The Shifting Conditions of Support Groups in Transition: An Ethnography of Respiratory Disease in Northern England

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THE SHIFTING CONDITIONS OF SUPPORT GROUPS IN TRANSITION

AN ETHNOGRAPHY OF RESPIRATORY DISEASE IN NORTHERN ENGLAND

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Breathlessness is a condition we all know something about, as it is normal to get out of breath when physically overexerted. However, breathlessness may also be an abnormal manifestation commonly understood, assessed, and defined as the first vital symptom of respiratory disease—such as in asthma, bronchiectasis, chronic obstructive pulmonary disease, or pulmonary fibrosis.

This dissertation is based on multi-sited ethnographic fieldwork conducted predominantly amongst support groups for people with respiratory disease in the North of England, and sheds light on how communities are formed around chronic breathlessness. By utilising (and reconceptualising) the postmodern framework of *biosociality*, this dissertation explores how people living with respiratory disease negotiate and incorporate different kinds of health-related knowledge in their everyday lives—explicitly in support group settings outside of the clinic.

People are living longer than ever before according to the World Health Organization, and chronic conditions are now the chief causes of death globally and have surfaced as major causes of disability and functional dependency. More specifically, in the United Kingdom 115,000 people die each year of chronic respiratory disease, which makes it one of the three biggest killer disease areas in the country. These mortality figures have remained stagnant for the past decades. What is more, in the era of neoliberalism respiratory care is individualised. Public health responses now emphasise the responsibility of individuals over collective or institutional responsibility, which is predominantly enforced through self-care and by training (or *activating*) patients in taking their medications and monitoring their pulmonary performance.

By attending to public health responses in neoliberal times where respiratory healthcare regimens are habitually individualised, this dissertation contributes to understandings of biomedical subjectivities. Explicitly, it examines how support groups—as biosocial gatherings—can be understood as technologies for bridging dialogues between subjective and collective bodily experiences of health, illness, and wellbeing.

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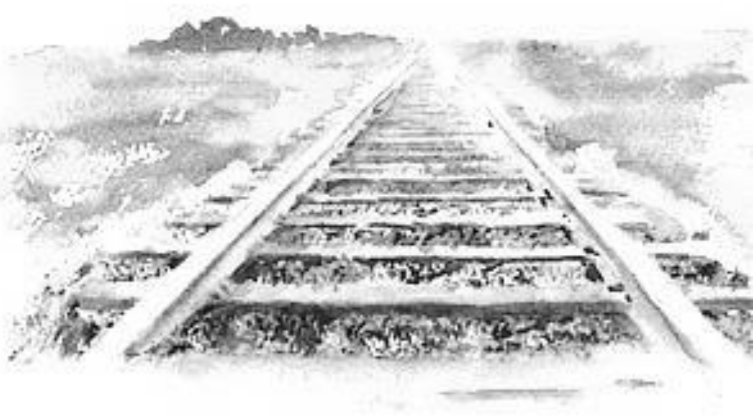
wellcome

TO WHERE WE HAVE COME,
AND TO WHERE WE ARE GOING.



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Abbreviations

AAA	American Anthropological Association
ARAS	Acute Respiratory Assessment Service
BE	Breathe Easy
BLF	British Lung Foundation
CCG	Clinical Commissioning Groups
CF	Cystic Fibrosis
CHS	City Hospitals Sunderland NHS Foundation Trust
COPD	Chronic Obstructive Pulmonary Disease
ILD	Interstitial Lung Disease
IPF	Idiopathic Pulmonary Fibrosis
LEEP	Lung Exercise and Education Programme
NHS	The National Health Service in the United Kingdom
PF	Pulmonary Fibrosis
PR	Pulmonary Rehabilitation
RVI	The Royal Victoria Infirmary
SB	Singing for Breathing
SLH	Singing for Lung Health
SSTHC	*Save South Tyneside Hospital Campaign*
STFT	South Tyneside NHS Foundation Trust
STSFT	South Tyneside and Sunderland NHS Foundation Trust
UK	United Kingdom
US	United States of America

Declaration

The contents of this thesis are produced solely for the qualification of Doctor of Philosophy at Durham University and consist of the author's original individual contribution with appropriate recognition of any references being indicated throughout.

Statement of Copyright

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Stockholm, 2021-04-23

Fredrik Nyman

In loving memory

of

MAUREEN JONES

(1953 – 2018)

and

LEON JONES

(1941 – 2019)

PART I

SETTINGS

~ CHAPTER ONE ~

INTRODUCTION

MAKING THE ‘INVISIBLE’ VISIBLE

“Research is formalised curiosity.
It is poking and prying with a purpose.”

Z. N. HURSTON

> There are 20 words to describe chest pain. Burning, squeezing, stabbing, tearing... Each one diagnostically useful. […] But there are no words to describe degrees of what he’s feeling right now: *shortness of breath*.[1]

Sadie (72) from Lanarkshire says, “As a keen cyclist and hill walker, I miss being able to just pop out for a walk” (British Lung Foundation, 2007b: 32). This statement, although simple, sums up the everyday experience for millions of people in the UK who live with a health condition that, due to its invisible nature, is rarely recognised as a legitimate reason for medical attention or concern. I am referring to *chronic breathlessness* (British Lung Foundation, 2007b, 2016); a somatic sensation oftentimes described as an intense tightening in the chest, or air hunger.

This dissertation is an ethnographic exploration of the lives of people with chronic breathlessness and respiratory disease in the UK. Particularly, it examines self-help and peer-support groups for people living with a breathing condition, and their families, friends, and other caregivers. Ultimately, the dissertation offers an ethnographic look into understandings of biomedical subjectivities by examining how peer-support groups, as biosocial gatherings, can also be understood as technologies for bridging dialogues between subjective and collective bodily experiences of health, illness, and wellbeing. The question at stake is:

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[1] Dr Gregory House (portrayed by Hugh Laurie) from the medical drama *House MD* says this about one of his patients in the episode “Informed Consent” (2006).

What is breathlessness and how are communities are formed around this somatic phenomenon?

The dissertation's approach towards and understanding of breathlessness extends beyond mere symptomatology. Rather it regards breathlessness as a somatic phenomenon "pregnant with historical, cultural and existential meanings that are often overlooked in the clinical context" (Macnaughton & Carel, 2016: 295). This represents an epistemic gap in knowledge, which Macnaughton and Carel maintain is an "unbridgeable mismatch of understanding not only of knowledge but also of how that knowledge might be obtained, between the clinic and the person who experiences breathlessness" (2016: 295). Somatisation, as such, is habitually understood as the tendency to experience psychological distress in the form of somatic symptoms (Lipowski, 1987, 1988), which may be initiated or perpetuated by emotional responses. Breathlessness fits this description.

The dissertation draws from ethnographic research undertaken as part of a five-year Wellcome Trust-funded project entitled *Life of Breath*. This project was interdisciplinary in nature and brought together researchers from several disciplines, including medical humanities, philosophy, anthropology, history of science, English literature, respiratory medicine, general practice, arts and health (e.g. Macnaughton & Carel, 2016; Oxley & Macnaughton, 2016; Malpass et al., 2019; Oxley et al., 2019). The research was conducted between 2017 and 2018 in the north-east of England via multi-sited ethnography, predominantly focusing on three support groups for people living with chronic breathlessness. These groups were all initially fully integrated members of the support group network known as *Breathe Easy*, which was launched by the British Lung Foundation (BLF) in the early 1990s. As this dissertation will come to illustrate, Breathe Easy groups exist to provide support and information for people living with chronic respiratory diseases all across the UK, all while raising awareness locally about this group of diseases. I will provide more details about Breathe Easy later in the dissertation.

SUPPORT GROUPS: A GROWING PHENOMENON

The support group phenomenon is growing worldwide, across national borders and socio-political systems (Adamsen & Rasmussen, 2001; Adamsen, 2002). Support groups (in the widest sense) of all sorts bring together people who are having or have had similar experiences, whether due to social or pathological conditions. While groups for health-related conditions like cancer, heart disease, or breathing disorders may be the most widespread (Hitch et al., 1994; Coreil & Mayard, 2006; Ussher et al., 2006; Gottlieb & Wachala, 2007; Bar-Lev, 2008; Mo & Coulson, 2008; Bell et al., 2010; McKevitt et al., 2016) there are also peer-support group networks focusing on addiction (Humphreys, 2003), stuttering and hearing loss (Bradberry, 1997; Southall et al., 2019), parenting, divorce (Kline et al., 1990; Molina, 2000; Frieman, 2002) and caregiving (Gage & Kinney, 1996; Butow et al., 2007).

Alcoholics Anonymous (AA) is thought to be the first modern support group to become an established organisation (Trice & Staudenmeier, 1989; Kurtz, 1991; Bloomfield, 1994; White, 1998; White & Kurtz, 2008; Travis, 2009). Since 1935, many have followed in its footsteps, seeking to institute peer-groups providing natural, organised support (Hatch & Kickbusch, 1983) and opportunities for people to share experiences and feelings of distress. Self-help did not arouse interest within the social sciences until the late 1970s (Katz & Bender, 1976a). It was social theorists Alfred Katz and Eugene Bender who put this area of research on the map via their book *The Strength in Us* (Katz & Bender, 1976b) in which they provide a definition of “support groups” that is still widely used (1976b: 9),

> [support groups] are voluntary, small group structures for mutual aid and the accomplishment of a special purpose. They are usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem, and bringing about desired social and/or personal change. The initiators and members of such groups perceive that their needs are not, or cannot be, met by or through existing social institutions.

Sociologists Richardson and Goodman have offered a similar definition, which contends that support groups are “groups of people who feel they have a common problem and have joined together to do something about it” (1983: 2). In terms of healthcare regimens, Barlow and colleagues write that “Self-help groups […] may rival all other forms of treatment sometime within the next century” (2000: 53). Their argument stems from research undertaken by Goodman and Jacobs (Jacobs & Goodman, 1989; Goodman & Jacobs, 1994) on the role of self-help within the national mental healthcare system in the US. Jacobs and Goodman not only suggest that self-help groups will assume a “central role in the nation’s mental health delivery system over the next two decades” (Jacobs & Goodman, 1989: 536) but also that the “number of people in public mutual support groups […] now rivals those in individual and group therapy combined” (Goodman & Jacobs, 1994: 489). Having that said, the overall image is further blurred by the fact that, as Goodman and Jacobs argue, formats of self-help groups often “resemble formats for classical group therapy” (1989: 489) in which private and informal groups become hidden from scholars’ view. Nevertheless, as Adamsen writes, the academic debate surrounding self-help groups lacks consistency.

> There is no clear consensus about the definition and the conceptualization of self-help groups. Terms like self-help groups, support groups, counselling groups, therapy groups and instruction groups are applied randomly both in research and in the clinical practice and this creates uncertainty about whether group initiatives are comparable or not. (Adamsen, 2002: 228)

Following Adamsen, this dissertation partially acts as a call to action. I contend that academics have yet to move beyond this phase which Adamsen characterises as lacking consistency and consensus. Barlow and colleagues write that support groups may come to “rival all other forms of treatment” (2000: 53) and this unanimity remains a significant issue, especially as the debate crosses and includes professions and professionals from a multitude of backgrounds. In this dissertation I urge for further discussion and re-evaluation of the “support group” concept. On the whole the approach to support groups in my chosen field has been emic. That is to say, I have investigated and recognised *how local people think* (Kottak, 2006); how people perceive and categorise their socio-cultural experiences, their rules for behaviour, and what has meaning for them as individuals and as a group. Henceforth, the only thing that matters is how my interlocutors make sense of their everyday lives, whether or not this corresponds to the existing research literature on support groups. I especially reinforce the need for a definition that recognises people's need for sociality and community, and how this sense of belonging can be understood as the underpinning of all existing support groups.

RESPIRATORY DISEASE AROUND THE WORLD

Geddes (2016) writes that it is important to recognise that respiratory diseases have shifted from predominantly infectious (tuberculosis and pneumonia) to chronic diseases of 'dirty air'. Asthma, chronic obstructive pulmonary disease (COPD) and lung cancer have all surged around the world. "The diseases have changed: some fade, some emerge and others come and go" (Geddes, 2016: 393), but our knowledge of these diseases (and the conditions which surround them) has developed. Scientific advances (in medical imaging and microbiology, especially) have improved our diagnostic practice, thus enabling quicker and more efficient interventions. Although complex, we are also more aware of the role environmental factors play in health and human behaviour, where mounting evidence "suggests that air pollution contributes to the large global burden of respiratory and allergic diseases including asthma, chronic obstructive pulmonary disease, pneumonia and possibly tuberculosis" (Laumbach & Kipen, 2012: 3).

Wainwright argues that, in addition to smoking, "other environmental factors, such as indoor and outdoor air pollution, might not only aggravate [respiratory disease] but also cause it" (2017: 333). New diseases have emerged from "industrial pollution and HIV, while better imaging has revealed others previously unrecognized" (Geddes, 2016: 393). Despite all the changes highlighted by Geddes (2016), therefore, respiratory disease remains a major killer, just as it was two hundred years ago.

Respiratory diseases are leading causes of death and disability all around the globe. The Forum of International Respiratory Societies[2] (FIRS) estimates that 4 million people die prematurely from a chronic respiratory disease each year. About 65 million people suffer from chronic obstructive pulmonary disease (COPD) and 3 million die from it each year, "making it the third leading cause of death worldwide" (Forum of International Respiratory Societies, 2017: 6). Asthma affects about 334 million people, and it is the most common chronic disease amongst children (affecting 14% of all children in the world). Public health surveys reveal major misconceptions about pneumonia, which kills millions of people annually. Pneumonia is a leading cause of death amongst children under five years old, and most adults are not vaccinated against it (and indeed remain unaware that the condition can be prevented through vaccination) (Ipsos MORI, 2017). The true mortality rates are still unknown and most likely underestimated (Marston et al., 1997; Porath et al., 1997).

Over 10 million people around the world contract tuberculosis (TB) each year and 1.4 million die from it; "making it the most common lethal infectious disease" (Forum of International Respiratory Societies, 2017: 6). Lung cancer kills 1.6 million people each year and is the deadliest of cancers. Tobacco smoke is a common cause for lung cancer (Timmermann, 2013; Dunger et al., 2015), and thus reducing tobacco consumption is an important step in improving respiratory health globally. Most respiratory diseases are preventable by improving air quality (Schwartz & Pepper, 2009; Brown et al., 2016; Wainwright, 2017). However, improving respiratory health also necessitates strengthening healthcare systems, using established "guidelines for health promotion and disease prevention, training medical personnel, research, and educating the populace" (Forum of International Respiratory Societies, 2017: 6).

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[2] The Forum of International Respiratory Societies is an organisation "comprised of the world's leading international professional respiratory societies presenting a unifying voice to improve lung health globally" (firsnet.org, 2020).

(i) …and in the United Kingdom

Marmot writes that for millions of people across the UK, the autonomic process of "breathing is something they have *had* to think about" (2016: 3). These are people for whom "the beautiful but delicate organs with which we breathe—the lungs—do not work as they should" (Marmot, 2016: 3). In 2001 the British Thoracic Society[3] (BTS) brought together a historical report entitled *The Burden of Lung Disease*, which provides statistics that show the huge health and economic burden of respiratory illnesses in the UK. The report was updated and reissued in 2006, showing that while the overall burden of respiratory disease is still growing, the overall death rate is improving, "with one in five people dying from respiratory disease in the UK in 2004, compared with one in four in 1999" (British Thoracic Society, 2006: i).

The Burden of Lung Disease brings many urgent issues regarding respiratory disease to the surface. For instance, the report shows that social inequality causes a higher proportion of deaths in respiratory disease than any other disease area in the United Kingdom: "44% of all deaths from respiratory disease are associated with social class inequalities compared with 28% of deaths from ischaemic heart disease" (British Thoracic Society, 2006: 3). Health inequalities have long been a cause of both concern and controversy in the UK (Smith et al., 2016), and the BTS alleges that these cases "would have been prevented if all men had the same death rate for respiratory disease as men employed in professional and managerial classes" (2006: 7). On the whole, one in three premature deaths in the UK (which equates to about 900,000 people) are attributable to socioeconomic inequality (Lewer et al., 2020) thus making it an urgent public health challenge to British legislators. Heart disease, lung cancer, and other lung diseases (such as chronic bronchitis) are the most widespread issues and cause almost 400,000 excess deaths between them (Lewer et al., 2020: 37).

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[3] The British Thoracic Society is a professional body for people in the field of respiratory medicine in the UK, and exists to "improve standards of care for people who have respiratory diseases and to support and develop those who provide that care" (brit-thoracic.org.uk, 2018).

The public urgency of respiratory disease in the UK was once again revisited in 2016, through the *Battle for Breath* report by the British Lung Foundation (BLF). Based on epidemiological research spanning three years, the report provides a "comprehensive overview of the extent and impact of lung disease across the UK" (British Lung Foundation, 2016: 8). Furthermore, the authors of *The Battle for Breath* reflect on *The Burden of Lung Disease* (British Thoracic Society, 2001, 2006) published a decade earlier, and show how the number of deaths from respiratory disease in the UK has roughly remained the same as those reported in 2006. That is, respiratory disease still kills roughly one person every five minutes (British Lung Foundation, 2016: 4). *The Battle for Breath* is a call to action, noting once more that respiratory disease is one of the three biggest killer disease areas in the UK, with about 115,000 deaths annually alongside 550,000 new diagnoses each year (British Lung Foundation, 2016: 4). It also revisits the issue of social inequality, showing that respiratory disease is a "major factor in widening health inequalities" (ibid. 2016: 5), drawing parallels between the most common respiratory diseases in the United Kingdom and social deprivation.

Respiratory disease, in truth, accounts for over 700,000 hospital admissions and over 6.1 million hospital bed days each year (British Lung Foundation, 2016: 4). *The Battle for Breath* confirms that the impact respiratory disease has on health and health services in the UK is comparable to that of non-respiratory cancer or cardiovascular disease. The BLF proposes that "better diagnosis and disease management would reduce this burden" (2016: 4), on emergency care in particular. Yet despite this, respiratory disease "has not received a similar level of attention and investment, and mortality has stagnated" (British Lung Foundation, 2016: 5). With their impact on health services being on equivalent levels, there is no sound reason for respiratory disease to not be on an equal footing with cancer and cardiovascular disease apropos research funding and public health priorities. This debate remains in the foreground of the dissertation, especially as it frames the anomaly that surrounds respiratory disease apropos disability and society.

THE PHENOMENOLOGY OF BREATH AND BREATHING

According to physiological understandings of breathing, "air enters the human body as an effect of contractions of the diaphragm and intercostal muscles, which brings the chest cavity into movement" (Górska, 2016: 43). Yet breath is more than simply a "reflexive action, not least because it can be controlled or manipulated at times, and can affect or be affected by experiences, environments and relationships" (Oxley & Russell, 2020: 3-4). Across centuries and countries, we all have one thing in common: we all breathe. This proves breathing as a physiological universality. Still, from a philosophical point of view (Irigaray, 1999, 2004b; Škof & Holmes, 2013), does it also perhaps make the breath *divine*? In her essay *The Age of the Breath*, Luce Irigaray writes: "The divine appropriate to women, the feminine divine, is first of all related to the breath" (2004a: 165). With this, Irigaray maintains that the woman is divine from birth; that she receives "the being divine with life, with breath, and that her original mistake—or sin—consists in not remaining faithful to her own breathing, to herself" (ibid.: 165). This is also how one may interpret the original sin narrated in Genesis.[4] As Irigaray writes:

> Why want to eat the forbidden fruit to gain knowledge, instead of cultivating one's own breath? Breathing itself incites to an awakening, and the divine knowledge is within me. To awake myself is more helpful for becoming familiar with such a science than leaving myself to appropriate knowledge that is not mine—even if it is called divine—and that cannot be of much use to me. (2004a: 165)

The Age of the Breath remains essential to feminist and women's literature, and is in a way a call to action to elevate women's rights; truly, "the woman's almost natural disposition to the divine does not tolerate the domination over nature, over the world, even arrogance towards them" (Irigaray, 2004a: 167). The displacement of women from themselves, Irigaray writes, "originates in a man's domination over nature—micro- or macrocosmic—as we can read in our mythologies" (ibid.: 167). By cultivating the divine within oneself, Irigaray recognises the practices of breathing that were developed by men in ancient cultures. All the same, she qualifies cultivating the divine within oneself as cultivating "the divine breath received as

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[4] *Genesis* is the first book of the Hebrew Bible and the Christian Old Testament.

human beings" (2004a: 168); breathing as a life force, breathing as a natural movement, not as we will it to be. As such, faithfulness and attention to one's own breathing is thus to be in agreement with and to support one's breathing as "the autonomous gesture of a human living" (Irigaray, 2004a: 165).

Having said that, what Irigaray contributes to the most is our understanding of the human body and embodiment (cf. Csordas, 1990) through an ontology of breath. As Oxley and Russell write, even though the merits of exploring breath as a phenomenon that is "at once intrinsically shared but contextually distinct, the meanings and embodiment of breath has seldom been examined as a central research theme in the humanities and social sciences" (2020: 4). Still, they bring Irigaray forward as an exception to this, arguing that she "questions conventional scholarly traditions to propose an ontology of breath as a means to explore the grounds where consciousness and body meet" (Oxley & Russell, 2020: 4). While her essay *The Age of the Breath* (2004a) stands significant, no doubt, in truth Irigaray presented her thoughts and ideas about breath and breathing much earlier. Namely in her book *The Forgetting of Air in Martin Heidegger* (1999), Irigaray attempts to reread and redirect Western philosophical thinking by placing her own philosophy around the essential element that has been forgotten by most philosophers: air. For centuries, the Western philosophical framework has focused on the act of *thinking*, to *air*, as a requisite for life, thought and action (Irigaray, 1999, 2001). Instead Irigaray believes that while Western thinking has blossomed in air, instead of analysing the very core of its existence, Western philosophers have overlooked it completely. This has subsequently created a void, "by using up the air for telling without ever telling of air itself" (Irigaray, 1999: 14). What emerges, Irigaray maintains, is a philosophy of forgetting, which in order to counterbalance she proposes a philosophy of breathing (2001: 310-311)—which is to say, a philosophy that is based on *air*.

Why, then, is it that air has been forgotten (or even neglected) within Western philosophy? Irigaray argues that this occurs because "[…] air does not show itself. As such, it escapes appearing as [a] being. It allows itself to be forgotten" (1999: 5; see also Apata, 2020). As such, air's ubiquitous presence becomes an absence, and thus, a path to oblivion. According to Irigaray, the human being is made of matter and breath and lives in earth, as well as air. However, Western philosophers, like Martin Heidegger, do not leave the ground; “whether it be that of the earth or that of logos” (Irigaray, 1999: 7). This aligns well with a fundamental issue in modern medical practice which is at the heart of this dissertation (and the title of this chapter). Namely as Macnaughton and Carel write, “In the clinical areas we consider, breathing and breathlessness are comparatively invisible” (2016: 295). This conceptual argument takes inspiration from research by Gysels and Higginson (2008; 2010; 2011) who describe the symptom of breathlessness (and the people suffering from it) as ‘invisible’. The invisibility stems from the fact that breathlessness is a condition (or symptom) that usually has a slow and surreptitious onset (Gysels & Higginson, 2008: 455), often attributed by those who experience it to ageing, lack of exercise, or smoking (Barnett, 2005; Ek & Ternestedt, 2008; Simonÿ et al., 2019; Van der Meide et al., 2020). The stigma and shame associated with smoking—and living with a smoking-related disease—are also factors that encourage people to hide their condition and its severity (Berger et al., 2010; Steinberg et al., 2010; Graham, 2012; Small et al., 2012; Oxley et al., 2019). People with respiratory disease risk social embarrassment and stigmatisation in many ways. In social settings, the severe dyspnoea and disruptive cough can be embarrassing for the sufferer. At the same time, “witnessing these symptoms may make bystanders uncomfortable, leading to more social awkwardness” (Berger et al., 2010: 917). As such, the invisibility of breathlessness has, as Macnaughton and Carel write (2016: 298), “a social element but is also political and economic in the clinical context”.

(i) The first vital symptom

While respiratory disease (the subject of this dissertation) comes with many symptoms and causes, *breathlessness* (the absence of breath) stands as the first vital symptom of disease (Currow & Johnson, 2015). Breathlessness exists as a physiological entity independent of a person’s lived experience, Nicholls write—and like pain, it is a “subjective phenomenon that can only be interpreted by the person experiencing it, and so it has proven difficult to quantify” (2003: 123). However, unlike pain, “there are no neural pathways that can be dissected to reveal the mechanical basis of the phenomenon” (Nicholls, 2003: 123). What is breathlessness and how are communities formed around this somatic phenomenon? This question is at the heart of this dissertation. Needless to say, the primary focus rests on the latter part (rather than on the former). What is breathlessness, then? While perhaps a trivial question, our understanding of the breath goes without saying because it comes without saying (cf. Bourdieu, 1977). As this dissertation illustrates, however, it should not. Breathlessness, shortness of breath, dyspnoea—this is a phenomenon which we all know something about, and (clinically speaking) it can be explained both physiologically and pathologically. Burki and Lee write that breathlessness “is perhaps the most common accompaniment of lung disease” (2010: 1196). Experienced breathlessness and recalled breathlessness are two different entities, however (Sandberg & Ekström, 2019); there is a need for more comparative research using the same measurement methods in the same settings in order to examine their relation. However, due to the nature of breath and breathing, it “can only be properly assessed in awake humans” (Burki & Lee, 2010: 1196). Nevertheless, Burki and Lee write that it is generally accepted (by science) that breathlessness (dyspnoea)

> […] involves central, peripheral (chest wall and lung receptors), and chemoreceptor mechanisms. Research in this field has consisted of studies of dyspnea or breathlessness in patients and normal subjects, as well as studies of related respiratory sensations, including the sensation of breath holding, the detection and perception of added respiratory loads, awareness of ventilation, and the ability to detect changes in PCO_2 and PO_2. (2010: 1196)

There is more to breathlessness than meets the eye (or the spirometer,[5] more likely). If there is something which this dissertation has shed light on, it is the fact that breathlessness is a highly subjective and personal experience. It can be measured and quantified—yet, in terms of its experience, there is so much more beneath the surface. The experience can be fleeting, a part of normal life—or a sign

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[5] A *spirometer* is an apparatus for measuring the volume of air inspired and expired by the lungs, and is the main piece of equipment used for basic Pulmonary Function Tests (PFTs).

of something more serious. When trying to make sense of breath and breathing, we find a mismatch in the understanding between what can be physiologically quantified and described (Aggarwal, 2009; Burki & Lee, 2010; Crisafulli & Clini, 2010) and what is physiologically or phenomenologically understood, embodied and experienced (Williams & Carel, 2018; Oxley & Russell, 2020; Williams, 2020). As the British Lung Foundation writes on its website (blf.org.uk, 2018), breathlessness

> […] is often dismissed as a normal part of ageing, so people don't tell their doctor. Some people feel responsible for causing their illness and don't feel they deserve help. While others don't realise they can get any help for their breathlessness. But getting a diagnosis is very important.

In terms of somatic sensations, service-users need not experience their abnormal breathlessness at the same level at which it is pathologically measured and defined. Their experience can be much worse or, in contrast, much better than what the onset of their disease envisages (Carel, 2015, 2018a, 2018c). Overall, people can experience very different levels of breathlessness. Gysels and Higginson write,

> Patients with minimal respiratory changes may suffer considerably, while others with severe disease may experience very little breathlessness. These varied experiences may relate to personal characteristics such as muscle strength and weight, psychological disposition and coping strategies, but also life experiences and cultural background. (2016: 156)

I came across many such narratives while travelling around the North of England. One such story could be the life of a gentle, old lady whose health deteriorated after hearing that her asthma had developed into COPD. Her lung capacity had not diminished; rather, her psychosocial health had been negatively affected by merely envisioning having to live with COPD. This narrative can be paralleled with one of a cheerful, old man in the same situation: he had been told that his asthma had developed into COPD. In contrast to the old lady, however, this man's lung capacity had decreased. Yet, this man disagrees with and questions his new diagnosis, because even though his condition has exacerbated (pathologically speaking), there are days on which he can run up the stairs without feeling overly breathless. Generally speaking, what this illustrates is that some people, as with everything, are able to cope better with their chronic disease than others are (Williams, 1993; Martz & Livneh, 2007; Bährer-Kohler, 2009; Smith, 2011 [1994]; Freer, 2015;

Fonseca et al., 2016). With improvements in sanitation, housing and education, alongside advances in research and the delivery of healthcare, there has been a steady decline in early and mid-life mortality (Lindsay et al., 2014; Harris & Helgertz, 2019). More people than ever before grow to extreme old age, and communities across the globe are now facing a situation without precedent: soon there will be more elderly people than children (WHO, 2011). Although people are living longer than ever before (WHO, 2014), a question remains: are we necessarily living better? Those who would have previously died from their condition may now survive to live longer, “but there is the emotional cost of long-term treatment and medical surveillance to consider” (Turner & Kelly, 2000: 124). However, the emotional dimensions of chronic conditions are often overlooked when medical care is considered. This applies to chronic breathlessness as it does to any other chronic disease condition.

