, probably if I'd had a couple of good massages, I'd probably have been a lot better a lot quicker'. But obviously, they can't do that at the moment. So it's a case of, I've got to make sure that I do exercises for myself. So that's something else I've got to think about in my day: looking after me. Well, I've always tried to look after me so that I'm okay to look after James. That's what I've got to be aware of now.

22 ‘Audrey’: It's not easy thinking about yourself.

21 ‘Linda’: No, no, you're right.

22 ‘Audrey’: I think that the thing is, when you're out as a couple, people know James has got Parkinson's. I always found that people used to say to me: 'How's Eric?' [...] Nobody ever said: 'How are you?' I obviously looked well. You don't see the mental thing, the stress and the anxiety.

21 ‘Linda’: Yes, I will usually, if anybody asks, I usually say: 'Oh, yes, I'm fine', you know, even if you're not, because a lot of the time people don't really want to know what's the matter, do they? They just want - you don't want to say: 'Oh...' like I have just been doing now, going through all my bits and bobs. But you know, you usually say: 'Oh, I'm fine, you know'. And yes, you're right. They say: 'Well, how is James getting on?'

ANDREA: So you've already got a barrier there. People aren't seeing you. With or without a mask, they're not seeing you. Stick a mask on top of that and there's even less likelihood of people picking up on those little nonverbal signals: if you're looking particularly tired or, you know...

22 ‘Audrey’: You don't, though, to be honest, when you're caring for somebody that has got an illness like Parkinson's. I might just be speaking for myself, but I found that when we went out, I always put on this: 'Oh, yeah, yeah, we're fine' and that you're like Tigger, almost. But it doesn't matter what people say to you. When you're at home, those curtains are closed and that door is locked, you're on your own. That's when your shoulders go down. And then the sadness comes.

21 ‘Linda’: Yes.

22 ‘Audrey’: But when you're out and about -

21 ‘Linda’: Yes

22 ‘Audrey’: - you always put a smile on your face because it's hard enough when there's one person, but when there's two of you - and the thing is, as well, they can't see if you've got depression or anxiety or stress or you're tired. They don't see that physically, they only see the [person] at the side of you with the dyskinesia or the shakes or whatever it is they've got.

21 ‘Linda’: Yes

22 ‘Audrey’: That is what they say immediately. And you're just the person that's holding their arm.

ANDREA: It's something about Parkinson's. There's a lot of hidden disabilities, but Parkinson's isn't one of them. Parkinson's, it's out there for all to see once you get to the mobility issues. I mean, there's a lot of hidden problems in Parkinson's....

22 ‘Audrey’: Oh yes, very much so.

ANDREA: ...but it's your classic movement disorder - I mean, they call them the 'movement disorder nurses', don't they? For want of a better term, there's a performative aspect to Parkinson's - Parkinson's performs through the person who has it?

22 ‘Audrey’: Yes.

ANDREA: And, you know, it draws the eye, doesn't it? It's an embodied condition....

22 ‘Audrey’: Yes.

ANDREA: ...that draws the eye to the person who has the Parkinson's and away from the carer. And it's very interesting what you were saying, Audrey, about how you put a mask on, when you go out?

22 ‘Audrey’: You do because you - like Linda says, you know, I think everybody's the same though. Even if you aren't feeling 100% well. Do you tell friends that you don't feel 100% well? You tend not to, don't you? Especially if you don't see - you might not see somebody for a month, or you see them, and they say: 'Oh, how are you?' And you always say: 'Oh, I'm fine'. And you're not. And with Parkinson's I think, actually, for me, you die a little bit inside every day as their illness progresses. As they're dying, you're dying as well. Because it's - there's nothing you can do to help. So you put this facade on, you become, you know, Dame Judi Dench - not quite as good and not on the same salary - but you do, you put a front on. And you know, even if you haven't - even if I didn't have an [‘Eric’] at the side of me, I would still say: 'Oh, yeah, yeah, I'm fine'.

ANDREA: It's interesting that you said that you could go a month without seeing anybody. Is that before the lockdown?

22 ‘Audrey’: Yeah, yeah, yeah.

ANDREA: So, caring, you've got social isolation?

22 ‘Audrey’: Yeah. Yeah.

ANDREA: I wonder how many carers, when lockdown happened, said: 'So what else is new? How's my life going to change that much?'

22 ‘Audrey’: Yes, possibly. Yeah, yeah.

21 ‘Linda’: Yes, I'll be honest, I didn't think it would be as bad as it has been going on. I thought: 'Oh, all those cupboards I thought I'd clean out, and drawers and things'. Because you're out so much that you don't get chance to do, you know, deep things in the house, you just clean and that's it. But it didn't turn out like that at all. So, you know, the little jobs that could be done were - it just turned into a nightmare. And I really felt I was - I don't like to say too much because James is in the next room - because it wasn't his fault, and he didn't always know what he was saying and doing, but... It was very difficult for him, but whatever he did, didn't seem to turn out right. And it just caused more stress. And when it went on for a couple of months, that's where I just thought: 'I don't know what I'm going to do'. And what can I do? And I didn't talk about anything to my daughter either, because I didn’t - she's got three children and a husband.

22 ‘Audrey’: Yes, we don't - you don't talk to your children about it. You know, your kids have all probably said the same to you, you know: 'You must tell us, you must tell us', but you think: 'Well, no, you've got your own life and you've got your children, you've got your work. You don't need to hear my problems'. But that's - to be honest, I think that's where we come in with each other, because [statement directed at 21 ‘Linda’] I'm happy for you to ring me if ever, ever, you're feeling like that, and you want to talk to somebody, bend my ear, Linda, I'm quite happy.

21 ‘Linda’: Thank you. Yes, I phoned the area, you know, supervisor to speak to her, then I phoned the Parkinson's nurse. And that's when they decided to drop some of his medication. And that sort of improved it. Because I mean, it was hallucinations, and it was getting scary.

22 ‘Audrey’: Ropinirole?

21 ‘Linda’: No, no, they didn't give him anything. They just took his Pramipexole, I think it's the Pramipexole, they dropped that. And then they - and then I managed to get to see, because still had

his dyskinesia, so we managed to see his consultant [name of doctor]. And then he, like, quartered his medication, which helped his mind. And he had a memory test as well, and he came out of that with flying colours. But if they'd seen him like three or four months before, it was totally different. But I would say, for two or three months I didn't know what I was going to do. I just, I couldn't help him. And through no fault of his own, all the jobs half done, things that were lost, and things that were done, and I had to clear them up. Things that were accidentally done that - he was trying, he obviously was trying to do little jobs because he felt he could do them. And he's always done them. But he was finding it difficult as well. Totally being in indoors week after week when normally we were out every day, obviously got to him as well. But the hallucinations and the anxiety - it was getting a bit scary. He was seeing the grandchildren, and thinking I was in bed when I wasn't in bed, and yeah... I mean, it's a lot better now. Gradually, he's got better. And I just have to sort of say to him: 'Well, I'm sorry', if he wants to do something. I'll say: 'Well, look, I'm sorry, you know, I don't think it's a good idea'. Because once he starts, and then maybe 10 minutes later he's so exhausted, he can't carry on with whatever it is.

22 ‘Audrey’: It's good that he wants to try, though.

21 ‘Linda’: Yes. And I appreciate he wants to try but -

22 ‘Audrey’: It doesn't make it easy for you.

21 ‘Linda’: Because then I've got to clear up. I wrote things down that he did, I'm not going to say what they are - nothing horrible, but just things that happened and I thought: 'I wish you hadn't done that because I now I've got to go and - you're trying to help by doing something and now I've got to go and clean it up'. I think going into lockdown, I thought: 'Yes, great', because we were doing puzzles and we have a game we play which you have to use your brain, but he couldn't concentrate on anything like that so we sort of gave up. But because we used to sit at the table and do a puzzle, you know, you can take yourself away from life and just carry on doing the puzzle, that takes you

away. But he couldn't concentrate that much on that. So, you know, that stopped. Playing this game stopped. And I'd try to clean out a wardrobe or something, but I couldn't. I said to him: 'It's like leaving a child who's not going to sit where you've told them to sit and "stay there, behave yourself"!' And I'd come back and I'd think: 'Oh, he's trying to help, I know he's trying to help me', but he's done something that I've then got to sort out, giving me more stress. But anyway, things are getting better, I'm glad to say. And I think that art is a medium that he really enjoys - when he's capable of doing it, as I say, this morning he felt he had to have a sleep, he couldn't do the video course. But it's a godsend, in a way, that he likes art. In fact his art class, which is usually on the Thursday morning, is now closed because of the rule of six - they've been told by the Council to close.

ANDREA: Something that really impressed me, Linda, about yourself and James, has always been how you've got a lovely programme of activities, you know, you had such a paced life before lockdown. Like you said, you had things to look forward to every day, a variety of activities, you could pace yourself to that variety, it was well thought out. And you had a flexibility around it as well. And suddenly those options have been shut right down, haven't they?

21 ‘Linda’: Oh, definitely. I don't think we'll ever get back to our sequence dancing. They're not dancing at all now, the teachers. In fact, one of the leaders phoned me this morning, the dancing holidays - it's been a busy day on the phone this morning, never got any phone calls for nine months, you know, and then the physiotherapist and this teacher - they live in Leeds and we used to go on dancing holidays with them. And they've managed to start a dance that is a social dance so if they're couples, and self-isolated, they can actually do a bit of that. But our girls in [name of town], it's sequence dancing and, as there are a lot of single ladies, they dance with everybody. Even I dance with some of the ladies if James didn't want to get up. So it's very difficult to know whenever that will start again. So we're literally down to doing things on Zoom now.

ANDREA: How often do either of you actually leave the house?

21 ‘Linda’: Well, I've tried to go - we've tried to go out at least once a week so that James can use his scooter. I had to take him to the doctor's, I think it was last week, when we were doing a Zoom meeting, when I had to take him to see the nurse because of his scalp. But as the weather's changed, it's quite chilly out, haven't really been out a lot. No, not at all. In fact, my son phoned this morning and I said: 'Oh, it's sunny' - he lives down south - and I said: 'Oh, it is sunny'. He said: 'Well, why don't you go out in the garden for an hour?' And I thought: 'Okay, I will'. But then with the phone calls...

ANDREA: And me!

21 ‘Linda’: And you! It's not your fault. I mean, I was - and then James wanted me to try and get the picture of the lesson he's doing [phone rings] And there's the phone again! Would you believe it? It's just [laughs] ... I'll let James get that. So I'd say in the last week or two, we haven't really been out at all.

ANDREA: And how about yourself, Audrey?

22 ‘Audrey’: To be honest, sometimes I've been out every day if it's just for a walk, but I might have only been in the garden right over the - you know, at the beginning of lockdown, it was so nice. I just spent a lot of time in the garden, doing the garden. But I'd joined an art group. Because I moved to [name of region], it'll be two years in December, and I joined an art group at [name of college]. And because they couldn't do the evening sessions, they were doing our lessons online, but also sending projects out by email - challenges and things. So I actually sat in the garden and did a lot of painting. [...] I can't - I honestly don't think I've been out that much, out and about, certainly didn't go in a supermarket for a long time. Or a shop, for a long time. But no, I certainly haven't been out as much as I did before lockdown. [...] I have my grandson three half days a week. But the strange thing is, my son used to come in two mornings, and have breakfast and then - you know, we'd have breakfast

together - and then he go off to work. Whereas now he drops his son at the end of the drive, and he runs up with his little rucksack on his back, and it's: 'Bye bye!' and that's it. So I haven't been near him. But the other thing I suddenly thought of the other day, even since right from beginning of lockdown in March, we haven't hugged or even bumped elbows. So yeah, that's weird. Weird.

21 ‘Linda’: That's been awful. James and I were just out walking one day - this is just before the kids went back to school - and our youngest granddaughter, she's 12, she was playing in the park, and she was with a friend. And she came running over to us with her arms out. And she stopped. And I said: 'Oh, we can't hug'. So, you know, we had a little chat, and then we went to our daughter's, because we were allowed to go there then, in the garden. I said: 'Oh, I saw [granddaughter's name]' and I said: 'You know, I wanted to hug her so much'. And she said: 'Oh, maybe you should have, because they're back in school next week'. And I thought... I wish I had now, because we're back to, you know, no hugs again. And that's that is very hard. Yeah, that is hard.

ANDREA: Yeah, it's as if our natural instinct to touch has been polluted by fear.

21 ‘Linda’: Yeah. Mm hmm.

ANDREA: [...] There's got to be such a legacy of fear attached to touch, even as we come out of COVID. Our instinct has changed. I mean, for a little girl to stop in her tracks, that just goes to show how embedded, how quickly embedded, fear of touch has become.

21 ‘Linda’: Yes. Actually, the children are very, they are very good. They never went out for weeks and weeks in the beginning. The 17 year old - I mean, my daughter said she's more: 'Sanitise your hands, wash your hands. sanitise your hands'. She said she's so, you know, adamant that you've got to do this. She was going to - well, she's at college. And she said that she's so strict with everything, that she's so sensible. It's lovely to see, but it's a shame, isn't it, that there's this fear put in. Because they're all afraid, they won't come in, they haven't been in. She came and we sat in the garden, and

they've all come, sort of individually at times, and they've sat in the garden. But they're all scared of giving it to us. So that's why we don't go out a lot. To - in a way, because I don't want to mix with somebody that might have it. I said to James: 'What if we catch it just for the sake of going to get a newspaper or something?' I run in and I pick up a newspaper, and then I just pay for it in the Do It Yourself thingy. And because the family are trying to keep us safe, it doesn't seem right to spoil that and go out somewhere and catch it. But he doesn't actually think - I don't think he's thinking. If he thinks he wants to go somewhere he'll say: 'Oh, well, let's just pop to...' without thinking that we can't actually do it, because it would mean mixing with people.

22 ‘Audrey’: If it's open!

21 ‘Linda’: Oh, I'll tell you what. I know it's a bit of a joke, but if I say: 'Oh, I think I'll have something or other' - I don't know, maybe a cream cake or something (on my diet!) - he says: 'Oh, well, let's pop to B&Q!' Because B&Q is the store that he's wanted to go to for the last nine months. And our son in law - well, actually daughter and son in law - they're quite good, they'll order things online for us if we want something, like stuff to glue the shower up together again and things. And our son in law went there, must have been two or three months ago. And he said it was absolutely awful. He said people were - they had markings on the floor, people were supposed to be keeping metre two metres apart - but then as you were queuing, people were walking right past you because they didn't want to queue up. And I said: 'Tell that to James, because he's dying to go to B&Q'. And I know, this is nearly 50 years. And he said it was awful. It felt very, very nervous about being out, so...

ANDREA: And it's all these familiar things that help to keep your wellbeing going. It's that - you know, even when you're poorly, there's a wellness within your illness that you can find. And you get your structures going, don't you? You get the rhythms of your day, you get your patterns going. When you're denied your wellness in your illness, it does come apart very quickly, doesn't it?

21 ‘Linda’ and 22 ‘Audrey’: Mm hmm.

ANDREA: And it's been such a - particularly the distancing has been the disruption, hasn't it?

21 ‘Linda’: Yes. And it's the fear that you might be good at distancing, but other people aren't. And quite often, that's what you see when you're out. People aren’t particularly worried about just walking straight past you. And they've gone past you before you think: 'Oh my goodness', you know: 'They're breathing on me. I shouldn't be here'. But the thing with masks, I find, that gives me a bit of anxiety as well, because I can't see with my glasses on. And I've tried putting stuff on the glasses. And then my daughter got me some with the vent in, and they don't work. I've obviously got to try and get a proper one. But if I wear it for more than a few minutes, that's so I can manage to go into Lidl, grab a paper and maybe a couple of bits, do the paying myself, and then out. And I'm all hot and bothered after it and, you know, anxious and think: 'Oh, I wish I hadn't had to do that'. But it is trying - I'm trying to sort of wean my way back into doing things like that. But now it's - now it seems, you know, not a good thing to do.

ANDREA: The path that you've marked out has been disrupted, hasn't it?

21 ‘Linda’: Again!

ANDREA: Yeah! This is something - this is a theme that has been emerging: that the communication about the distancing and about how to wear your mask, what situations need to have PPE, that is directly influencing how we actually communicate while we've got the mask on, or while we're having to do it on Zoom because we can't be in the same room. There is a blurring of the boundaries. When we started looking at designing this project, we thought it would be all about how you use your eyebrows and how you express yourself - you know, literally express yourself. And yes, it is about that, absolutely. But time and again, what seems to be coming through is: 'I can't concentrate on working out what people are trying to say behind the mask, because I'm constantly going through in my mind: "Is this correct? Is my distance right today? Are we supposed to be wearing a mask in this circumstance? Why are you wearing, or why are you not wearing your mask?"' We've still got all this novel information coming at us that we're having to process because the rules haven't settled down in our minds. And that's distracting us from just going: 'Right. What you're trying to say to me again?' It's interesting, Linda, that you and James had to go down to the doctor's surgery. Can you tell me a bit more about how that experience was?

21 ‘Linda’: Well, because James has solar keratosis [lesions that can progress to squamous cell carcinoma] and he was for a few years - probably five or six years - he was attending a clinic for the dermatology. He's had various things done to his head. He was discharged in 2018 because it was a lot better, and the idea was to keep it better himself with creams and washing hair, shampoo and things. And then during 2019, it started to come back. Whatever he did, it was like scabby, and now he's sort of bald anyway, so it shows up more. And she given us a year and if it was coming back, and he wanted to see the clinic, we could ring them, and we wouldn't have to go to our doctor. Well, when he said: 'Oh, it's. you know, it's getting worse because it itches' - and if he touches it, and the scabs come off, and then it's rather nasty - well, when I found the paperwork and I phoned up, we were about a month over the date. And they said: 'Oh, I'm very sorry, but you've got to go back to your doctor'. Well, this was about, I think it was either September or October, and then sort of by the time we did it, you know, you're coming up to Christmas, and then we didn't do anything about it. And then of course January, February, no chance of really getting to see the doctor anyway. And then it's all got worse. Well, obviously lately, he's not, erm... it's been difficult for him. And it's got worse, and the rubbing... they get - they looked really, really nasty this weekend. So on the Monday, just phones up and I was given a phone call with one of the nurses and explained what was happening. And she said: 'Well, I really need to see it'. She couldn't really, obviously, she couldn't say over the phone, she couldn't say... So that's what we had to do, was pop down to the surgery so the nurse could have a look at it. And then she just had one look at him and she said: 'I'll refer you to the dermatology clinic'. So that's how that happened.

ANDREA: So it's one of those situations where in-person is the only way.

21 ‘Linda’: Yes.

ANDREA: It's not one of those situations where there's a viable workaround.

21 ‘Linda’: No.

ANDREA: I mean, did they offer a video consultation where James would [indicates holding camera phone to head] his head like that?

21 ‘Linda’: No, they didn't actually. I mean, I was surprised what she said. I thought they might prescribe some cream or something to start with. But she said: 'Oh, no, I'll have to have a look at it'. And so, we went down, which was good. And then we actually got a letter saying he has an appointment. But it's for January.

22 ‘Audrey’: Oh, January?

21 ‘Linda’: Yes, it's January. When we got it, it was like four months, got to wait about four months. So in that respect it's, you know, it's quite a long time.

ANDREA: That's quite a wait.

21 ‘Linda’: It is. Actually, I meant to phone up and find out, because he was going to [name of town] clinic. That's where he was seeing them. And this is [name of city]. With [city], I know from past experience, [city] parking is a nightmare. So what we started doing was doing the park and ride and then getting off at the bus stop and just walking through. But as his walking's so bad - I mean, he's saying: 'I'll be all right, I'll be all right' - and then coming back, we were getting all the school kids - and this is a one o'clock appointment, so probably the schoolchildren will be trying to get this bus as well. So the bus stop was always busy. So I'm worried whether - with a walker, it's going to be too big for the bus, or if he takes his stick, is he going to have difficulty walking? It's not far, but it could be far enough to exhaust him. That's an ongoing thing I'm thinking about at the moment, maybe asking

- but they may not be doing any clinics in [town], I don't know. They may not be able to do anything at the moment. So you know, it's unfortunate.

ANDREA: It's interesting that quite a lot of these issues would be issues at any time, wouldn't they? And there are some things that need to be tackled, that are beyond just the issues with PPE and distancing - the infection control rules - for life to be made a bit easier for carers. The sort of pre-existing challenges that, if they had been tackled - like better parking, support, you know, fast track referrals, things like that - it would make the life of somebody who needs health and social care easier when the infection control stuff got put on top of it. There would be more flexibility, more wriggle room, for people to find their path through this time. So yeah, this seems to be these sort of themes about pre-existing services. A good pre-existing service has meant the current challenges are more surmountable, but if there's poor pre-existing issues, things have been exponentially harder. So, you know, the life of a carer was already difficult and was already isolated, and you were already wearing your mask in a psychological way, in a sort of 'grin and bear it' kind of way. And it's just sort of amplified the effects of this extra layer that has been imposed on the lives of carers. Am I making this up? Put me right, ladies, put me right if I'm going off on one here. What do you think of that idea?

21 ‘Linda’: Yeah, it is. It's all extra pressure, isn't it? Yeah, you've got a worry of making sure you don't go out and catch COVID, you've got to care for your partner, and then I've got - I have been thinking about it, about cancelling it because I don't know whether I can get into [city hospital]. As I say, he was going for lymph node checks for a couple of years. And he could walk better then. But to park - quite often I would have to stay in the car park and he would go in and then I'd find a parking spot, you know? It was difficult then, but at least we were fitter if you like. But now it's - I've left it, because I'm grateful for an appointment, but I have to think now of what he's going to be like in four months' time. I don't know whether I'll be able to get him there as I know that all the dis - and we didn't have a disability badge then, because he didn't feel he needed it - but all the disability parking

spaces, if I remember rightly, were - they've got big car park, you know the car park at [city hospital] do you? As you go in there was... I'm sure that disability parking spaces were... They were behind the barrier, which I don't even think there were disability spaces inside the barrier, were there? they're all outside.

22 ‘Audrey’: I don't know, to be honest.

ANDREA: I was sat in on a council meeting last night, of the Health and Wellbeing Scrutiny Committee - a different council - and one of the counsellors brought up a question about what is being done to support carers during this time. And the answer that came from the CCG representative was: 'Oh, that's not a problem. We're not getting anybody, you know, asking us for help so I don't think you've got a problem there'. What do you think's going on there?

22 ‘Audrey’: The majority of carers won't ask, that's why.

21 ‘Linda’: No, that's right.

22 ‘Audrey’: They want somebody to say to them: 'Do you need any help?'

21 ‘Linda’: Mm hmm.

22 ‘Audrey’: Because you don't bother - I suppose in a way you don't feel that things are bad enough, if I say that, in your mind. You feel things aren't bad enough for you to be able to ask for help [link interrupted]. But I just feel, as well, that there isn't much out there. I think a lot of people are quite ignorant to what carers put up with, what carers have to do. They like to wash their hands of it. If it doesn't happen to them, they're not interested, effectively, I think. And I don't think - it was bad enough before COVID and I can't imagine that it's got any better so I should imagine [link interrupted] if anything, because the last thing on the list will be: 'What can we do for carers?'

ANDREA: Yeah. And the irony is, when all the services had to withdraw because of the distancing, a lot of people were left holding - I was gonna say holding the baby, but - the person with the condition. It was almost as if - have you ever seen those comedy scenes where there's soldiers on a parade ground, and the volunteers are told to step forward and everybody steps back?

21 ‘Linda’: Steps back, yes!

ANDREA: And you're left standing: 'I didn't move forward, but...?' 'Right! You!' And I think COVID has made that happen a lot of the time, you know, people who would just pop in and see their mum on a Friday, just to have a catch-up, maybe make the tea. Suddenly they've turned around and realised: 'I'm it, there's nobody else, suddenly there's nobody else coming in here and mum can't go out and access what she used to. Suddenly, I'm a carer. How do you do this?'

22 ‘Audrey’: Yes.

ANDREA: And there's this sudden change in identity that people have experienced due to COVID. It seems quite a transformative kind of situation.

22 ‘Audrey’: Yeah, I just think, I don't know - unless carers speak out, I don't know how that can be made any different. And I think carers are a fantastic breed, and I'm not talking about myself. I'm talking about, you know, the people that I've known over the years that have cared for somebody. Unconditional. It's just it's incredible, the love and affection that people will give. And yes, I must admit as well, you get very frustrated and angry and want to throw the teddy out of the pram and, and it is very hard. But if you don't speak out yourself, I don't know what will trigger it, I don't know how you can get a trigger. Do you get a trigger from your GP when somebody is diagnosed with something and you know that their partner is going to be their carer? Should that be a trigger? Is there enough medical support out there? It seems there isn't, because the nurses are disappearing. For example, for us, Eric was under a consultant to [name of major hospital], which is a well known

hospital. He had the deep brain operation, and he had that done in [a different city]. But at that stage he was - well, he was he was still at home, but the operation didn't work. And the appointments with the consultant were getting further and further apart. And I know a couple of our members were saying: 'I haven't seen a consultant for two years, I haven't seen one for 18 months'. And we used to see a consultant, perhaps once every six months. But we'd see a Parkinson's nurse once every six months, so we did see somebody every three months. And they were also on the end of the phone. But gradually that got worse. There was one day I was at work and my husband rang me very, very distressed. And he said: 'Ring [name], ring [name]' and that was the Parkinson's nurse. And I said: 'Just ring her, just ring her'. And when I rang, it was an answering machine and it said: 'This service is no longer being provided. Please contact the consultant's secretary'. So I rang the consultant's secretary, who told me that none of the services were being provided, including the consultant, because the funding had been stopped and they were all - all neurologists - were being transferred to [name of hospital in a different area]. And to get to see anybody, we had to go back to our GP to be re-referred.

21 ‘Linda’: Gosh, that's awful.

22 ‘Audrey’: And this was after the deep brain hadn't worked, and you can imagine he was very stressed, I was very stressed, who the hell do you go to? And also, we had a fantastic support worker when we were in [name of city with the major hospital], but they were cutting back on them as well, Parkinson's were cutting back on the support workers. And she was having to move and take over, she was covering [name of four cities] instead of just [name of city with major hospital] area. So we never saw her much again, neither. And you just - you really start feeling you're on your own. But we were fortunate in a lot of ways, because Eric was still under the surgeon at [hospital where surgery took place]. And I contacted him and he said: 'Don't worry, we'll take you on under our consultants'. So we had to come down to [name of city] every time, which was very hard for Eric because he'd lost an awful lot of weight at that stage and had no flesh on the bottom, bless him. And the journey down

is only 40 minutes, but it was - it might have been four hours for him, it was so hard for him. But at least we were able to see a consultant. But that's what you're up against because the NHS has been wracked to bits and we're losing people left, right and centre. And the only person out there is you supporting - or that's how it feels, you're on your own in this one, big time. And all I can say is I'm glad he's not here now because it's a hell of a lot worse now than it was then. And I know he wouldn't have coped with lockdown, not seeing me. They had sickness and diarrhoea for two weeks and we weren't allowed in - because he went into care - nearly drove him mad: 'Come and see me! Come and see me!' 'I can't, I can't!, They won't allow me in!'

ANDREA: Audrey, I'm so sorry to hear about that.

22 'Audrey': It's not just me, it's everybody, and that's what's happening now, unfortunately. That's just my tale but I'm sure Linda can tell you the same thing.