While breathing may be a basic physiological process, its bodily function exceeds the lay and biomedical discourses and clinical paradigms that define it (Caroci & Lareau, 2004; Carel, 2014, 2015; Currow & Johnson, 2015; Calverley, 2017). It is a bodily function that allows us to speak, laugh and sing. Breathing allows us to connect with the outside world and our physical surroundings. It reflects our state of mind and, though automatic (Ambrosino & Scano, 2004; Petersen et al., 2008; Gigliotti, 2010; Jensen et al., 2016), can be also consciously controlled. For many people, breath has spiritual or symbolic significance (Dillon, 2001; Chen, 2003; Eigen, 2004; Caciola, 2005; Lande, 2007; Cassidy, 2012; Górska, 2016, 2018; Nieuwenhuis, 2018; Škof & Berndtson, 2018a; Allen, 2020); thus, the personal and cultural meanings of breath and breathing go beyond the simple act of keeping us alive (cf. Irigaray, 2004a).

Oxley and Russell write, in sum, that breath is more than “simply a reflexive action, not least because it can be controlled or manipulated at times, and can affect or be affected by experiences, environments and relationships” (2020: 3-4). I argue that this complexity, which is the nature of breath and breathing, often is overlooked and needs to be addressed more properly. This has to be embraced by all—academics, medical practitioners, and policy makers alike—if we are to bring further understanding to what breath, breathing, breathlessness, and respiratory disease all have come to signify and stand for in today's society. It is about time to denaturalise the given (Lock & Farquhar, 2007: 212); in this case, *breath*, while also acknowledging that it is through questioning its inherent essence that we might begin to comprehend just what breath *is* (phenomenologically speaking), and what it means to live and breathe (Macnaughton, 2020; Oxley & Russell, 2020). After all, by providing context for what "otherwise has been left unseen, unelaborated or taken for granted, it offers a way to begin to make the invisible, visible" (Oxley & Russell, 2020: 22).

(ii) *Beyond* phenomenology

Needless to say besides anthropology, this dissertation also falls within the field of breath and body studies (cf. Oxley & Russell, 2020). Studying the experience of breath, breathing and breathlessness and, indeed, the air and atmospheres (Ingold, 2007; Anderson, 2009; Wainwright, 2017; Górska, 2018; Nieuwenhuis, 2018; Škof & Berndtson, 2018a; Ojani, 2021) is inherently phenomenological in nature. The motivation, extensive as it may be, stems perhaps from the wish to research such phenomena without viewing them exclusively as subjects of scientific investigation. As phenomenologist Havi Carel writes (2017: para. 4)

> Recent work in the neurophysiology of breathlessness shows that the same brain pathways are activated in breathlessness as are in pain, hunger, and thirst. This may lead us to explore the possibility that breathlessness bears a family resemblance to pain, but is not analogous to it. It also makes salient the need for a phenomenological analysis, which may reveal how the experience of breathlessness is similar or dissimilar to other unpleasant sensations such as pain, hunger, and thirst.

Phenomenology, simply put, is the philosophical method for studying lived experience; and as such, a method for "examining pre-reflective, subjective human experience as it is lived prior to its theorization by science" (Carel, 2016: 2). Having that said, phenomenology is not a unified movement. Far from it actually, as Zahavi shows (2018), phenomenology draws upon different authors and philosophers who all share a common family resemblance but also come with many significant differences. Gabriella Farina illustrates this further, who writes that:

> A unique and final definition of phenomenology is dangerous and perhaps even paradoxical as it lacks a thematic focus. In fact, it is not a doctrine, nor a philosophical school, but rather a style of thought, a method, an open and ever-renewed experience having different results, and this may disorient anyone wishing to define the meaning of phenomenology. (2014: 50)

As such, phenomenology is uniquely positioned within philosophy, which certainly explains its long history of researchers who combine phenomenology with qualitative or quantitative methods (Kersten, 1989; Zahavi, 2018). In light of this, Guilbeau (2014) explains phenomenology as a type of qualitative research that focuses on answering the "what is it" question, rather than questions of frequency or magnitude (such as "how much" or "how many"). Therefore phenomenology as a qualitative method, Guilbeau writes, "[…] does not oppose the quantitative method but simply asks a different question in order to further explicate the meaning of the phenomenon" (2014: para. 1). However, such assorted nature comes with disparities; especially when it comes to the study of health, illness, and disease. As Nicholls explains, where quantitative research "assumes that there is a pathological basis to illness, phenomenologists believe that illness is constructed through the person's experiences" (2003: 125). Intrinsically, people diagnosed and living with the same illness ('sharing a biology' in one sense)—like respiratory disease, for example, will not experience the illness in the same way. Thus, while people may have identical pathologies, "one person will be living independently, self-medicating, working, socialising, and mobile; while the other is dependent, socially isolated, depressed, and removed" (Nicholls, 2003: 125-126). Therein lies a fundamental problem with a phenomenological approach: while phenomenology may be a "useful method for *describing* the lived experiences of illness, it remains severely impoverished as a *theory* for explaining it" (Sholl, 2015: 408).

Unlike phenomenology, which does not see "the illness experience as derived from an objective disease entity" (Carel, 2012: 102), this dissertation very much seeks to theorise and explain lived experiences of illness in a broader context. The dissertation instead draws from a Foucauldian biopolitical framework, where "disease is constituted by the clinical gaze of modernity" (Anderson, 1995: 67) and biopolitics "very much operates through and not in spite of communities" (Friedner, 2010). By acknowledging the role stigma holds in biosociality (‘the social relations formed through shared biomedical conditions’) while also differentiating between private and public biosocial experiences, the dissertation shows that through biosociality derives “acts of biosolidarity, where advocacy can improve the visibility and recognition of illness groups” (Bradley, 2021: 1). While some might call this post-phenomenology, which aims to overcome the limitations of subjectivism and its largely dystopian stance toward science and technology (Ihde, 2009; Rosenberger & Verbeek, 2015; Aagaard et al., 2018), I take issue with such an explanation. As Ihde writes, while a post-phenomenology clearly owes its roots to phenomenology, “it is a deliberate adaption or change in phenomenology that reflects historical changes that respond to contemporary science and technology studies” (2009: 5). For anthropological work, Weiss writes, Ihde brings to these reflections “a much greater awareness of the role of technology in shaping and constituting the human being” (2008: 5). However, while post-phenomenology is a “pragmatic philosophical approach for reflecting explicitly on how experience of being in the world for humans” (Wainwright, 2018: 427) is mediated by some kind of technology, material artefact, or ‘thing beyond’—as a method, it still derives and depends on description rather than explanation. We see this in Wainwright’s work, who argues that while post-phenomenology “adds a productive material and technological flavour to phenomenology” (2018: 426) it still lacks a critical approach, which is needed to engage with the political economy of various human–technology relations.

In response, although phenomenology remains highly significant and influential in the study of breath, breathing and breathlessness, in writing this dissertation I choose to walk in another direction. Instead, this dissertation looks to approaches that not only acknowledge but also critically interrogate the political economy of health (Morsy, 1979, 1981; Baer et al., 2004) where I explore, theoretically, the intersections between Foucauldian biopower, biopolitics, governmentality, technologies (Foucault, 2008, 2010), and perspectives on the embodied subject. As Oxley and Russell argue, breath needs to be “understood in broader terms than the clinical, as a mode of relating to the world, engaging with others, objects, environments and technologies" (2020: 4). If one is to contribute with novel (inter)disciplinary perspectives that explore "breath as a multifaceted phenomenon, both intrinsically shared and contextually distinct" (Oxley & Russell, 2020: 3)—one has to dare explore what lies beyond and move out of one's (disciplinary) comfort zone (cf. Niinimäki et al., 2017). While acknowledging the possible contributions of phenomenology in the study of health, disease, and illness, there are severe limitations of bringing phenomenological insights to bear on the problems facing philosophy of medicine (Sholl, 2015). These issues need to be properly addressed if phenomenology is to further add anything substantially new to the current debates in health care policy (e.g. Taylor & Hawley, 2010; Dilworth et al., 2013; Gerrits et al., 2019). After all, as Sholl writes, in phenomenology there is a tendency to present a rather "impoverished view of naturalism such that the possible descriptions available to naturalists are often misrepresented or misunderstood, resulting in a straw man argument" (2015: 392). This may explain why many critics have accused philosophical phenomenology of being dry, abstract, and 'airy fairy' (Allen-Collinson, 2016; Smith & Sparkes, 2016).

Naturalism, Sholl explains, habitually describes the body solely in objective terms and thus consequently mistakenly understands illness as merely "local biological dysfunctions" (2015: 395). Being that naturalism is deemed inadequate on its own or overall (Ferry-Danini, 2019) the role of phenomenology, in response, is often declared to be to fill this gap by instead focusing on lived experience or subjectivity. As Carel puts it: "The naturalistic approach provides a limited, biological picture of illness and therefore fails to help us understand the experience of illness" (2008: 5). However, as Sholl explains, this broad (and ambiguous) view of naturalism is problematic for several reasons. For one, by claiming that "naturalism views 'illness' in 'purely' biological terms" (Sholl, 2015: 397) this critique seems to have confused and misunderstood the conceptual difference between disease and illness; as in disease is something that needs to be cured, whereas illness is something that needs to be managed (e.g. Eisenberg, 1977; Young, 1982; Pool & Geissler, 2005; Bhugra & Malhi, 2013). Additionally, a fundamental problem with the phenomenological approach is that its description of what naturalism is—and "what it has to offer in terms of understanding disease” (Sholl, 2015: 400)—seems to bear little resemblance to what is, in truth, possible from within a naturalistic framework such that it seems to be nothing more than a ‘straw man’ argument (whereas the real subject of the argument was not addressed or refuted).

Having said that, although people’s experiences of breathlessness as lived ‘prior to theorization’ are essential to this dissertation (and will remain so in all respects), instead, by looking to Foucauldian and postmodern theory (Danaher et al., 2000; O’Farrell, 2005; Faubion, 2014; Lemm & Vatter, 2014), this dissertation will lay its focus on examining people’s lives (with breathlessness) through practices and local circumstance that come to ‘embody’ (subjectivate) the subject *as* a subject (Foucault, 1982; Flynn, 1985; Ong-Van-Cung, 2011; Rebughini, 2014; Cremonesi et al., 2016a; Oberprantacher & Siclodi, 2016). The subject, in this scenario, refers to the subjects of scientific investigation (cf. Gigliotti, 2010; Mietola et al., 2017); the people who live with breathlessness (due to respiratory disease) and agreed to participate in the study which this dissertation draws upon. That is, how is the ill person embodied *as* an ill person? How is ‘the subject’ understood within Foucauldian theory? Truth be told, Foucault’s account of the subject has a double meaning: it relates to both being a “subject of” and being “subject to” socio-political forces. Intrinsically, *autonomy* is a word that Foucault tended to avoid in his analysis of power relations and resistance (e.g. Danaher et al., 2000; Foucault, 2000; Faubion, 2014). In fact, Cremonesi and colleagues write that such reluctance (from Foucault, needless to say) in speaking of autonomy

> […] has often been assumed by critics as the marker of Foucault’s dismissal of political agency in his account of power relations. In particular, it is in his work on disciplinary power that, according to these criticisms, Foucault would have left no room for the autonomy of the subject. (2016b: 1)

This perhaps explains Foucault’s rejection of phenomenology, as well as of the “subject” and of “origins” (Shiner, 1982: 312). However, as Shiner writes, although Foucault’s rejection of “positions associated with phenomenology is evident throughout his writings, what is not so evident are the grounds for this rejection” (ibid.: 312). The conclusion chapter in *The Archaeology of Knowledge* (2002 [1969]) stands out amongst Foucault’s writings, particularly because in this piece he once again reiterates his rejection of a search for origins, for formal *a prioris*, and founding acts. Instead, his archaeology, Foucault explains, has aimed all along to free history from the grip of phenomenology. In his own words:

> To treat archaeology as a search for the origin, for formal a prioris, for founding acts, in short, as a sort of historical phenomenology (when, on the contrary, its aim is to free history from the grip of phenomenology), and then to object that it fails in its task, and that it never discovers more than a series of empirical facts. (Foucault, 2002 [1969]: 224)

An additional poststructuralist critique of phenomenology, Stoller argues (2009), concerns the purported immediacy of ‘perceptual experience’. This critique aims at the assumption that in the act of perception an “object can be experienced in an immediate way and that this object of perception can, in turn, be described in an unmediated way” (Stoller, 2009: 712). Certainly, most of the criticisms that Deleuze, Derrida, and other poststructuralist philosophers pose regarding phenomenology (Shiner, 1982; Lawlor, 2002; Noë, 2007; Stoller, 2009; Reynolds, 2010; Mckenna & Evans, 2013; Sholl, 2015; Zahavi, 2018) revolve around issues to do with time and transcendental philosophy. One of their main objections, Reynolds writes, is that phenomenological descriptions of the experience of time focus, “predominantly if not exclusively, on the manner in which time gathers, or conjoins rather than disjoins” (2010: 56). In comparison, although Derrida’s criticism of Husserlian[6] phenomenology and the philosophy of presence (e.g. Lawlor, 2002; Allison, 2005; Boos, 2008; Bellou, 2013; Mckenna & Evans, 2013) is more direct and detailed, from a poststructuralist point of view Foucault’s critique remains interesting in its own right because of the empirical and socio-political issues he raises (Shiner, 1982; Deleuze, 1986). By drawing together comments and arguments scattered throughout various texts and writings we are able to specify, Shiner argues, not only those aspects of phenomenology which are the target of Foucault’s critique—“but also the arguments on which his critique is based” (1982: 312). The result, Shiner writes (1982), should enable us to see more clearly what is at stake, philosophically,

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[6] This refers to Edmund Husserl (1859-1938); the principal founder of phenomenology, and thus one of the most influential philosophers of the 20th century.

in the debates surrounding Foucault's poststructuralist critique of "origins"—especially the assertion that his approach is radically relativistic.

Vastly inspired by poststructuralist writings, this dissertation follows suit and draws on this body of literature which criticises pure phenomenology (Noë, 2007) and the purported immediacy of perceptual, embodied experience (Stoller, 2009). In summation, while phenomenology is hugely significant to the study and understanding of breath and breathing (and will remain so in the foreseeable future), this dissertation dissociates itself from the phenomenological approach to studying lived experience. Although the dissertation does acknowledge Irigaray's ontology of breath (2004b) as well as her philosophy of air and breathing (1999, 2013), the dissertation asserts that while phenomenology is a good method for describing lived experiences of illness and disease it lacks severely when it comes to explaining these experiences. Even if explanation is not the sole aim in phenomenology, "there are still many problems that arise at the level of description" (Sholl, 2015: 408). This aligns well with Foucault's critique of phenomenology, which focuses on three concepts: the subject, the life-world, and the intentional-historical quest of origins (Shiner, 1982: 312). The centrepiece, however, is Foucault's rejection of the subject as origin "in favour of a body of anonymous rules governing discourse" (ibid.: 312). Intrinsically, Foucault (2002 [1966], 2002 [1969]) sees phenomenology as *the* philosophy which currently provides justification for the primacy of the subject. Not only does Foucault reject the foundational role of the subject; he also reverses the relation envisaged in phenomenology (Shiner, 1982), and thus argues that the subject receives whatever powers and position it has from the rules of formation inherent in discursive practices (cf. Faubion, 2014; Cremonesi et al., 2016a).

What is at stake in phenomenology, Górska writes, "is not a submission to a merely physiological understanding of human embodiment or to a delimitation of breathing as a universal and homogenous research object" (2016: 46; see also 2018, 2021). Instead, the aim is to discuss the relationalities of bodily *agentialities* as they are described and delimited in physiology, as to "problematize the universalizing approach of physiology and to argue for the constitutiveness of differentiation as part of the bodily processes described" (Górska, 2016: 46). What is at stake in this dissertation, nonetheless, is the dynamic and bidirectional interactions between biological phenomena and social relationships and contexts, "which constitute processes of human development over the life course" (Harris & McDade, 2018: 2). The centrepiece is the notion of biosolidarity; that is, biosocial groups do not simply exist, and "must first be formed and found and their sustainability requires ongoing work and care from biosocial actors themselves" (Bradley, 2021: 1). The circular looping effects of biosociality and biosolidarity, Bradley writes, demonstrate the way that community activism and biosociality reproduce one another (2019, 2021). Through reflections from her role as an anthropologist, Bradley considers biosolidarity as a methodological tool "that can help scholars to navigate the boundaries between relatedness, sociality and advocacy in the field and beyond" (2021: 1). This dissertation draws inspiration from such an approach, where focus is on explanation rather than description.

WHAT IS *BREATHLESSNESS*?

I now turn to the notion of breathlessness itself. What do I mean when I refer to breathlessness? Moreover, what do I mean by *chronic* breathlessness? I am not referring to what Macnaughton and Carel call 'normal breathlessness'—that is, being short of breath, "a condition we all know something about […] as part of normal life" (2016: 297), through exercise, stress, or other physiological exhaustion, which often is dismissed as a normal part of ageing. Instead, I am referring to *abnormal* breathlessness, which differs substantially from the former "in its many forms in clinical contexts, where it is regarded as a 'symptom'" (Macnaughton & Carel, 2016: 297). There is a clinical (pathological) term for it: *dyspnoea*, the subjective sensation of breathing discomfort (Heinzer et al., 2003; Gracely et al., 2007; e.g. Aggarwal, 2009; Burki & Lee, 2010; Gigliotti, 2010; Carel, 2016).

Within the wider context of breathlessness, more specifically, I refer to certain pathology: *respiratory disease,* disorders or infections that affect the lungs and cause breathing problems (Montenegro, 1984; Murray, 1986; Williams, 1993;

Dartnell & Ramsay, 2005). That is, I look at breathlessness (the symptom) *through* the lens of respiratory disease (the pathology). The range of clinical and medical conditions that fall under the umbrella of *respiratory medicine* stretches far and wide. From “cancers to obstructive sleep apnoea, interstitial lung disease to airways disease, occupational lung disease to respiratory infections” (Hubbard, 2006: 557), the variety found in respiratory medicine is not observed in other hospital-based specialties. Ultimately, I refer to excessive breathlessness experienced as a result of enduring activities which commonly would be considered trivial: climbing stairs or hills, walking down the street to the local shop, putting on one’s socks in the morning (cf. Gysels et al., 2007). As I have written elsewhere,

> […] *breathlessness is a very personal experience*. It can be fleeting or a sign of something more serious. It allows us to speak, laugh, and sing. It connects us to the outside world and physical surroundings. It reflects our state of mind and can be consciously controlled. (Nyman, 2018: para. 14)

Although breathlessness, indeed, is a “very personal” and subjective experience, how is it made sense of? As noted, Macnaughton and Carel write that in clinical contexts breathlessness is very much regarded a symptom (2016: 297); in other words, something pathological. Often, when I have told people that I study breathlessness, their response has been “what do you mean?” As Marmot writes,

> Breathing is something we all do, day in, day out, every day of our lives. It is so innate that most of us rarely stop to think about it. We think less of breathing than of the life it sustains. (2016: 3)

Breathing is taken for granted to the extent that it rarely crosses our minds, and this extends to breathlessness as well. To me this became even clearer in everyday conversations about my research, where people seemed to struggle to grasp both what it meant to study breathing and breathlessness and what these phenomena entail in and of themselves.

This begs the question: what *is* breathlessness? How is it made pathological in clinical contexts? There are many scales with which to classify and characterise dyspnoea (Crisafulli & Clini, 2010). While breathlessness is difficult to quantify, as Chris Stenton writes, it may still be “necessary […] if the symptoms of a particular group are to be summarized and compared” (2008: 226). In clinical practice, “the quantitative assessment of [breathlessness] can be useful for defining the patient's real level of respiratory disability" (Crisafulli & Clini, 2010: 203). In terms of clinical scales, the most frequently used are the Medical Research Council (MRC) dyspnoea scale (Bestall et al., 1999; Stenton, 2008), as well as the Baseline Dyspnoea Index and Transition Dyspnoea Index (Witek & Mahler, 2003; Crisafulli & Clini, 2010). There are also several psychophysical scales in use, such as the Borg scale or the Visual Analogue Scale (VAS), which both seek to assess symptom intensity in response to a specific stimulus, like exercise, through the use of numeric values (Noseda et al., 1992; Crisafulli & Clini, 2010). Much like in the process of assessing acute pain: the higher the number, the worse the sensation of breathlessness will be (Figures 1.1 and 1.2).

Shortness of Breath
Modified Borg Dyspnea Scale

0	Nothing at all
0.5	Extremely Slight (just noticeable)
1	Very Slight
2	Slight
3	Moderate
4	Somewhat Severe
5	Severe
6	
7	Very Severe
8	
9	Extremely Severe (almost maximal)
10	Maximal

Figure 1.1: The Borg scale; modified to work in accordance with dyspnoea.

(© HealthUnlocked | Photo taken by the author)

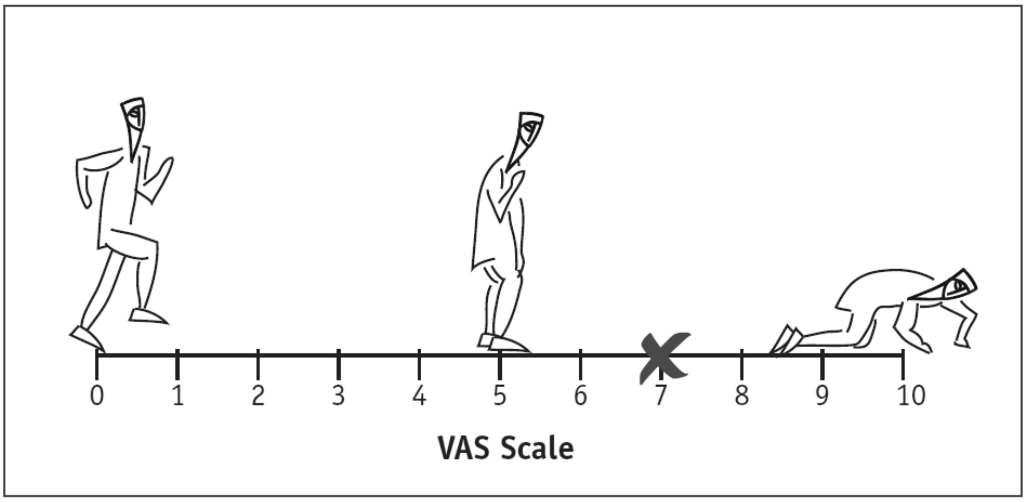

Figure 1.2: The Visual Analogue Scale, as used for breathlessness.

(Reprint from Ambrosino & Scano, 2004: 104)

The MRC dyspnoea scale was first published in 1952, after Fletcher and colleagues (Fletcher, 1952; Fletcher et al., 1959; Fletcher & Pride, 1984) studied the respiratory problems of Welsh coal miners at the MRC Pneumoconiosis[7] Unit in the 1940s (Stenton, 2008: 226). The scale itself is devised as a short questionnaire, allowing a numeric value (Figure 1.3) to be placed on each breather's exercise capacity. This questionnaire rapidly developed into what we now know as the MRC breathlessness scale, and has been in widespread use ever since (Fletcher, 1952; Stenton, 2008).

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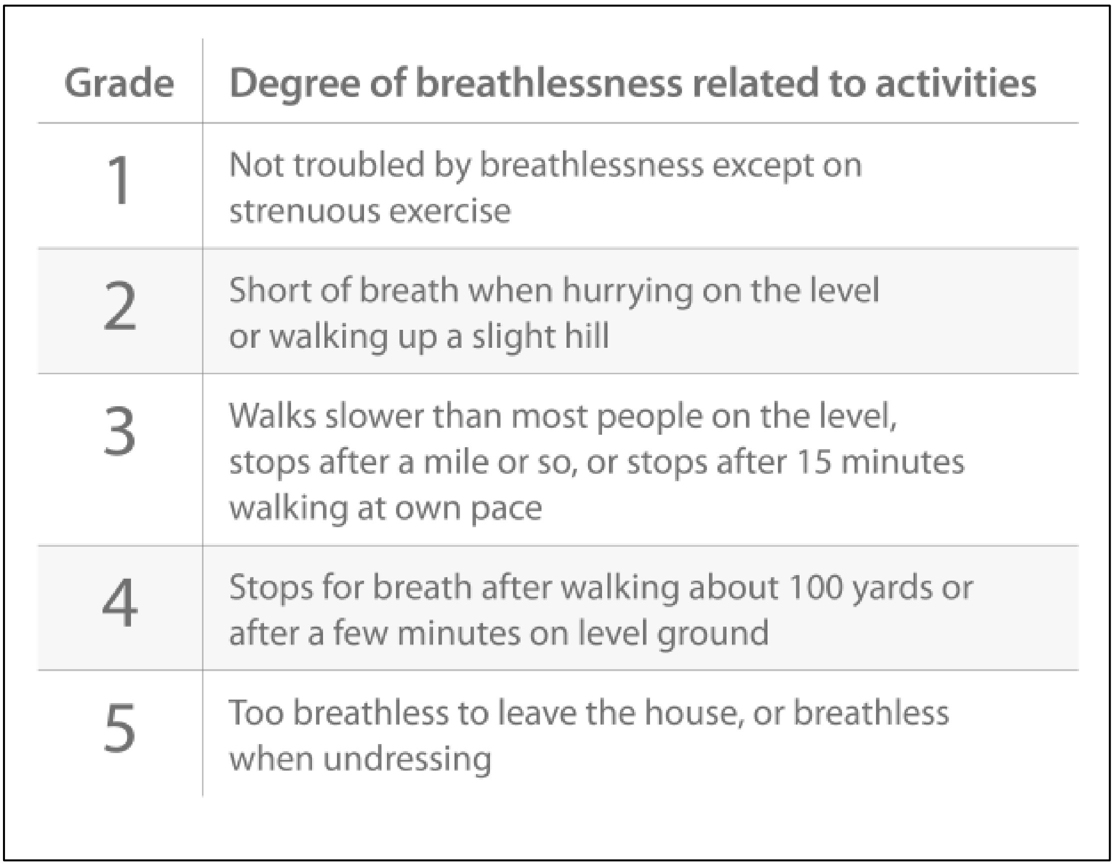
[7] Pneumoconiosis is the general term for a class of interstitial lung diseases where inhalation of dust has caused interstitial fibrosis (American Thoracic Society, 2004: 691). It is a common occupational disease, typically from years of dust exposure during work in mining; textile milling; shipbuilding, ship repairing, and/or shipbreaking; sandblasting; industrial tasks; and/or agriculture (Schenker et al., 2009: 988-989).



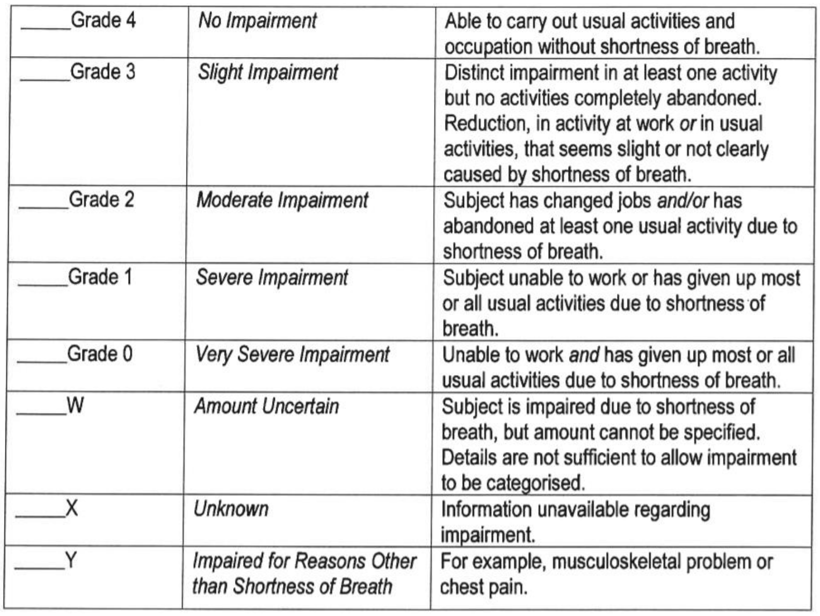
Grade	Degree of breathlessness related to activities
1	Not troubled by breathlessness except on strenuous exercise
2	Short of breath when hurrying on the level or walking up a slight hill
3	Walks slower than most people on the level, stops after a mile or so, or stops after 15 minutes walking at own pace
4	Stops for breath after walking about 100 yards or after a few minutes on level ground
5	Too breathless to leave the house, or breathless when undressing

Figure 1.3: The MRC Breathlessness Scale, adapted from Fletcher (1952).