21 'Linda': Well, I must admit, James is not that bad at the moment. But I've been really scared these last few months. And this is where I've been - I mean, I suppose in a way, because I wondered in the beginning, when does a carer become a carer? I thought: 'Oh you silly fool, you're caring all the time', but to actually start caring. And this is what I'm finding that's really scaring me these last few months, because now I'm feeling my role is changing and I'm doing all the little extra jobs that James doesn't do. They're not much in themselves, like taking the bin out or, you know, taking the recycling out - do this, that, and the other - and things that James would automatically do. And gradually I'm doing... On the ironing - I mean, with my neck, I've had terrible problems doing the ironing - well, quite often he would take over and, you know, he would help me do that. Now I'm doing it all myself. So it's not much at the time but it's - gradually I'm now tending to do, you know, so many other things. And I don't, you know, criticise him for that at all, because he can't help it. He'll take the bin out if he can but, I mean, if he's stuck in a doorway and he can't move, how can I expect him to do these things? I'm beginning to feel now that I've upped my game now, to actually being a proper

carer. And it's feeling quite scary. Funnily enough, I had a call this morning, it was the social - I call her social worker, I suppose she isn't, but she is a support worker, I think she said from the council, because I'm on the carers list. She phoned this morning, because they're starting a course. I think - did I say this in the beginning? If I'm repeating myself, I do apologise. It's to do with - it's video, next week, she's starting - about four or five weeks - but it's to help you with your computer, and where to get help for claiming, you know, if you want a blue badge or things like this, different things. I said: 'Well, Yes, I will'. And now, a few - well, a few years now, because James was going through a really bad patch after his medication had been changed and he was having trouble with mobility - she came to see us to, you know, fill the form in for... Did she do the blue badge? It was before he got a blue badge, and I've kept in touch with her. At the time, it just happened this particular morning, he was really bad and I'd been putting some washing in the washing machine and I pulled my back. So I was sitting there crippled with a heated pillow on my back, and she came to see us both and she said: 'You know, I think I could get you some back massage or something'. So anyway, over the years, she did. I used to get a couple of vouchers a year where - and then I used to pay the lady for the other times I went - but this is the only thing that's kept my back from going, you know, where I've been laid in bed for weeks - well, not for weeks, just you know, a few days. And so when she phoned up today, I thought: 'Oh, well, good, because I haven't had a back massage since lockdown'. But I think it's the Pilates that's keeping me - apart from pulling my shoulders - but I think it was doing the Pilates that helped keep my back sort of okay, because I couldn't go more than a month or five weeks and I only had to be leaning, maybe at the bottom of the bed making the bed or something, and my back would just go. And then I would be incapacitated. And I thought: 'Whoa', you know, 'I can't have this if I'm looking after James'. I thought: ‘I don't know what I'm going to do’, because she gave up when we went into lockdown, obviously, because she didn't want to do it. And then, so I thought: 'Well, you know, maybe this lady at the council will help me to get things, to organise me and think ahead - you know, what do I need, and who can I ask?' That's the thing, because I would never think of phoning, actually phoning the council, to help me.

ANDREA: So the direction of health has to be proactive, from the services to the carers?

22 ‘Audrey’: Yes.

21 ‘Linda’: Yeah.

22 ‘Audrey’: Because, Andrea, if they don't, how the hell do we know, pardon my French, but how do we ever know what there is out there? Where do you start to look? Who do you start to ask? And I always said, [link interrupted] to our Parkinson's nurse. Because Eric, when he was first diagnosed, didn't want to know: 'I don't want any information on it'. And I went on Parkinson's website. And our youngest at that stage was 10. Eric had Parkinson's 19 years, and the youngest, [name] was only 10 years old when Eric was diagnosed. So I got a book about, you know, 'a parent with Parkinson's' sort of thing with Victoria Coren [?] to explain it to him. The only place I thought there would be was Parkinson's UK, I didn't know about anything else until we got letters from, you know, about an appointment to see a consultant and everything. I mean, till you get diagnosed with something like that you are [link interrupted], you don't look at anything, do you really?

21 ‘Linda’: No.

22 ‘Audrey’: I suppose in a sense you don't want to, you have to. I said to our Parkinson's nurse - because she said to me, you know: 'Is there anything that we can do?' - and I said: 'Well, actually, what would be nice is whenever you get somebody that's diagnosed, when you see them for the first time, give them a pack of information of who they can go to for help. Not just Parkinson's UK, but your council, Carers UK is another one - I know they are around about - DIAL [Disability Information and Advice Line] - Disability information and... something else it stands for, you tell me, I don't know, but D, I, A, L - DIAL - they were fantastic, they helped to fill forms in for Disability Living Allowance, all that sort of thing. But information leaflets about what you can claim for, where you can go to for help, disability support within the home - you know, having your bathroom adapted, or a stairlift or,

you know, all that sort of information that you don't have - because not everybody's computer literate. A lot of people diagnosed with Parkinson's - now know a lot are younger these days - but a lot of people who are older, that wouldn't know how to switch a computer, on let alone search for something. So what do they do? Where do they look?

ANDREA: Because if we're going to wait for somebody to self-identify as a carer - like you very eloquently described there, Linda - there'll be people waiting an awful long time and getting into a right pickle before they think about reaching out for help, if they ever do because you don't want to lose your identity as a wife or a husband, that's your identity, that's who you are.

22 ‘Audrey’: That's the title, that is it, yeah, you're first and foremost you're - you know, you're a carer, mother, housewife, if you're a worker, whatever job it is you're doing, and then finally, you're you.

ANDREA: It's so neat, the top-down processes and structures of care that come from on high, they sort of go: 'Right, and when the carer contacts us...' It's as if somebody magically, the moment their loved one gets a diagnosis, like Superman they rip their shirt off and underneath there's a t-shirt which says: 'I'm a carer'.

21 ‘Linda’ and 22 ‘Audrey’: Yes. Yeah.

ANDREA: And everybody's in a nice, neat box and... But life's messy, isn't it?

21 ‘Linda’ and 22 ‘Audrey’: Yeah. Yes.

ANDREA Those experiences from the actual ground where you have this - your description, Linda, of that transition that you feel that you're going through right now, COVID's given it a shove, hasn't it? A big scary shove.

21 ‘Linda’: Yes. I must admit James has done, he's done very well and the doctor's always said: 'Oh, he's doing extremely well'. And even in January when he saw him, although I thought his dyskinesia was getting a bit worse because it was affecting his driving, he then said... he looked, he walked in and - with a stick now, but - and he said: 'He's doing so well, I don't want to adjust his medication at the moment, because I think he's doing very well'. But - and then like a month later, it was downhill.

22 ‘Audrey’: But that's the problem with Parkinson's.

21 ‘Linda’: Yeah.

22 ‘Audrey’: Sometimes there’s a massive [link interrupted] and they don't come back from it.

21 ‘Linda’: And that is, that was the big worry, that he'd got so bad that, you know, it just seemed to be, you know, jumping in straight away - from being reasonable and being able to get out and do things, to seeing my daughter's dog which comes to visit. She's a beautiful King Charles Cavalier spaniel, and we borrow her sometimes because she's adorable, but it's a bit scary when he thinks he's seen the dog in the house. But thinking about the council, and managing to get these back massages, to start with I think I was getting about six months' supply. But then when COVID hit I was getting two months. And basically, as far as I can see, it's down to money, it's whether they get the grant for these things, so... And I've always thought: 'Well, there's probably worse people - there's people with worse things to, you know, happening to them than there is to me'. But at the end of the day, if not everybody can get more than two, and, there's no money there to actually ... it's spread very thin. So, I mean, I don't know where they get their grants from. From the government, I imagine.

ANDREA: And what happens is, if something good is diluted so much, and then they point to it as evidence that it doesn't work, then things get discontinued. Because the evaluation that - I mean, a course of six massages, sort of like once a week for six weeks, you really do feel a cumulative benefit.

But if you're getting two massages in six months, you're just barely touching the surface. I mean, it's
a lovely- it's lovely, but... You're not touching the surface, and the evidence that you could collate to
show its efficacy is just not there because you're not getting the full experience. It's the same.
Audrey, with your specialist nurse. I mean, having a specialist nurse at the end of the phone is an
incredible resource and you can gather evidence to prove that is the case.

22 ‘Audrey’: Oh she was absolutely great. To be honest, the thing for us was our consultant was
obviously a neurologist, but he wasn't - his speciality wasn't Parkinson's, he specialised in
Parkinson's, strokes, head injuries, MS - you name it, anything to do neurological, he was a specialist
in it. She was the [Parkinson's] specialist as far as I was concerned. She was the one that did all the
training, she went to all the conferences, she learned all the new stuff. And it was often when we'd
had a meeting with her, she would say: 'All right, well, I'm going to do [link interrupted], I'll send it to
[name of specialist]' - who was the consultant - 'I'll send it to your GP as well. And I'll just change - I'll
change his medication'. And she would tell the consultant what Eric's medication was going to be
because she was the one that knew more than he did.

ANDREA: And knew Eric.

22 ‘Audrey’: Yes, and knew Eric inside out. She knew [him] inside out. And that was really sad. And
she - I mean, they actually... she was so good a nurse that they borrowed her as matron. Then we
had another nurse who was supposedly a Parkinson's specialist, but she wasn't. And you could ring
and you left a message and it might be [link interrupted] before she got back to you. And she'd say:
'Oh, I'll have to speak to [name of consultant] because I don't know the answer to that'. And then it'd
be another week before she got back to you. So it was like that. Whereas with [name of original
specialist nurse], you'd have to leave a message, but she would ring me back, usually within an hour.
And she'd give you the answer. And then when he became matron permanently, that's when they did
away with the service altogether.

ANDREA: Yeah. So this distancing is pre-existing COVID, isn't it? There has been institutional withdrawal, an institutional distancing.

21 ‘Linda’: Yeah, yeah.

22 ‘Audrey’: Yeah. And I think that - I say I know [names of two members of the Parkinson's UK branch], both. I mean, they're the ones that have said. I think it's 18 months since [name] has seen a consultant, and two years since [name] has. And I know the services at [name of town] are far and few between now. And it's sad that it's not there, because Parkinson's is not going away. I don't know when or if, but right now, nobody's ever going to recover from it. They're only gonna get worse. I mean, we need that support. You know, I always used to say Eric was the one that had Parkinson's, but I was the one living with it. And I honestly believe it's the carers - quite selfishly, I think it's the carers that need support for the Parkinson's sufferers.

ANDREAS: Thank you Audrey. I'm just looking at the time here. I know we started earlier than we thought. And you've got a delicious crispbread waiting for you, Linda!

21 ‘Linda’: I'll lose more weight if I don't eat it, won't I?! [...] Anyway, it's been lovely to talk to you, and Audrey.

ANDREA: And if there's anything that comes to your mind later on, just drop me an email. The information here has been so valuable.

22 ‘Audrey’: I was going to say, have we actually discussed what you wanted to discuss?

ANDREA: We've covered what's important. And if it's important to you, that means it's important to me, instead of the other way around. That's the way research should go. We need to know what's important to you, and roll with that. So thank you.

APPENDIX D: EXAMPLE CASE ANALYSIS

21 ‘Linda’: Parkinson's support volunteer

22 ‘Audrey’: Parkinson's support volunteer

Linda and Audrey were interviewed together from their respective homes on Teams on October 1 2020. They were both support volunteers for a local branch of Parkinson’s UK, using their experience of being carers for their husbands to support others. Linda was living with her husband ‘James’, who had Parkinson’s which was affecting his mobility and cognition. Audrey lived alone: her husband ‘Eric’ had died with Parkinson's in 2017 [22/33] after being diagnosed for 19 years [22/519].

PRE-EXISTING CONDITIONS

Audrey described how carer isolation unconnected to the pandemic was both social and physical. Audrey said: ‘**When you're at home, those curtains are closed and that door is locked, you're on your own. That's when your shoulders go down. And then the sadness comes**’ [22/115]. ‘And with Parkinson's I think, actually, for me, **you die a little bit inside every day as their illness progresses. As they're dying, you're dying as well. Because it's - there's nothing you can do to help**’ [22/142]. Audrey agreed that, **even before the pandemic, carers could go a month without seeing anybody** [22/150].

Audrey spoke of carers in heroic terms, with a caveat that their heroism has limits which required external intervention. Audrey said: ‘I think carers are a fantastic breed, and I'm not talking about myself. I'm talking about, you know, the people that I've known over the years that have cared for somebody. Unconditional**. It's just it's incredible, the love and affection that people will give. And yes, I must admit as well, you get very frustrated and angry and want to throw the teddy out of the pram and, and it is very hard**’ [22/427] […] ‘**I always used to say Eric was the one that had Parkinson's, but I was the one living with it**. And I honestly believe it's the carers - quite selfishly, **I think it's the carers that need support for the Parkinson's sufferers**’ [22/613].

Linda and James made a success of living with Parkinson’s by maintaining a social life around sequence dancing clubs and dancing holidays [21/217].

Linda and Audrey described how carers were reluctant to reach out for help due to unrealistic expectations of their coping abilities. Linda said she '**would never think of phoning […] the council, to help me**' [21/510]. Linda agreed when Audrey said: '**The majority of carers won't ask […] They want somebody to say to them: "Do you need any help?"'** […] Because you don't bother - I suppose in a way **you don't feel that things are bad enough, if I say that, in your mind. You feel things aren't bad enough for you to be able to ask for help**' [22/402].

Audrey said carers in need of support were being forced to rely on self-advocacy because there seemed to be no mechanism to trigger proactive or anticipatory support, which was essential because it was unreasonable to expect carers to have an understanding of what kind of information they would be requiring from the role bestowed on them by fate rather than choice. Audrey said, 'if they don't, how the hell do we know, pardon my French, but how do we ever know what there is out there? Where do you start to look? Who do you start to ask?' [22/515] […] 'I don't know how you can get a trigger. Do you get a trigger from your GP when somebody is diagnosed with something and you know that their partner is going to be their carer? Should that be a trigger?' [22/431]. 'Unless carers speak out, I don't know how that can be made any different' [22/426]. 'If you don't speak out yourself, I don't know what will trigger it' [22/431].

Audrey identified how the moment of diagnosis was not the time to overburden a patient and their family with information. Instead, it was critical time to engage sympathetically with a patient and their family with a view to an ongoing relationship. Audrey said: 'Because Eric, when he was first diagnosed, didn't want to know: "I don't want any information on it"' [22/517] '…til you get diagnosed with something like that you are [link interrupted], you don't look at anything, do you really?' [22/523]. 'I suppose in a sense you don't want to, you have to' [22/527]. Linda agreed [21/526].

Audrey said, when Eric was first diagnosed, she was left to support her family's adjustment to the news on her own and would have appreciated finding out sooner about the organisations who eventually helped her. Audrey said: 'I went on Parkinson's website. And our youngest at that stage was 10' [22/518]. 'So I got a book about, you know, "a parent with Parkinson's" sort of thing […] to explain it to him [22/520]. Audrey said: '…what would be nice is whenever you get somebody that's diagnosed, when you see them for the first time, give them a pack of information of who they can go to for help. Not just Parkinson's

UK, but your council, Carers UK is another one - I know they are around about - DIAL [Disability Information and Advice Line] […] - they were fantastic, they helped to fill forms in for Disability Living Allowance, all that sort of thing. But information leaflets about what you can claim for, where you can go to for help, disability support within the home - you know, having your bathroom adapted, or a stairlift or, you know, all that sort of information that you don't have' [22/529].