(© British Lung Foundation | blf.org.uk, 2018)

The MRC breathlessness scale consists of five statements that cover the range of respiratory disability from none (Grade 1) to almost complete incapacity (Grade 5). Still, as Stenton writes (2008: 226), the MRC breathlessness scale does not quantify breathlessness itself, but rather, "quantifies the disability associated with breathlessness by identifying that breathlessness occurs when it should not (Grades 1 and 2) or by quantifying the associated exercise limitation (Grades 3–5)." Moreover, apart from determining potential incapacity, the MRC breathlessness scale is also widely used by health professionals to describe "patient cohorts and stratify them for interventions" (Stenton, 2008: 226) such as pulmonary rehabilitation. Although I will touch upon such health-based interventions in more detail later on in this dissertation, simply put, pulmonary rehabilitation (henceforth *PR*) is an "endurance-based exercise programme and condition-specific education […] recommended for all individuals living with a lung condition and chronic breathlessness" (Oxley et al., 2019: 1). These programmes commonly run over a minimum period of six weeks, "with at least two sessions per week supervised by a multidisciplinary team" (Oxley et al., 2019: 1). Psychophysical scales, such as the Borg scale and VAS, are commonly used during PR sessions.

The Baseline Dyspnoea Index (BDI) and Transition Dyspnoea Index (TDI) are also, as mentioned, clinical scales commonly used to quantify breathlessness. In the words of the American Thoracic Society (2016: para. 1), BDI (Figure 1.4) is an "[i]nterviewer-administered rating of severity of dyspnea at a single state. It provides a multidimensional measurement of dyspnea based on 3 components that evoke dyspnea in activities of daily living, in symptomatic individuals". In relation to this, TDI (Figure 1.5) measures "changes in dyspnea severity from the baseline as established by the BDI" (American Thoracic Society, 2016: para. 2). While the assessment of dyspnoea in patients relies in clinical practice on the modified MCR breathlessness scale, the BDI and TDI scales are mainly used in clinical trials (Perez et al., 2015).



_____Grade 4	*No Impairment*	Able to carry out usual activities and occupation without shortness of breath.
_____Grade 3	*Slight Impairment*	Distinct impairment in at least one activity but no activities completely abandoned. Reduction, in activity at work *or* in usual activities, that seems slight or not clearly caused by shortness of breath.
_____Grade 2	*Moderate Impairment*	Subject has changed jobs *and/or* has abandoned at least one usual activity due to shortness of breath.
_____Grade 1	*Severe Impairment*	Subject unable to work or has given up most or all usual activities due to shortness of breath.
_____Grade 0	*Very Severe Impairment*	Unable to work *and* has given up most or all usual activities due to shortness of breath.
_____W	*Amount Uncertain*	Subject is impaired due to shortness of breath, but amount cannot be specified. Details are not sufficient to allow impairment to be categorised.
_____X	*Unknown*	Information unavailable regarding impairment.
_____Y	*Impaired for Reasons Other than Shortness of Breath*	For example, musculoskeletal problem or chest pain.

Figure 1.4: The Baseline Dyspnoea Index (BDI).

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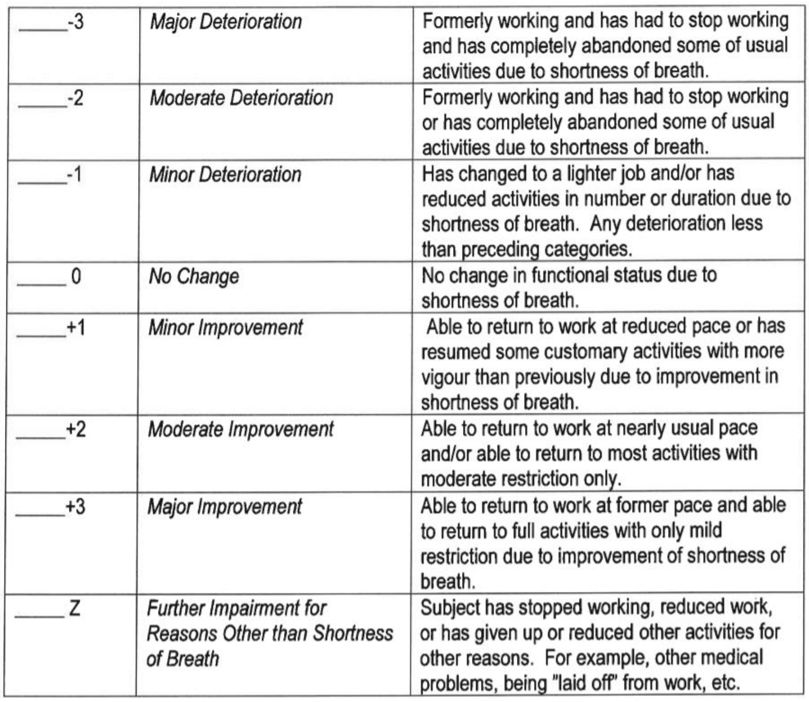

_____-3	*Major Deterioration*	Formerly working and has had to stop working and has completely abandoned some of usual activities due to shortness of breath.
_____-2	*Moderate Deterioration*	Formerly working and has had to stop working or has completely abandoned some of usual activities due to shortness of breath.
_____-1	*Minor Deterioration*	Has changed to a lighter job and/or has reduced activities in number or duration due to shortness of breath. Any deterioration less than preceding categories.
_____ 0	*No Change*	No change in functional status due to shortness of breath.
_____+1	*Minor Improvement*	Able to return to work at reduced pace or has resumed some customary activities with more vigour than previously due to improvement in shortness of breath.
_____+2	*Moderate Improvement*	Able to return to work at nearly usual pace and/or able to return to most activities with moderate restriction only.
_____+3	*Major Improvement*	Able to return to work at former pace and able to return to full activities with only mild restriction due to improvement of shortness of breath.
_____Z	*Further Impairment for Reasons Other than Shortness of Breath*	Subject has stopped working, reduced work, or has given up or reduced other activities for other reasons. For example, other medical problems, being "laid off" from work, etc.

Figure 1.5: The Transition Dyspnoea Index (TDI).

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Breathlessness has also, however, been recognised as a “multidimensional construct” (Petersen et al., 2008; Oxley & Macnaughton, 2016) that extends beyond these clinical scales. Writing for the American Thoracic Society, Parshall and colleagues define breathlessness as “a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity” (2012: 436). It is a sensation whereby “[s]pecific physiological processes may be linked to corresponding sensory descriptors” (Parshall et al., 2012: 435): the most distinct descriptors are the work (or effort) required to take a breath, chest tightness, and ‘air hunger’ or unsatisfied inspiration. The sensory-perceptual mechanisms pivotal to these feelings of work or effort are akin to those related to exercise (although experienced when undertaking far less vigorous activities), whereas chest tightness refers to specific stimulations in conjunction with *bronchoconstriction*, or, “the [abnormal] constriction of the airways in the lungs due to the tightening of surrounding smooth muscle, with consequent coughing, wheezing, and shortness of breath” (Douglas & Elward, 2010: 164). Air hunger, lastly, refers to the sensation of not being able to breathe in sufficient air, or of needing to breathe in more air than one is able, which typically results in deep, rapid, and laboured breathing caused by an increased respiratory drive due to abnormally low blood oxygen (Liotti et al., 2001; Banzett et al., 2008; Petersen et al., 2008; Smith et al., 2009; Jensen et al., 2016).

In light of these terms, how is breathlessness diagnosed and quantified? As we can read on the BLF website (blf.org.uk, 2018), there are certain tests medical practitioners may perform in order to distinguish the underlying causes behind a patient’s abnormal breathlessness. Breathing and lung function tests (also known as pulmonary function tests), including spirometry, lung volume tests, and lung diffusion, are amongst the most common.

Spirometry is a test used to help diagnose and monitor certain lung conditions by measuring how much air one can breathe out in one forced breath. It is carried out using a device called a *spirometer*, which is a small machine attached by a cable to a mouthpiece (Braun, 2014; NHS, 2018). Lung volume tests, in contrast, are used by healthcare professionals to determine whether a person's lung condition is restrictive or obstructive (blf.org.uk, 2018). An obstructive lung condition refers to a narrowing of the airways inside the lungs, which means that the lungs never empty completely, and more air remains in the lungs than normal after breathing out. Some examples of obstructive respiratory conditions are chronic obstructive pulmonary disease (COPD), asthma, and bronchiectasis (NHS, 2018). A restrictive lung condition, on the other hand, means someone cannot fill their lungs fully with air because the lungs are restricted from expanding fully, having lost their elasticity, as happens in conditions such as pulmonary fibrosis and sarcoidosis (NHS, 2018).

Lastly, lung diffusion testing is designed to test how well a person's lungs allow oxygen and carbon dioxide to pass in and out of the blood. This process is called diffusion. When breathing, one inhales air containing oxygen through the nose and mouth. This air travels down the *trachea* or windpipe into the lungs. The *bronchi*, branching from the trachea, are the primary passageway for air to get into the lungs (Dartnell & Ramsay, 2005). Once in the lungs, the air travels through a series of increasingly smaller structures (or passageways) called *bronchioles*, and eventually reaches tiny air sacs called *alveoli* (Figure 1.6). The trachea, bronchi, bronchioles, and alveoli make up the lower respiratory tract.

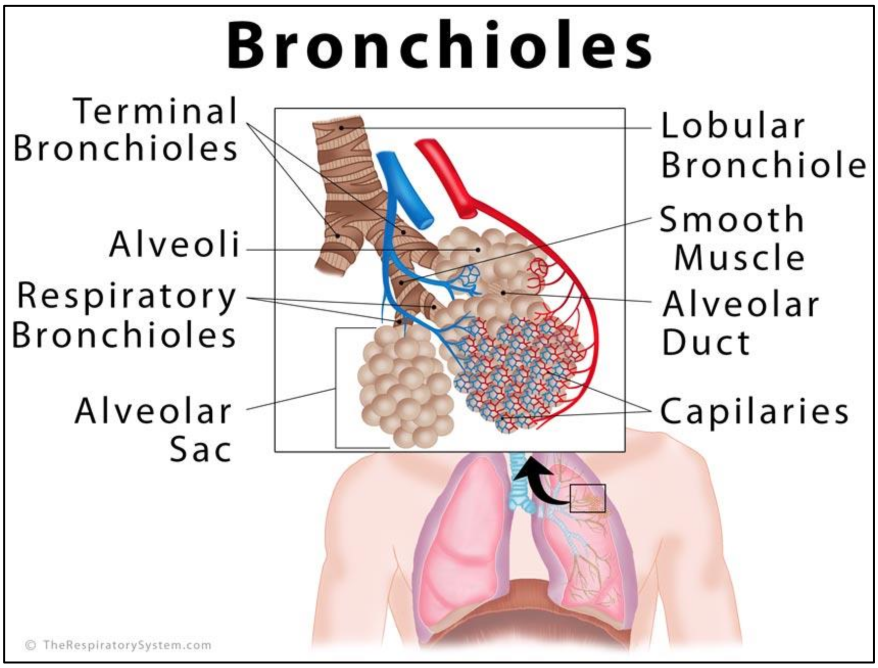

Figure 1.6: Bronchioles diagram.

(© TheRespiratorySystem.com)

From the alveoli, oxygen enters the blood via nearby blood vessels in a process called oxygen diffusion. Once the blood is oxygenated, it carries oxygen throughout the entire body (Dartnell & Ramsay, 2005; Burki & Lee, 2010). The term *hypoxemia* refers to abnormally low levels of oxygen in the blood, specifically “oxygen deficiency in arterial blood” (Eckman, 2010: 208). Hypoxemia is a common sign of problems related to breathing or circulation and may result in symptoms such as shortness of breath. As can be read on the Mayo Clinic’s website[8]

> Hypoxemia is determined by measuring the oxygen level in a blood sample taken from an artery (arterial blood gas). It can also be estimated by measuring the oxygen saturation of your blood using a pulse oximeter—a small device that clips to your finger. Normal arterial oxygen is approximately 75 to 100 millimetres of mercury (mm Hg). Values under 60 mm Hg usually indicate the need for supplemental oxygen. Normal pulse oximeter readings usually range from 95 to 100 percent. Values under 90 percent are considered low. (2019: para. 2-3)

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[8] The Mayo Clinic is a non-profit academic medical centre based in Rochester, Minnesota, focused on integrated clinical practice, education, and research (The Mayo Clinic, 2019). It is home to the Mayo Clinic Alix School of Medicine, in addition to many of the largest, best-regarded residency education programs in the United States.

In respiratory diseases (both obstructive and restrictive) these ranges may not apply, however, and medical practitioners will determine what is normal (or habitual) for each specific case and condition (The Mayo Clinic, 2019). For instance, it is not exceptional for people with severe COPD to maintain their pulse oximeter levels between 88 to 92 percent. In the case of asthma, on the other hand, the use of home oxygen therapy “is known to be effective and should be administered when oxygen saturation levels fall below 94 percent” (Okpapi et al., 2013). That said, the numbers above are all standardised measurements; statistics or “abstractions that help us explain variation” (Rose, 2016: para. 1). Breathing may be a basic physiological process, but it also carries deep cultural and personal meanings. It is associated intimately with our state of mind and is unique amongst our bodily processes in being both autonomic and controllable (Jensen et al., 2016). Although it may seem like an effortless act to most, breathing for individuals with lung disease can require extra energy and thus be physically challenging. The act of breathing is unique to each of us, as is the experience of respiratory disease.

THE DISEASE-ILLNESS APPROACH: A DEBATE OF DEFINITIONS

Kaplan-Myrth writes that health and medical anthropologists, historically speaking, argue that illness narratives are not “merely accounts of symptoms but a mechanism through which people become aware of and make sense out of their experiences” (2007: 1268). There is a transformation in place—phenomenologically speaking (Carel, 2016)—from something ‘lived’ to something ‘interpreted’. Through this transformation, Kaplan-Myrth argues, meaning and structure are created in “the dialogue that takes place between the patient and physician” (2007: 1268). That is to say, illness narratives include both lived (embodied) experiences and interpretations of these experiences. Thus, keeping Kaplan-Myrth’s notion in mind, I will mark out a few contextual concepts and definitions before proceeding. These concepts are significant to the context at hand and while not analytical tools, per se, they should not be left to stand as taken-for-granted notions.

So far, I have used pathological terms such as *lung* disease, *pulmonary* disease, and *respiratory* disease synonymously. Although they are legitimate semantic equivalents, each of these three terms has implications of their own. “Lung disease” implies a disease of the lungs, as does “pulmonary disease”. The word *pulmonary* derives from the Latin root *pulmo* (lung). However, the term ‘pulmonary disease’ is rarely used in everyday speech, more commonly applied as medical terminology, denoting specific pathologies such as chronic obstructive pulmonary disease (COPD) or idiopathic pulmonary fibrosis (IPF). This illustrates what Rebecca Oxley (2016) describes as a “disconnect between clinical and lay perspectives” as to how ailments of the chest and lungs are understood, assessed, and defined. As Oxley and Macnaughton argue (2016: 257), this disjunction becomes clear in research that

> describes how the measurement of dyspnoea [breathlessness], in terms of its neurophysiological properties, and of lung capacity through spirometry, are not always aligned to the intensity and discomfort of breathlessness, nor how it is lived on a day-to-day basis.

The same can certainly be drawn from the ‘language of dyspnoea’, as named by Scano and colleagues (2005): “the very words used to explain and express breathlessness” (Oxley & Macnaughton, 2016: 257). Scano and colleagues write (2005: 380) that dyspnoea is a “general term used to characterise a range of qualitatively distinct descriptors that vary in intensity, and are influenced by a wide variety of factors”. Overall, their argument is that using certain verbal descriptors may contribute to “the understanding of the mechanisms of [breathlessness], and assist in identifying or predicting a specific diagnosis” (Scano et al., 2005: 380 ff). However, as Oxley and Macnaughton (2016) note, there is an apparent tension between the personal and emotive language applied by patients and the often technical terms used by healthcare professionals. Breathlessness does not have to be the primary concern identified by those who suffer from it.

Although the experience of breathlessness is clinically understood as "a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity" (Parshall et al., 2012), for the people living with it, chronic breathlessness might be experienced and expressed through significant changes to personal routines, habits, or livelihood. Such discrepancies in depiction may, according to Oxley and Macnaughton, "affect recognition of breathlessness and/or underlying medical conditions, and call for a further understanding of the subjective ways dyspnoea is conceived of" (2016: 380). That is, language is fundamental when it comes to understanding breathlessness pathologically, but also when it comes to making sense of how people experience breathlessness and how it affects their everyday lives. Language does, after all, extend beyond the modest sentence boundary. It is not a mechanical process; it occurs naturally.

On the other hand, respiratory disease denotes diseases of the chest and lungs. The term 'respiratory' is an adjectival form of *respiration* (i.e., the movement of air or dissolved gases into and out of the lungs). The respiratory system (Figure 1.7) is a collection of organs in which the lungs are imperative. I will also be referring to medical conditions (pathologies) through their main shared symptom of *breathlessness.* This goes alongside the term 'breathing disorder'—that is to say, a disorder that affects the breathing. However, when referring to breathlessness, I denote the overall disease area and the specific symptom (Macnaughton & Carel, 2016), rather than separate diseases with their own pathologies.

This is part of my overall argument. As lung disease is difficult to treat and tends to deteriorate over time, patients may well be told by their doctors that 'there is nothing more we can do'. Medical practitioners are trained to treat diseases (*pathologies*), not symptoms (Macnaughton, 2016; Nyman, 2018). In seeking to care for people living with chronic respiratory disease, medical practice must move beyond treating pathologies to patient-centred care focused on relieving pain and suffering derived from symptoms such as chronic, pathological breathlessness.

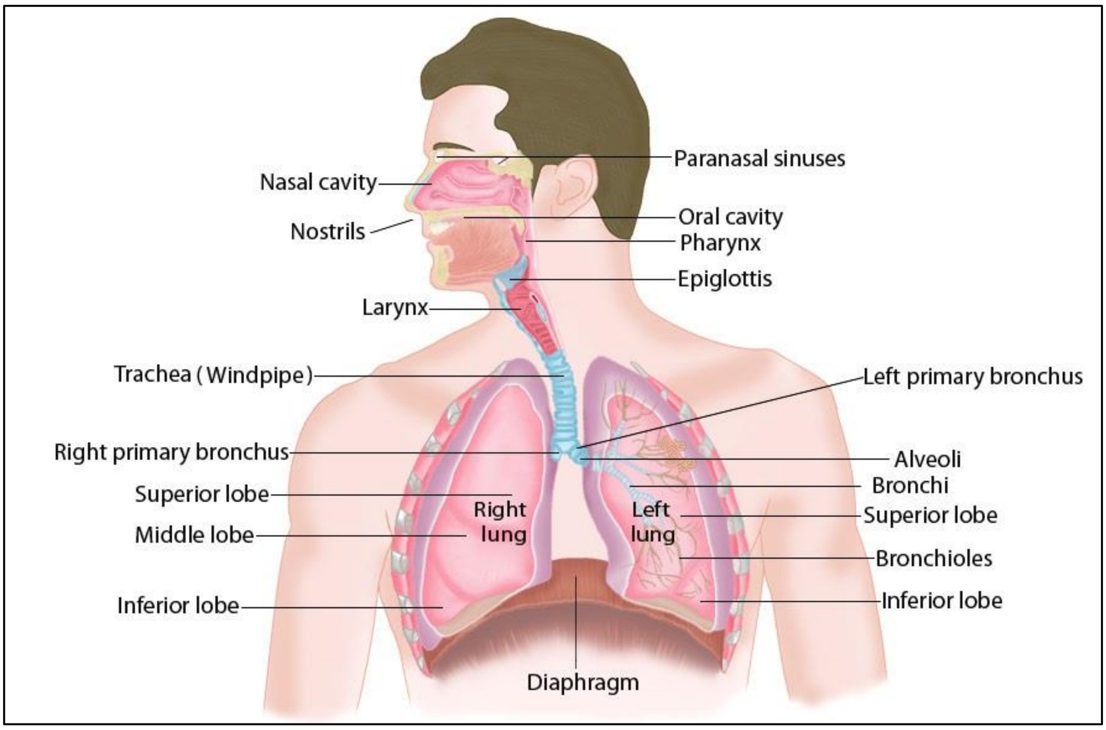

Figure 1.7: The respiratory system of the human body.

(©TheRespiratorySystem.com)

I also shift between labelling these diagnoses as illnesses or diseases. Although it is again easy to assume these are synonymous terms, as Arthur Kleinman (1989: 3) writes, they do convey “something fundamentally different” from each other. In the words of Leon Eisenberg (1977), patients *suffer from illnesses* while doctors *diagnose and treat diseases*. I am also beguiled by how Eric Cassell situates this distinction: “Illness is what the patient feels when he goes to the doctor, disease is what he has on the way home” (1976: 53). Eisenberg reminds us that (reaffirmed by Dinesh Bhugra and Gin Malhi [2013]) patients suffer from illness. They are therefore “by and large, interested in illness and its implications” (Bhugra & Malhi, 2013: 795), focused on how their lives may change. By contrast, as previously argued (e.g. Eisenberg, 1977; Young, 1982; Kleinman, 1989; Macnaughton & Carel, 2016; Carel, 2018c), doctors are trained to diagnose, deal with, and treat diseases. This, unfortunately, may give rise to a “major discontinuity in states of being and perceived role performances, thereby creating dissonance and a disjunction between the patient and the doctor" (Bhugra & Malhi, 2013: 795). This point has been reiterated by Oxley and Macnaughton (2016) as mentioned above. What can we draw from this? Illnesses are experiences of "discontinuities in states of being and perceived role performances", while diseases, "in the scientific paradigm of modern medicine, are abnormalities in the function and/or structure of body organs and systems" (Eisenberg, 1977: 9). Parallel to this debate, Pool and Geissler (2005) write that a similar distinction can be made between cure and healing:

> […] doctors may cure disease, but that does not necessarily mean that the patient's illness is healed. Cure implies the absence of disease, or its expulsion from the body, whereas healing refers to the improvement of the ailing body and the well-being of the ill person. (Pool & Geissler, 2005: 53-54)

Lastly, although most importantly, holistically speaking it is far from useful to distinguish these perspectives from one another. As Pool and Geissler so elegantly put it (2005: 55), as with emic and etic

> …illness cannot always be conveniently separated from disease. While doctors may try to keep their interpretation of disease neutral and objective, subjective aspects of the patient's experience will always impinge, and patients will obviously perceive and experience aspects of the biomedically defined disease as well as the more subjective aspects of the illness.

Patienthood is, after all, a social state (personhood), not merely a biological one (Eisenberg & Kleinman, 1981; Degnen, 2017, 2018). Pool and Geissler show (2005) that both social and cultural factors are involved in the risk of becoming sick, as much as in how sickness is defined and symptoms interpreted and responded to. As they write, "People decide to become (or remain) patients, as well as being defined and labelled as patients by doctors" (Pool & Geissler, 2005: 53). To make matters even more complex, alongside definitions of 'illness' and 'disease' there is the concept termed *sickness*, which is to say the circumstances in which society "decides what is 'deviant' and what is seen as 'sick', attracting benefits such as sick leave" (Bhugra & Malhi, 2013: 795). Arthur Kleinman defines 'sickness' as the "understanding of a disorder in its generic sense across a population in relation to macrosocial (economic, political, institutional) forces" (1989: 6). He argues that illness and disease should not be understood as separate entities, but rather as explanatory models for sickness. However, Pool and Geissler write (2005) that there are scholars who use the term ‘sickness’ to refer to both illness and disease, while others give ‘sickness’ a more specialised meaning, “using it to refer to the process in which illness and disease are socialized” (ibid. 53).

In summation, let me put it like this: a patient will interpret their experience of asthma or COPD as an illness, while the physician understands, describes, and treats this experience as a disease. Sickness, on the other hand, is how society perceives the patient to feel (and even appear) with regards to their illness experience. With perceptions come expectations that determine how this patient can (and should) act as an ‘ill person’. This is where the stigma of lung disease comes in, as people with lung disease may look well, making it difficult to convince other people that they “have a serious lung condition—even [their own] family” (British Lung Foundation, 2015a). A stigma of self-infliction and moral weakness is “linked to a value judgement of people living with the disease” (Halding et al., 2011: 104). As Allan Young writes, ‘sickness’ is merely a “blanket term to label events involving disease and/or illness” (1982: 265). In the words of Kleinman and Eisenberg (1981), medical anthropologists need to acknowledge that their domain is always going to be ‘sickness’, considering illness and/or disease from the side-lines[9] (as ‘sickness’), in how these conditions are interpreted and institutionalised, despite the fact that the academic contributions will predominantly be with regards to either illness or disease.

Finally, there is one further conceptual aspect to attend to regarding the descriptive definition or classification I will be employing for the people living with respiratory disease: ‘the patients’, as they would be known as in some contexts. I primarily refer to these individuals as ‘people who live with chronic breathlessness or respiratory disease’ which is purely descriptive terminology. Alongside this, I will also apply ‘service user’ to denote the fact that “the person who uses healthcare services is patently a user” (Neuberger, 1999: 1756). Another term that would be

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[9] This assumes one remains well and in good health. As an example, phenomenologist Havi Carel lives with a chronic lung disease and does not study breath, breathing and breathlessness from the side-lines (2015, 2016). The same can be said for Liz Price and Liz Walker (2015) who studied autoimmune disease in the wake of their own worsening health.

applicable is applied by anthropologist Timothy Choy: ‘breathers’ (Choy, 2011, 2012). The downside of this term, however, is that we are all (respiratory disease or not) breathers. Thus, to avoid confusion I refrain from using it as a key concept, unless I directly quote Choy and his work. In contrast, I will employ the term ‘patient’. Several of my interlocutors actively defined themselves as patients, thus making it an emic term (Geertz, 1973: 27). However, this term is far from unproblematic (Neuberger, 1999; Entwistle & Watt, 2013). As Julia Neuberger writes (1999: 1756), the word “patient”

> …conjures up a vision of quiet suffering, of someone lying patiently in a bed waiting for the doctor to come by and give of his or her skill, and of an unequal relationship between the user of healthcare services and the provider. The user is described simply as suffering, while the healthcare professional has a title, be it nurse or doctor, physiotherapist or phlebotomist.

In this language, the ‘patient’ turns truly passive in “bearing whatever suffering is necessary and tolerating patiently the interventions of the outside expert” (Neuberger, 1999: 1756). As Neuberger argues, it derives from the ‘patient’ ideal as passive, whereby the strongest argument against the use of this term “is that the word itself indicates immediately the unequal nature of the relationship with medical practitioners, and ‘objectifies’ the person who is the user” (1999: 1756). Thus, the term ‘active patient’ becomes a contradiction. For the same reason, I refrain from describing my interlocutors as ‘sufferers’ or ‘victims’. While some of the people I met did refer to themselves as ‘sufferers of disease’, who am I to say, judge, or determine whether they are actually suffering? The same goes for the term ‘victim’. While these people can indeed be seen and understood as victims of their conditions, this terminology would not only limit them to be defined by their diseases (or pathologies)—which they do not wish to be (British Lung Foundation, 2015a)—but it would also fail to acknowledge them as agents. Although “[c]ontemporary texts in sociology and anthropology often position themselves morally by stating, ‘These people are not victims, but agents’” (Dahl, 2009: 391), this does not necessarily have to be the case. While there are people who are more commonly defined by the marks made on them, rather than by the marks they themselves have made on the world, victimhood does not in itself diminish or eradicate agency. In relation to this, Entwistle and Watt (2013) write that, for decades, healthcare leaders and patients' advocates have struggled to improve patients' experiences of the way healthcare is delivered. They suggest that in order to correct tendencies for health care to be either "too disease-centred" or "too system- or staff-centred" (2013: 29), more person-centred care should be adopted, treating patients as *persons* (Entwistle & Watt, 2013). This view is central within the holistic framework foregrounded in this dissertation, where individual, personal experiences of respiratory disease are always the centre of attention.

DISSERTATION OUTLINE

The dissertation is divided into three parts, consisting of eight chapters: Settings (Chapters 1 to 3), Moments (Chapters 4 to 6), and Epilogues (Chapter 7 and Concluding Remarks).[10] **Chapter 1 (Introduction)** draws out the overall themes and context of the dissertation, and the questions at stake. **Chapter 2** offers a literature review of the biosocial approach as the postmodern condition I embrace it to be. The chapter considers the notion of 'biosociality' (as framed by Paul Rabinow) in understanding the dichotomous relationship between nature and culture, or the biological and the social: a debate fundamental to the process of social formation around shared biological conditions. Drawing upon a predominantly Foucauldian framework, the chapter ponders the usefulness of 'biosociality' in the context of support groups formed for the self-management of respiratory conditions. Following this, **Chapter 3** describes the study design, particularly the methodology. The multi-sited (unbounded) nature of the ethnographic fieldwork is discussed in detail and the chapter also deliberates on the selected field-sites in the north-east of England, as well as the ethics of fieldwork.