Audrey warned of the pre-existing need to diversify provision of information and support for carers beyond websites to account for the digital divide. Audrey said: 'because not everybody's computer literate. A lot of people diagnosed with Parkinson's - now I know a lot are younger these days - but a lot of people who are older, that wouldn't know how to switch a computer, on let alone search for something. So what do they do? Where do they look?' [22/536].

Audrey described the metaphorical mask worn by the carer as a coping strategy. This existed prior to, and independently of, pandemic mask-wearing and distancing. Audrey explained: '…I found that when we went out, I always put on this: "Oh, yeah, yeah, we're fine" and that **you're like Tigger, almost**' [22/113]. 'When you're out and about […] **you always put a smile on your face because it's hard enough when there's one person, but when there's two of you…**' [22/118]. Linda concurred: 'If anybody asks, I usually say: "Oh, yes, I'm fine", you know, even if you're not, because a lot of the time people don't really want to know what's the matter, do they?' [21/104]. 'Even if you aren't feeling 100% well. Do you tell friends that you don't feel 100% well? You tend not to, don't you? Especially if you don't see - you might not see somebody for a month, or you see them, and **they say: 'Oh, how are you?' And you always say: "Oh, I'm fine". And you're no**t' [22/140] […] '**So you put this facade on, you become, you know, Dame Judi Dench - not quite as good and not on the same salary** - but you do, you put a front on. […] even if I didn't have an "Eric" at the side of me, I would still say: "Oh, yeah, yeah, I'm fine"' [22/145]. Linda didn't confide in her daughter about her deteriorating physical and mental health because 'she's got three children and a husband' [21/164]. Audrey recognised this behaviour: '**You don't talk to your children about it**. You know, your kids have all probably said the same to you, you know: **"You must tell us, you must tell us", but you think: "Well, no, you've got your own life and you've got your children, you've got your work. You don't need to hear my problems**"' [22/166].

Linda and Audrey described how, even before the pandemic, carers were not seen: the cared-for were the focus of attention. Audrey said: 'I always found that people used to say to me: "How's Eric?" [...] **Nobody ever said: "How are you?"** I obviously looked well' [22/102]. Linda agreed: 'Yes, you're right. **They say: "Well, how is James getting on?"**' [21/107]. Audrey continued: '...they can't see if you've got depression or anxiety or stress or you're tired. They don't see that physically, **they only see the [person] at the side of you with the dyskinesia or the shakes or whatever it is they've got [22/121]. 'And you're just the person that's holding their arm**' [22/125] [...]

A carer loses their identity. Audrey said: **'...you're first and foremost you're - you know, you're a carer, mother, housewife, if you're a worker, whatever job it is you're doing, and then finally, you're you**' [22/544].

Linda's avoidance of painkillers to keep alert illustrated how carers would make decisions which adversely affected their own health in order to continue providing care for their loved ones. Because James was no longer driving, Linda avoided taking the painkillers she had been prescribed for muscular pain to keep herself free from their side effects in order to be fit to drive [21/92].

Invisibility of carers had exacerbated a tendency towards allocation of resources based on self-interest rather than need. Audrey said: '**I think a lot of people are quite ignorant to what carers put up with, what carers have to do. They like to wash their hands of it. If it doesn't happen to them, they're not interested**, effectively, I think. And I don't think - it was bad enough before Covid and I can't imagine that it's got any better so I should imagine [link interrupted] if anything, because the last thing on the list will be: "What can we do for carers?"' [22/408].

Self-care had become another task for Linda, which was only persevered with for the sake of her husband. Linda said: 'something else I've got to think about in my day: looking after me. Well, **I've always tried to look after me so that I'm okay to look after James**' [21/96] [...] '**But there's not always time**' [21/87]. Audrey agreed: 'It's not easy thinking about yourself' [22/99]. Linda had been diagnosed as pre-diabetic and was on an eating plan as part of her treatment: 'I have to do a WeightWatchers nine-month course to try and get the numbers down. And that's sort of taxing in itself, because I don't feel ill with that' [21/84]. 'It's very boring' [21/90].

When help was offered proactively, it was welcomed. Linda benefitted from proactive carer support prior to the pandemic and had an ongoing relationship with a support worker prior to the pandemic. Linda had been visited by a support worker and 'kept in touch with her' [21/494]: she had visited her during a previous deterioration in James' mobility [21/491] prior to the pandemic to arrange James' blue badge [21/492], and spotted Linda's own need for support: 'it just happened this particular morning, he was really bad and I'd been putting some washing in the washing machine and I pulled my back. So I was sitting there crippled with a heated pillow on my back, and she came to see us both and she said: "You know, I think I could get you some back massage or something". So anyway, over the years, she did. I used to get a couple of vouchers a year…' [21/494].

Linda's musculoskeletal problems, exacerbated by her carer role, had benefitted from subsidised massage but this had been reduced prior to Covid [21/571]. Linda's musculoskeletal problems had benefitted from massage [21/94], 'the only thing that's kept my back from going' [21/499]. Linda said: 'I couldn't go more than a month or five weeks and I only had to be leaning, maybe at the bottom of the bed making the bed or something, and my back would just go. And then I would be incapacitated. And I thought: "Whoa", you know, "I can't have this if I'm looking after James"' [21/504]. The provision of subsidised massages had been reduced prior to Covid [21/571]. Instead, Linda said: 'I've got to make sure that I do exercises for myself' [21/96].

Audrey, whose husband Eric had Parkinson's but died in 2017 [22/33], described the pain experienced by carers who are separated from their loved ones when they are in a formal care facility. Audrey said: 'I know [Eric] wouldn't have coped with lockdown, not seeing me. They had sickness and diarrhoea for two weeks and we weren't allowed in - because he went into care - nearly drove him mad: 'Come and see me! Come and see me!' 'I can't, I can't!, They won't allow me in!' [22/466].

Audrey described a pre-pandemic abandonment of families living with long-term conditions, specifically Parkinson's, due to de-funding. Audrey said: 'Is there enough medical support out there? It seems there isn't, because the nurses are disappearing' [22/434-01/10/20] […] **'…the NHS has been wracked to bits and we're losing people left, right and centre. And the only person out there is you supporting - or that's how it feels, you're on your own in this one, big time.** And all I can say is I'm glad Eric's not here now because it's a hell of a lot worse now than it was then' [22/463]. Audrey described how, prior to the pandemic, ‘Eric was under a consultant to [name of major hospital], which is a well-known hospital. He had the deep brain operation, and he had that done in [a different city]. But at that stage he was - well, he was still at home, but the operation didn't work. And the appointments with the consultant were getting further and further apart. And I know **a couple of our members were saying: “I haven't seen a consultant for two years, I haven't seen one for 18 months”**. And we used to see a consultant, perhaps once every six months. But we'd see a Parkinson's nurse once every six months, so we did see somebody every three months. And they were also on the end of the phone. But gradually that got worse. **There was one day I was at work and my husband rang me very, very distressed. And he said: “Ring [name], ring [name]!” and that was the Parkinson's nurse. And I said: “Just ring her, just ring her!”. <u>And when I rang, it was an answering machine and it said: “This service is no longer being provided. Please contact the consultant's secretary</u>”. So I rang the consultant's secretary, who told me that none of the services were being provided, including the consultant, because the funding had been stopped** and they were all - all neurologists - were being transferred to [name of hospital in a different area]. **<u>And to get to see anybody, we had to go back to our GP to be re-referred</u>**’ [22/435-01/10/20]. ‘And this was after the deep brain hadn't worked, and you can imagine he was very stressed, I was very stressed, **<u>who the hell do you go to?</u>** And also, we had a fantastic support worker when we were in [name of city with the major hospital], but they were cutting back on them as well, Parkinson's were cutting back on the support workers. And she was having to move and take over, she was covering [name of four cities] instead of just [name of city with major hospital] area. **<u>So we never saw her much again, neither. And you just - you really start feeling you're on your own</u>**’ [22/451-01/10/20]. ‘I know the services at [name of town] are far and few between now. And it's sad that it's not there, because Parkinson's is not going away. I don't know when or if, but right now, nobody's ever going to recover from it. They're only gonna get worse. I mean, we need that support’ [22/610-01/10/20].

Audrey and Linda described the physical pre-pandemic barriers specific to their husbands living with progressive conditions. Audrey said: ‘…we were fortunate in a lot of ways, because Eric was still under the surgeon at [hospital where surgery took place]. And I contacted him and he said: “Don't worry, we'll take you on under our consultants'. So **<u>we had to come down to [name of city] every time, which was very hard for Eric because he'd lost an awful lot of weight at that stage and had no flesh on the bottom, bless him. And the journey down is only 40 minutes, but it was - it might have been four hours for</u>**

him, it was so hard for him. But at least we were able to see a consultant. But that's what you're up against…' [22/456]. Linda said James 'was going for lymph node checks for a couple of years. And **he could walk better then. But to park - quite often I would have to stay in the car park and he would go in and then I'd find a parking spot**, you know? It was difficult then, but at least we were fitter if you like[22/386] […] '**don't know whether I'll be able to get him there** as I know that all the dis - and we didn't have a disability badge then, because he didn't feel he needed it - but all the disability parking spaces, if I remember rightly, were - they've got big car park, you know the car park at [city hospital] do you? As you go in there was... I'm sure that disability parking spaces were... They were behind the barrier, which **I don't even think there were disability spaces inside the barrier, were there? they're all outside**' [22/390].

Audrey described the pre-pandemic benefits of specialist nurses who have a deep understanding and close relationship with families with specific conditions, working autonomously within a flattened hierarchy – and the damage done when the service was lost. Audrey said her original Parkinson's specialist nurse 'was absolutely great. To be honest, the thing for us was our consultant was obviously a neurologist, but he wasn't - his speciality wasn't Parkinson's, he specialised in Parkinson's, strokes, head injuries, MS - you name it, anything to do neurological, he was a specialist in it. **She was the specialist [in Parkinson's] as far as I was concerned. She was the one that did all the training, she went to all the conferences, she learned all the new stuff**. And it was often when we'd had a meeting with her, she would say: "All right, well, I'm going to do [link interrupted], I'll send it to [name of specialist]" - who was the consultant – "I'll send it to your GP as well. And I'll just change - I'll change his medication". And she would tell the consultant what Eric's medication was going to be because **she was the one that knew more than he did** [22/586] […] '…**and knew Eric inside out. She knew [him] inside out**. And that was really sad. And she - I mean, they actually... **she was so good a nurse that they borrowed her as matron**. Then we had another nurse who was supposedly a Parkinson's specialist, but she wasn't. And you could ring and you left a message and it might be [link interrupted] before she got back to you. And she'd say: "Oh, I'll have to speak to [name of consultant] because I don't know the answer to that". And then it'd be another week before she got back to you. So it was like that. Whereas with [original specialist nurse], you'd have to leave a message, but she would ring me back, usually within an hour. And she'd give you the answer. And then **when she became matron permanently, that's when they did away with the service altogether**' [22/596].

Linda’s husband James had solar keratosis on his scalp [21/324], which can be a precursor to squamous cell carcinoma. He had been under the care of a dermatologist, who discharged him in 2018 with self-care advice [21/328]. When it became worse at the end of 2019 the dermatologist would not see James without a re-referral. Linda said: ‘when I found the paperwork and I phoned up, **we were about a month over the date. And they said: 'Oh, I'm very sorry, but you've got to go back to your doctor”**’ [21/332].

COMMUNICATION IN THE PRESENCE OF PPE/DISTANCING

Linda described how wearing a mask was, in itself, an anxiety trigger due to her vision being reduced by misting. Linda said: ‘…with masks, I find, that gives me a bit of anxiety as well, because I can't see with my glasses on. And I've tried putting stuff on the glasses. And then my daughter got me some with the vent in, and they don't work. I've obviously got to try and get a proper one. But if I wear it for more than a few minutes, that's so I can manage to go into Lidl, grab a paper and maybe a couple of bits, do the paying myself, and then out. And I'm all hot and bothered after it and, you know, anxious and think: 'Oh, I wish I hadn't had to do that' [21/300].

Linda and Audrey both expressed the pain of deprivation of touch from their children/grandchildren. Linda was unable to hug her 12-year-old granddaughter: ‘She was playing in the park, and she was with a friend. And she came running over to us with her arms out. And she stopped. And I said: “Oh, we can't hug”. So, you know, we had a little chat, and then we went to our daughter's, because we were allowed to go there then, in the garden. I said: “Oh, I saw [granddaughter's name]” and I said: “You know, I wanted to hug her so much”'. And she said: “Oh, maybe you should have, because they're back in school next week”. And I thought... I wish I had now, because we're back to, you know, no hugs again. And that's that is very hard. Yeah, that is hard’ [21/254]. Audrey said: ‘I have my grandson three half days a week. But the strange thing is, my son used to come in two mornings, and have breakfast and then - you know, we'd have breakfast together - and then he go off to work. Whereas now he drops his son at the end of the drive, and he runs up with his little rucksack on his back, and it's: “Bye bye!” and that's it. So I haven't been near him. But the other thing I suddenly thought of the other day, even since right from beginning of lockdown in March, we haven't hugged or even bumped elbows. So yeah, that's weird. Weird’ [22/247].

A culture of fear within Linda and James' family, driven by their commitment to shielding the couple, shaped Linda and James' confinement behaviour which prevented them from leaving the house or having anyone come inside their home. Linda said their family were 'all scared of giving it to us. So that's why we don't go out a lot' [21/272]. Linda was contemplating having an in-person home consultation from gym staff but was worried about inviting them in due to the increase in Covid prevalence [21/61]. Linda and James' 17-year-old granddaughter was 'so strict with everything, that she's so sensible. It's lovely to see, but it's a shame, isn't it, that there's this fear put in. Because they're all afraid, they won't come in, they haven't been in' [21/269]. Linda ruled out activities which would involve mixing with people: '…because the family are trying to keep us safe, it doesn't seem right to spoil that and go out somewhere and catch it' [21/278] […] 'I said to James: "What if we catch it just for the sake of going to get a newspaper or something?"' [21/274]. Linda and James joked about their longing for the simple but impossible act of browsing at James' favourite shop: '…it's a bit of a joke, but if I say: "Oh, I think I'll have something or other" - I don't know, maybe a cream cake or something - on my diet! - he says: "Oh, well, let's pop to B&Q!" Because B&Q is the store that he's wanted to go to for the last nine months' [21/281].