Chapters 4 to 6 represent the empirical parts of the dissertation and draw upon the ethnographical material collected between 2017 and 2018. **Chapter 4** specifically offers a brief historical biography of the Breathe Easy support group network; how the network came to be, and how the network grew out of its relationship with the British Lung Foundation. The question at stake in this chapter regards the neglect of

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[10] I have borrowed these section titles from Nigel Rapport (2008).

respiratory health in the public health agenda of the UK and considers the historical conditions that led to the formation of two charitable organisations seeking to elevate respiratory diseases as a public concern: the BLF and the Breathe North Appeal (the latter later merged with the former to become its branch in the north-east of England). The chapter then shifts its focus towards the Breathe Easy support group network, which officially launched in 1991 and later expanded across the UK. It offers a ‘thick description’ of the systemic nature of the Breathe Easy groups and how the groups function in a more pragmatic sense. Lastly, the chapter deliberates on recent changes within the BLF and its services, and how this has affected the Breathe Easy network.

Chapter 5 focuses on people’s experiences of partaking in Breathe Easy groups. Specifically, the chapter looks at how individual members approach and make sense of their groups as a form of social support that they cannot obtain elsewhere. It discusses how the academic debate surrounding support groups suffers from a lack of consistency and offers a description of two primary aspects identified as fundamental to attending a Breathe Easy meeting, which I name “sociality as support” and “support as sociality”. The former does not only refer to the actual social interaction that goes on within the groups, but also how the groups themselves may be understood as *safe spaces*. The latter entails, in a similar sense, more than mere mutual support between the members but also the process of acquiring skills with which to cope with one’s chronic breathlessness *through* sociality. The chapter illustrates and discusses the differing values of what it means to be part of a Breathe Easy group.

Chapter 6 attends to the notion of patient advocacy, especially in regard to how the Breathe Easy network can be said to exist and act beyond the needs of its members, but also considering local healthcare communities throughout the UK. The chapter focuses mores specifically on the metropolitan borough of South Tyneside and the Breathe Easy group active in the town of South Shields, and further details the NHS *Path to Excellence* transformation scheme affecting the South Tyneside District Hospital. The chapter is centred on the journey which the Breathe Easy group in South Tyneside goes through as it not only supports the local district hospital, but also the overall borough community.

Chapter 7 provides a detailed discussion of the primary research question that is at stake: *What is breathlessness, and how are communities formed around this somatic phenomenon?* What follows are thematic analyses, all structured in line with the previously presented empirical chapters: *biomedical needs* (Chapter 4), *biosocial needs* (Chapter 5), and *biopolitical needs* (Chapter 6). All three draw closely upon the material and questions raised in each individual chapter. The section on biomedical needs discusses how biosociality manifests itself out of the common goal to address public health urgencies; in this case, to elevate respiratory disease to the same footing as cancer and cardiovascular disease in terms of UK health priorities. Next, the section on biosocial needs returns to the question of neoliberal governance in healthcare practice and discusses how the support group phenomenon is growing globally as a care complement due to respiratory services being individualised. In neoliberal times, private citizens are held responsible for their own health, which thus creates the need for social support that is otherwise inaccessible. Lastly, the section on biopolitical needs discusses the relation between biosociality and biological citizenship, especially with regards to how patient activism rises as an expression of autonomy and pastoral power in the light of shared biological conditions. This is explicitly done through the case of the South Tyneside District Hospital and the *Path to Excellence* transformation scheme in the North East, and how the local Breathe Easy group as a result chose to change how it operates as a support group.

The eighth and final chapter (Concluding remarks) offers a brief deliberation on the coronavirus disease 2019 pandemic (COVID-19), specifically drawing parallels between the global issues that came to surface and the wider themes of the dissertation. The issue of COVID-19 aligns well with the contribution of this dissertation, especially in terms of widespread health inequalities and healthcare services being stretched to the limit around the world, and the systemic neglect of respiratory health as a matter of public health urgency (mainly due to its ‘invisible’ nature). The chapter considers the relation between the notions of community, society, and biosociality. Through the example of COVID-19, the chapter illustrates how mutual aid formations are more relevant than ever on the research agenda. In summation, the chapter ponders the lessons learned and the overall contributions that have been put forward in the dissertation as a whole.

~ CHAPTER TWO ~

FROM PHENOMENOLOGY TO BIOSOCIALITY

A POSTMODERN ARGUMENT

"Poststructuralists believe there is never one, definitive outcome. This view of learning is full of creativity, opportunity, and forward movement."

E. SMITH SLEIGH

INTRODUCTION

The invisibility of breathlessness may be a well-recognised problem, yet as Oxley and Macnaughton write, "the meaning of breathlessness for those who live with it is poorly understood in respect of its subjective, cultural, and experiential significance" (2016: 256). Considering how the sensation of breathlessness can be understood, in the words of Wainwright, as an "environmental embodiment" (2017: 342); a sensation embedded within a cultural context in which "air, its qualities, and its impact on health are attributed significant meaning" (ibid.), studying breathlessness via a phenomenological lens (which I discussed in the previous chapter) may help in uncovering "the normal, pre-reflective ways of existing in the world, providing opportunities for self-reflection and understanding" (Williams & Carel, 2018: 153). However, while a phenomenological description and explanation remains "indispensable to our understanding of the difficulties faced by patients" (Williams & Carel, 2018: 146), no comprehensive phenomenology of breathlessness still exists to date. Silvia Stoller writes that phenomenology is very much considered a philosophy of *lived experience* (2009). However, in the wake of French poststructuralism[11] beginning in the 1970s, "the concept of experience within phenomenology has come in for heavy criticism" (Stoller, 2009: 707). In consequence, experience has increasingly fallen into opprobrium; almost becoming

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[11] Foucault, Derrida, Deleuze, Lacan as well as Baudrillard, to name a few (Angermüller, 2007).

a ‘dirty word’ (Grosz, 1993). In fact, Jonathan Sholl puts this concern into words most extraordinarily: that is, “while phenomenology might be a useful *method* for describing the lived experiences of illness, it remains severely impoverished as a *theory* for explaining it” (2015: 408, emphasis in original). It still remains unclear exactly how a phenomenological perspective stands distinct from what one finds in psychology and its various subfields—which not only describe, but also *explain* lived experiences (e.g. Rose, 1996; Braun & Clarke, 2006; Edwards, 2008). This impoverishment, Sholl maintains, needs to be significantly addressed “if phenomenology is to add anything substantially new to the debates” (2015: 408) that cannot already be found in more nuanced naturalistic approaches to understanding medical concepts and practices (e.g. Lupton, 2003; Burri & Dumit, 2007; Lock & Nguyen, 2010; Baer & Singer, 2012; Trnka, 2017; Kenner, 2018)—or even “literary descriptions of the experience of illness” (Sholl, 2015: 408).

With this in mind, and also considering Foucault’s critique of phenomenology in his “rejection of the subject as origin in favour of a body of anonymous rules governing discourse” (Shiner, 1982: 312), which I discuss later, the dissertation distances itself from phenomenology and instead goes in another theoretical direction. As such, this chapter (progressively entitled “From Phenomenology to Biosociality”) introduces key literature and perspectives that inform this dissertation and seeks to outline the theoretical framework I use to analyse the lived experiences of my interlocutors, which is done from the view of biosocial theory (cf. Harris & McDade, 2018; Singer et al., 2019). Being a transdisciplinary approach to understanding human development, behaviour and health, the biosocial perspective draws upon

> […] models and methods from the biological, medical, behavioral, and social sciences. It conceptualizes the biological and the social as mutually constituting forces, and blurs boundaries between phenomena inside the body and outside of the body. (Harris & McDade, 2018: 3)

In this chapter (and dissertation, overall) I not only attend to people’s individually lived experiences of respiratory disease, but also shed light on their collectively shared experiences through the peer-support groups they attend. More specifically, what this dissertation contributes to the field of health and medical anthropology is a reconsideration of “biosociality” and its eclectic principles. In its widest sense, biosociality refers to formation processes whereby people come together through shared biological conditions. In order to contribute to this theoretical model, I contend that we need to gain further understanding of the organisation and function of such biosocial gatherings and their meaning for individual members. Throughout this dissertation, I illustrate how this can be achieved by using an ethnographic approach to look at how biosocial groups (like peer-support groups for people with respiratory conditions) transition, adapt and develop over time.

In the words of Mark Nichter, the “meanings and experience of bodily sensations are biosocial and need to be studied in the context of social change” (2008: 186). Brekke and Sirnes write that the concepts of biocitizenship and biosociality were “in many ways developed as a reaction to the former critique of genetification and fears of a return of eugenics” (2011: 347). Although this framework has been criticised for its ‘biological determinism’ (Walsh & Wright, 2015; Happe et al., 2018) in referring to everyday sociality simply by incorporating the aspect ‘bio’ within its scope, in this dissertation I want to draw further attention to the framework’s origin. Thus, following on from what Rebecca Marsland writes, I argue that if biosociality is to be understood and further developed in nuanced ways, we need to take “sociality and locality as seriously as we do *bio*” (2012: 470, emphasis added). That is to say, while the biological conditions themselves are fundamental to the biosocial framework, people’s positions and reactions to the group assemblies are *as* central (if not more) to how the actual biosocial formation processes play out. This dissertation serves as an example of this.

What is the ‘biosocial approach’?[12] The approach fundamentally builds on Paul Rabinow’s early work on DNA and genomics (1992, 1996b, 1999) where he outlines the dogmatic transition from sociobiology to biosociality. By and large Rabinow’s work draws upon Michel Foucault’s philosophy and political thought (2003b, 2007,

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[12] I would like to add that this notion stands with what Merrill Singer and colleagues call the *bio-sociocultural approach* (2019: 1), which reflects the anthropological endeavour to address health as an aspect of the human condition. The starting premise of health anthropology, the authors argue (2019: 1), is that “health-related issues, including disease and treatment, how and why one gets sick, and the nature of recovery, are far more than narrow biological phenomena”. That is to say, these processes are all “heavily influenced by environmental, political-economic, social-structural, and sociocultural factors as well” (Singer et al., 2019: 1).

2008, 2010, 2014a) and thus the term biosociality is to be understood as a response to Foucault's panoptical worldview (2015) and bio-political thoughts (2008), wherein the term provides insights into the "relationship between subjects, communities, and power" (Friedner, 2010: 342). Having that said, my application of the biosocial framework will nonetheless draw from a broader body of literature assembled by, principally, Sahra Gibbon, Carlos Novas, and colleagues (Gibbon, 2007; Gibbon & Novas, 2008a; Novas, 2008; Gibbon et al., 2010; do Valle & Gibbon, 2015). I also draw upon Adriana Petryna (2002, 2004, 2011) and her work on biological citizenship, as well as Nikolas Rose (1996, 1999, 2007, 2013a) and his thoughts on the politics of life.

The dissertation seeks to contribute to the aforementioned body of literature, to which I turn in search of abstract explanations for social interaction and everyday life. This is an area which I believe earlier work on biosociality and biocitizenship has neglected. Namely, if we look to its origin, biosociality theory primarily sought to explain the increased interest in genomic knowledge of one's biological conditions such as chronic illness (Rabinow, 1992), while neglecting to explain how people interacted with, upon, or in light of this (new) knowledge, as well as with each other. This is where, as Paul Rabinow writes (1992), genetics "will cease to be a biological metaphor for modern society" in which biosociality emerges through a new form of self-production (based on subject formation and the exchange of biological knowledge). Subject formation and embodiment are key to understanding biosociality as a postmodern biopolitical paradigm—particularly when it comes to the notion of social solidarity in patient movements and support groups. In this chapter I introduce what this may reveal, more specifically, when looking at how communities emerge around chronic breathlessness.

The chapter is organised as follows. In view of how I approach support groups as a phenomenon that extends beyond its social setting to more of a resource whereby people share and exchange knowledge, the chapter starts out by defining the Foucauldian understanding of 'technology' (is based on the ancient word *techne*). It then reviews the wider conceptual framework consisting of biosociality and Foucault's *Technologies of the self* (1988). I particularly focus on the said transition from sociobiology to biosociality and the concomitant refinement of biosociality theory, where nature once again comes to be understood as superior to culture. Together these concepts will offer the foundation from which to understand not only how peer-support groups (as social constructs and self-technologies) work in a pragmatic sense, but also how and why they materialise in the first place. While the argument is indeed generalisable, this dissertation looks specifically at the case of the United Kingdom (UK). The increasing admiration for support groups in the UK, I contend, is a direct result of shifting neoliberal responsibilities in the nation's healthcare and welfare practices. This is especially evident in respiratory care, which is becoming more and more individualised (Trnka, 2017; Kenner, 2018) and demands new forms of autonomy and patient activation (Korpershoek et al., 2016). In turn, biosocial groups become more vital than in the past.

***TECHNE* AND FOUCAULT'S ART OF GOVERNANCE**

An essential concept for this dissertation is *technology*. However, I am not referring to the verbatim sense of the term; nor to the science or study of the practical or industrial arts, or applied sciences; nor to technical terminology, or methods or processes for handling a specific technical problem, which are all axioms we could find in a thesaurus. Rather, I am referring to *techne*—a term that etymologically derives from the Greek word τέχνη, often translated as "craftsmanship," "craft," or "art" (Behrent, 2013). In philosophical terms, the application of *techne* resembles *epistēmē* (ἐπιστήμη)—knowledge, science, or understanding—in the implication of a principled system of understanding (or simply *know-how*). That is to say, *techne* is the art (or craft) itself while *epistēmē* (episteme) is the knowledge or understanding of that said art and its application. *Techne* differs in that its intent is making or doing as opposed to disinterested understanding (or disinterested '*theoria*') (Behrent, 2013: 93). According to Richard Rojcewicz (2006), Martin Heidegger holds that for the people of ancient Greece and Rome, the concept of *techne* had strong parallels with that of *episteme*. Heidegger himself particularly cities Plato, who seemingly used the two terms interchangeably (see Rojcewicz, 2006: 44 ff). Needless to say, by and large *techne* and *episteme* each denote knowledge and knowing (or *know-how*); as Daniela Carpi writes, "both words are names for knowledge in the widest sense" (2011: 54).

All the same, Les Back writes (2018) that there is "scepticism about the humanistic practice of portraiture from a wide variety of poststructuralist and anti-humanist traditions of social analysis." In writing a 'person' (or translating, as Back puts it)—or *knowledge*, for that matter—there are several significant philosophical and political judgements to be made. During interviews, for instance, Les Back writes (2018) that while a Freudian psycho-analyst would be listening for "hidden meanings within a biographical portrait," a phenomenologist (à la Merleau-Ponty) would attend to how the respondent's lifeworld was portrayed. On the other hand,

> a Foucauldian poststructuralist may not be interested in the specific portrait of the interviewee as a subject at all but rather take note of the *discourses and forms of power* that shape the words articulated. (Back, 2018: para. 11, emphasis added)

That is to say, Foucauldian scholars examine society through practices and local circumstance where they focus on the 'embodied subject'—rather than the subject itself (Hacking, 2004; Speziale, 2017). Explicitly, this framework rejects the search for a 'true self', as the self is seen and understood as a series of practices rather than a predetermined matter (Foucault, 1988; Gutting, 2005; Smith, 2015). Thus, poststructuralism—as a critical ethos and not a theory, per se—constitutes the most important means to truly grasp the deep-seated relations between power, knowledges, and subjects. Michel Foucault is a key figure in poststructuralist theory, and I stand with Colin Koopman, amongst others, who writes that Foucault's work on power *matters now more than ever* (2013, 2017). Koopman's argument is that Foucault's lasting prominence lies not in having established some "new master-concept that can explain all the others" (2017: para. 5), but rather because

> [p]ower, in Foucault, is not another philosophical godhead. For Foucault's most crucial claim about power is that we must refuse to treat it as philosophers have always treated their central concepts, namely as a unitary and homogenous thing that is so at home with itself that it can explain everything else. (2017: para. 5)

Foucault's philosophy and political thought have much relevance to the scope of this dissertation. As Foucault emphatically specifies in *Discipline and Punish* (1991 [1975]), in the modern—or *neoliberal*—world, economic productivity goes hand-in-hand with political powerlessness and docility. Neoliberalism, briefly put, refers to a theory of political economic practices that

> proposes that human well-being can best be advanced by liberating individual entrepreneurial freedoms and skills within an institutional framework characterized by strong private property rights, free markets, and free trade. (Harvey, 2007: 2)

Over the past decade, neoliberalism has become a popular concept within anthropological scholarship (Ganti, 2014). However, as Ganti writes, this 'popularity' has also elicited a fair share of criticism (2014: 90). Aihwa Ong maintains that neoliberalism "seems to mean many different things depending on one's vantage point" (2006: 1) and when surveying the literature, the term appears "quite polysemic without a singular referent" (Ganti, 2014: 91). In her review article of the term, Ganti identifies four main referents: 1) "a set of economic reform policies […] concerned with the deregulation of the economy"; 2) "a prescriptive development model that defines very different political roles for labor, capital, and the state"; 3) "an ideology that values market exchange as 'an ethic in itself'"; and 4) "a mode of governance that embraces the idea of the self-regulating free market" (2014: 91). While all four referents play their part in our understanding of neoliberalism, Foucault predominantly refers to the modern (neoliberal) world in terms of ideology and governance (2007, 2010, 2014a). More specifically, as Audier writes, Foucault "was very interested in neoliberal thought, in neoliberal epistemology. He tried to grasp how neoliberalism puts into motion a full-blown political theory, a theory of government" (2015: 404). This is the understanding of neoliberalism employed throughout this dissertation.

Since the 1980s, social inequalities in health (that is, unfair differences in health outcomes between social groups) have entered the political agenda all over the world (Vallgårda, 2007; Smith et al., 2016). Neoliberalism may be connected to these issues; as history shows, "neoliberal precepts were propounded with increasing force in the UK and the USA, preparing the way for the election of

Thatcher in 1979 and Ronald Reagan in 1980" (Smith et al., 2016: 127). This is why neoliberalism, as such, remains hugely significant to this dissertation. Neoliberal reforms have, amongst other things, led to deep changes in healthcare systems around the world; especially "on account of their emphasis on free market rather than the right to health" (Sakellariou & Rotarou, 2017: 1). In the UK specifically, neoliberal policy has resulted in the propagation of "private-capitalist ownership combined with the privatisation and commodification of public goods, the public economy and public services" (Fuchs, 2016: 168). People with disabilities, in particular, may be disadvantaged by such reforms, due to their increased healthcare needs and lower socioeconomic status (Collins et al., 2015; Sakellariou & Rotarou, 2017). Consequently as respiratory care becomes more individualised (Trnka, 2017; Kenner, 2018), this very much affects people living with chronic breathlessness. Even more so if we consider how in the UK lung disease continues to be a major factor in health inequalities, where someone from

> […] the most deprived section of society is two-and-a-half times more likely to have COPD, and nearly twice as likely to develop lung cancer, as someone from the least deprived section of society. (Marmot, 2016: 3)

Two recent ethnographies—by Trnka (2017) and Kenner (2018)—help illustrate this disparity further specifically by looking at how neoliberal governance, in focusing on economic growth, has overshadowed collective approaches to health all around the world. Trnka and Kenner both use asthma as a case study and argue that asthma is a problem whose solution lies not in medicine—but in governance. In terms of health and medical care this can be seen most obviously in the rise of personal responsibility, which has now shifted onto the service-user (e.g. Rose, 2007; Trnka & McLauchlan, 2012; Trnka, 2014; Trnka & Trundle, 2014). As Trnka writes,

> In an increasing number of contexts, reform movements focused on promoting neoliberal values of personal responsibility are reshaping twenty-first-century personhood. Often part of moves to devolve a range of social services from the state onto individuals under the banner of increasing individual "choice," advanced liberal reforms both enable and require people to take on greater personal autonomy, self-responsibility, and self-reliance. (2017: 7)

In her book, Trnka very much considers the promotion of these ‘new kinds of people’ (the subjects of advanced neoliberalism, by way of explanation). Focusing on childhood asthma more specifically, Trnka deliberates on how new health-care policies; “in particular the promotion of self-responsibility and patient expertise in light of the restructuring of state and private health services” (2017: 9), bring forth not only different kinds of medical and scientific practices but also new forms of patient experiences and novel contestations amongst states, citizens, and private companies “over rights and responsibilities to care for the sick” (ibid. 10).

Following suit in her book on asthma care in the United States, Kenner (2018) contributes further to the study of the political economy that surrounds breath and breathing. Using multi-sited ethnography across seven U.S. cities to examine the myriad infrastructures and material practices of care that mediate the relationship between disordered breathing and the environment (2018: 21), Kenner maintains that asthma is not a new problem; today the disease is merely being reshaped by “changing ecologies, healthcare systems, medical sciences, and built environments” (2018: 6). When it comes to advanced liberalism, Kenner writes that she joins with other social science researchers in arguing that “asthma care has been individualized in neoliberal ways” (2018: 8) where “[…] public health responses have tended to emphasize the responsibility of individuals—taking medication, cleaning home environments, and monitoring pulmonary performance—over collective responsibility” (ibid.). This aligns well with what Trnka reasons in her book. It also further illustrates that nowhere is the “constitution of responsibilized subjects more evident” (Trnka, 2017: 8) than in the area of health, where governments and private enterprise around the world unremittingly reorganise the provision of health and medical care. As such, people are continually encouraged to engage in an “ever-growing array of activities and responsibilities to improve or maintain their own mental and physical well-being” (Trnka, 2017: 8).

(i) Techne and biopower

When it comes to technology apropos governance, Foucault himself “never had much to say about the technological advances that were transforming French society in the 1950s” (Behrent, 2013: 55)—or about technology in its broadest or most conventional sense either. Nevertheless, ‘technology’ as a conceptual framework appears frequently in Foucault’s writing and is integral to his overall philosophy. Behrent writes that

> Foucault primarily typically employs the term—as well as the related and in French often synonymous one of ‘technique’—to refer not to tools, machines, or the application of science to industrial production, but rather to methods and procedures for governing human beings. (2013: 55)

Foucault defines the Greek word *techne* as a “practical rationality governed by a conscious aim” (O’Farrell, 2005: 158). Although commonly understood in a rather narrow scientific context, Foucault generally prefers the word ‘technology’ as the translation of *techne* (which he uses to encompass the broader meanings of its application). As O’Farrell shows (2005: 158), Foucault often uses the words techniques and technologies interchangeably—although overall, techniques tend to be specific and localised while technologies are more general collections of specific techniques. To illustrate more specifically what such a technology (*techne*) could look like in the eyes of Foucault, I will employ the concept of biopower. According to Foucault (2007: 16), the concept of biopower refers to

> the set of mechanisms through which the basic biological features of the human species became the object of a political strategy, of a general strategy of power, or, in other words, how, starting from the eighteenth century, modern western societies took on board the fundamental biological fact that human beings are a species.

The word ‘mechanisms’ here, I argue, should be understood as the conditions by which certain technologies are wielded. As documented in his lectures at the Collège de France in Paris, Foucault argues that biopower is a technology that incorporates certain aspects of ‘disciplinary power’ (2003b, 2007, 2008). Discipline should itself be understood as a power mechanism that “regulates the behaviour of individuals in the social body" (O'Farrell, 2005: 133).[13] In addition, as O'Farrell explains, if disciplinary power fundamentally is about training the deeds and manners of social bodies, then biopower is about "managing the births, deaths, reproduction and illnesses of a population" (O'Farrell, 2005: 130). The following sections will briefly outline what Foucault means by 'biopower', and how the concept relates to other notions central to his philosophy. This Foucauldian framework is, overall, key to the argument that informs this dissertation, and I will refer back to it throughout my discussion.

As a 'technology', what does biopower encompass? As Foucault writes, on the whole, biopower relates to the practice (*techne*) of modern nation states and the regulation of their subjects (cf. citizens, inhabitants) through "an explosion of numerous and diverse techniques for achieving the subjugations of bodies and the control of populations" (1978: 140). Reflecting on how O'Farrell explains Foucault's mind-set (2005: 130 ff), this is an example in which we can clearly distinguish what Foucault means by technique vis-à-vis technology. Techniques are localised practices—in this case, the actual mechanisms through which nation states regulate their subjects. Technology, on the other hand, refers to the overall agenda of biopower itself; that is, the collection of techniques employed by nation states. Hence, biopower is a technology of power for managing human bodies in large quantities. This is largely achieved through what Foucault names 'disciplinary institutions' (*institution disciplinaire*) in *Discipline and Punish* (1991 [1975]). Schools, prisons, barracks and hospitals are examples of such historical disciplinary institutions, manifested in their modern form in the nineteenth century with the

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[13] It is significant to note that the English translation of the original French title, *Surveiller et punir*, has proved unsatisfactory on various accounts. The translator of *Discipline and Punish*, Alan Sheridan, writes in his translator's note (1995) that:

> *To begin with, Foucault uses the infinitive, which, as here, may have the effect of an 'impersonal imperative'. Such a nuance is denied us in English. More seriously the verb '*surveiller*' has no adequate English equivalent. Our noun 'surveillance' has an altogether too restricted and technical use. Jeremy Bentham used the term 'inspect'—which Foucault translates as '*surveiller*'—but the range of connotations does not correspond. 'Supervise' is perhaps closest of all, but again the word has different associations. 'Observe' is rather too neutral, though Foucault is aware of the aggression involved in any one-sided observation. In the end Foucault himself suggested* Discipline and Punish*, which relates closely to the book's structure.*

Industrial Revolution (Foucault, 1991 [1975], 2003 [1973], 2008). As Gilles Deleuze explains, discipline “cannot be identified with any one institution or apparatus”

> […] precisely because it is a type of power, a technology, that traverses every kind of apparatus or institution, linking them, prolonging them, and making them converge and function in a new way. (1986: 26)

The distinctive quality of this political ‘technology of power’ is that it allows for, as Thomas Lemke explains it, the control of “human bodies through an anatomo-politics of the human body and biopolitics of the [entire] population” (2011: 36). Here we find yet another set of concepts that carry huge weight in this framework: *anatomo-politics* and *biopolitics*. Although comparable (and sometimes used interchangeably), the former is seen as the historical precursor, as well as an important contemporary internal mechanism, of the latter. Yet as Lemke writes, “Foucault’s use of the term ‘biopolitics’ is not consistent and constantly shifts meaning in his texts” (2011: 34).

On the whole, biopolitics is a complex term that was coined by Foucault himself (2003b, 2008) and has been applied and (re)developed in social theory ever since its first application. In social theory it is conceptualised to examine the strategies and mechanisms (or *techniques*) through which human life processes are managed under regimes of authority (a *technology*) over knowledge, power and the processes of subjectivation (Lemke, 2011: 119). However, unlike biopolitics, which aims to regularise and manage human bodies and populations to a global extent, *anatamo-politics* is directly tied to the aforementioned disciplinary institutions. These sets of mechanisms are employed to grind individuals down through a ‘disciplinary effect’, operationalised through disciplinary institutions by means of surveillance, punishment (prisons) or in preparation for a specific economic use or function (schools) (Foucault, 1991 [1975], 2003 [1973]). Needless to say, as Lemke (2011: 119) notes, biopolitics and anatamo-politics alike function through the “triadic processes” conceptualised by Foucault (1982): knowledge, power, and subjectivation.

To borrow a definition offered by Paul Rabinow and Nikolas Rose (2006: 195), biopolitics (or *biopower*) typically involves “a relation between ‘letting die’ […] and making live […] that is to say, strategies for the governing of life.” This terminology is further explored by Lemke in his work on biopolitics (2001, 2011, 2015), which he describes as characterised by power mechanisms that operate in the form of ‘deduction’ i.e. deprivation of goods, products and services. As he writes, the “unique character of this technology of power consists in the fact that it could in extreme cases also dispose of the lives of the subjects” (Lemke, 2011: 35-36), thus fundamentally operating as a right for social appropriation of human bodies. Nonetheless, as we can infer from Lemke’s work, a great deal of the inconsistency with which the concept of biopolitics has been positioned in more recent decades lies in the notion of what one takes as one’s starting point: is life the determining basis of politics, or is the object of politics life itself? Lemke writes:

> What some people take to be a trivial fact (“Doesn’t all politics deal with life?”) marks a clear-cut criterion of exclusion for others. For the latter, politics is situated beyond biological life. From this point of view, “biopolitics” has to be considered an oxymoron, a combination of two contradictory terms. (2011: 2)

On the other hand, as is shown, Foucault essentially avoids this conflict by making his starting point the assumption that

> life denotes neither the basis, nor the object of politics. Instead, it presents a border to politics—a border that should be simultaneously respected and overcome, one that seems to be both natural and given but also artificial and transformable. (Lemke, 2011: 4-5)

In summation, Lemke argues that Foucault’s concept of biopolitics “orients itself not only against the idea of processes of life as a foundation of politics” (2011: 33), but also preserves its critical distance from theories that, in the end, view life as the object of politics. Biopolitics stands for a constellation and does not, as Foucault writes, enhance traditional political proficiencies and structures through new domains and questions—nor does it produce an extension of politics (Lemke, 2011: 33). Rather, biopolitics transforms political structures, and reformulates concepts of “political sovereignty and subjugates them to new forms of political knowledge” (Lemke, 2011: 33). Explicitly, biopolitics creates new functions for control, management, and power of human subjects in large groups; bodies and entire populations. Or, as Foucault writes himself, “governmental concerns of fostering the life of the population” (2007: 377-378). This is the fundamental difference between discipline and biopolitics, where discipline “is the technology deployed to make individuals behave”—whereas “biopolitics is deployed to manage [a] population; for example, to ensure a healthy workforce” (Foucault, 2003b: 239-64). Moreover, this is where biopolitics as the governmental practice and political deployment of biopower (Rabinow & Rose, 2006; Thompson et al., 2007; Wright & Harwood, 2009; Friedner, 2010; Macgregor, 2012; Nading, 2013; Porter, 2013; Lazarsfeld-Jensen, 2014; Nieuwenhuis, 2016, 2018; Škof & Berndtson, 2018a; Brown & Nading, 2019; Brown, 2019) intersects with biosociality.