The fear of others' lax interpretation of PPE and distancing rules was a major motivator for Linda's decision to stay housebound with James. Linda wanted to deter James from acting on his longing: '…our son-in-law went there, must have been two or three months ago. And he said it was absolutely awful. He said people were - they had markings on the floor, people were supposed to be keeping metre two metres apart - but then as you were queuing, people were walking right past you because they didn't want to queue up. And I said: "Tell that to James, because he's dying to go to B&Q"' [21/285]. Linda stayed confined because she was afraid of others' interpretations of distancing: '…it's the fear that you might be good at distancing, but other people aren't. And quite often, that's what you see when you're out. People aren't particularly worried about just walking straight past you. And they've gone past you before you think: "Oh my goodness", you know: "They're breathing on me. I shouldn't be here"' [21/297]. Linda had been 'trying to sort of wean my way back into doing things like that. But now it's - now it seems, you know, not a good thing to do' [21/306].

Access to a private garden, and the weather to make it accessible, shaped wellbeing. Linda and James' garden was a place where they kept contact with their family: 'they've all come, sort of individually at times, and they've sat in the garden' [21/272]. James' deterioration meant he had begun to rely on a scooter to move around which limited the couple's options for outdoor exercise [21/71], but 'as the weather's changed, it's quite chilly out, haven't really been out a lot. No, not at all' [21/229]. The colder weather and Linda's insistence on adhering to 'rule of six' distancing rules meant Linda and James 'can't even see our family, because we'll be seven. And we can't isolate in the house, so we would usually sit in the garden. So we can't even do that now' [21/51]. Audrey also described how her garden was a haven which made her solitary withdrawal tolerable, even enjoyable: '…at the beginning of lockdown, it was so nice. I just spent a lot of time in the garden, doing the garden. But I'd joined an art group. Because I moved to [name of region], it'll be two years in December, and I joined an art group at [name of college]. And because they couldn't do the evening sessions, they were doing our lessons online, but also sending projects out by email - challenges and things. So I actually sat in the garden and did a lot of painting' [22/240].

CHANGING IDENTITY

Linda said the lockdown had made her feel a frightening shift in her identity as a carer. Linda said: '**I've upped my game now, to actually being a proper carer. And it's feeling quite scary**' [21/484] 'I've been really scared these last few months' [21/472]. '**I wondered in the beginning, when does a carer become a carer? I thought: "Oh you silly fool, you're caring all the time", but to actually start caring. And this is what I'm finding that's really scaring me these last few months, because now I'm feeling my role is changing…**' [21/473].

ISOLATION

Linda modified her behaviour during the interview because of the close proximity to her husband who could adversely react to what she said or did. Linda said she did not 'like to say too much because [James] is in the next room' [21/161].

Linda's husband James had been hallucinating about elements of family life which isolation had prevented, and Linda had worried that the rapid deterioration she had witnessed would be irrecoverable. James' cognitive deterioration had been affecting his behaviour. Linda said: 'He didn't always know what he was saying and doing' [21/161], which was a progression to which Audrey referred: 'Sometimes there's a massive link interrupted] and they don't come back from it' [20/565].Linda said: 'And that is, that was, the big worry - that he'd got so bad that, you know, it just seemed to be, you know, jumping in straight away, from being reasonable and being able to get out and do things, to seeing my daughter's dog which comes to visit' [21/566]. 'He was seeing the grandchildren, and thinking I was in bed when I wasn't in bed' [21/187]. 'It was hallucinations, and it was getting scary' [21/174]. However, at the time of the interview Linda said: 'things are getting better' [21/206], 'it's a lot better now. Gradually, he's got better' [21/188].

Distancing deprived Linda and James of the strategies which had been central keeping physically and socially active. Linda and James' sequence dancing clubs and dancing holidays [21/217] were suspended indefinitely [21/225]. **Linda thought she and James would never go back** [21/217]. The local council had instructed **James' in-person art class to close 'because of the rule of six**' [21/209]. This meant 'we're literally down to doing things on Zoom now' [21/225]

Linda initially saw lockdown as an opportunity to calmly engage in cognitive and practical activities, but this ended in failure. Linda said: 'Going into lockdown, I thought: "Yes, great", because we were doing puzzles and we have a game we play which you have to use your brain, but he couldn't concentrate on anything like that so we sort of gave up' [21/198] [...] 'you can take yourself away from life and just carry on doing the puzzle, that takes you away. But he couldn't concentrate that much on that. So, you know, that stopped' [21/201].

Linda's husband James's increasing inability to be cognitively or physically occupied presented made lockdown 'a nightmare' for Linda as a carer without respite [21/159]. Linda said: 'I'll be honest, I didn't think it would be as bad as it has been going on. I thought: "Oh, all those cupboards I thought I'd clean out, and drawers and things". Because you're out so much that you don't get chance to do, you know, deep things in the house, you just clean and that's it. But it didn't turn out like that at all. So, you know, the little jobs that could be done were - it just turned into a nightmare' [21/156]. Due to physical deterioration, James was no longer able to do his usual household tasks that he once did automatically, such as helping with the ironing when Linda's neck began to hurt [21/479], or taking out the recycling [21/476]: 'He'll take the bin out if he can but, I mean, if he's stuck in a doorway and he can't move, how can I expect him to do these things?' [21/483]. James would attempt tasks which he could not complete: 'It was very difficult for him, but whatever he did, didn't seem to turn out right. And it just caused more stress' [21/162]. 'And through no fault of his own, all the jobs half done, things that were lost, and things that were done, and I had to clear them up. Things that were accidentally done that - he was trying, he obviously was trying to do little jobs because he felt he could do them. And he's always done them. But he was finding it difficult as well. Totally being in indoors week after week when normally we were out every day, obviously got to him as well' [21/182]. Linda found this physical and emotional challenge led to moments where she would have to direct James' behaviour: 'I'd try to clean out a wardrobe or something, but I couldn't. I said to him: "It's like leaving a child who's not going to sit where you've told them to sit and "stay there, behave yourself"!' And I'd come back and I'd think: "Oh, he's trying to help, I know he's trying to help me", but he's done something that I've then got to sort out, giving me more stress' [21/203]. 'I just have to sort of say to him: "Well, I'm sorry", if he wants to do something. I'll say: "Well, look, I'm sorry, you know, I don't think it's a good idea". Because once he starts, and then maybe 10 minutes later he's so exhausted, he can't carry on with whatever it is' [21/188]. The intensity and duration of the situation led to a sense of despair: '…when it went on for a couple of months, that's where I just thought: "I don't know what I'm going to do". And what can I do?' [21/163] [...] 'for two or three months I didn't know what I was going to do. I just, I couldn't help him' [21/181].

INSTITUTIONAL DISTANCING

For Linda and James during the pandemic, medical support was available but involved negotiating obstacles: carer reluctance to ask for help; lack of medical services; engagement; and physical infrastructure of buildings. Linda's desperation led to her making the first move, phoning the Parkinson's UK area and the Parkinson's nurse [21/172]. As a result, James' medication was adjusted, which helped reduce the hallucinations [21/173]. This was followed up with an in-person consultation with James' consultant, who quartered his Pramipexole medication [21/178] and conducted a cognition test which showed that James' memory had improved. However, Linda noted that James' condition had become more labile [21/560] but this was not apparent to the doctor: 'In January when he saw him, although I thought his dyskinesia was getting a bit worse because it was affecting his driving, he then said... he looked, he walked in and - with a stick now, but - and he said: "He's doing so well, I don't want to adjust his medication at the moment, because I think he's doing very well". But - and then like a month later, it was downhill ' [21/558].

Linda’s concerns over accessibility of services when negotiating distancing and PPE requirements made the offer of a medical appointment seem more dangerous and difficult than the consequences of missing it. James’ solar keratosis condition became unmanageable during James’ lockdown deterioration, [21/337], and a telephone and subsequent in-person consultation with the GP practice nurse resulted in the re-referral to the dermatologist [21/343]. An appointment was scheduled for January 2021 [21/353], but Linda was thinking about cancelling [21/384] due to worries about disabled parking and access at the hospital [21/393], and the prospect of crowds using park and ride [21/363]. These concerns were based on the pre-existing barriers to care she had experienced Linda said James ‘was going for lymph node checks for a couple of years. And he could walk better then. But to park - quite often I would have to stay in the car park and he would go in and then I'd find a parking spot, you know? It was difficult then, but at least we were fitter if you like. But now it's - I've left it, because I'm grateful for an appointment, but I have to think now of what he's going to be like in four months' time. I don't know whether I'll be able to get him there as I know that all the dis - and we didn't have a disability badge then, because he didn't feel he needed it - but all the disability parking spaces, if I remember rightly, […] I'm sure that disability parking spaces were... They were behind the barrier, which I don't even think there were disability spaces inside the barrier, were there? they're all outside’ [21/386].

Linda found lockdown made self-care more difficult than ever. Linda found confinement, combined with baking and eating cakes, was not helping with her weight [21/85]. The increase in workload was causing Linda musculoskeletal problems. which, in the past, had benefitted from massage [21/94] but the massage therapist had stopped practicing at the beginning of lockdown [21/507].

Linda welcomed the proactive offer of help from a support worker already known to her. On the day of the interview Linda had been contacted by a support worker as a result of being on the carer’s list, and she had agreed to attend an online course ‘to help you with your computer, and where to get help for claiming […] a blue badge or things like this' [21/485].

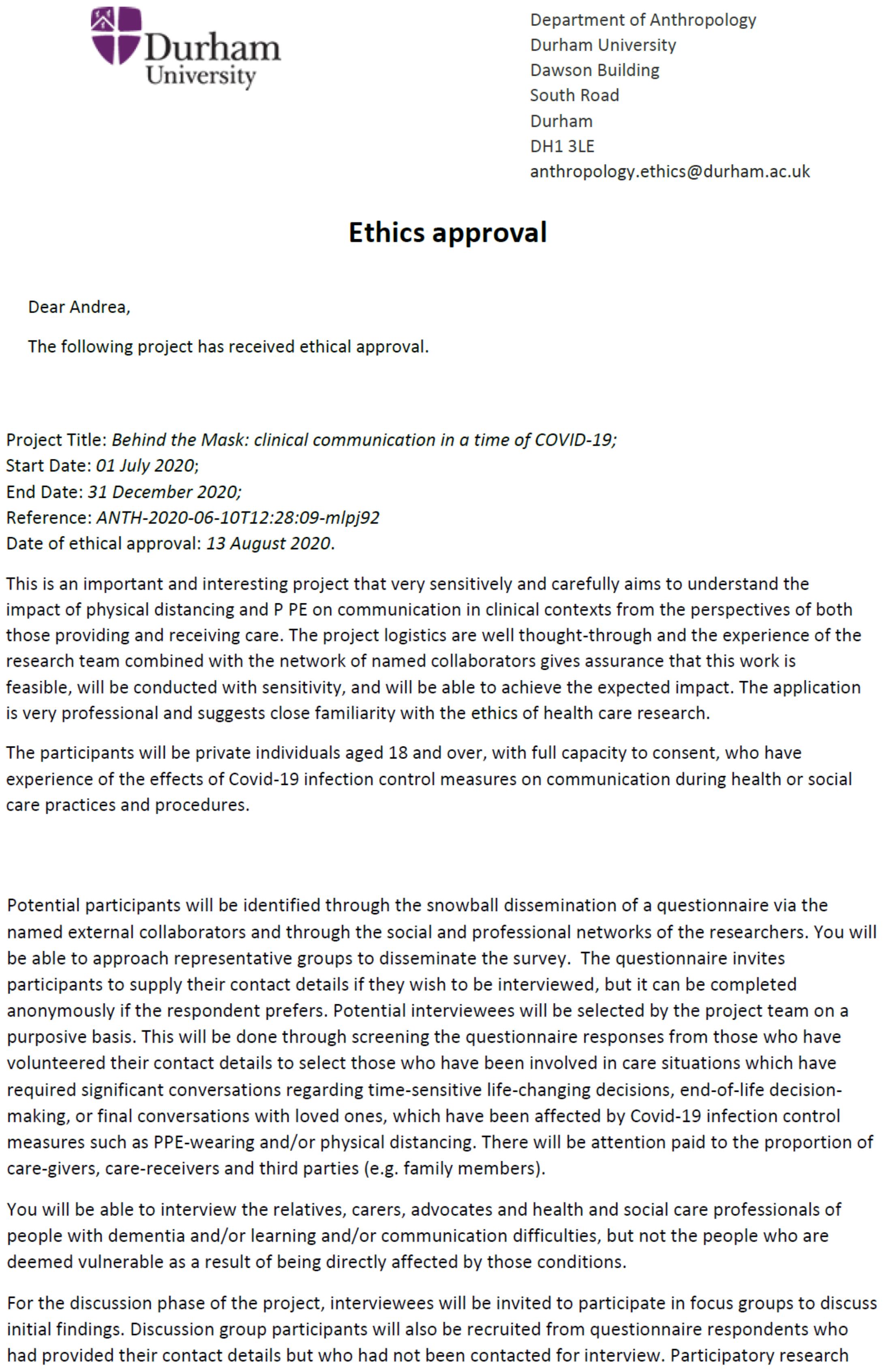
Peer support came for Linda as a result of an organic, opportunistic reaching-out in remote conversations. During our interview, Audrey offered peer support to Linda. Speaking directly to her on our Teams call, Audrey said to Linda: ‘I think that's where we come in with each other, because I'm happy for you to ring me if ever, ever, you're feeling like that, and you want to talk to somebody, bend my ear, Linda, I'm quite happy' [20/169].