In regulating subjects through “an explosion of numerous and diverse techniques for achieving the subjugations of bodies and the control of populations” (Foucault, 1978: 140), this not only enables the control and power over the subjects themselves but also their interaction with one another. Thus, I contend that biosociality is to be understood as a reaction to (or consequence of) biopolitics, whereby social interaction equals sociality;[14] the practices that people “engage in to establish, maintain or dissolve, emphasize or hide, social relationships” (Pool & Geissler, 2005: 118). Sociality frames, as Carrithers writes (1992: 34), the capacity for “complex social behaviour” and partly stems from the ability to “mend a failed aspiration carried within the idea of culture”. While sociality habitually has always possessed a rich sociological connotation (where the quality and complexity of interaction has been seen as superior), Carrithers seeks to reinforce the understanding of sociality through a biological lens (1992: 38). Namely, he advances that if sociality (as an analytical notion) is to be at all useful, it needs to be defined from a strict evolutionary perspective. Carrithers’s attempt at such a conception draws upon the idea of inherited traits expressed in individual organisms (‘attributable to the frequencies of genes’), where sociality is inherently “established through the force of natural selection” (1992: 38).

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[14] While symbiotic, *sociality* is to be understood differently from *society*, which implies a bounded whole constituted by social units (assembled or individual) entering into relations (Pool & Geissler, 2005: 118).

In conclusion, sociality (as practice) may be understood through both a sociological and evolutionary lens. Nonetheless, the scenario at hand presents itself in a complex way, whereby the nature-culture divide is, once again, brought to the surface. This debate is fundamental to the understanding of biosociality theory as well, where the question at stake is: in terms of human behaviour, what is superior—nature or culture? I will be attending to this query in the forthcoming sections, where I also draw out the origins of biosociality (understood as a postmodern condition).

CULTURE AS PRACTICE: FROM SOCIOBIOLOGY TO BIOSOCIALITY

Over the past decades, the ontological status of the human body has been under rigid scrutiny from anthropologists and other scholars (Martin, 1994, 2001; Mol, 2002; Harris & Robb, 2012; Cohn & Lynch, 2017). In particular, anthropologists have sought to move away from the idea of the body as something 'naturally given'—something that precedes culture (Ortner, 1972; Slocum, 1975; Ortner, 1984; Freeman, 2001). This idea was expressly (and securely) anchored during the eighteenth and nineteenth centuries in the traditional nature-culture-opposition (Ortner, 1972). It was in 1992, in the wake of the Human Genome Project,[15] that anthropologist Paul Rabinow first wrote about (and thus coined) the concept of biosociality. The objectivism of social factors, Rabinow writes, "is now giving way to a new genetics and the beginnings of a redefinition and eventual operationalization of nature" (1992: 244), which he principally deliberates in relation to the so-called transition from sociobiology to biosociality. In brief, sociobiology is "the systematic study of the biological basis of all social behavior" (Wilson, 1975: 4), and its disciples have primarily concerned themselves with the study of "animal societies, their population structure, castes, and communication, together with all of the physiology underlying the social adaptations" (ibid. 4). Nonetheless, as Wilson

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[15] The Human Genome Project was an international scientific research project with the goal of determining the sequence of nucleotide base pairs that make up human DNA, and of identifying and mapping all of the genes of the human genome from both a physical and a functional standpoint (Rabinow, 1992, 1996a; Ingold & Pálsson, 2013; Pálsson, 2013).

states, the discipline later proceeded to incorporate “the social behavior of early man and the adaptive features of organization in the more primitive contemporary human societies” (1975: 4) within its scope.

Rabinow contends that in terms of biosociality, the “new genetics will prove to be a greater force for reshaping society and life than was the revolution in physics” (1992: 240-241). This argument is foregrounded within a paradigm whereby the new genetics is considered to be “embedded throughout the social fabric at the micro-level by a variety of biopolitical practices and discourses” (ibid. 240-241), which Rabinow argues will come to carry with it its own distinctive promises and dangers. That is, while these said biopolitical practices indeed enable the reshaping of social mobilisation (whereby nature is based on culture understood as practice), these practices may also come to reinforce the (socio)biological determinants of human behaviour, culture, and social order (Sahlins, 1976; Gibbon & Novas, 2008a). According to Canadian philosopher Ian Hacking (2006: 81), Rabinow actually coined the concept of *biosociality* “partly as a joke, to counter the sociobiology that had been fashionable for some time.” Hacking writes (2006: 81)

> Rabinow was interested in groups and the criteria around which they form. Of course, human beings are biosocial beings: biological animals and social animals. But the fact that many *groups* of people can be loosely characterized in both biological and social ways, and that the ‘bio’ and the ‘social’ reinforce each other, prompted his term. This phenomenon is immediately evident: what are families or extended kinship structures if not biosocial groups?

The conceptualisation of ‘biosociality’ stems from this field and thus I deem it necessary to draw out its origin. Sociobiology seeks to explain social behaviour in terms of evolution and biological conditions. Or, as Rabinow phrases it, “sociobiology is culture constructed on the basis of a metaphor of nature” (1992: 241). Sahlins writes (1976: x) that the field of sociobiology

> occasioned a crisis of *connaissance* and *conscience*, of knowledge and public consciousness, with overtones as much political or ideological as they have been academic. (Emphasis in original)

Namely, Sahlins argues that sociobiology challenges the “integrity of culture as a thing-in-itself, as a distinctive and symbolic human creation” (1976: x). As a science, it offers nothing but a “biological determination of human interactions” grounded within the general evolutionary predisposition of "individual genotypes to maximize their reproductive success" (Sahlins, 1976: x). Sahlins does not consider sociobiology to be a mere extension of orthodox evolutionary theory, or "something which does not break with the accepted *paradigm*" (Ruse, 2012: 107, emphasis added). As stated by Michael Ruse (2012: 107), Sahlins believes that sociobiology breaks with the past and becomes impregnated

> with all kinds of Western ideological socio-economic ideas that affect it not just normatively […] but in its very metaphysical or epistemological roots.

What can be drawn from all of this? On the whole, it is evident that biosociality theory stems from the eighteenth and nineteenth century nature-culture divide (Ortner, 1972, 1984), which can be understood as one of the theoretical foundations of contemporary anthropology. Needless to say, the nature-culture divide is deeply intertwined with the social versus biological debate. In earlier forms of anthropology (where Marshall Sahlins fits, and whom Paul Rabinow draws upon) it is alleged that genetic determinism fails to underline the importance of culture, thus making it obsolete. As history shows, the founders of contemporary anthropology hoped to gain theoretical insight from these perceived tensions between nature and culture (Ortner, 1984). In the end, the dispute has come to be framed by the question (a question still very much at stake) of whether the entities of nature and culture function separately from each other, or if they are in a continuous biotic relationship with one another (Nettle, 2009; Bennett, 2015; Mortensen, 2015). Biosociality, as originally framed by Paul Rabinow (1992, 1996a) and those that followed him (e.g. Gibbon, 2007; Gibbon & Novas, 2008a; Novas, 2008; Dimond et al., 2015; do Valle & Gibbon, 2015) argue for the latter—which is an approach I adopt throughout this dissertation. As Rabinow writes,

> in biosociality nature will be modeled on culture understood as practice. Nature will be known and remade through technique and will finally become artificial, just as culture becomes natural. (1992: 241)

This approach can be seen reflected in the peer-support groups for people with chronic illnesses that are the focus of this thesis. What 'came first'—the biological conditions (pathologies) or the social formations behind the groups? While the peer-support groups themselves may never have come to exist without their members receiving an official diagnosis from their GPs (and seeking support for them), this does not mean that the groups (or their agendas) are in any way dependent on these diagnostic frameworks. On the contrary: depending on how peer-support groups choose to act or advocate (in accordance with their biologies), they may very well come to shape the practices and/or understandings behind the diagnoses (or pathologies) themselves (e.g. Barbot, 2006; Dumit, 2006; Landzelius, 2006a, 2006b). In fact, some medical conditions are not named or conceptualised until after people come to gather around them and their symptoms—or when the practice of counting them came into being. In the words of Ian Hacking, where social change creates new categories of people "[…] the counting is no mere report of developments. It elaborately, often philanthropically, creates new ways for people to be" (1986: 222-223). For instance, as Joseph Dumit illustrates in his work on chronic fatigue syndrome and multiple chemical sensitivity, "when emergent uncertain illnesses are also highly contested, [biological] facts function differently" (2006: 587). In these times of struggle and lack of legitimacy, what people turn to is collective action and perseverance. Specifically, practices of *contra-tactics*; in this case, what Dumit names "creative use of existing categories, and deploying available counter-facts within the rules of the system" (2006: 578).

Having that said, Dumit advances that the use of counter-facts is not a "general solution" (2006: 578) but merely a process which allows for people to live and cope better within current social institutions. What this means in the long run, I contend, is that the drive behind patient activism and advocacy may stem from many things. On one hand, it may stem from gaps in medical knowledge (and uncertain, contested biological facts). On the other, in terms of healthcare provision, patient advocacy may also be a reaction to austerity, including insufficient financial means (due to funding cuts or disagreements in expenditure). The latter is a growing global issue in the era of neoliberalism (Sakellariou & Rotarou, 2017).

The reasons behind low and poor access to health services may very well also be found in the nature of the medical conditions themselves. This is what Gysels and Higginson (2008) argue in their study of experiences of breathlessness in patients with chronic obstructive pulmonary disease (COPD). Gysels and Higginson illustrate how patients' struggles with chronic breathlessness not only stem from the symptom's slow and clandestine onset, but also from people's continuous interaction with environments and institutions that confer stigma upon the condition itself and discredit patient experience (2008: 457-458). This speaks to how Joseph Dumit writes that biomedical facts may play "crucial roles in persuading participants how to render judgements"—yet are simultaneously also "susceptible to being framed and reframed by the participants" themselves (2006: 578). After all, subject formation is "predicated upon the body" (Friedner, 2010: 340) where the body becomes the locus of power, and biomedical knowledge is an apparatus that may be employed to "support or refute specific world views and practices" (Raffaetà, 2017: 13).

"THINKING ABOUT BIOLOGY AND CULTURE"

Following up on the notion of the body as the locus of power, although biomedical knowledge is an apparatus capable of refuting both ontological and cosmological views, Meloni and colleagues write that it has become increasingly evident that the "separation between the social and the biological was not something written in stone, a logical necessity, but rather the contingent effect of a specific history" (2016: 8). In a similar manner, Keller writes that the notion of 'human nature' may be historically specific, "invoked at particular times, in particular cultural contexts, but the question to which that notion is addressed is unarguably more general" (2016: 26). Thus, it is important to note that concepts like *social biology* and *biosocial* "are not free of historical connotations" (Meloni et al., 2016: 8).

Community, social formation, and sense of belonging are all central themes in many research settings across the social sciences (Jack, 2013). However it is in light of the previously mentioned Human Genome Project where Rabinow (1992, 1996a) argues that an increasingly significant form of collectivity will come to grow through biosociality (Dimond et al., 2015: 1). That is to say, biosociality acknowledges the significance of biomedical knowledge in assembling genetic identities and producing (and reproducing) social relationships based on collective 'biologies'. For that reason, biosociality is "often imagined as a new form of social solidarity" (Dimond et al., 2015: 1), which, however, has not come without its fair share of criticism (Walsh & Wright, 2015; Happe et al., 2018).

This brings us back to the historically fundamental nature-culture divide within anthropology (Ortner, 1972; Slocum, 1975; Freeman, 2001). How do understandings of the biological and the social reinforce each other, especially in the context of support groups for people with chronic breathlessness? Moreover, how are we to define these two (unclear) dichotomies? As Rabinow writes, if sociobiology is "culture constructed on the basis of a metaphor of nature" then biosociality is when nature becomes "modeled on culture understood as practice" (1992: 241). Will biology (nature) always be understood as obstinate and predetermined, and sociality (culture) merely as collectively shared practices? Erik Mortensen suggests that the process of cultural learning and transmission[16] may be used to bridge the gap between the two dichotomies, "for it uses a trial and error based approach that shows how humans are constantly learning, and that they use social learning to influence individual choices" (Mortensen, 2015: 254-255). Mortensen argues that this is observable in how the more superficial aspects of culture remain intertwined with nature and genetic variation (2015)—and thus, by means of social learning and adaption, nature becomes more intertwined (and thus, redefined) with culture since these dichotomous flanks now come to reinforce one another.

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[16] *Cultural learning* (or cultural transmission) is the way a group of people or animals within a society or culture tend to learn and pass on information. The concept is central to much contemporary anthropological theory, but what is understood by the phrase and how it might best be studied is still highly contested (Ellen et al., 2013).

On the whole, nature and culture are now viewed as more intertwined than ever before; hence, the divide between the two has grown rather obsolete (Nettle, 2009; Giblett, 2011). In line with these developments, the understanding of and approach to the idea of biosociality (and biosocial formation, broadly speaking) have changed over the years as well—most likely, I contend, in response to the aforementioned divide between ideas on where nature and culture are seen to reinforce one another (in terms of adaptation and variation).

Let me provide some examples of this. For instance, in Sahra Gibbon and Carlos Novas's pioneering edited volume *Biosocialities, Genetics and the Social Sciences*, they (re)approach the notion of biosociality in light of new empirical research "to chart the shifts in social relations and in ideas about nature, biology and identity brought about by developments in biomedicine" (2008a: i). More specifically, the editors and contributors critically interrogate the biosocial framework to assess "its usefulness for examining a range of developments in the contemporary life sciences, whilst also thinking through how it may be put to work in new ways" (Gibbon & Novas, 2008a: 1). This is partially done by placing emphasis upon three conceptual arenas of biosociality and its widespread currency: 1) emergent identity practices; 2) the distinction between nature and culture; and 3) the overall framework's "heuristic approach to examining emergent and unfolding arenas of scientific inquiry" (Gibbon & Novas, 2008a: 1). As Gibbon and Novas write, the volume seeks to respond and contribute to the wider debate on socialities that may emerge in times when "understandings of what a disease is and the ways of acting upon illness [are] undergoing a process of considerable change " (2008a: 2).

Paul Rabinow himself contributes to this volume with a chapter in which he revisits (and reflects on) his early work, detailing the framework now known as *biosociality* (2008: 188 ff). Besides reaffirming how the notion initially stood in contrast to the "crude form of biological and evolutionary determinism" (Rabinow, 2008: 188) found in sociobiology, Rabinow describes how he coined the term against a background of scenes from Thomas Mann's novel *The Magic Mountain* (2005 [1927]). Originally published as *Der Zauberberg* in 1924, the story follows young Hans Castorp as he decides to visit his tubercular cousin in a sanatorium in Davos, Switzerland. His departure is repeatedly delayed by failing health, and what at first appears to be a minor bronchial infection is later diagnosed as *tuberculosis*. Its pages filled "with disease ravaged bodies and tormented souls," Rabinow writes how Mann's novel moved him in how it "seemed more pertinent to how disease, science, and fate were confronted than the thin narratives of socio-biology or its successors" (2008: 188).

Rabinow concludes his chapter by asking whether biosociality still possesses analytical power. He contends that it does—especially since its "contours of applicability, the specification of its elements, and the range of variations it covers are now clearer" than ever (Rabinow, 2008: 192). Despite this, Rabinow adds that he never intended for biosociality to stand as a universal; that is, the term "does not apply everywhere and at all times" (2008: 192). On the other hand, he also writes that there is a "distinct gratification in watching emerge its more precise delimitations, its boundaries, and the extent of its dynamic range" (Rabinow, 2008: 192) and he calls for a broader range of concepts and refinement in addressing the themes that materialise from the wider biosocial debate. In terms of refinement in biosociality theory, I assert that this is already in practice and has been vividly embraced by several social science scholars. This can, for instance, be seen in papers by Raffaetà (2017) and Vrecko (2008), which I have found particularly stimulating in drawing out the significance and applicability of frameworks that particularise biosocialities in this day and age. These papers offer novel case studies, illustrating how biosociality not only regards the social reorganisation of biology but also biological reorganisation of the social.

Raffaetà (2017) addresses parental groups campaigning against paediatric vaccinations in Italy. In this well-timed paper, Raffaetà challenges the valuable (yet highly partial) representation of the relation between nature (biology) and culture (sociality) whereby "culture has primacy over nature as it provides the model for nature in a biotechnological age" (2017: 13). By investigating selected campaigns against paediatric vaccinations in Italy, Raffaetà illustrates how these parental groups "affirm the priority of nature over culture, thus extending the notion of biosociality" (Raffaetà, 2017: 13). As she writes, these groups are a form of biosociality by proxy; "their members campaign for the biological rights of their children, not for their own bodies" (Raffaetà, 2017: 16). Parental advocacy practices come to affirm and defend the advocators themselves as good parents in society. On the whole, the disposition is that these parental groups meet in name of "the primacy of the organic over culture, of normativity over normality" where a healthy body is one that is "truthful to a vital order" (Raffaetà, 2017: 20). This contrasts with postmodern understandings of the human body, where the body is not seen as a naturally given entity (Martin, 1994, 2001; Mol, 2002; Harris & Robb, 2012; Cohn & Lynch, 2017). However, it resonates well with Georges Canguilhem's distinction between organic and social normality/normativity as overlapping domains (1989 [1966]: 100), whereby "the organic has autonomy and logical priority over culture" (Raffaetà, 2017: 20) because sociocultural norms, like physiology

> […] cannot impose on life just those ways whose mechanism is intelligible to it. Diseases are new ways of life. Without the diseases which incessantly renew the area to be explored, physiology would mark time on well-trod ground. (Canguilhem, 1989 [1966]: 52)

In contrast, Vrecko (2008) interrogates biosocial dynamics in the industry and science of gambling. Vrecko's analysis of the politics of gambling (and its regulation) is foregrounded within a body of research in political economy that states how the "negative consequences associated with gambling are not just social problems, but neurobiological ones" (2008: 50). Seeking to further investigate the interactions between these understandings of the social and the biological in gambling addiction, Vrecko turns to Paul Rabinow's work on biosociality. His intention, he writes, for turning to this framework is not only to

> […] contribute to a sociological analysis of the biomedical problematization of pathological gambling, but also to use pathological gambling as an empirical case study in order to reflect upon the potentials and limits of the concept of biosociality itself. (Vrecko, 2008: 52)

Vrecko's approach to biosociality theory is therefore both critical and transformative. As discussed earlier in this chapter, while biosociality originally (and habitually) alludes to the ways in which "biological sciences provide a basis for new forms of social organization and identification" (ibid. 52), Vrecko suggests that the framework may also work as a point of departure for thinking ingeniously about

> the mutations of politics, culture and biology in ‘post-disciplinary’ societies which are moving away from panoptic strategies of behavioural surveillance and welfarist regimes of social regulation, towards rationalities and interventions that draw upon newly emerging technoscientific capacities to understand, shape and control human biology at the molecular level. (2008: 52)

That is to say, Vrecko seeks to illustrate how the notion of biosociality not only serves to highlight “possibilities for new forms of identity making on the basis of shared knowledge about genes” (Lock, 2005: 50), but also to draw further attention to more encompassing views of how the biological re-organises the social. More specifically, he wants to shed light on the manifold ways in which

> changing scientific and medical understandings of our bodies have led to new configurations of social space, new communities and classifications, and the rise of novel sorts of institutions, norms, tastes and values. (Vrecko, 2008: 53)

Nevertheless, neither the biological nor the social constitutes a taken-for-granted category that is open to empirical analysis in a class by itself. Having that said, as Vrecko suggests, the discrepancies between the biological (nature) and the social (culture) persist as highly significant in specific contexts where they “continue to operate as sources of difference, meaning and value in contemporary societies” (2008: 63). In the case of pathologised gambling addiction, for instance, while biology may be socially malleable and politics biologised, the distinction between society and biology remains highly significant (Vrecko, 2008: 64).

In light of the debate apropos the biological and the social, this dissertation seeks to contribute to this theoretical discussion, through looking at negotiations between subjective and collective sensations of chronic breathlessness in peer-support settings outside the clinic and the conditions whereby sociality around this symptom is manifested. While there is a ‘group self’ (Kohut, 1985) to be understood as a “collective project with inherent ambitions, ideals and resources” (Karterud & Stone, 2003: 7), groups are inherently social assemblies founded on shared mutual interests and common practices. Thus, it is inevitable that support groups may come with incompatible notions of welfare—a collective group one which, in itself, stems from several subjective ones. Does the individual always come second to the group? Where does this leave us in terms of an emphasis on either nature or culture? This dissertation sheds light on this by looking at how sociality in support groups (based on biology) further reinforces the biological through acts of (bio)citizenship.

THE SUPPORT GROUP *AS* (SELF) TECHNOLOGY

This dissertation extends the biopolitical paradigm (where biosociality is key) by accentuating the significance of mutual aid and peer-support in developing self-management practices for chronic illness, such as respiratory disease and chronic breathlessness. Two distinct (yet entwined) biomedical ambiences are at stake here: the subjective and the collective. More explicitly, how can the study of support groups (through biosociality) help us further understand and conceptualise the bridge between subjective and collective bodily experiences of health and illness? In answering this question, I turn once more to postmodern understandings of the body and the embodied subject: Foucault's notion of *technologies of the self* (1988). This section draws out my conceptual approach to the support group as a unit (or *thing-in-itself*) that extends beyond its social setting. I show that the support group is more than the setting (or scenery) where its members meet. It is an art or craftsmanship (*technology*) erected on collectively shared experiences, which its members may turn to, and utilise as a resource (through mutual aid) in developing their skills and expertise in the practice of self-management of a chronic illness. In the words of Foucault, it is a resource that permits individuals

> to effect by their own means or with the help of others a certain number of operations on their own bodies and semis, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality. (1988: 18)

The form of power that Foucault contemplates here is a form of governmentality (1991, 2010). That is, a process of organised practices whereby individuals are governed and actively negotiate their own identities (cf. Danaher et al., 2000; Morris, 2017) and become subjects, transformed through voluntary engagement in the process called *subjectivation* (Foucault, 1982, 1985): the process whereby an object becomes a subject. In contemplating *self-technologies*, Foucault's initial objective was to draw out a history of the sociocultural ways in which humans "develop knowledge about themselves" (1988: 18). However, as he writes, the goal was never for this knowledge to be accepted at face value but rather, to be analysed "as very specific 'truth games' related to specific techniques that human beings use to understand themselves" (Foucault, 1988: 18).

Foucault contends that there are four major types of technologies through which humans develop knowledge, "each a matrix of practical reason" (1988: 18), as follows: 1) *technologies of production*, "which permit us to produce, transform, or manipulate things"; 2) *technologies of sign systems*, "which permit us to use signs, meanings, symbols, or signification"; 3) *technologies of power*, "which determine the conduct of individuals and submit them to certain ends or domination, an objectivizing of the subject"; and 4) *technologies of the self* (Foucault, 1988: 18; see also MacLullich, 2003; O'Farrell, 2005; Morris, 2017). While each technology rarely functions alone, they are all associated with a specific (individual) type of domination that implies certain modes of training and modification upon the body. Foucault was predominantly interested in the two latter technologies of power (domination) and the self, where he attempted a "history of the organization of knowledge with respect to both domination and the self" (1988: 18). This is made apparent in, for instance, how he studied madness: not in terms of the criteria of formal sciences, but to "show how a type of management of individuals inside and outside of asylums was made possible by this strange discourse" (Foucault, 1988: 18; see also 2006 [1961]).

Foucault does not seek to merely discuss the subject in terms of theory (cf. 1982), but also in relation to practices from late antiquity and ancient times. Again, we find ourselves immersed in ancient Greek terminology whereby Foucault's research focuses on the concept of *epimelēsthai sautou* (επιμελεισθαι εαυτου), commonly translated as "to be concerned with oneself" (Foucault, 1988; Faust, 1998; MacLullich, 2003). While this notion now has grown rather obscure, according to

Foucault, for the ancient Greeks it was “one of the main rules for social and personal conduct and for the art of life” (1988: 19). Nevertheless, how does one practice concern for oneself? This question brings us to another main conceptual feature in understanding the notion of *technologies of the self*: expertise.

According to McNeil, the term expertise is associated with *skill* and *knowledge* (as well as ‘expert’s opinion’)—“thus encompassing the on-the-job abilities of craftspeople and the more codified knowledge of professionals” (McNeil, 2016: 56). Expertise is important in at least three respects (Rose, 1996: 156-157). First and foremost, as expertise seeks to ground authority, it “scientifically and objectively creates distance between self-regulation and the state, which is essential for liberal democracy” (Chinnasamy, 2017: 6 ff). For instance, a “good” citizen is said to be self-made, with this individual “adopting a series of proficiencies and practices that become innately individual” (Brown, 2014: para. 3). This citizen is held in contrast to the state, “free to act with minimal impediment from things political” (ibid.) . Secondly, expertise is able to mobilise (and be mobilised) within political argument in many distinctive ways, “producing a new relationship between knowledge and government” (Rose, 1996: 156). More specifically, knowledge is directly relevant to governance as a crucial input to the process (Fazekas & Burns, 2012: 10): a resource for political decision-making and an instrument for direct policy implementation. Knowledge also plays an indirect role in “influencing actors’ behaviour” on both an individual and collective level (Fazekas & Burns, 2012; Jack, 2013).

Third and lastly, as Nikolas Rose writes, “expertise operates through the particular relation that it has with the self-regulating capacities of subjects” (1996: 156). That is to say, while bound to experts (holding codified knowledge), subjects are simultaneously positioned as free to choose, for the “plausibility inherent in a claim to scientificity and rationalized efficacy binds subjectivity to truth, and subjects to experts, in new and potent ways” (Rose, 1996: 156). Thus, expertise works by means of the logic of choice and through transformations of the ways in which individuals institute themselves. Or, as Rose contends, through an indoctrination of desires for self-development, expertise itself can “guide […] through claims to be able to allay the anxieties generated when the actuality of life fails to live up to its image" (1999: 88). Thus the notion of expertise brings us back full circle to my previous deliberation on *techne* and *episteme*. That is to say, techne and episteme both denote knowledge (and knowing) in the implication of a principled system of understanding, wherein a skill or knowledge is otherwise recognised as expertise.

SELF-MANAGEMENT AS PRACTICING AUTONOMY

Let me now return to the conceptual approach and understanding of the support group as something that extends beyond its social scenery. In conceptualising the support group *as* (self) technology, I draw inspiration from the work of Dick Willems (1998, 2000, 2001), a Dutch general practitioner turned philosopher. In a 2000 paper, Willems deliberates on how the practice of self-management can be understood as practicing autonomy, drawing upon Foucauldian theory and emphasising people with asthma (which speaks well to the theme of this dissertation). Willems reaffirms how Foucault's work comprehends tools as useful for analysing the "*innovative* and *productive* elements of self-management" (2000: 31, as in original). Willems is referring to the notion of *technologies of the self.* As mentioned, in constructing this conceptual framework Foucault has largely restricted himself to ancient Greek and early Christian understandings of the knowledge (or concerns) for one's body. For Willems, these techniques are to a large extent "technologies of the soul" (2000: 31). This relates to the precept of being "concerned with oneself" (*to practice oneself*), which, as mentioned, was an important principle of the good life in ancient Hellenistic culture. As Willems explains, this precept later came to grow and evolve together with the maxim of *knowing oneself* (2000: 31), which derives from the Delphic[17] principle or maxim of *gnothi seauton* (γνῶθι σεαυτόν) (Foucault, 1988: 19; Willems, 2000: 31). In terms of self-management as a bodily practice, this deliberation clarifies the symbiotic relation between practice, knowledge, and expertise: namely, one cannot practice

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[17] This refers to the city of Delphi in Greece. Delphi is an ancient sanctuary that grew rich as the seat of Pythia, the oracle (and high priestess of the Temple of Apollo) who was consulted about important decisions throughout the ancient classical world (Kindt, 2016). The ancient Greeks considered the centre of the world to be in Delphi, marked by the stone monument known as the Omphalos of Delphi (Kindt, 2016).

and maintain proper self-care of one’s body without ‘knowing thyself’. Yet, how does one know oneself? How does one *practice* oneself? Here the practice of self-management binds together with self-monitoring behaviour, which in itself can be understood as a continuous diagnosis of one’s own body (Willems, 2000: 23).