DIGITAL DIVIDE

Audrey warned of the need to diversify provision of information and support for carers beyond websites to account for the digital divide. Audrey said: 'because not everybody's computer literate. A lot of people diagnosed with Parkinson's - now I know a lot are younger these days - but a lot of people who are older, that wouldn't know how to switch a computer, on let alone search for something. So what do they do? Where do they look?' [22/536].

Online socialising had limited success for Linda and James due to poor connectivity and issues with content creators. Linda and James' in-person activities were suspended which meant 'we're literally down to doing things on Zoom now' [21/225] where couple tried to maintain social activities, including Pilates [21/502], but poor online connectivity and issues with content creators limited success: 'James started this online video course and it's been a disaster because we didn't have internet last night, as I said, for hours and then he found out that there'd been a lesson. And although he's behind, he's still trying to do a painting that's a pen and ink. And then the guy, in fact, himself - the teacher - is having problems videoing it and sending it. And it's Venice in four parts. And James has only got three. But this morning, he couldn't keep up. So he's doing it in his own time. And then he couldn't get the lessons that the guy had already allegedly done. So it's been a bit difficult for him' [21/53].

APPENDIX E: ETHICS APPROVAL



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Ethics approval

Dear Andrea,

The following project has received ethical approval.

Project Title: *Behind the Mask: clinical communication in a time of COVID-19;*
Start Date: *01 July 2020*;
End Date: *31 December 2020;*
Reference: *ANTH-2020-06-10T12:28:09-mlpj92*
Date of ethical approval: *13 August 2020*.

This is an important and interesting project that very sensitively and carefully aims to understand the impact of physical distancing and P PE on communication in clinical contexts from the perspectives of both those providing and receiving care. The project logistics are well thought-through and the experience of the research team combined with the network of named collaborators gives assurance that this work is feasible, will be conducted with sensitivity, and will be able to achieve the expected impact. The application is very professional and suggests close familiarity with the ethics of health care research.

The participants will be private individuals aged 18 and over, with full capacity to consent, who have experience of the effects of Covid-19 infection control measures on communication during health or social care practices and procedures.

Potential participants will be identified through the snowball dissemination of a questionnaire via the named external collaborators and through the social and professional networks of the researchers. You will be able to approach representative groups to disseminate the survey. The questionnaire invites participants to supply their contact details if they wish to be interviewed, but it can be completed anonymously if the respondent prefers. Potential interviewees will be selected by the project team on a purposive basis. This will be done through screening the questionnaire responses from those who have volunteered their contact details to select those who have been involved in care situations which have required significant conversations regarding time-sensitive life-changing decisions, end-of-life decision-making, or final conversations with loved ones, which have been affected by Covid-19 infection control measures such as PPE-wearing and/or physical distancing. There will be attention paid to the proportion of care-givers, care-receivers and third parties (e.g. family members).

You will be able to interview the relatives, carers, advocates and health and social care professionals of people with dementia and/or learning and/or communication difficulties, but not the people who are deemed vulnerable as a result of being directly affected by those conditions.

For the discussion phase of the project, interviewees will be invited to participate in focus groups to discuss initial findings. Discussion group participants will also be recruited from questionnaire respondents who had provided their contact details but who had not been contacted for interview. Participatory research methods will be permissible in discussion groups to provide analysis of initial findings as they emerge from the survey and interviews.

The research will be conducted in accordance with Covid-19 regulations. Therefore, interactions will take place online via remote methods (e.g. Teams, Zoom, Skype, phone), with researchers and participants sheltering in place, unless and until social distancing restrictions are officially relaxed. Durham University guidelines on social distancing will be adhered to throughout the project https://www.dur.ac.uk/research.innovation/governance/ethics/considerations/people/covid-19/.

Should face-to-face interactions be allowed under the relaxation of pandemic regulations, any additional social contact restrictions which might apply to individual participants would also be observed before an offline location would be considered. Once these criteria are met, face-to-face interactions would then be considered on a case-by-case basis following an individual risk assessment.

Should circumstances permit offline meetings and you intend to conduct face-to-face meetings, please inform the Ethics Committee first, so that we can approve it. Please be aware that if you make any significant changes to the design, duration or delivery of your project, you should contact your department ethics representative for advice, as further consideration and approval may then be required.

Best wishes,

Professor Nayanika Mookherjee

Chair, Ethics Committee

Department of Anthropology,

Durham University

APPENDIX F: DATA MANAGEMENT PLAN

Behind the Mask: clinical communication in a time of COVID-19

A Data Management Plan created using DMPonline

Creators: Andrea Lambell, First Name Surname, Paul CHAZOT, Jane Macnaughton

Affiliation: Durham University

Funder: Durham University Covid-19 Response Fund

Template: DU Standard RDM Template: Version one

ORCID iD: 0000-0002-7289-4037

Grant number: 29/05/2020

Project abstract:

The study will use questionnaires, interviews and focus groups of people who have given or received healthcare during the Covid-19 pandemic to: Identify how occluded social interaction (including physical distancing and the use of masks, hair coverings and gloves) affects caring communication in a clinical context Identify how, and to what extent, clinicians and their patients/clients can adapt to the circumstances Formulate recommendations for adaptations to practice which minimise distress and facilitate communication in health and social care settings

Last modified: 15-07-2020

Data collection

What data will you collect or create?

Data collected:

Responses to anonymous online questionnaire. A paper version will be made available on request. NB: Personal contact details will be embedded in some of the questionnaire responses because the questionnaire will give the option for participants to volunteer their contact details in order to take part in interviews and/or focus groups.

Audiovisual recordings of interviews and focus groups which will take place using University-based Teams account.

Data created:

Transcriptions of interviews and focus groups

Coded notes from transcriptions

How will the data be collected or created?

The questionnaire will be generated and managed using onlinesurveys.ac.uk, accessed via Durham University's account.

Paper versions of the survey will be generated on request and sent to collaborators for anonymous distribution through their networks. Stamped envelopes addressed to the he Anthropology Department in Dawson Building will be provided with the paper questionnaires. Returned paper questionnaires will be collected and kept in a locked metal box in Andrea Lambell's home. Once Dawson Building is fully accessible, the paper records will be transferred on-site and kept securely within the department.

The interviews and focus groups will take place on Teams via the University's Teams account, where they will be recorded. Teams will be used in preference to Zoom, due Teams' encryption and transcribing functionality. The recordings will be uploaded to a Shared Research Storage folder provided specifically for this project by Durham University.

If any interviews take place by telephone, or in person (should participants request this once pandemic restrictions are lifted by Durham University), audio recordings will be made using an encrypted hand-held recording device (not a mobile phone or a device connected to the Internet). These recordings will be uploaded to the Shared Research Storage folder, then deleted from the hand-held device.

How much data do you expect to produce?

As each 1-hour Teams recording occupies 400MB, it is possible that we will generate more than 20GB of data, but less than 1TB.

Documentation and metadata

What documentation and metadata will accompany the data?

The data will be accompanied by the data management plan and data access statements noting any restrictions e.g. ethical / commercial.

Ethics and legal compliance

How will you manage any ethical issues?

Prior to any work beginning, the project will go through the University's Ethical review and approval process as described in the Ethics Policy. Any high risk areas (including data-related) will be highlighted and appropriate management and mitigation approaches put into place.

Each participant will be allocated an anonymisation code. The participants' names and contact details will matched to the anonymisation code in a key, which will take the form of a Word document which will be kept in the project's Shared Research Storage folder provided by the University. From this point, the anonymisation code will be used to identify the participant.

The information sheet and consent form will be sent as Word attachments by University email to the participant, who will be encouraged to download, sign, scan and return by email. For participants who are unable or unwilling to do this, an alternative method will be offered: at the beginning of the first interview, the information sheet and consent form will be read out by the researcher, and the participant's verbal responses will be recorded. Verbal the arrangements for consent, and how you will ensure appropriate security in compliance with data protection requirements, e.g. through anonymisation. Both the Word consent documents, and the Teams recordings which contain verbal consent, will be kept in the project's Shared Research Storage folder.

If participants do not wish to have their interviews recorded, the Teams session will not be recorded. Notes will be taken instead. These will take the form of a Word document or handwritten paper notes. Word documents will be saved in the Shared Research Storage folder, and paper notes will be kept in the locked metal box at Andrea Lambell's home.

If a participant is a health or social care professional, they will be participating in the study as a private individual. Their participation will take place outside of their employment hours.

The project topic concerns significant health conversations in stressful situations, so there is a possibility that interviews may involve emotional and/or sensitive disclosures. Therefore, care will be taken to ensure that both the participants and the researcher are in a safe and private space before the interviewing takes place. Before interviewing begins, a source of support will be identified for the participant to contact if the process provokes any adverse emotional reactions.

It is not foreseen that any further ethical issues will arise within the project, however if they do, appropriate advice will be sought from the Anthropology Department ethics convenor and the University's Research Data Management service.

How will you manage copyright and Intellectual Property Rights (IPR) issues?

Broad IPR positions will be addressed within the project set-up documentation; Contracts, collaboration agreements etc. In the eventuality that the project produces commercially valuable IP then this will be handled in accordance with the agreed position and the University’s Intellectual Property Policy

Short-term storage and management of active research data

How will the data be stored and backed up during the research?

Electronic data will be stored in a Shared Research Storage folder provided by Durham University specifically for this project, and will be backed up according to the frequency and backup site supplied as part of the SRS package. Hard copy data will be stored in a locked metal box at Andrea Lambell's home until full access to Dawson Building is reinstated. It will then be transferred to a secure storage facility on site.

How will you manage access and security?

Andrea Lambell (research assistant), Prof Jane Macnaughton (project PI), Professor Andrew Russell and Dr Paul Chazot (project co-PIs) will have access to the data.

The data will be accessed off-site via Virtual VAR. Paper-based data will be transported between Dawson Building and Andrea Lambell's home via locked metal box.

Collaborators will be provided with a fully anonymised report from the project. They will not have access to the data itself.

Data deposit and long-term preservation

Which data are of long-term value and should be retained, shared, and/or preserved?

The anonymised, de-identified research data may be of use in future historical assessments of the Covid-19 pandemic.

What is the long-term preservation plan for the dataset?

Anonymised, de-identified project data will be retained for validation / reuse purposes in line with the University’sResearch Data Management Policy for 10 years from the date of publication or end of the project if there are no publications.

Anonymised or non-sensitive research data will be deposited in the University'sResearch Data Repository.

Data sharing

How will you share the data?

It is expected that research data requiring release into the public domain in support of publication will be non-sensitive. Data will be linked via DOI within the publication record itself. Broader sharing will be dependent on considerations such as available consent and commercial potential.

Are any restrictions on data sharing required?

None are expected for non-personal data. Data will be shared under a CC-BY-NC licence which will require attribution to both funder and Durham University.

Responsibilities and resources

Who will be responsible for data management?

As stated in the Research Data Management (RDM) policy, the principal investigator has overall responsibility for research data management. Support is available through the RDM Service. It is not expected at this point that any of the PI's responsibilities will be devolved to any other members of the project team however if they are, then the data management plan will be updated to detail this.

What resources will you require to deliver your plan?

No additional resources are required beyond those already made available by the University.

APPENDIX G: INFORMATION SHEET

Andrea Lambell
Department of Anthropology
Durham University
Dawson Building
South Road
Durham
DH1 3LE

07834 603093

andrea.r.lambell@durham.ac.uk

Behind the Mask: Information Sheet

I'm Andrea Lambell, a research associate working with a team from Durham University's Department of Anthropology, studying the effects of the Covid-19 pandemic infection control measures on communication. We'd like to invite you to take part in an interview for this research project. This form offers you some information and we hope it'll help you decide whether or not you'd like to participate. If you need help in reading or understanding this form, please let us know.

About me. As well as being a researcher, I'm a complementary therapist with 14 years' experience working in palliative care as part of a team of healthcare workers. I completed my BSc (Hons) with the Open University while I worked full-time for a hospice, then I became a full-time Anthropology Masters student at Durham University in 2018. I'm now completing a PhD in palliative care.

What is the project? The Behind The Mask project aims to learn more about how your important healthcare conversations have been affected by the need to stay apart, and by the need to wear masks, gowns, visors and gloves (Personal Protective Equipment, or PPE). We will also look at the ways in which people have tried to manage these barriers. We may use the findings to develop ways to help patients and their loved ones communicate with healthcare workers while staying safe.

Why have I been invited to take part? You responded to our anonymous questionnaire, and kindly provided us with your contact details in response to our invitation to take part in interviews or discussion groups.

Do I need to take part? No: it's entirely your choice.

What do I need to do? Andrea would interview you for around an hour, inviting you to talk about your experiences of receiving or giving care during the pandemic and the lockdown. Because of the current infection risks, Andrea would interview you remotely: if possible online via Teams or if not by telephone.

What might be the risks and benefits to taking part? We will be discussing significant events in your life, which might bring back upsetting memories. If this is the case for you, we'll do all we can to signpost you to sources of support. By talking about your experiences in a confidential and safe space, you will be will be playing an important part in efforts to improve healthcare.

What will happen to the information I provide?

1. The recording of your interview will be kept on the University's password-protected cloud drive. Andrea will type out the interview to a written transcript, which will also be kept on the password-protected cloud drive.

2. All transcripts will be edited to ensure your *anonymity*. This means that you'll be given a pseudonym that doesn't identify you, and that we'll never use your pseudonym in ways that make you identifiable.

3. Everything that you tell Andrea will remain *confidential*. This means that, unless you say something to indicate that someone is at serious risk of harm, she will not tell anyone what you have said.

4. We will pay careful attention to *data security* and will follow the regulations of Durham University. This means that:
   a. Signed consent forms will be scanned and stored on a password-protected cloud drive.
   b. Andrea's notes will be saved to a password-protected cloud drive.
   c. Consent forms and notes will be destroyed three years after the end of the study.

5. We will pay careful attention to *data protection*, in accordance with GDPR (2018) legislation. This means that:
   a. Andrea won't keep any records that you haven't specifically agreed to.
   b. You can ask Andrea to show you anything she has written about you, as long as it does not infringe upon the confidentiality of others.
   c. You can ask Andrea to destroy your consent form and to remove all mention of you from notes and focus group transcripts.