This is especially prevalent in respiratory care, where technical devices “such as inhalers function as mediators between a person using them and the drug, or between the complaint and its relief” (Willems, 2000: 24). In this context, and within these relations, technical devices (like inhalers) shift from being mere objects to becoming subjects (or even *agents*) in their own right (Gell, 1998: cf. ; Latour, 2005; Chua & Elliott, 2013; Russell, 2019). All in all, patients require mediating devices to achieve proper knowledge of their selves. By these means, proper (as in *effective*) self-managerial and monitoring behaviour turns into a type of expertise, or codified knowledge, whereby service-users successfully practice upon themselves as to “effect by their own means […] a certain number of operations on their own bodies” (Foucault, 1988: 18). On the whole, this process can be understood through the lens of subjectivation (Foucault, 1982, 1985): that is to say, the process whereby an object transforms into a subject.

Willems illustrates how the process of subjectivation not only becomes evident, but also significant, in clinical self-management programmes by how they come to constitute “a modified self-practice” (2000: 34). These programmes are, in and of themselves, technologies of the self through the “delegation of the management from the physician to the patient” (Willems, 2000: 34), whereby the patient obtains “the competence to intervene in their own treatment regime” (2000: 27). Here, Willems argues, self-management programmes become mediators, providing patients with a “chance to decide when and how they change their treatment regimes” (2000: 29). Needless to say, competence comes to stand for expertise in an obvious process of patient subjectivation, in this case also widely known as *patient activation*: the process whereby patients are subjected to developing “the motivation, knowledge, skills, and confidence to make effective decisions to manage their health” (Greene & Hibbard, 2012: 520).

By means of biopolitics, medicine (as paradigm and practice) has become a medium that defines a way of life (Rose, 2007; Foucault, 2008). What Willems proposes is that self-management practices can be understood as a "redistribution of characteristics and competences" between patients, medical professionals, and technical devices (2000: 30). It is with this conceptual framework in mind that I advance the notion of the support group as a *technology* (and by extension, a *mediator* between individual subjects) in itself. As Willems illustrates (2000: 32), self-management practices can be conceptualised as prolonged (subjective) self-care practices in consultation and in relation between patient and practitioner. That is, a practice whereby the patient subject is activated and becomes an agent; a "doctor of oneself" (cf. Furin, 1997; Mallia, 2013; Larsson et al., 2016).

The argument that I seek to advance throughout this dissertation is that support groups may be understood to act in a similar manner. By actively participating in support groups, members turn knowledges and competences (of the 'self') into practice, whereby later exchanged for (or challenged by) competing maxims. These practices may transform and modify individual members' self-practice regimes and by extension, I contend that, like technical devices (inhalers, etc.), the support group itself becomes a mediator between subjective embodied experiences of health and illness. The support group, while an assembly of self-made subjects, thus transforms into a collective body: an agent in its own right, acting on behalf of (or in conflict with) individual members' needs and wishes. All at once, the group remains a technology (*techne*) in that it further constitutes a craftsmanship (codified knowledge) in the implication of a principled system of understanding: a "technology of the self" forged within a maxim of collectively shared practices.

In conclusion, self-management practices transform (and develop) the relationship between patients and their bodies. As Willems put is, "they become people with bodies that need more or less intensive maintenance in a specific form" (2000: 36). This can, I argue, also be said about support groups (as *mediating technologies*). Moreover, by extension, support groups not only transform the relationship between individuals and their separate bodies but also the relationship between individuals themselves, whereby a collective body is later transformed and constituted.

CONCLUSION

In this chapter I have reviewed the most prominent anthropological and sociological literature with reference to the analytical notion of biosociality, a social process whereby sociality is founded on shared biological conditions. It is to this body of literature that I contribute this ethnographic study of support groups for people with chronic breathlessness in the north-east of England. Throughout this chapter I have revisited historical debates apropos the nature-culture divide and provided necessary background to justify my own approach, which I have named the 'biosocial approach'. This is a framework that looks at where culture (the social) and nature (the biological) reinforce and reorganise one another as binaries, thus illustrating how this separation is not set in stone. The dissertation is a novel contribution to biosociality theory in that it offers a detailed discussion of negotiations between subjective and collective experiences of chronic breathlessness, where the support group setting becomes a resource for bridging dialogues between incompatible bodily experiences of chronic illness. The dissertation fills a gap in rich ethnographic accounts of chronic breathlessness that are contextualised in a time of neoliberal governance where respiratory care, especially, is habitually individualised. In the next chapter, I describe the process of fieldwork, the multiple sites of inquiry and the various methods incorporated into my ethnographic approach.

~ CHAPTER THREE ~

STUDY DESIGN

METHODS, FIELD-SITES, ETHICS

"Good, sound research projects begin with straightforward,
uncomplicated thoughts that are easy to read and understand."

J. W. CRESWELL

INTRODUCTION

In this chapter I convey my methodology. Roger Sanjek defines three canons of ethnographic validity: 1) theoretical underpinnings; 2) the ethnographer's path; and 3) field-note evidence (1990: 395). This chapter will focus on the ethnographer's path. As Sanjek writes, "As a measuring stick of ethnographic validity, accounts of an ethnographer's fieldwork path should be incorporated in ethnographic writings" (1990: 400). Accordingly, I disclose how I came to design and perform the study that this dissertation documents by presenting and discussing my methods of choice, as well as field-sites and ethical considerations.

The chapter is organised as follows. In view of how this dissertation is grounded in an interdisciplinary research project (*Life of Breath*), I start by discussing my efforts (as an anthropologist) to align myself with the process that is characteristic of interdisciplinary collaboration. I then discuss my chosen methods in more detail, consisting of ethnographic fieldwork, participant-observation, interviews and focus group work. Additionally, I provide a more in-depth discussion of certain debates that align with my research framework, such as what constitutes 'multi-sited' (or unbounded) fieldwork and the (de)construction of 'the field' as an arbitrary single-layered location. I also describe certain participatory research aspects of my methodology, and the limits such approaches may bring about in ethnographic research. The chapter ends with a reflection on research ethics.

AN ANTHROPOLOGIST'S INTERDISCIPLINARY EFFORT

> To be interdisciplinary you need to be disciplinary first—to be grounded in one discipline, preferably two, to know the historicity of these discourses before you test them against each other. (Foster, 1998: 162)

This dissertation, although positioned in the discipline of anthropology, is a product of a larger interdisciplinary collaboration. While not collaborative in the truest sense of the word (as I solely have acted as its principal researcher), this thesis does present conversations across the United Kingdom with people living with chronic breathlessness, their family and friends, caregivers, nurses and other health professionals, as well as health activists, non-profits and academics. The study has been an integrated part of the Wellcome Trust-funded project known as *Life of Breath* (Figure 3.1) , an interdisciplinary project on breathing and breathlessness, that sought to achieve the fullest possible understanding of breath, breathing and breathlessness by drawing on both biomedical information and cultural, literary, historical and phenomenological research.

The project took place between 2015 and 2020, where it involved researchers from a range of faculties and departments based at Durham University and the University of Bristol, along with health professionals and 'experts-by-experience' (e.g. Bensing, 1991; Hibbard et al., 2004; Hibbard et al., 2005; Fraser et al., 2006; Newbould et al., 2006b; Gysels et al., 2007; Greene & Hibbard, 2012). In *Life of Breath*, researchers from mixed disciplinary backgrounds have all approached breathing and breathlessness as phenomena pregnant with

> historical, cultural and existential meanings that are often overlooked in the clinical context […] [T]his represents an epistemic gap: an apparently unbridgeable mismatch of understanding not only of knowledge but also of how that knowledge might be obtained, between the clinic and the person who experiences breathlessness. (Macnaughton & Carel, 2016: 295)

Figure 3.1: The Life of Breath project logo.

(© Life of Breath)

Working across dissimilar academic disciplines is far from simple and straightforward. As Margit Warburg writes, working with people across disciplines means, for instance, "that ethical standards regarding the professional interaction with individuals must be obeyed" (2018: 230). Additionally (and especially), when it comes to health-related research topics,

> not all informants are patients, as the anthropologists also study the patients' cultural environment. This includes other people, relatives, friends, and the physicians themselves, who all may influence the health care behaviour of the prospective and identified […] patients and shape collective opinions about the disease. (Warburg, 2018: 229-230)

Life of Breath has branded itself an 'interdisciplinary' project. What do we mean by that? For Choi and Pak, terms like multidisciplinary, interdisciplinary and transdisciplinary[18] "have been used to denote efforts that involve several disciplines. However, these terms are ambiguously defined, applied and often used interchangeably" (2006: 352). *Multi*disciplinarity, for instance, is said to contrast dissimilar disciplinary perspectives in an additive manner, meaning two or more

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[18] Sometimes another concept is added to these three: *cross-disciplinarity*. However, many scholars see this as a general term used to refer to any research activity that involves two or more academic disciplines (Foster, 1998; Choi & Pak, 2006; Davies, 2007; e.g. Bernard, 2011; Fitzgerald & Callard, 2014; Callard & Fitzgerald, 2015; Callard et al., 2015; Warburg, 2018). This is the definition I will be adopting for this dissertation.

disciplines each provide their viewpoint on an issue (or research anomaly) from their own perspectives. Overall, multidisciplinarity is perceived to involve little interaction across disciplinary boundaries (Foster, 1998; Choi & Pak, 2006). *Inter*disciplinarity, on the other hand, combines two or more disciplines (cf. Callard & Fitzgerald, 2015) and it is recognised that each discipline can affect the research output of the other. Lastly, *trans*disciplinarity is a collaborative effort in which two or more disciplinary perspectives transcend one other to form a "new holistic approach" (Jeder, 2014) in which the whole is greater than the sum of its parts.

Where do we place *Life of Breath* in this? While those involved in the project have shifted in describing the project as either multi- or inter-disciplinary as if these concepts were synonymous, as I have outlined above, they are not. More specifically, if multidisciplinarity implies little interaction across disciplines, this does not describe *Life of Breath* well. While flawed and often unsuccessful in its implementation, the project's aim was to encourage and maintain advanced collegiate interaction between (and across) different academic disciplines, including Anthropology, Arts, Philosophy, Health and Medicine, English Literature, and Medieval Studies. Over and above public outreach and engagements, in my case this has been done through two kinds of gatherings: 1) bi-monthly meetings with my colleagues at Durham University, known as *Air Time*; and 2) bi-annual meetings with colleagues from both Durham and Bristol, known as *Breathing Space*. Thus, the term 'interdisciplinarity' may fit *Life of Breath* rather well: we have aimed at new levels of integration and interaction between scholars of different disciplinary backgrounds. Moreover, we have always acknowledged that we may come to affect the research outputs of one other. As Wilkinson and Smailes write,

> that's the goal of interdisciplinary approaches—that through working with Researcher A from another discipline, Researcher B will somehow change the theories or methods they typically use in their home discipline. This goal makes interdisciplinary work difficult. (2015: 3)

This, I firmly believe, has not been a key aspect of working in *Life of Breath*; or, if it has, it was not something that I myself came to embrace much. Interdisciplinary work (if we choose to use this term) does not benefit from expecting, or seeking, change in or from other scholars. Rather, collaborators should value and draw inspiration from their colleagues, without necessarily having to either adapt or modify one's own core methodological (or theoretical) outlook. This brings us back to transdisciplinarity, which seeks to transcend dissimilar perspectives in order to form new holistic approaches. While *Life of Breath* has not aimed to develop any new holistic approach per se, it has sought to achieve further momentum for 'critical medical humanities' as an approach or methodology, rather than a discipline in itself. To the best of our knowledge, *Life of Breath* is one of the first attempts to apply medical humanities understanding and approaches

> …to the study of 'somatic' phenomena—breathing and breathlessness—with a view to challenging and broadening the evidence base on which breathing symptomatology is addressed clinically. (Macnaughton & Carel, 2016: 294)

Simply put, critical medical humanities involves (Fitzgerald & Callard, 2014; Viney et al., 2015; Fitzgerald & Callard, 2016)—"embracing entanglements". Moreover, Viney and colleagues write that the critical medical humanities approach enables a "widening of the sites and scales of 'the medical' beyond the primal scene of the direct clinical encounter" (2015). This may be achieved by recognising that

> the arts, humanities and social sciences are best viewed not as in service or in opposition to the clinical and life sciences, but as productively entangled with a 'biomedical culture'… (Viney et al., 2015: 2)

This is not intrinsically 'new'. Rather, for *Life of Breath* and its members, applying this approach has been a way to reinforce something that was already there—although hidden, neglected, or even taken for granted. While this dissertation is the result of a collaborative effort it is not by default interdisciplinary. While I in my role as an anthropologist never have doubted the theoretical prospects found in other disciplines, methodologically speaking, this work is ethnographic at its core. In this collaborative environment, I can only say that I have progressed in my role as researcher and scholar generally, but also as an anthropologist specifically. That is, I have gained many insights from colleagues across several disciplines. While I claim to have already been confidently and decisively based in the anthropological discipline and its practice—as Foster (1998) suggests one should—this confidence has without a doubt grown stronger through collaboration.

METHODS

Thomas Hylland Eriksen states that most anthropologists "depend on a combination of formal techniques and unstructured participant observation in their fieldwork" (2015: 34). Based in the discipline of anthropology (and principally trained in social anthropology), for this study I have predominantly applied qualitative frameworks and methodologies. Ethnographic fieldwork and mixed-method interviews were my main methods of choice, alongside engaging intermittedly in participant observation and focus group work with support groups (primarily) and other selected individuals across the UK.

(i) Ethnography / Ethnographic fieldwork

> [The objective] of anthropology, I believe, is to seek a generous, comparative but nevertheless critical understanding of human being and knowing in the one world we all inhabit. The objective of ethnography is to describe the lives of people other than ourselves, with an accuracy and sensitivity honed by detailed observation and prolonged first-hand experience. My thesis is that anthropology and ethnography are endeavours of quite different kinds. This is not to claim that the one is more important than the other, or more honourable. Nor is it to deny that they depend on one another in significant ways. It is simply to assert that they are not the same.
>
> (Ingold, 2008: 69)

Ethnography encompasses the process or method (fieldwork), intellectual effort or paradigm (thinking) as well as a product or rhetorical style (writing) (Bate, 1997: 1151). That is to say, unlike the other methods I will come to designate, ethnography can be understood more as a methodology i.e. a collection of methods or sources, or a 'strategy for knowledge', meaning a practice that is "strategically conceived by the ethnographer who must use methods in order to gain information with which to construct knowledge" (Reinhold, 1994: 477). In this section, I aim to convey how I have approached ethnography as a method (in conducting fieldwork).

Fieldwork has (although not without dispute) become one of the most commonly cited "defining criteria of anthropology" (Amit, 1999: 1). Peter Wogan writes that the centrality of ethnographic fieldwork to anthropology's disciplinary identity has led to the matter being put "in strong terms" (2004: 130). For instance, fieldwork, in the words of Clifford Geertz, is a form of "deep hanging out" (1998: 69); a research method of immersing oneself in a cultural group or social experience on an informal level. However, rather than getting stuck on what it *is*, should we not ask ourselves what it *adds* as a method? Sherry Ortner writes that (1984: 143),

> The attempt to view other systems from the ground level is the basis, perhaps the only basis, of anthropology's distinctive contribution to the human sciences. It is our capacity, largely developed in fieldwork, to take the perspective of the folks on the shore, that allows us to learn anything at all—even in our own culture—beyond what we already know.

I believe the phrase 'distinctive contribution' is what we need to take to heart here. Fieldwork is an act, or art, as Wolcott argues (2004), a performance that has become integral to the anthropological discipline's ethos, culture and pedagogy. I am convinced fieldwork is so integral because it is valued for its ability to fulfil a wide range of roles, many of which link to substantial bodies of relevant literature that speak to both disciplinary debates and to wider academic and non-academic audiences. Conducting ethnographic fieldwork involves engagement in intense in-depth research that may come with many emotional and practical challenges. Ethnographic research is an intensely personal experience for the fieldworker; as Simpson (2006: 126) puts it, "you don't do fieldwork, fieldwork does you". Although fieldwork has developed to incorporate sites and social interaction that extends beyond the intrinsically actual, such as virtual worlds including both game and nongame environments (Kelty, 2008; Faubion & Marcus, 2009; Nardi, 2010; Pearce, 2011; Boellstorff et al., 2012; Boellstorff, 2015), the archetypal ('being-there') ethnographic fieldwork has rarely seen long-distance methods of communication as an appropriate way to go about this work. Not only is one expected to be physically present in the field (Hastrup & Hervik, 1994: 3), but the duration of fieldwork is also seen as critical (Okely, 1992).

In my case, like many before me (Amit, 1999; Coleman & Collins, 2007; Faubion & Marcus, 2009), fieldwork involved intense physical and emotional engagement. Perdita Phillips redefines fieldwork as *fieldwalking* (2007), which I find to be a novel contribution. It speaks well to what Lee and Ingold say about emotions being realised in the 'act of walking'; they are channelled through and manifest like an actual movement of the body (2007: 71). They write that:

> [W]alking does not, in and of itself, yield an experience of embodiment, nor is it necessarily a technique of participation. Rather, both embodiment and participation presuppose some kind of attunement, such that both the ethnographer's pedestrian movements and those of the people she or he is with are grounded in shared circumstances. (Lee & Ingold, 2007: 67)

Lee and Ingold sought to explore the relationship between the practices of walking, the experience of embodiment and forms of sociability. I take their argument to be that participating (as anthropologists) is not about walking into (entering) a field-site but walking (socialising) *with* people. It is not about face-to-face relations, but heading in the same direction, sharing vistas and encountering (or even retreating from) the same threats or obstacles (Lee & Ingold, 2007; Ingold & Vergunst, 2008; Ingold, 2010).

I conducted my fieldwork in two separate periods, between April and October 2017 and between January and August 2018. During the first period, my activities mostly involved dispersed exploratory work and familiarising myself with the field and the groups. The groups I followed principally consisted of elderly people (between 60-80 years old), and I imagine at first it probably seemed a bit strange to them that I—a student in his late twenties—was 'hanging around' with a group of seniors. I distinctly remember a few occasions upon which I received rather confused glances from some of the support group-members themselves and other people in our surroundings (if we were all out on a fieldtrip or similar).

However, my participants quickly grew accustomed to my presence, although they continued to struggle to pinpoint what exactly I was doing there and what my research was about. That I was interested in researching 'people living with a lung condition' and how such groupings managed on an everyday basis was easy to convey and comprehend. However, what seemed more difficult for the diverse group members to grasp was how my research was designed, and how it could contribute to current practices. In fact, I had to remind some people that I was not a medical student, but a social scientist interested in the social aspects of medicine and ill health. By the time Christmas I reached the second half of my fieldwork, clear themes had started to emerge and the second period primarily revolved around mapping out these threads to see where they would take me.

(ii) Participant observation

Fieldwork and participant observation are relatively symbiotic terms; they are commonly performed instantaneously and each is often treated as "defining criteria of anthropology" (Amit, 1999: 1). Yet there is a (sometimes blurry) distinction. Participant observation is "designed to capture people's day-to-day routines and experiences, enabling the researchers to determine what people actually do opposed to just say" (Dixon, 2017: 54). However, as Martyn Hammersley writes, "'Ethnography', and cognate terms like 'qualitative method', 'case study', 'participant observation' etc. are not well-defined in their usage" (1992: 29). This touches upon the earlier point, that ethnography encapsulates a multitude of meanings. Thus, for the purpose of clarification, in this dissertation (in its overall argument) I will regard ethnography as a methodology (strategy through which to obtain knowledge), and ethnographic fieldwork and participant observation as methods (used to gain information). As we can read in classic anthropological work (e.g. Malinowski, 1922; Mead, 1928; Evans-Pritchard, 1937) and in the history of anthropological theory (Barnard, 2000), participant observation has emerged as the principal approach to ethnography and ethnographic research by anthropologists. The method has relied on the cultivation of personal relationships with local participants and respondents as a way of learning about cultures, involving both observing and participating in the social life and habits of a group.

Overall, participant observation has enabled anthropologists to formulate first-hand accounts of their respondents' lives and gain novel insights into different ways of being. In my case, participant observation played out in following my research participants wherever their lives led them. My fieldwork activities primarily took place at sites in northern England where my interlocutors usually gathered, e.g. in public locales, churches, participants' homes or other mutually convenient locations. I attended support group-meetings as my main fieldwork activity. However, activities were not limited to group meetings but also incorporated other activities the participants took part in, including lunch and dinner gatherings, fieldtrips, outdoor walks, exercise sessions and various fundraising and charity events. I also aimed from the start to collaborate with different individuals who, in the end, volunteered to take part in my research, e.g. health activists, charity workers, clinicians and other allied health professionals. Thus, alongside following individuals living with a lung condition themselves (and their families and friends) my fieldwork practice also entailed engaging with other individuals in their day-to-day activities.

(iii) Interviews

As H. Russell Bernard writes, the “concept of ‘interviewing’ covers a lot of ground, from totally unstructured interactions, through semi-structured situations, to highly formal interactions with respondents” (2011: 156). For this study, I applied multiple sets of interviewing techniques: unstructured, semi-structured and structured. The reason for this was, although somewhat planned, also because of circumstances; as Eriksen argues, depending on the “kind of fieldwork one is engaged in, structured interviews […] and other techniques may be required to varying degrees” (2015: 34). Considering the different positions my participants held (patient, nurse, charity officer, etc.), I had to adjust each interview to each interviewee’s specific needs.

Bernard separates unstructured interviews from semi-structured in terms of control; while unstructured interviewing can take place at any time and in any place (in the form of small-talk or mundane chats), semi-structured interviewing is always a “scheduled activity” (2011: 156). Furthermore, while semi-structured interviews are open-ended, they do follow a loose script and cover a list of pre-determined topics. Most of the time I was able to conduct semi-structured interviews; however, they could differ quite significantly. For instance, with some individuals, I did not have to ask very detailed questions: I only had to mention certain themes, and they would respond with very elaborate narratives. Some people, on the other hand, were more inclined to give rather short responses, requiring me to continuously ‘feed’ the conversation with follow-up questions. In terms of ‘thickness’ of ethnographic detail (Geertz, 1973: 3 ff.), however, all interviews contributed to the same extent; each interaction simply demanded a different approach.

I also conducted a few relatively structured interviews, in situations where I knew the interviewee would not have much time to spare (e.g. staff from the British Lung Foundation). Annette Lareau (1996) is of the opinion that staying beyond the stated interview-time shows a lack of respect for the respondents, so for these interviews, I prepared a list of clear questions and stated that I did not expect our talk to take more than an hour. During one of these interviews, I was only required to ask a few follow-up questions; the interviewee independently read from the list of questions I had provided. Otherwise, if I was not asked, I never stated an estimated time for each interview and let them run their course, as I wanted to give each respondent enough time to go through what they wanted to tell me. I do recall one occasion where I might have outstayed my welcome; however, I believe this was due to a simple misunderstanding (I was under the impression that the respondent had no other scheduled engagement, but she had, which she forgot to inform me about and thus I cut the interview short).

For people who experience breathlessness, activities that rely on speech may hold many challenges. Thus it was particularly important to always make sure I gave my respondents opportunities to pause (or stop) the interview, and take as many breaks as they felt they needed. Overall, I conducted twenty-six (26) interviews, although some were with the same person(s) twice. Interviews were conducted in the participants' homes or other mutually convenient locations, such as where the groups usually meet, in a café, or even over the phone or Skype. The choice of location for each interview was always made in agreement with and in consideration of each respondent's needs. For instance, due to its intimate nature, I never suggested an interview should take place in someone's home, but allowed them to suggest it.

The interviews lasted between thirty minutes and four hours. They were all recorded (with verbal and written consent) on an encrypted device, where I later transcribed them (more or less verbatim). A few of the interviews were conducted in small groups and thus the number of interviewees does not reflect the overall number of interviews. I interviewed thirty-three (33) people in total. The interviews were principally conducted with support group members; people who live with breathlessness and their families; and various health professionals such as Respiratory Nurse Specialists, health choir and singing leaders (see Lewis et al., 2016; Lewis et al., 2017) and staff from the British Lung Foundation.

(iv) Focus group work

The focus group method originates from research by Paul Lazarsfeld and Robert Merton in 1941 at Columbia University and, as has been frequently reported, the commercial potential of their pioneering work was immediately clear (Merton, 1987; Merton et al., 1990 [1956]; Lee, 2010; Bernard, 2011). A focus group is a gathering of deliberately selected individuals who participate in a planned discussion. Focus groups are, as Bernard (2011) writes, recruited with the direct purpose of discussing a particular topic—“anything from people's feelings about brands of beer to their experience in toilet training their children” (2011: 172), to determine the potential reactions that could be expected from a larger population. Unlike an interview, which usually occurs with a single individual, the focus group method allows members of the group to interact and influence each other during the discussion. As the name suggests, focus group work (or interviews) are always done in groups; however, as Bernard argues (2011: 172), not all group interviews are focus group interviews.

Anthropologists might sometimes find themselves in an interview situation with multiple people, who continuously “insert themselves into the conversation” (Bernard, 2011: 172). Although this would constitute a completely adequate group interview, it does not make them focus groups. With that said, the line between my group interviews and actual focus group work may appear somewhat indistinct. I approached the support groups on the basis of them being ‘support groups for people living with a lung condition’ (i.e. focus groups). Alongside that, at multiple group meetings, I initiated wider group discussions on specific topics, which also incorporated methodological facets of focus group work.

FIELD-SITES

I am well aware of that so far I have mostly referred to my research participants (these 'support groups') as simply groups, groupings or individuals. Thus, I would now like to direct my attention towards my ethnographic field-sites. My research came to be primarily focused on three support groups, all based in northern England (County Durham and South Tyneside, more specifically). When I say 'follow', I mean this in quite a literal sense. Ultimately, my approach to the study that this dissertation is based on was primarily informed by the practice of 'following-the-thing' coined by Appadurai (1986, 2006), and later expanded upon by Marcus (1995). This thing-following practice, as Marcus writes,

> involves tracing the circulation through different contexts of a manifestly material object of study (at least as initially conceived), such as commodities, gifts, money, works of art, and intellectual property. (1995: 106-107)

Nevertheless, turning to Alison Hulme (2016), I do acknowledge the need to reflect upon the potential struggles with implementing a practice that was born in an age of early globalisation. As Hulme writes (2016: 157), back in the late '80s and early '90s, "tracing things was easier", whereas now, some objects may be "unfollowable, their trajectories highly changeable and punctuated by numerous ruptures". With this in mind, I would rather define my method in terms of yo-yo fieldwork (Wulff, 2002). That is to say, "yo-yo movements between [and] around" sites (and agents) in Stockholm where "my repeated returns [served] to strengthen my bonds to the field" (Wulff, 2002: 122-123).

The three groups that I 'followed' are Breathe Easy groups: part of a nationwide network that provides support and information for people living with a lung condition, and for those who look after them (Centre for Health Service Studies, 2016). The network was set up by the British Lung Foundation (BLF) in the early 1990s and over the past two decades, the BLF has made a significant progress in making this a nationwide network. There are about 230 Breathe Easy groups across the UK (Figure 3.2), although as I have come to experience, the level of activity varies widely between groups. For instance, some groups have very few members and others only exist 'on paper'.

Figure 3.2: A map of all currently active Breathe Easy groups (according to the British Lung Foundation); estimated to be around 230 groups.

(Imagery ©2018 Data SIO, NOAA, U.S. Navy, NGA, GEBCO, Landsat / Copernicus)

For a period of 14 months, I engaged with these three support groups:

- **Breathe Easy Darlington**, in Darlington (County Durham)
- **Breathe Easy Durham Dales**, in Bishop Auckland (County Durham)
- **Breathe Easy South Tyneside**, in South Shields (Tyne and Wear)

Breathe Easy (BE) groups are run by their members, with help and support from the British Lung Foundation (BLF) and occasionally other local actors or charities as well. The groups typically meet once a month and members arrange all kinds of things for their meetings, from talks on local patient services and advice from health care professionals to arts and crafts and trips to museums, the theatre or the seaside. BE groups are officially part of the BLF, as they run under their charity numbers.[19] Although far from being the only respiratory health charity active in the UK, the BLF

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[19] The British Lung Foundation is a “registered charity in England and Wales (326730), Scotland (038415) and the Isle of Man (1177)” (blf.org.uk, 2018).

is the only one concerned with all types of lung conditions. The charity was formed in the mid-1980s (discussed further in Chapter 4) and initially focused solely on funding research on respiratory health. Later on they also took up campaigning for better health services and care for people with lung conditions, alongside spreading the word about the causes and signs of lung disease and how to prevent it (blf.org.uk, 2018). Nowadays, the charity also focuses on bringing people with lung disease together, specifically through the Breathe Easy support group network but also through their web community and pen-pal schemes, while also providing publications of their own (blf.org.uk, 2018). Breathe Easy groups are easily recognisable through their banners (Figure 3.3), which depict the BLF logo in a clear blue sky with white clouds. The banners are often used when groups are out in public, or simply to announce where their meetings are held.

Figure 3.3: Materials and banner from Breathe Easy Durham Dales, photographed at the Newgate Shopping Centre in Bishop Auckland.

(© British Lung Foundation | Photos taken by the author)

(i) Secondary field-sites

While the three specific local Breathe Easy groups were my entry points into the field of respiratory health, my research took me to several places in Britain. Moreover, initially I made occasional visits to other groups of interest as well, in an attempt to explore the wider landscape of support groups for people living with a lung condition. However, these visits decreased as the time and cost of travel proved untenable in the long run, but also due to questions of access and research focuses compatibility. In this section, I will briefly outline these groups.

Initially I had a fourth group in mind, based in Sheffield (South Yorkshire), but this was not possible due to the time and cost of regularly travelling to Sheffield. At another early point in my fieldwork, I also paid a few visits to a group based in Newcastle upon Tyne: the Northern Region Idiopathic Pulmonary Fibrosis[20] (IPF) Support Group. This is a local support group for anyone affected by IPF and shares a similar history with the Breathe Easy network. It was initially set up with provision from the BLF alongside other charities, and unlike many other IPF groups in the UK it remains led by its members rather than hospital staff. The reason for this[21] is that IPF is such a rare condition that it is more feasible to host support groups in clinical settings (in close relation with clinical trials and expert staff). Today the group is part of the Action for Pulmonary Fibrosis[22] (APF) network. As my fieldwork progressed and my research focus narrowed, it became less germane to visit this group and I prioritised support groups targeting a wider range of lung conditions. I did, however, interview a few people from this group and some of their narratives are included in the dissertation.

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[20] Idiopathic pulmonary fibrosis, or IPF, is a lung condition that causes progressive scarring of the lungs. The build-up of scar tissue is called *fibrosis*. Fibrosis causes the lungs to become stiffer and lose their elasticity so they are less able to inflate and take oxygen from the air (blf.org.uk, 2018).

[21] The source for this statement is a public lecture/seminar held by Wendy Dickinson from Action for Pulmonary Fibrosis (APF) in Newcastle upon Tyne (16th August, 2017).

[22] Action for Pulmonary Fibrosis (APF) is a charity that specifically targets IPF and other cases of pulmonary fibrosis (PF). It was founded in 2013 by patients, family members and IPF specialists, as they all recognised the need for a national IPF charity focusing on improving the quality of life for patients with PF and IPF, and funding research (actionpulmonaryfibrosis.org, 2018).

In addition to these groups, I also made visits to and interviewed people from two 'Singing for Lung Health'[23] (SLH) groups located in Burnley (Lancashire) and Halifax (West Yorkshire) respectively. SLH is an initiative from the BLF and is an increasingly popular intervention for people with lung conditions (Lewis et al., 2016; Lewis et al., 2017). There is increasing evidence suggesting that singing regularly as part of a group is good for people's general health and wellbeing, and it seems to be especially good at improving quality of life for individuals living with a lung condition (Lewis et al., 2016; Lewis et al., 2017). However, as with the group in Sheffield, in the long run, it was not judicious to continue to make regular visits to Burnley and Halifax. Lastly, in 2017 I attended the annual LAM Action General Meeting held in Birmingham. LAM Action is an UK-based organisation for women with the rare lung condition *lymphangioleiomyomatosis*[24] (commonly known as LAM). Like similar charities, LAM Action aims to provide support, information and encouragement to those with LAM and their families, alongside helping to educate health professionals about LAM and advance research into the condition, while simultaneously raising funds to drive these activities (lamaction.org, 2019).

In terms of more independent agents, I also met with selected members of staff from the BLF in Leeds, London, and Newcastle upon Tyne, as well as Respiratory Nurse Specialists in the Acute Respiratory Assessment Service[25] (ARAS) team at the South Tyneside District Hospital located in South Shields. Towards the end of my fieldwork, I also attended a few gatherings of the Save South Tyneside Hospital Campaign (SSTHC), who held meetings in Jarrow, South Shields, and Sunderland. I should say that the SSTHC is not a support group, but a health activist movement (Epstein, 1998; Damen et al., 2000; Brown et al., 2004; Landzelius, 2006a, 2006b; Epstein, 2008), which primarily consists of campaigners, advocates, and local

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[23] These groups are also known as Singing for Breathing (SB) (Lewis et al., 2016).

[24] LAM is a rare lung condition that affects a certain type of muscle cell. It occurs almost exclusively in women, and the cause is still unknown. Symptoms include breathlessness, which may worsen with time, and it can cause a pneumothorax (or collapsed lung). Because this condition is so rare, it may take some time to get a full diagnosis (blf.org.uk, 2018).

[25] "The Acute Respiratory Assessment Service (ARAS) provides a specialist service for the assessment, management and treatment maximisation of patients with respiratory conditions who live in South Tyneside" (stft.nhs.uk, 2018).

politicians, as well as (to a lesser degree) patients, their families and friends. The rationale behind paying visits to these gatherings was simple: this movement and its interests very much aligned with those of Breathe Easy, alongside general public health concerns in the UK.

In April 2016, it was announced that the South Tyneside District Hospital would be downgraded as part of a so-called ‘alliance’ between City Hospitals Sunderland (CHS) and South Tyneside NHS Foundation Trust (STFT). This resulted in a loss of acute services in May 2016, and the SSTHC was initiated to oppose this process (savesouthtynesidehospital.org, 2018b). People throughout the borough of South Tyneside joined the campaign distressed about the potential disaster for the people of South Tyneside. Since then, the SSTHC has organised several demonstrations with many taking place outside the District Hospital (savesouthtynesidehospital.org, 2018b). I will delve further into this dispute later on in Chapter 6.

UNBOUNDED PRACTICE: FIELDWORK ON THE MOVE

As can be read online at ‘Discover Anthropology’ (a web resource operated by the Royal Anthropological Institute’s Education Outreach Programme), there is a general consensus amongst anthropologists that “fieldwork came to be considered part of the practice of social anthropology with the work of one of the founding fathers of British anthropology”: Bronislaw Malinowski (e.g. 1922). Unlike the now largely superseded ‘armchair anthropologists’[26] before him, Malinowski promoted that instead of researching other people and cultures from the comfort of one’s own office or a library, anthropologists ought to go ‘into the field’, to live with the people being researched, engage in their community, and participate in their everyday lives and routines (Malinowski, 1922). Since Malinowski’s time, fieldwork—traditionally, away from one’s ‘own’ society—has been regarded as an essential and almost compulsory part of an anthropologist’s professional training.

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[26] Simply put, armchair anthropologists usually refer to late nineteenth-century and early twentieth-century scholars coming to conclusions without going through the usual anthropological motions; i.e. fieldwork or lab work (cf. Barnard, 2000).

Even today many anthropologists still consider (and advocate) that performing fieldwork in the strict traditional 'Malinowskian' sense is the most prominent, distinguished and authentic characteristic of anthropological research (discoveranthropology.org.uk, 2018).

Whether or not this could be said to be the archetypal way of doing fieldwork, it does not capture how I approached or performed it, as my fieldwork activities were predominantly conducted on the move (or in movement). That is to say, I principally focused on following specific individuals or groupings and their routines, wherever these ended up taking them. Throughout my fieldwork, I commuted between my main residence and multiple field-sites, rather than embedding myself (cf. Lewis & Russell, 2011) in a single location.[27] I primarily used public transport in getting from one place to another—train, bus and metro—but when it came to shorter distances, I was occasionally offered lifts by my research participants or colleagues. There are a great many analytical toolkits in place that can describe and be applied to this sort of framework I engaged in e.g. multi-sited (Marcus, 1995; Hage, 2005; Falzon, 2009), multi-local (Amit, 1999; Marcus & Fischer, 1999 [1986]; Wulff, 2002), trans-local (Hannerz, 2001), transregional (Marsden, 2016), arbitrary (Candea, 2007) or unbounded (Candea, 2007; Falzon, 2009).

Although these concepts are (marginally) distinct in meaning, emphasis and utilisation, they all move beyond the perception of 'the field' as a limited, single, bounded location. Although the late 1990s is commonly seen as the time when George Marcus (1995, 1998) made 'multi-sited ethnography' the methodological trend it has now become (in and beyond anthropological circles), the concept had been called for as early as in 1986 when Marcus and Michael Fischer published the first edition of *Anthropology as Cultural Critique* (Marcus & Fischer, 1999 [1986]). According to Matei Candea (2007), referred to simply as 'multi-locale ethnography' (rather than multi-sited), Marcus and Fischer sought to use the concept to acclimatise the anthropological discipline to the "changing realities of what had

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[27] Having that said, for the second half of my fieldwork I started to focus more on the metropolitan borough of South Tyneside.

been known since the 1970s as the ‘world-system’, and in the 1990s became increasingly glossed as ‘globalization’” (2007: 168).

(DE)CONSTRUCTING THE FIELD: DOING ANTHROPOLOGY ‘AWAY’

In the previous section I discussed and reviewed physical and practical aspects of performing fieldwork. Following this thread, I now seek to challenge understandings of what constitutes ‘the field’ (as site, location, discourse or imagination) in the strict traditional sense, which may have been arrived at by common consent and hence become normative. In *Anthropological Locations*, Gupta and Ferguson write (1997: 15) of how anthropology’s emphasis on “the field”

> …enables certain forms of knowledge, but blocks off others. With the idea that knowledge derived from experience in “the field” is privileged comes a foregrounding of face to-face relations of community, while other, less localized relations disappear from view.

What constitutes ‘the field’, and how does one experience it? Charlotte Davies writes that for anthropologists, “the selection of research topic has been so intimately connected with the choice of research site as to be virtually the same” (2007: 39). Gupta and Ferguson (1997) further discuss this differentiating process in the context of an evaluative hierarchy within anthropology. By delineating the key consequences of the construction of ‘the field’ through the practice of fieldwork, they outline a number of themes, one of which refers to the radical separation of ‘the field’ from ‘home’, and the related creation of what they name a “hierarchy of purity of field sites” (Gupta & Ferguson, 1997: 12). That is, anthropology has a hierarchical outlook on the appropriateness of the various field-sites researchers can engage with. They argue that,

> [t]he very distinction between “field” and “home” leads directly to what we call a hierarchy of purity of field sites. After all, if ‘the field’ is most appropriately a place that is ‘not home’, then some places will necessarily be more ‘not home’ than others, and hence more appropriate, more ‘fieldlike’. All ethnographic research is thus done ‘in the field’, but some ‘fields’ are more equal than others—specifically those that are understood to be distant, exotic, and strange. (Gupta & Ferguson, 1997: 13)

This further begs the question of what is anthropology ‘at home’? This “is not as easy a concept to define as its name seems to suggest” (Mughal, 2015: 121). Until a few decades ago, the idea of an anthropology at home was a “paradox and a contradiction of terms” (Peirano, 1998: 105). Yet during the course of the twentieth century, the distances between ethnographers (and allied scholars) and those they researched persistently decreased, as “the approach, not the subject matter, had unwittingly always defined the anthropological endeavor” (Peirano, 1998: 105). Caroline Knowles (1999: 54) argues that “[h]ome and field invoke the duality of belonging and alienation, familiarity and investigation, which implicitly function as fieldwork strategies”. At home, Carol Greenhouse claims (1985: 261), “we struggle to see through the ordinary to the extraordinary, whereas elsewhere, we struggle to achieve the ordinary”. Yet our sense of familiarity ‘at home’ can be deceptive as well: not just in terms of how the familiar may conceal the extraordinary, but also how the “cultural concept of ‘familiarity’ is built on premises that modern anthropologists do not entirely share” (Greenhouse, 1985: 261).

I was born and bred in Stockholm and received both my bachelor’s and master’s degrees at Stockholm University. Both dissertation projects (and all the relevant fieldwork) were conducted in central Stockholm. Thus, my groundwork in anthropology was fully based on experiences of doing research ‘at home’. About six months after graduation, I was accepted into a PhD programme at Durham University, Durham (UK). Although an experienced traveller, this was the first time I had lived outside Sweden on a permanent basis. My fieldwork was also completely based in the UK, putting me in an interesting position in relation to my fellow PhD students, who had all come to Durham to return ‘home’, engaging with the UK-based diaspora from their home countries or other locations they were already significantly familiar with, while I was proposing to conduct fieldwork in a place (away from ‘home’) to which I had just relocated.

These circumstances brings us back to one of the themes that Gupta and Ferguson (1997) emphasise in *Anthropological Locations:* how the construction of 'the field' leads to the construction of a normative anthropological subject i.e. an anthropological 'self' against which anthropology sets its 'Others' (Gupta & Ferguson, 1997: 12). However, ideas about Otherness, they write, "remain remarkably central to the fieldwork ritual" (1997: 16), and any conception of an 'Other' has further implications for the identity of the self. Yet, what 'home' and 'field' are as concepts and how anthropologists organise the relation between them, as Knowles argues, "are issues worthy of further investigation" (1999: 54). Furthermore, drawing out what home and field are turns complicated in cases where people live 'multi-locale' lives; although as George Marcus (1995) points out, the traditional practice of fieldwork is already multi-sited (unbounded). This further relates to what Matei Candea writes about self-limitation and arbitrary locations in ethnographic fieldwork. He proposed the kind of bounded field-site that is

> premised on the realization that any local context is always intrinsically multi-sited. Even in a small village in the north of Corsica, it is not multi-sitedness that is the problem, but sitedness. (Candea, 2007: 175)

Although Durham was now my 'home', it was more a 'place of residence', even Durham University made a distinct difference between my 'permanent (home) address' (Stockholm) and my 'term address' (Durham) and I was only able to visit Stockholm at Christmas. All these views refer to 'home' as a mere location; a physical space. What marked me out from local UK people (and thus what I could call 'home') was cultural dynamics: habitus (Bourdieu, 1977) in the ways I acted, behaved or talked. However, referring to what Gupta and Ferguson say, "if 'the field' is most appropriately a place that is 'not home', then some places will necessarily be more 'not home' than others" (Gupta & Ferguson, 1997: 13), where does this place the UK in relation to Sweden? With the expansion of the European Union (EU), its internal single market and standardised system of laws, alongside the emerging 'global citizenship' movement transcending geography or political borders (Shaw, 2000), some countries (in e.g. Asia or Africa) may have appeared more 'not home' to me than other European countries.

(i) Insider/outsider

I am trying to make sense of insider/outsider relations, in relation to places deemed as more or less ‘like home’, and what implications that had for me during fieldwork. When it comes to theorising about so-called Otherness, there is a large body of literature. Robert Merton (1972) discusses the dichotomous structure that emerges when dealing with so-called *Insiderism*, or the *Insider Doctrine:* the characteristic behaviour of insiders. Simply put, Merton defines social life as divided into different bodies, or collectives. That is, social groupings where individuals are either insiders or outsiders, depending on with whom they share a sense of belonging. Merton’s argument is that we all perform the roles of insiders and outsiders as ‘possessors’ of specific social statuses (or capitals) (1972: 21). Only insiders are able to comprehend the configurations within “their” own body (collective) and they all share certain insights, which could be deemed obscure to those outside of that collective (Merton, 1972: 15). Merton adopts a structural conception of the two sides:

> Insiders and Outsiders are here defined as categories in social structure, not as inside dopesters or the specially initiated possessors or esoteric information on the one hand and as social-psychological types marked by alienation, rootlessness, or rule breaking, on the other. (1972: 22)

Merton goes on to criticise and deconstruct the values on which this notion rests. He states that he finds it challenging to only speak about either being “inside” or “outside” of a collective, as an individual can be part of different groups concurrently (Merton, 1972: 29). That is, if the structural entity is divided into various bodies, there are separate collectives for different ethnicities, nationalities, sexes, gender, sexualities and so forth. How would such a separation manifest for an individual belonging to more than one of these collectives? Merton argues that,

> [w]e no longer ask whether it is the Insider or the Outsider who has monopolistic or privileged access to social truth; instead, we begin to consider their distinctive and interactive roles in the process of truth seeking. (1972: 36)

Although some adjustment to a new life in the UK was required of me as a foreign Swede, I imagine that the overall process was easier than it would have been for some people of other nationalities, as I am an English-speaking, white man with an university education. Although not a native English speaker, I retained a great deal of social and cultural capital by possessing a Swedish passport. Nevertheless, my position as a foreigner was prominent during fieldwork and often marked me out against my research partners and participants. My English accent is good and I am often mistaken for an Englishman by both other foreigners and native Britons; I am also asked “What’s your accent?” by people who cannot ‘place’ me.

Although language was a useful resource, however, it was also something used to further distinguish me as a foreigner. I was often praised for ‘how well I could speak English’. Although well-intentioned, I doubt people think about the social boundaries they build (and uphold) by proudly calling attention to foreigners speaking ‘their’ language. Yet being a foreigner came with perks as well. I often played the ‘stupid foreigner card’, which in some situations enabled me to ‘get away’ with clumsiness or a lack of understanding (something I imagine locals would not have been able to do).

PARTICIPATORY RESEARCH: BOUNDARIES AND LIMITS

Life of Breath aspired to initiate partnerships in the co-production of knowledge with its diverse stakeholders. In line with this, I have sought to incorporate participatory research approaches in my work. Participatory research is an umbrella term that comprises a range of methodological approaches and techniques, all with the objective of handing power from the researcher to the research participants (Kindon et al., 2007). These approaches involve researchers and participants working together to examine a problematic situation and change it for the better. As Kindon and colleagues write, participatory research is defined by “a collaborative process of research, education and action [...] explicitly oriented towards social transformation” (2007: 9).

Needless to say, I see a distinction between participatory ‘methods’ and ‘approaches’. For me, fully-fledged participatory (action) research (PAR) involves a clearly framed action-oriented methodology, where the goal is for the research participants to attain a position of power. Participatory approaches, on the other hand, do not incorporate these action-oriented features to the same extent. Rather, these approaches seek to (re)integrate inclusion and collaboration into how research is designed, finding a balance between researchers and researched, without fully becoming comprehensive action research. Participatory methods and approaches are not ‘participatory’ in or by themselves: such tools can only be truly participatory when they are applied by individuals whose attitudes encourage and enhance commonality and mutuality between all parties involved (Koch & Kralik, 2006; Kindon et al., 2007; McIntyre, 2008).

Participatory research approaches do not come without challenges or criticism (Cooke & Kothari, 2001). These approaches cannot be rushed into; they require time and talents, trust-building and showing awareness and consideration of social boundaries (Kindon et al., 2007). As Kindon et al. write, “for academics to undertake participatory and action-oriented research […] they must bridge ‘two conflicting social worlds’” (2007: 2). Rather than evading or bypassing power relations, participatory research (even if executed properly) can itself be understood as a power practice, “which differs little from other externally imposed forms of research” (see also Cooke & Kothari, 2001; Kapoor, 2005; Kindon et al., 2007: 20). Building on these theories, I would like to discuss where my research sits in this. Throughout this chapter I have consistently referred to my so-called ‘research participants’ as just that—participants. Yet at the same time I apply a method termed ‘participant observation’. This may seem oxymoronic, “in that the two activities, or the roles they suggest, cannot be pursued simultaneously” (Davies, 2007: 82) and the method is an attempt to be both objective and subjective.

Are these terminologies mutually exclusive or symbiotic? In anthropology (and ethnographic research more broadly) the vocabulary of subjectivation is rich and ranges across participants, informants, interlocutors, consociates, collaborators, consultants, partners and friends (Driessen, 1998). These terms can be found challenging (‘friends’ especially), as they appear to try to remove (or at least blur) the power dynamics between researcher and researched. Where does one draw the line, and who is in position to do so? Although our research subjects are typically (but not necessarily) human (Russell, 2019), as Bob Simpson (2011) argues, the anthropological subject does not easily fit the notion of a so-called "human subject" commonly presumed by medical ethics. Simpson continues (2011: 384):

> [W]hilst anthropologists engage with subjects who are indeed human, they would not normally think of themselves as studying 'human subjects' in the medical sense, or as part of the legacy of experimentation… […] Fundamentally, selfhood is seen as a situationally defined project, rather than one to be defined essentially.

I struggle to see how my respondents are full-fledged 'participants'. I certainly asked them and they agreed to participate in my research (and signed consent form), but I did not provide any 'research facilities' nor did I invite them to any sites I inhabit myself. On the contrary—I needed my respondents' permission to come to any meetings or events they arranged, all part of their commonplace routines. That is, I am the one seeking to participate. Then, is 'participants' really an appropriate description for the group in which I was included? Although selected individuals involved in my research have openly described me as a "colleague, [group] member and friend" and I too would very much like to see us as equals (as partners or collaborators), using the term loosely, I feel, would potentially undermine and neglect the power dynamics that are at play. To quote Tineke Abma, "[…] Health research is conducted to produce knowledge that may ultimately lead to better treatments for patients. Patients do not, however, have a large influence on research" (2006: 425). Whether or not my intentions were good or my respondents approved of my approaches, in the end, as the primary researcher, I am in full control of what is accepted or rejected when disseminating the results.

(i) Engaged observer

Anthropology has long been associated with an ethos of 'engagement' (Sanford & Angel-Ajani, 2006). In seeking to establish a partnership with my (so-called) research participants, my own position and ways of engaging with them as researcher took multiple turns. I started out as a detached observer but remained very much 'seen' and noticed by the members of the groups I observed. My direct engagement in activities was low, as I primarily focused on getting a feel for the diverse social settings. Nevertheless, as time passed, people grew accustomed to me, which also raised the expectation that I would engage more. This was wholly mutual, and meant that conversations were instigated *with*, rather than *about,* me. Raymond Gold (1958) suggests that while in fieldwork the ethnographer may adopt one of four possible roles, ranging from completely detached observation with no participation to fully immersing oneself in the environment:

- Complete observer
- Observer-as-participant
- Participant-as-observer
- Complete participant

Referring to my own experience in the field, however, I sense that these roles may not be as clearly differentiated as they first appear. I very much doubt any ethnographer stays fixed within one role throughout their fieldwork. Each role brings about its own advantages and disadvantages. If complete participation encompasses, as Gold writes, that the “true identity and purpose of the complete participant […] are not known to those whom he observes” (1958: 219), this approach neglects many well-acknowledged ethical issues. It is covert research (Spicker, 2011) and even though undercover ethnography has, from certain angles, been useful (in e.g. uncovering a hidden global market in human flesh (Scheper-Hughes, 2004)), it is still seen as a deceptive and dishonest practice that cannot easily be rationalised. This is also closely related to the notion of *going native*, which “refers to the danger for ethnographers to become too involved in the community under study, thus losing objectivity and distance” (O’Reilly, 2009: 87). Although I grew close to some individuals (and their cause) in my field, alongside not entering every social situation with a clear research agenda in mind, I do not sympathise with this approach, as I always made sure to fully disclose my purpose to everyone I came into contact with.

Having that said, with regard to ‘complete participation’, there were times when my engagement became action-oriented; an ‘engaged observer’ (Sanford & Angel-Ajani, 2006) in terms of emotional bonding and sympathy, wanting to see direct results for my research participants-partners. For instance, on one occasion I was asked to mediate between one of the groups and an establishment they were in collaboration with. As common terms had not yet been established between the two, I was asked to help them design a proper (yet casual) partnership agreement.

Overall, I predominantly shifted between the roles of observer-as-participant and participant-as-observer. Although I principally was there to observe and conduct research, I became entangled in some of the groups' interests and undertakings. I also signed official membership forms for two of the groups, which definitely blurred the boundaries of insider-outsider relations.[28] It seems to me that anthropologists (or ethnographers more broadly) rarely distinguish between participation and observation; and if they do, it tends to be done in shallow ways. For instance, how would I go about observing a support group-meeting without participating? Am I not participating by physically being in the same room as the members? And if I was to attend and aim to remain a 'true observer', would I have to turn down any social interaction instigated by the group members? Such behaviour would undoubtedly damage my relationship with them, which would make further fieldwork difficult.

What, then, constitutes 'proper participation'? If we look at classroom ethnography, it has been argued that in such situations it is only possible to engage in moderate participation (Ambjörnsson, 2004; DeWalt & DeWalt, 2011; Wang, 2013); the ethnographer is neither a teacher preparing lectures nor a student sitting through them and thus it is not possible to enter as a full participant. Having said that, participant observation truly appears (as I mentioned earlier) oxymoronic: "the two activities, or the roles they suggest, cannot be pursued simultaneously" (Davies, 2007: 82). As Faubion and Marcus write, "fieldwork is not what it used to be" (2009: 1) and yet it is still a practice anthropologists have been undertaking since Malinowski (1922) reinstated its value in the early 1900s, and it is still valued for those same reasons.

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[28] Having that said though, the act of signing membership forms also involved aspects of personal health and safety. As I did spend a lot of time with these groups, if something was to happen to me while I was with them, they needed my emergency contact information (for example).

ETHICS

I designed this project in accordance with the American Anthropological Association's (AAA) Statement of Ethics (2012). Ethical approval was granted at Durham University by the Department of Anthropology's Ethics Committee on March 6, 2017. I later made some amendments, which were all accepted on May 31, 2017. Also, as previously mentioned, I had the support and approval of the BLF Service Development Manager for the North to pursue this research. The principles of the AAA recommend, as Dixon puts it, for

> …anthropologists to carefully consider the structural circumstances informing ethnographic encounters and, moreover to remain aware that ethical conduct is a process that begins the moment research is conceived and continues after ethical clearance is granted. (2017: 57)

According to the AAA Statement of Ethics, "[a] primary ethical obligation shared by anthropologists is to do no harm" (2012: 1), and it is imperative for each researcher to think through all the possible ways the research might cause harm. Before I began my fieldwork, I carefully weighed all the potential consequences and inadvertent impacts my research and actual participation could have on those involved. In line with what Dixon writes, I approached acquiring informed consent as an ongoing (teleological) process. Initial informed consent was never, in any way, definite. Before asking my participants to sign a consent form, I provided an information sheet giving details about me and my research, and what it would entail for them to participate in this study. The sheet contained my contact information and stated that if for any reason they would like to withdraw (partially or completely) from the study, they could do so at any time and without any disadvantage. This procedure speaks well to what can be read in the AAA's Statement of Ethics (2012: 3) about informed consent, including

> …sharing with potential participants the research goals, methods, funding sources or sponsors, expected outcomes, anticipated impacts of the research, and the rights and responsibilities of research participants.

Moreover, this process also emphasises establishing expectations regarding anonymity and credit. That said, all my participants were anonymised throughout my fieldwork (and will be throughout this dissertation). Transcriptions have been shared with each of them and edited when they felt certain details had to be clarified. Although I have anonymised individuals, I have not anonymised locations, social groups or organisations. This would have been unachievable, as I would have had to anonymise the whole region of North East England. However, this does not come without issues. Although there are strategies available to make each individual difficult to identify, I imagine it would not be difficult for some group members to pick out each other’s personal narratives, no matter how I chose to edit or present them.

Primary data and any other confidential information have not been shared with anyone but the research participants themselves. In taking precautionary measures when writing my field-notes, I refrained from naming or pointing anyone out to an unnecessary extent, which was achieved by applying encryption techniques and pseudonyms early on in my work (cf. Kurzwelly, 2015). Some data, such as contact information and consent forms, have either been stored on a password-protected computer or locked away in my office in the Department of Anthropology. Nevertheless, in accordance with the ethical principles, I was bound to present to my research participants all possible impacts of participation. I made it clear to them that, despite my best efforts, confidentiality may be compromised, and outcomes could always differ from those originally anticipated.

CONCLUSION

This chapter has documented the methodology of my ethnographic journey across the North-East of England. It has described how I initially made contact with three Breathe Easy groups, which ultimately became the main focus of the research, and what methods I used to explore the members' experiences of living with chronic breathlessness. The chapter also highlights the multi-sited approach taken, which besides ethnographic fieldwork also included participant-observation; focus group work; and various forms of interviewing with Breathe Easy members and their families, respiratory nurses and allied health professionals, and staff from the British Lung Foundation. This wide-ranging ethnographic approach to studying support groups for people with chronic breathlessness in the UK helped achieve the aims of the study in that I met with a very diverse group of people from different areas who all live with dissimilar respiratory conditions, and thus demand different things from their respective support groups. Furthermore, I was able to explore the links which tied each individual, group, and community to the larger political-economic factors at play by not only having built rapport up with the support groups themselves and local health professionals, but also the wider framework that the British Lung Foundation (and by extension, the Breathe Easy groups) navigates. The next chapter (empirical in nature) provides some background on the British Lung Foundation and their mission, as well as how the Breathe Easy support group network came into existence.

PART II

MOMENTS

~ CHAPTER FOUR ~

THE MAKING OF A SUPPORT GROUP NETWORK

A BIOGRAPHY OF "BREATHE EASY"

"If you have a lung condition, you can't sit around and wait for
other people to look after you—you need to take care of yourself!"