How do I find out more about this study? You can contact Andrea at any time, with any questions or concerns, or to leave the project. If you'd like to speak to someone else, you can also contact the principal investigator of the project:

Professor Jane Macnaughton
Email jane.macnaughton@durham.ac.uk

APPENDIX H: CONSENT FORM

Andrea Lambell
Department of Anthropology
Durham University
Dawson Building
South Road
Durham
DH1 3LE

07834 603093

andrea.r.lambell@durham.ac.uk

Behind the Mask: Consent Form

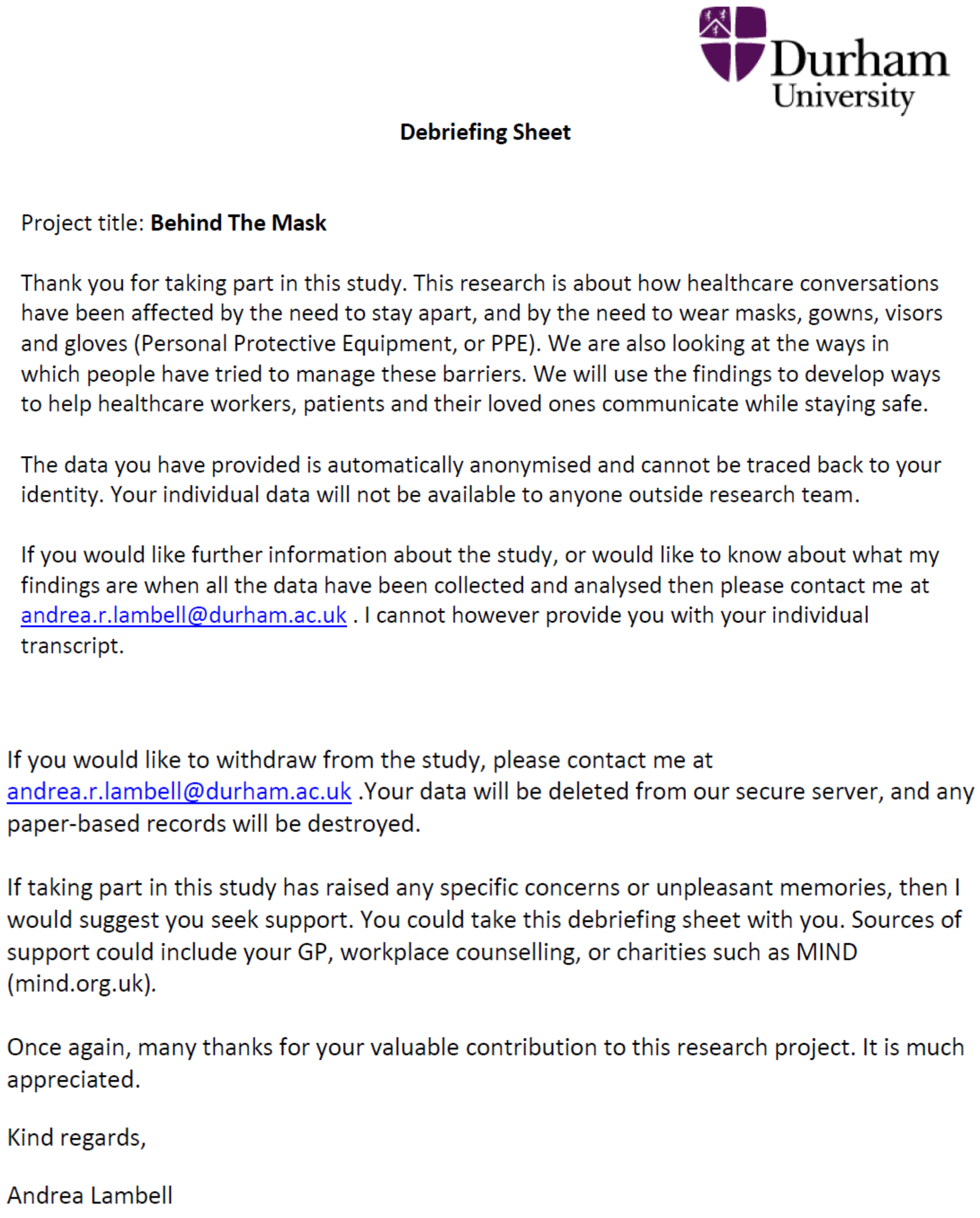
Please initial if you agree

1. I have read and understood the information sheet. ☐
2. I have asked all the questions that I need to ask for now, and I understand that I can ask any other questions at any point. ☐
3. I understand that taking part in this project is entirely voluntary, and that I can withdraw at any time. ☐
4. I agree to take part in interviews. ☐
5. I agree to take part in discussion groups. ☐
6. I agree the interview/discussion group being recorded. ☐
7. I understand that Andrea may use anonymised quotations from our recorded conversations in reports or articles that may be published. ☐

Participant name ___________________________
Signature ___________________________
Date ___________________________
Phone no ___________________________
Email ___________________________

Researcher name Andrea Lambell
Signature _______________
Date _______________

APPENDIX I: DEBRIEFING SHEET



Durham
University

Debriefing Sheet

Project title: **Behind The Mask**

Thank you for taking part in this study. This research is about how healthcare conversations have been affected by the need to stay apart, and by the need to wear masks, gowns, visors and gloves (Personal Protective Equipment, or PPE). We are also looking at the ways in which people have tried to manage these barriers. We will use the findings to develop ways to help healthcare workers, patients and their loved ones communicate while staying safe.

The data you have provided is automatically anonymised and cannot be traced back to your identity. Your individual data will not be available to anyone outside research team.

If you would like further information about the study, or would like to know about what my findings are when all the data have been collected and analysed then please contact me at andrea.r.lambell@durham.ac.uk . I cannot however provide you with your individual transcript.

If you would like to withdraw from the study, please contact me at andrea.r.lambell@durham.ac.uk .Your data will be deleted from our secure server, and any paper-based records will be destroyed.

If taking part in this study has raised any specific concerns or unpleasant memories, then I would suggest you seek support. You could take this debriefing sheet with you. Sources of support could include your GP, workplace counselling, or charities such as MIND (mind.org.uk).

Once again, many thanks for your valuable contribution to this research project. It is much appreciated.

Kind regards,

Andrea Lambell

APPENDIX J: CLUSTER ANALYSIS

The clustering calculation allocated each respondent to one of the three clusters: it placed together the respondents who shared many characteristics with the others in each specific cluster and who were also dissimilar in some respects to the members of the other clusters. The specific statistically significant findings which formed the pattern of clusters were the differences concerning: perceptions of communication with others wearing face coverings ($p \leq 0.000$); conflicted attitudes towards communication with people who are wearing face coverings ($p \leq 0.003$); feelings when in proximity of a person wearing PPE ($p \leq 0.000$); conflicted feelings when near a person wearing PPE ($p \leq 0.000$); feelings about the imposed avoidance of touch ($p \leq 0.000$); level of satisfaction with care intervention ($p \leq 0.030$); perceptions of the comfort and ease of use of PPE ($p \leq 0.000$); perceptions of communication while wearing PPE ($p \leq 0.000$); conflicted feelings about communicating while wearing PPE ($p \leq 0.050$); and attitudes to the imposed avoidance of touch when communicating at work ($p \leq 0.014$).

This grouped the respondents into three clusters of roughly equal proportions: Cluster 1 were the ‘Habituated’ (n=143), whose responses indicated that they were reconciled to communication in the presence of masks, PPE and distancing; Cluster 2 were the ‘Sensitised’ (n=151), who were more likely to hold consistently negative thoughts and feelings about the experience of communicating in the presence of masks, PPE and distancing; and Cluster 3 were the ‘Conflicted’ (n=170), whose responses indicated the highest incidence of conflicted and contradictory feelings about the experience of communication in the presence of masks, PPE and distancing. The extent of conflicted or contradictory feelings and attitudes to masks, PPE and the imposed avoidance of touch and proximity suggests the widespread presence of an inner turmoil or normlessness.

The clear definition between the three clusters, and the evenly distributed number of members, supported the theory that it was equally likely that a person could become habituated, sensitised, or could wrestle with contradictory feelings of safety and threat when communicating in the presence of PPE and distancing. However, when the demographics of each cluster’s members were ascertained, the assumption outlined earlier in this chapter about *who* could be predicted to be more likely to be habituated or sensitised were *not* supported.

The only statistically significant demographic was the presence or absence of an impairment which affected communication. Respondents who did not report a communication impairment were significantly over-represented in the ‘Habituated’ cluster and significantly under-represented in the ‘Sensitised’ cluster, whereas, conversely, respondents who reported one or more communication impairments were significantly over-represented in the ‘Sensitised’ cluster and significantly under-represented in the ‘Habituated’ cluster ($\chi^2 = 6.606$ with 2 *df.* $p \leq 0.037$).

There was *no* statistically significant under- or over-representation in any cluster of people who needed health or care services during the pandemic compared to those who did not. This finding is informative because it challenges the supposition that an experience of care need in the presence of PPE and/or distancing would lead to the formation of a specific outlook concerning masks, PPE or touch which was different from those who did not need care.

There was *no* statistically significant under- or over-representation in any cluster of people depending on the dynamics of care giving and receiving they experienced during the pandemic compared to those who did not. This finding is notable because it challenges the assumption that a particular power dynamic in any experience of care interaction creates a specific outlook concerning masks, PPE or touch which is different from those whose experienced other power dynamics.

There was *no* statistically significant under- or over-representation of ‘Conventional’, ‘CAM’, or ‘Dual’ healthcare practitioners in any cluster, challenging the conjecture that respondents who practice non-conventional therapies will be more likely to hold views which challenge measures recommended by the scientific establishment. The diversity of opinion and beliefs within this group is shared in equal measure by respondents from conventional healthcare backgrounds.

These findings suggest that habituation and sensitisation to the embodied experience of being in the presence of PPE and distancing were influenced by factors beyond the person’s intrinsic perception.

Cluster membership

TABLE 5: Cluster membership - Communication impairment

KEY:	Under-represented:	🟧	Over-represented:	🟩

	Cluster 1 n=143	Cluster 2 n=151	Cluster 3 n=170
No communication impairment*	126	117	145
One or more communication impairments*	17	34	25
Visual impairment**	1	10	12
Hearing impairment***	9	15	10
Speech impairment	8	3	3
'Other' impairment	2	3	4

*Respondents who did not report a communication impairment were significantly over-represented in Cluster 1 and significantly under-represented in Cluster 2, whereas respondents who reported one or more communication impairments were significantly over-represented in Cluster 2 and significantly under-represented in Cluster 1 ($\chi^2 = 6.606$ with 2 *df*. $p \leq 0.037$)

**Respondents with visual impairment were significantly over-represented in Clusters 2 and 3 ($\chi^2 = 8.677$ with 2 *df*. $p \leq 0.013$).

***Respondents with hearing impairment were significantly over-represented in Cluster 1 ($\chi^2 = 15.924$ with 2 *df*. $p \leq 0.000$).

The findings suggest that the experience of communicating in the presence of masks, PPE and distancing is different for respondents who have communication impairments compared to those who do not. It also suggests the experience is different for those who have a hearing impairment compared to people with visual impairments.

<table>
<tr><td colspan="5">TABLE 6: Cluster membership – experience of care</td></tr>
<tr><td>KEY:</td><td>Under-represented:</td><td>🟧</td><td>Over-represented:</td><td>🟩</td></tr>
<tr><td></td><td>Cluster 1
n=143</td><td>Cluster 2
n=151</td><td colspan="2">Cluster 3
n=170</td></tr>
<tr><td>Needed health or social care during pandemic</td><td>73</td><td>74</td><td colspan="2">80</td></tr>
</table>

There was *no* statistically significant under- or over-representation in any cluster of people who needed health or care services during the pandemic compared to those who did not. This finding is notable because it challenges the assumption that an experience of care need in the presence of PPE and/or distancing would lead to the formation of a specific outlook concerning masks, PPE or touch which is different from those who did not need care.

<table>
<tr><td colspan="5">TABLE 7: Cluster membership – Care dynamics</td></tr>
<tr><td>KEY:</td><td>Under-represented:</td><td>🟧</td><td>Over-represented:</td><td>🟩</td></tr>
<tr><td></td><td>Cluster 1
n=143</td><td>Cluster 2
n=151</td><td colspan="2">Cluster 3
n=170</td></tr>
<tr><td>Neither gave nor needed care</td><td>24</td><td>26</td><td colspan="2">31</td></tr>
<tr><td>Needed care only</td><td>29</td><td>27</td><td colspan="2">31</td></tr>
<tr><td>Gave care only</td><td>49</td><td>51</td><td colspan="2">60</td></tr>
<tr><td>Both needed and gave care</td><td>41</td><td>47</td><td colspan="2">48</td></tr>
</table>

There was *no* statistically significant under- or over-representation in any cluster of people depending on the dynamics of care giving and receiving they experienced during the pandemic compared to those who did not. This finding is notable because it challenges the assumption that a particular power dynamic in any experience of care interaction creates a specific outlook concerning masks, PPE or touch which is different from those whose experienced other power dynamics.

<table>
<tr><th colspan="4">TABLE 8: Cluster membership – Health and care workers</th></tr>
<tr><td>KEY:</td><td>Under-represented: 🟧</td><td colspan="2">Over-represented: 🟩</td></tr>
<tr><td></td><td>Cluster 1
n=143</td><td>Cluster 2
n=151</td><td>Cluster 3
n=170</td></tr>
<tr><td>Conventional</td><td>44</td><td>31</td><td>49</td></tr>
<tr><td>‘CAM’</td><td>34</td><td>53</td><td>44</td></tr>
<tr><td>Dual</td><td>10</td><td>10</td><td>8</td></tr>
</table>

There was *no* statistically significant under- or over-representation of ‘Conventional’, ‘CAM’, or ‘Dual’ healthcare practitioners in any cluster. This finding challenges an assumption that respondents who practice non-conventional therapies will tend to hold views which run counter to the norm. The diversity of opinion and experience within this group is shared in equal measure by respondents from conventional healthcare backgrounds.

The survey, which was not designed with a statistical analysis in mind, did not ask questions about demographics such as age, gender, ethnicity, or socioeconomic determinants, so demographic markers were limited. However, demographics relevant to care communication were identifiable and, apart from the significant under- and over-representation of respondents who reported communication impairments, the clusters are not differentiated by those demographics. Broadly speaking, a variety of perceptions, behaviours and experiences are evenly distributed regardless of whether the respondents are receivers of care, informal caregivers, practitioners of conventional or non-conventional interventions, and/or people with impairments that affect communication (e.g., visual, hearing and speech). This is ‘between-group homogeneity’. At the same time, within each group of people there is also evidence of different perceptions, behaviours, and experiences (‘within-group heterogeneity’**)**. Instead, they are shaped by variations in thoughts and feelings – i.e. there is in-group heterogeneity and between-group homogeneity.

Differences between clusters

Mann-Whitney tests were then used to determine differences between respondents where the characteristic was binary (e.g., Conflicted/not conflicted). Where there were more than two options for the characteristic (e.g., Conventional/CAM/Dual; Care giver-receiver/care-giver only/care-receiver only/no care interaction), Independent Kruskal-Wallis tests were used in relation to the statements. Post-hoc Mann-Whitney tests using Bonferroni-adjusted alpha level of 0.017 (i.e. 0.05 / 3) were used to compare differences between all pairs of clusters. Table 9 indicates all variables where there was a statistically significant difference between clusters.

Conflicted and contradictory feelings were more prevalent in Group 3, whilst a more positive outlook on communication in the presence of masks, PPE and distancing tended to be expressed by respondents in Group 1. Group 2 members are more likely to hold consistently negative thoughts and feelings about the experience of communicating in the presence of masks, PPE and distancing.

Cluster 1's identity could be described as 'Conformists', Cluster 2 'Strugglers', and Cluster 3 'Conflicted conformists'. These blunt labels can serve as a heuristic device in subsequent thematic analysis. By giving a broad indication of the respondent's position, cluster identity can add a layer of context when analysing an individual's free-text responses.

TABLE 9: Differences between clusters

Variable:	Cluster 1 ‘Conformists’	Cluster 2 ‘Strugglers’	Cluster 3 ‘Conflicted conformists’	Probability level
Perceptions of communication with others wearing face coverings	Least negative	Most negative	Between 1 and 2	$p \leq 0.000$
Conflicted attitudes towards communication with people who are wearing face coverings	Least conflicted	Some evidence of contradictory thoughts	Most conflicted	$p \leq 0.003$
Feelings when in proximity of a person wearing PPE	Least negative	Most negative	Between 1 and 2	$p \leq 0.000$
Conflicted feelings when near a person wearing PPE	No respondent conflicted	Some evidence of contradictory feelings	Some evidence of contradictory feelings	$p \leq 0.000$
Feelings about the imposed avoidance of touch	Least negative	Most negative	Between 1 and 2	$p \leq 0.000$
Level of satisfaction with care intervention		Less satisfied than Cluster 3 only		$p \leq 0.030$
Perceptions of the comfort and ease of use of PPE	Least negative	Most negative	Between 1 and 2	$p \leq 0.000$
Perceptions of communication while wearing PPE	Least negative	Most negative	Between 1 and 2	$p \leq 0.000$
Conflicted feelings about communicating while wearing PPE	More conflicted than Cluster 2	Least conflicted	More conflicted than Cluster 2	$p \leq 0.050$
Attitudes to the imposed avoidance of touch when communicating at work	Less negative than Cluster 2	Most negative	Less negative than Cluster 2	$p \leq 0.014$

APPENDIX K: NORTH-SOUTH SOCIOECONOMIC AND HEALTH CHARACTERISTICS

TABLE 10: Comparison of North and South socioeconomic characteristics **Source: ONS, 2023b (2021 census)**

	Integrated Care Board (Vicky – South) **Population: 1,199,549** **969,158 (80.8%) working or seeking work**						**Integrated Care Board (Gary – North)** **Population: 2,966,487** **2,446,294 (82.5%) working or seeking work**					
Socioeconomic group	**South ICB no. of residents**	**Level of health**		**%**	**N of VG/G versus F/B/VB**	**% of VG/G versus F/B/VB**	**North ICB No. of residents**	**Level of health**		**%**	**N of VG/G versus F/B/VB**	**% of VG/G versus F/B/VB**
L1, L2, L3: Higher managerial admin professional occupation	**126,581 (10.55%)**	**1:VG**	**62,834**	**49.64%**	**111,557**	**88.13%**	**237,649 (8.01%)**	**1:VG**	**114,269**	**48.08%**	**204,565**	**86.08%**
		2:G	**48,723**	**38.49%**				**2:G**	**90,296**	**37.99%**		
		3:F	**11,870**	**9.38%**	**15,024**	**11.87%**		**3:F**	**25,560**	**10.76%**	**33,084**	**13.92%**
		4:B	**2,516**	**1.99%**				**4:B**	**5,958**	**2.51%**		
		5:VB	**638**	**0.50%**				**5:VB**	**1,566**	**0.66%**		

Socioeconomic group	**South ICB no. esidents**	**Level of health**		**%**	**N of VG/G versus F/B/VB**	**% of VG/G versus F/B/VB**	**North ICB no. of residents**	**Level of health**		**%**	**N of VG/G versus F/B/VB**	**% of VG/G versus F/B/VB**
L4, L5, L6: Lower managerial admin professional occupation	**202,818 (16.91%)**	**1:VG**	**92,439**	**45.58%**	**172,306**	**84.96%**	**444,252 (14.98%)**	**1:VG**	**188,648**	**42.46%**	**363,411**	**81.80%**
		2:G	**79,867**	**39.38%**				**2:G**	**174,763**	**39.34%**		
		3:F	**23,381**	**11.53%**	**30,512**	**15.04%**		**3:F**	**60,037**	**13.51%**	**80,841**	**18.20%**
		4:B	**5,597**	**2.76%**				**4:B**	**16,403**	**3.69%**		
		5:VB	**1,534**	**0.76%**				**5:VB**	**4,401**	**0.99%**		
L7: Intermediate occupations	**132,342 (11.03%)**	**1:VG**	**53,668**	**40.55%**	**107,256**	**81.04%**	**284,710 (9.60%)**	**1:VG**	**106,965**	**37.57%**	**221,917**	**77.94%**
		2:G	**53,588**	**40.49%**				**2:G**	**114,952**	**40.38%**		
		3:F	**18,916**	**14.29%**	**25,086**	**18.96%**		**3:F**	**45,730**	**16.06%**	**62,793**	**22.06%**
		4:B	**4,932**	**3.73%**				**4:B**	**13,704**	**4.81%**		
		5:VB	**1,238**	**0.94%**				**5:VB**	**3,359**	**1.18%**		

Socioeconomic group	South ICB no. esidents	Level of health		%	N of VG/G versus F/B/VB	% of VG/G versus F/B/VB	North ICB no. of residents	Level of health		%	N of VG/G versus F/B/VB	% of VG/G versus F/B/VB
L8, L9: Small employers and own account workers	115,944 (13.00%)	1:VG	47,654	41.10%	93,544	80.68%	201,059 (6.78%)	1:VG	73,501	36.56%	153,771	76.48%
		2:G	45,890	39.58%				2:G	80,270	39.92%		
		3:F	16,438	14.18%	22,400	19.32%		3:F	33,856	16.84%	47,288	23.52%
		4:B	4,637	4.00%				4:B	10,576	5.26%		
		5:VB	1,325	1.14%				5:VB	2,856	1.42%		
L10, L11: Lower supervisory and technical occupations	52,367 (4.37%)	1:VG	19,330	36.91%	40,741	77.80%	156,784 (5.29%)	1:VG	53,374	34.04%	114,110	72.78%
		2:G	21,411	40.89%				2:G	60,736	38.74%		
		3:F	8,399	16.04%	11,626	22.20%		3:F	29,205	18.63%	42,674	27.22%
		4:B	2,492	4.76%				4:B	10,329	6.59%		
		5:VB	735	1.40%				5:VB	3,140	2.00%		

Socioeconomic group	South ICB no. esidents	Level of health		%	N of VG/G versus F/B/VB	% of VG/G versus F/B/VB	North ICB no. of residents	Level of health		%	N of VG/G versus F/B/VB	% of VG/G versus F/B/VB
L12: Semi-routine occupations	112,844 (9.41%)	1:VG	37,261	33.02%	83,340	73.85%	324,290 (10.93%)	1:VG	98,163	30.27%	226,742	69.92%
		2:G	46,079	40.83%				2:G	128,579	39.65%		
		3:F	21,204	18.79%	29,504	26.15%		3:F	66,744	20.58%	97,548	30.08%
		4:B	6,538	5.79%				4:B	24,340	7.51%		
		5:VB	1,762	1.56%				5:VB	6,464	1.99%		
L13: Routine occupations	106,626 (8.89%)	1:VG	34,435	32.30%	77,228	72.43%	344,456 (11.61%)	1:VG	96,268	27.95%	227,411	66.02%
		2:G	42,793	40.13%				2:G	131,143	38.07%		
		3:F	20,647	19.36%	29,398	27.57%		3:F	77,100	22.38%	117,045	33.98%
		4:B	6,855	6.43%				4:B	31,017	9.00%		
		5:VB	1,896	1.78%				5:VB	8,928	2.59%		

Socioeconomic group	South ICB no. esidents	Level of health		%	N of VG/G versus F/B/VB	% of VG/G versus F/B/VB	North ICB no. of residents	Level of health		%	N of VG/G versus F/B/VB	% of VG/G versus F/B/VB
L14: Never worked and long-term unemployed (involuntary exclusion)	**69,093** **(5.76%)**	**1:VG**	**15,817**	**22.89%**	**40,109**	**58.05%**	**271,673** **(9.16%)**	**1:VG**	**49,186**	**18.10%**	**136,668**	**50.31%**
		2:G	**24,292**	**35.16%**				**2:G**	**87,482**	**32.20%**		
		3:F	**18,479**	**26.75%**	**28,984**	**41.95%**		**3:F**	**80,065**	**29.47%**	**135,005**	**49.69%**
		4:B	**7,717**	**11.17%**				**4:B**	**40,262**	**14.82%**		
		5:VB	**2,788**	**4.04%**				**5:VB**	**14,678**	**5.40%**		
L15: Full-time students	**50,543** **(4.21%)**	**1:VG**	**35,145**	**69.53%**	**47,272**	**93.53%**	**181,421** **(6.12%)**	**1:VG**	**118,058**	**65.07%**	**167,719**	**92.45%**
		2:G	**12,127**	**23.99%**				**2:G**	**49,661**	**27.37%**		
		3:F	**2,527**	**5.00%**	**3,271**	**6.47%**		**3:F**	**10,904**	**6.01%**	**13,702**	**7.55%**
		4:B	**571**	**1.13%**				**4:B**	**2,261**	**1.25%**		
		5:VB	**173**	**0.34%**				**5:VB**	**537**	**0.30%**		

Socioeconomic group	South ICB no. esidents	Level of health		%	N of VG/G versus F/B/VB	% of VG/G versus F/B/VB	North ICB no. of residents	Level of health		%	N of VG/G versus F/B/VB	% of VG/G versus F/B/VB
Does not apply	**230,391** **(19.21%)**	**1:VG**	**188,329**	**81.74%**	**224,195**	**97.31%**	**520,193** **(17.54%)**	**1:VG**	**426,684**	**82.02%**	**504,066**	**96.90%**
		2:G	**35,866**	**15.57%**				**2:G**	**77,382**	**14.88%**		
		3:F	**4,958**	**2.15%**	**6,196**	**2.69%**		**3:F**	**12,652**	**2.43%**	**16,127**	**3.10%**
		4:B	**935**	**0.41%**				**4:B**	**2,732**	**0.53%**		
		5:VB	**303**	**0.13%**				**5:VB**	**743**	**0.14%**		

TABLE 11: Comparison of North and South health characteristics **Source: ONS, 2023c (2021 census)**

Quality of health	South n	South n	South %	South %	North n	North n	North %	North %
Very good	**586,912**	**997,548**	**48.93%**	**83.16%**	**1,325,116**	**2,320,380**	**44.67%**	**78.22%**
Good	**410,636**		**34.23%**		**995,264**		**33.55%**	
Fair	**146,819**	**202,001**	**12.24%**	**16.84%**	**441,853**	**646,107**	**14.89%**	**21.77%**
Bad	**42,790**		**3.57%**		**157,582**		**5.31%**	
Very bad	**12,392**		**1.03%**		**46,672**		**1.57%**	

‘Gary’ and ‘Vicky’ both worked as NHS specialist pain management physiotherapists. Their interviews took place on 9 October 2020 (Vicky) and 22 October 2020 (Gary). They had contrasting experiences of delivering healthcare in the presence of PPE and distancing. For an insight into the underlying causes of the diverse narratives, I considered the demographics of the populations with whom they worked using the census statistics which were gathered on 21 March 2021, five months after the interviews. The Office for National Statistics provided socioeconomic and self-reported health status for each of England’s 42 Integrated Care Board (ICB) catchment areas (Office for National Statistics, 2023a, 2023b). ICBs have the responsibility for NHS budgets, functions, and performance. They replaced England’s Clinical Commissioning Groups in July 2022. I compared the population statistics for the two ICB areas in which Gary and Vicky practised. Gary’s was in Northern England, and Vicky’s was in the South.

The population of North ICB was 2,966,487, 247.3% larger than South ICB (1,199,549).

The percentage of population of the North ICB who did not describe their health as ‘Very Good’ or ‘Good’ was 21.77%, which was 4.93% higher than the South ICB (16.84%). The number of people in North ICB who did not describe their health as ‘Very Good’ or ‘Good’ was 646,107, which is 319.85% more than in South ICB (202,001).

The National Statistics Socio-economic Classification (NS-SEC) indicates a person's socio-economic position based on their occupation and other job characteristics. Categories are assigned based on a person's occupation, whether employed, self-employed, or supervising other employees. I mapped the census wellbeing statistics onto the NS-SEC 10-category scale and used the five-class version of reporting to indicate a socioeconomic gradient (Office for National Statistics, n.d.)

The South ICB had a higher proportion of people in managerial, administrative and professional occupations. For both populations, lower levels of ‘Very Good’ and ‘Good’ health were reported by people on the lower levels of the socio-economic gradient.

The populations of both ICB areas reported a lower percentage of ‘Very Good’ or ‘Good’ health according to the further down the socioeconomic gradient.