PETER[29]

INTRODUCTION

In humans, the lungs are the most exposed of all the internal organs. This may explain why respiratory diseases have remained, and continue to remain, centre stage in disability and mortality rates all over the world. However, with the exception of the coronavirus disease outbreak in December 2019 (Ghosh, 2020; Godlee, 2020; Heymann & Shindo, 2020; Higgins et al., 2020; Manderson & Levine, 2020; Mehdi, 2020; Yanow & Good, 2020; Zeegen et al., 2020; Manderson et al., 2021; Zhang, 2021), respiratory diseases have largely shifted from being infections to becoming diseases of dirty air (Geddes, 2016). On the one hand, infections have declined (primarily in high-income countries), with some conditions making a return; on the other hand, disease conditions like asthma, chronic obstructive pulmonary disease, and lung cancer have surged rapidly (Geddes, 2016: 393). In the United Kingdom more specifically, more than 8 million people have been diagnosed with asthma and about 1.2 million with chronic obstructive pulmonary disease (British Lung Foundation, 2016: 14), or *COPD*, an umbrella term for different obstructive conditions characterised by long-term breathing problems and poor airflow. This compares to, for instance, tuberculosis (TB), for which there were only 2,707 hospital admissions in 2011 (British Lung Foundation, 2016: 18). Needless to

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[29] This quote has been used by the British Lung Foundation in a multitude of their publications. One of these is a piece on their website (blf.org.uk, 2018) entitled *Keep Active, Keep Well*. The person cited is simply referred to as *Peter*—most likely a pseudonym. Peter lost one of his lungs to cancer.

say, whether infectious in nature or not, respiratory diseases continue to make an impact on acute and emergency services all around the world.

Bearing all of this in mind, this chapter seeks to frame the history of conditions which cause respiratory disease and respiratory health as continual processes of “construction and contestation” (Atkinson, 2015: 32). Geddes writes that “diseases have changed: some fade, some emerge and others come and go, but all through this period our knowledge has grown” (2016: 393). Medical science understands the lungs better than ever before, which has opened up certain opportunities and flexibilities in terms of respiratory health treatment and management. That being said, where do support groups come into the picture? At heart in this chapter is Foucault’s art of governance (Brunon-Ernst, 2013; Audier, 2015) and the distinction between sociobiology and biosociality. What drives human behaviour, especially when it comes to chronic disease? Can human behaviour solely be explained on a biological basis through evolution, or does human behaviour shape and determine our understanding of biology? The argument that I bring forward in this chapter is that to properly comprehend the inherent purpose of support groups for people living with chronic disease (also to be understood as *self-technologies*), it is important to gain a grasp of the different social, historical, and medical conditions through which said groups manifest.

I describe these cross-cutting connections between knowledge and relations ethnographically, especially where respiratory disease becomes the point of intersection. I do so, more specifically, in light of how respiratory disease “is one of the three biggest killer disease areas in the UK” (British Lung Foundation, 2016: 4) where mortality rates have also remained stagnant for the past decade. This contingency is not seen in other widespread disease areas in the UK—like cardiovascular disease or cancers—in which mortality rates have decreased with each passing year (British Thoracic Society, 2006). Yet, in comparison, funding for respiratory research is about one tenth of that allocated to these two disease areas (Jarrold, 2016; Nyman, 2018).

The chapter is organised as follows. On the whole, the chapter offers insights into how communities are formed around the biomedical need (and strive) to elevate respiratory health as a public health priority in the United Kingdom. This is a process which I deem inherently biosocial, with biosociality indisputably at heart. Although according to Raffaetà (2017), it may also be biosociality extended: a social process whereby people affirm the priority of nature over culture. I introduce the chapter by conveying the history of the British Lung Foundation and its overall operation, wherein I especially draw attention to the point in time when the United Kingdom was short of a third-sector organisation focusing specifically on respiratory health. This brings us to the mid-1980s, when the British Lung Foundation was founded by Professor Sir Malcolm Green, a British physician with an interest in respiratory physiology. In the section that follows, I draw attention to the Breathe North Appeal, another respiratory health charity that was instated in the North East instantaneously with the British Lung Foundation. The series of events that follow form the backbone of the Breathe Easy support group network, which was officially launched by Trevor Clay in Birmingham in 1991.

Later on in the chapter, I attend more closely to the Breathe Easy groups with which I met during my fieldwork across North East England. Subsequent to drawing out when and for what purpose the Breathe Easy network was initially established, I provide personal narratives on how three Breathe Easy groups located in the North East came together through interventions by the British Lung Foundation. This is, in simple terms, biosociality and biosolidarity in practice: where people move from isolation towards community (Bradley, 2021). Furthermore, I set out the scenes for how Breathe Easy meetings habitually proceed in terms of venues, events, and decision-making, for which the group committees become imperative for how each group operates. As the chapter ends, I turn my attention to more modern times. Specifically, I draw out the historical and structural changes that took place from within the British Lung Foundation during the mid-2010s, which led to the termination of regional offices around England as well as key members of staff who all worked closely with Breathe Easy groups across the United Kingdom. As will be made clear, I argue that this process can be understood from looking to the rise of neoliberalism in the UK and around the world (Cotoi, 2011; Audier, 2015; Fuchs, 2016): how global institutions are inherently being consumed by neoliberalism, whereby they fail to act decisively to reduce poverty and social inequality (Sakellariou & Rotarou, 2017). This series of events are fundamental to understanding the relationship between the British Lung Foundation and the Breathe Easy support group network, which has grown to be rather frail following all recent changes to how the charity operates.

BRITISH LUNG FOUNDATION

As a starting point, I want to briefly convey the history of the British Lung Foundation (Figure 4.1), which self-proclaims to be "the only UK charity looking after the nation's lungs" (blf.org.uk, 2018). Jarrold (2016) writes that when the charity was first set up, there was a particular lack of funding and focus with regard to respiratory research in the UK. Needless to say, over 30 years later, respiratory research continues to be "[…] consistently underfunded and the [UK] government is not putting a focus on respiratory research, as it has for cancers and cardiovascular disease" (Jarrold, 2016). As the Breathe Easy support group network and its members remained the primary focus throughout this research project, direct engagement with the British Lung Foundation was largely limited during my fieldwork. That being said, it is important to understand the establishment of this organisation, as it forms the backbone of the Breathe Easy support group network and, even more so, because the network was initially set up by a Trustee of the British Lung Foundation and continues to remain an official part of the charity's structure. This includes (amongst other things) running all Breathe Easy campaigns under the British Lung Foundation's charity numbers, which means that the groups fall under the UK legislation that covers fundraising by not-for-profit organisations.[30] In addition, the goals and values habitually held by all Breathe Easy

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[30] As the UK officially consists of multiple autonomous entities (or countries), the British Lung Foundation holds several separate charity numbers. These are: England and Wales (326730), Scotland (038415), and the Isle of Man (1177) (blf.org.uk, 2018). The British Lung Foundation is also

groups are largely entwined with those of the British Lung Foundation (which is something that I will assert further on in this chapter).

Figure 4.1: Logo of the British Lung Foundation, 1985–2012 (left); 2012–currently (right). The red balloon has always been their symbol of choice, although the first version also denotes “0_2”; the chemical compound for molecular oxygen.

(©British Lung Foundation | Photos taken by the author)

Although rich in nature, the history of the British Lung Foundation has not been properly documented (neither by themselves nor by historians). Thus, my literary sources have been rather limited. In working to gather consistent documentation on the charity’s history, I have had to rely on a variety of archival, online, oral and other secondary sources—putting my skill of source criticism to the test. However, I also made sure to interview past and present staff members of the British Lung Foundation, which proved to be very useful in drawing out key points and proceedings in the charity’s history. One former staff member with whom I met (and to whom I will refer only as “B”) had worked for 22 years at the British Lung Foundation but, unfortunately, was made redundant in March 2018 following a new

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active in Northern Ireland but due to the country’s self-determining Charity Commission, it does not hold a charity number for that region.

strategy put forth by the charity's Board of Trustees. Before being made redundant, "B" had held the position of Regional Manager in the North East and Yorkshire regions combined. "B" and their team had had an office in the Sir G.B. Hunter Memorial Hospital located in Wallsend (historically *Wallsend on Tyne*), a town in North Tyneside, not far from Newcastle upon Tyne.

When "B" first came into post in 1996, there had been quite a lot of focus on fundraising activities. That being said, "B" and their team had also spent much of their time on setting up new Breathe Easy groups around the North East. As "B" remembered it, back in 1996 there were a total of two Breathe Easy groups in the two northern regions: one was located in Gateshead (North East) and the other in Leeds (Yorkshire). In the whole of the UK overall, "B" believed that there had been about 20 support groups. As of the time of writing, the British Lung Foundation takes pride in having been able to subsequently set up "a nationwide support network" of approximately 230 Breathe Easy groups across the length and breadth of the nation (Centre for Health Service Studies, 2016). However, the accuracy of this number (230) is up for debate, as the British Lung Foundation has struggled to keep a proper record of all the Breathe Easy groups in the past. Nevertheless, the groups can be found in all corners of the nation—from the Isle of Wight and Helston (Cornwall) in the South and South West regions of England to Aberdeen in the far north of Scotland. There are also several located in London and the surrounding areas, as well as five groups in Northern Ireland and even one group on the self-governing Crown Dependency of the Isle of Man (which the map from Chapter 3 illustrates).

According to "B", their work tasks as Regional Manager were diverse and multifaceted. Yet the tasks also related very much to "what the charity did nationally", as "B" put it.[31] Since the British Lung Foundation's formation, all of its regional branch offices (which had been actively running until a few years ago) had been quite independent in how they operated regionally. As the regional offices

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[31] Unless something else is stated, all of the direct quotes in this section come from the interview transcript. The interview was conducted in Newcastle upon Tyne on June 18, 2018.

were largely involved in community fundraising (which is a localised activity), independence in how they operated remained a necessity. Be that as it may, another prominent duty of the Regional Managers was that of actually setting up Breathe Easy groups. According to their estimations, "B" believed that over the years, they had personally been responsible for setting up nearly 30 groups in the regions of the North East and Yorkshire. I know for a fact that they had been personally involved in establishing the three support groups with which I met during my fieldwork: Breathe Easy Darlington, Durham Dales, and South Tyneside.

The British Lung Foundation (BLF) was initially set up by Professor Sir Malcolm Green in 1984 as a response to the prevailing lack of funding and attention with regard to respiratory research in the United Kingdom. Malcolm Green is a (now retired) British physician who once held the position of Vice-Principal of the Imperial College School of Medicine,[32] as well as Head of the National Heart and Lung Institute (NHLI) incorporated within the said School. Green was based at Royal Brompton Hospital in London. After the BLF's official launch in March 1985, Professor Green acted as the charity's Chairman for 10 years, until 1995, when he became its President—a role which he held until 2001. Professor Green's own website claims that he

> …steered the [BLF] through its early years into a national medical research charity now raising £6M annually, for respiratory research, for helping patients who live with lung disease, and for making more widely known the importance of lung disorders.
> (malcolmgreen.net, 2018)

While remaining a rather small charity (at least in comparison to those in the areas of cardiovascular disease and non-respiratory cancers), to this day the BLF's voluntary income continues to remain stagnant at £6–8M annually. On the whole, Malcolm Green's overall goal had been to form a medical charity in the UK offering respiratory disease the same amount of attention and research support that had largely gone to cardiovascular disease. Back then, for instance, only an estimated

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[32] "Imperial College School of Medicine (ICSM) is the medical school of Imperial College London in England, and one of the United Hospitals. It was formed by the merger of several historic medical schools, and has core campuses at South Kensington, St Mary's Hospital, London, Charing Cross Hospital, Hammersmith Hospital and Chelsea and Westminster Hospital" (imperial.ac.uk, 2018).

0.7% of the Medical Research Council’s income was spent on respiratory research, “despite the high death rates in the UK from respiratory disease” (malcolmgreen.net, 2018). By alluding to the alarming proportion of the UK population suffering from lung conditions in the late 1980s (and the huge social and economic burden that these cases placed on healthcare services), Professor Green mapped out an overwhelming need for more respiratory research, which was the underlying rationale that led to the foundation of the BLF. As I have already disclosed, however, although over 30 years has now passed, the situation of respiratory research in the UK remains largely unchanged (British Lung Foundation, 2016; Jarrold, 2016). For instance, as can be read in the public health report *Battle for Breath* (British Lung Foundation, 2016: 4), respiratory disease kills

> […] 115,000 people each year, the equivalent of one person every five minutes. These mortality figures are roughly the same as those reported by the British Thoracic Society a decade ago. In comparison, the number of deaths from heart disease went down by 15% from 2008 to 2012.

In order to fully understand how Breathe Easy groups function in their role as mutual-aid support groups, it is necessary to outline the groups’ relationship with the BLF. For this purpose, I interviewed Martin, a high-ranking operative within the BLF. When I inquired as to whether it would be possible for me to conduct our interview in person (rather than via telephone), Martin invited me to come to London and meet with him at the BLF’s main office and headquarters (Figure 4.2).

Figure 4.2: Headquarters of the British Lung Foundation (BLF); 73–75 Goswell Road, London, EC1V 7ER.

(Photo taken by the author)[33]

Our meeting proved to be valuable. Although I was already familiar with the BLF's early history at this stage, Martin started by telling me about Professor Sir Malcolm Green and how he and his colleagues (back in the 1980s) had realised that "although there were lots of medical research charities in existence, there wasn't one that [explicitly] focused on lung disease".[34] Originally, the aims of the BLF (as Martin put it) were to raise money charitably and put it into funding research. I was told that, initially, funding research had been the primary concern of the BLF; "and that was it" (Martin). Yet, further down the line, as the BLF started to grow and develop as a charity, it was decided by its Board of Trustees that it would be appropriate for them to expand and diversify their charitable activities and services.

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[33] This figure has previously been used by the author in a magazine article published by *The Northern Review* (see: Nyman, 2018).

[34] Unless something else is stated, all of the direct quotes in this section come from the interview transcript. The interview was conducted in London on August 3, 2018.

However, funding research as such remains a “core part” of what the BLF is all about, Martin made it clear. Needless to say, nowadays the charity structure their work (and overall mission) largely around what is characteristically described as their “three main pillars of work” (British Lung Foundation, 2018), that is, to offer *hope*, *help* and a *voice*.

According to Martin, the services that seek to provide people with *hope* derive from the medical research that the BLF funds. This is research that, on the whole, aims to improve care and treatment for people living with a lung condition in the UK, and thus (as Martin put it) “give hope for a future that will be better” for these individuals and their families. This aspect fits well with the BLF’s second pillar of work: *help*. This pillar is built on how the charity work to help patients (and their families) in dealing with their lung condition—or as stated in their report *Bringing hope, help and a voice*: “[they] empower people affected by lung disease through support, services and information” (British Lung Foundation, 2018: 2). This empowerment process is, outwardly, put into force in a multitude of ways. According to Martin, the BLF offers “patient-focused information on different lung conditions”, specifying how people can live with, and manage, their conditions in the most efficient of ways. This information is largely found and accessed online, primarily through the BLF’s own website (blf.org.uk, 2018), but the information is also dispersed through printed leaflets that can be found in the majority of NHS facilities.

Alongside this activity, the BLF also runs a helpline service which was introduced back in 2004 and is now fully based at the regional office in Liverpool. The helpline is open Monday to Friday, 9 a.m. to 5 p.m., and people may call about any respiratory-health-related issue—including how to manage one’s condition, options regarding medications, and helping people to accept their diagnosis (blf.org.uk, 2018). When the helpline celebrated its 10th anniversary in 2014, the BLF posted the story of Carol (a BLF helpline officer) online, who reflected on her journey:

> [T]he launch of the helpline was just a trial to see if it would be a useful way of sharing information. The BLF was formed in 1985 but had never offered direct help and support in this way before, so it was really exciting to be involved in such a huge step forward for the charity.
>
> There wasn't a way for people with lung conditions to get advice and support from anybody but their own doctor or nurse, and we wanted to see if our helpline could help [...] Ten years—and thousands of calls—later we're still here and have helped so many people in so many ways.
>
> I still remember waiting for the first call to come in. It was so nerve-racking because this was all new to me. I already had 10 years [of] experience working on other helplines, but the world of lungs was unexplored territory—I had just 3 months to learn as much as possible about lung health, and the practical and emotional issues of living with a lung condition.
>
> —Carol (blf.org.uk, 2018)

The Breathe Easy support group network falls under the category of 'help service'. As Martin described them to me, the BE support groups are a "face-to-face, peer-to-peer support group network" in which people can come and meet other individuals who share similar experiences to their own. Through attending these peer-to-peer gatherings people can learn more about their lung conditions and receive support from one another, while also meeting and making new acquaintances that have similar issues and experiences to their own.

The third and last pillar is that of *offering a voice*. Martin informed me that this aspect of the BLF's work is principally practised through the charity's press and campaigns team. This team is, according to Martin, explicitly "responsible for giving lung disease a voice". Overall, the team works to gain as much press coverage about respiratory diseases as possible, alongside covering what the charity has done thus far to tackle issues surrounding respiratory health in the UK overall. During our interview, Martin also mentioned that the BLF works hard to "influence other people who work in this sphere". This primarily refers to the UK government. Allegedly, the BLF's press team regularly seeks to run a multitude of campaigns seeking to raise awareness about lung disease and specific aspects of lung disease—all to influence the government to do more for people who struggle with lung disease. To summarise, over the years the BLF has evolved and diversified from simply providing research funding to focusing on implementing a multitude of patient services, alongside providing information, and running public health campaigns. However, while the charity habitually (and proudly) describes itself as "the only UK charity looking after the nation's lungs" (blf.org.uk, 2018), this is far from being the case—which I will explain in the following sections.

THE BREATHE NORTH APPEAL

While Professor Sir Malcolm Green has been a leading figure in advocating for further attention to issues surrounding respiratory health in the UK as a whole, initially the BLF was based only in London. Respiratory diseases, however, remained a national public health issue that stretched beyond the southern regions of the UK. During my interview with "B", I was informed about a likeminded appeal for attention to respiratory health that had been set up in North East England (where my research was based). This appeal, which later became a fully registered charity in its own right, held the name *the Breathe North Appeal* (charity no. 327935). Furthermore, the appeal had seemingly been put into force at around the same time that the British Lung Foundation was established, in 1984 or 1985, and as the official launch of the BLF had not been held until March 1985, "B" informed me that "it might have been just a few months before the Breathe North Appeal […] launched as well".

Following this interview with "B", I set out to gather additional data on the Breathe North Appeal. As a first step, I turned to the Charity Commission's online archives. Here I found that, although no longer listed as an 'active body', this appeal had once been registered under the name Breathe North Appeal Limited. The records contained only a brief description of the charity's objectives:

> The relief of persons suffering from diseases of the chest and lungs in particular by the promotion of medical research into the prevention, treatment, alleviation and cure of the said diseases and the dissemination of the useful results of such research for the benefit of the public and by the promotion of postgraduate training and the creation of fellowships in hospital medical centres and research institutes.
>
> *(Details from the Charity Commission; document in author's possession)*

With regard to their charitable approach, the Breathe North Appeal had purportedly focused on providing resources and support to other charities or voluntary bodies. As the records read, the Breathe North Appeal provided grants to organisations and sponsored or undertook research themselves (as cited above). While extraordinarily accidental, the incidence of these two charities (i.e., the BLF and the Breathe North Appeal) manifesting when they did could have been a mere coincidence. In line with the theory of trans-cultural diffusion (Winthrop, 1991; Kuklick, 1996), the connection between them could perchance be explained as a mere transmission of cultural characteristics or traits (in this case, an idea or a common need) from one cultural centre to another (Titiev, 1958: 446). In this case, the cultural centres would be London (the UK capital) and North East of England (a region holding strong industrial heritage in British culture) (Thirlway, 2015).

However you choose to look at it, the Breathe North Appeal seems to have come into force for the same reason as that of the British Lung Foundation (BLF), that is, to fill a void, especially in terms of supporting respiratory research on the public health agenda. More specifically, "B" told me that the Breathe North Appeal was supposedly formed after a group of chest physicians from across the North East region came together seeking to fund the establishment of a regional lung research centre in Newcastle upon Tyne. This is a trait that the Breathe North Appeal shares with the BLF (as Professor Malcolm Green's medical speciality was respiratory physiology). Said physicians' resolve proved to be successful, as they later managed to institute the Sir William Leech Centre for Lung Research. Initially this centre was located in Wallsend Chest Clinic next to the Sir G.B. Hunter Memorial Hospital (in which the Breathe North Appeal was based), but it later relocated to Freeman Hospital in Newcastle upon Tyne. Freeman Hospital is one of the main organ transplantation hospitals in modern-day Britain, and it held its institutional specialist position back in the 1980s as well. Back then, Freeman Hospital was the primary cardiothoracic referral centre in North East England, making it an excellent venue for a respiratory research centre.

Ultimately, the Breathe North Appeal came to merge with the BLF in 1996 to become its official branch in the North East region. It was at this point that "B" was recruited to become the Regional Manager. The venue was kept as it was until 2013, when the majority of the BLF regional offices in England closed down.

THE FIRST 'BREATHE EASY' GROUP IN 1991

Respiratory disease places a huge burden on healthcare services in the UK, and the British Lung Foundation is purportedly dedicated to improving the lives of people affected by lung conditions of all types. A cornerstone of this activity has been the development of the network known as Breathe Easy, wherein groups

> […] promote self-care via peer support, education and information giving. Integral to the success of the network are passionate and community-based volunteers, who drive groups forward to increase the health and wellbeing of their attendees.
>
> (Centre for Health Service Studies, 2016: 9)

As a support group network, Breathe Easy was officially launched in April 1991. As I have been told by different staff from the BLF, the first group was set up in Birmingham and back then it was solely known as the *Breathe Easy club* (Clay, 1994). Setting up this consumer-centred network had, from the start, been an aspiration of Trevor Clay (Figure 4.3), a British nurse and formerly the first male General Secretary of the Royal College of Nursing (RCN).[35] Born in 1936 in Nuneaton (Warwickshire), Clay began his nursing career in 1957 after having finished his degree at Brunel University in London. That being said, it was not until 1982 after he became the General Secretary of the RCN that Clay became more of a public figure in his roles as both public trade union official and negotiator. Furthermore, in terms of respiratory disease, not only was Clay a Trustee of the British Lung Foundation, but he was also a sufferer diagnosed with emphysema (COPD) in 1973 at the age of 37. When he retired from the RCN in September 1989 due to illness, with a

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[35] The Royal College of Nursing (RCN) is a membership organisation and trade union with more than 432,000 members in the United Kingdom. It was founded in 1916, receiving its royal charter in 1928. The majority of its members are registered nurses, but student nurses and healthcare assistants are also members. The RCN describes its mission as "representing nurses and nursing, promoting excellence in practice and shaping health policies" (rcn.org.uk, 2018).

membership in excess of 285,000 people, “[…] no labour organisation unaffiliated with the Trades Union Congress surpassed the RCN in size, and none had a greater rate of expansion” (Casey, 1994). Clay passed away in 1994, aged 57, in the wake of his emphysema.

Figure 4.3: Trevor Clay in 1982.

(©The Royal College of Nursing)

People who knew Trevor Clay personally describe how he (due to his condition) understood the limits of those living with breathing difficulties and recognised the need for people with similar conditions to get together on a regular basis to support one another. In a book endorsed by the BLF, medical writer Tom Smith (2011 [1994]: 81-82) writes that living as Clay did with emphysema,

> […] he launched Breathe Easy to provide a positive public face for lung disease and to give it a voice that could not be ignored by government, Members of Parliament, health professionals and the general public. His legacy lives on.

A similar paragraph can be read in Bellamy and Booker’s book on COPD:

> [The aim of Breathe Easy] is to remove the phrase ‘there’s nothing more that can be done’ from the vocabulary of health professionals. Not only does it have a devastating effect but it is simply not true. What is meant is that there is no magic, no cure, but there is always something that can be done. (2004: 193)

In light of Clay's legacy, the BLF has over the past two decades made "impressive progress" (Centre for Health Service Studies, 2016: 7) in setting up a nationwide support group network of about 230 Breathe Easy groups for those living with lung conditions, as well as their family and friends who support them. Whether or not the initial objective was for these community-based groups to grow into the nationwide network that they have now become is difficult to make out, but it would certainly not have been possible without the circle of people sharing Clay's dedication to improving patient care and support in the area of respiratory disease. Respiratory disease is, after all, one of the three biggest killer disease areas in the UK (British Lung Foundation, 2016: 4) and better management is "desperately needed to improve the quality of life of those who have it" (British Lung Foundation, 2007b: 12) in order to help ease the enormous burden that these conditions place on health services and individual sufferers throughout the United Kingdom.

NARRATIVES ON HOW THREE GROUPS CAME TO BE

Although the first Breathe Easy group officially launched in 1991, it did not take long for the BLF to expand and grow from simply accommodating one 'club' to maintaining a UK-wide network of about 230 groups (blf.org.uk, 2018). With approximately 20 active groups in 1996, this means that (starting in 1992) the BLF must have installed (on average) about five new Breathe Easy groups per year. The expansion did not end here, though. Considering how by 2016 the Breathe Easy group network had grown to 230 groups (according to the BLF's own estimation), this means that between 1997 and 2016 the enlargement grew from launching five groups per year to between 11 and 12 (on average).

That being said, the three Breathe Easy (BE) groups to which I grew close are all relatively young members of this network constellation. Both BE Darlington and BE South Tyneside were instated in 2009 (thus celebrating their 10-year anniversaries in 2019). BE Durham Dales was initiated two years later. As each group is supposed to retain and practise certain autonomy from the start (especially in terms of how members organise and administer their continuous activities), BE groups are seldom set up solely through external interventions. I have been informed that selected individuals living with chronic breathlessness have habitually been approached either by clinical staff in their own localities (urged on by the BLF) or by the BLF themselves through public outreach. There are also groups who were set up through support from another already established group in a neighbouring community (with partial support from the BLF). BE South Tyneside, for example, had been approached by the BLF to aid the charity in reinstating a BE group in the county borough of Gateshead. The latter group, however, did not survive for a long period of time. As I was told by a member of BE South Tyneside:

> *We've been asked before to go to… well, somewhere [Gateshead] where they've been trying to start a new group and help them how to get on with stuff. We worked hard in the beginning, and so, but the biggest problem was getting people in. You know, but our local Gazette puts in our info every so often—when we're meeting and where, and things like that. We're getting a bit of publicity there.*

Getting a group up and running takes time and dedication and it cannot be taken for granted that a group will survive. In Burnley and Halifax, I met two Singing for Lung Health groups (Lewis et al., 2016; Lewis et al., 2017), both of whom originated in local Breathe Easy groups. I was told by members of both groups that for a long period of time these Breathe Easy constellations existed only on paper, before officially disbanding in 2018 or 2019. In an interview with Maria (71), a member of Singing for Breathing in Halifax, she told me the story of her group. She first heard of the singing group at a Breathe Easy meeting but said group had soon folded. As she described it herself during our interview:

> *It is still there… [sighs] but nobody was interested in just meetings and there weren't enough of us to ask around whether anyone wanted to come and give talks. So, basically… I think the singing group has rescued us—the group, if you know what I mean. It… Breathe Easy, that is… has now become a singing group. But it's still the same people with the same lung problems—and we all understand each other. It's just very, very good. I would say… the Breathe Easy group has not been officially shut down; it's just sort of…* stagnant*, because I can't see it generating, especially as the BLF has said that there are so many groups saying the same thing—they're struggling to get new members.*

In comparison, Carole (82), a member of Singing for Lung Health in Burnley, had never heard of Breathe Easy support groups until I mentioned them. Having recently joined the singing group, Carole's resolve had always been to learn how to manage her respiratory condition (COPD) through the practice of singing.

> *Fredrik: I wanted to ask you… Were you ever involved with the Breathe Easy group here in Burnley when it was active?*
>
> *Carole: …no.*
>
> *Fredrik: Maybe you haven't even heard of it?*
>
> *Carole: No, I haven't heard of it. I hadn't heard of it until you mentioned it just now.*
>
> *Fredrik: Well, it was connected to the Singing for Lung Health group, although it was more… in the "traditional" support group style…*
>
> *Carole: Oh, yeah…*
>
> *Fredrik: It was not about singing, but more about seeking mutual understanding through the support from one another. Sometimes they invited speakers…*
>
> *Carole: Oh, yes…*
>
> *Fredrik: …yeah. 'Cause I talked to your choir leader about it, and I was very curious to hear about… that there used to be a Breathe Easy group here in Burnley, but then it…*
>
> *Carole: …withered away?*
>
> *Fredrik: Yes!*

What these two narratives show is that as a brand (and, by extension, consumer service), Breathe Easy does not always work. In these cases, the Breathe Easy groups in Burnley and Halifax both quickly lost ground and became stagnant, only to exist on paper for a long period of time. As a result, members gradually started to walk away and, instead, turn their attention to participating in the local singing groups—which remain active and well attended to this day.

(i) Darlington

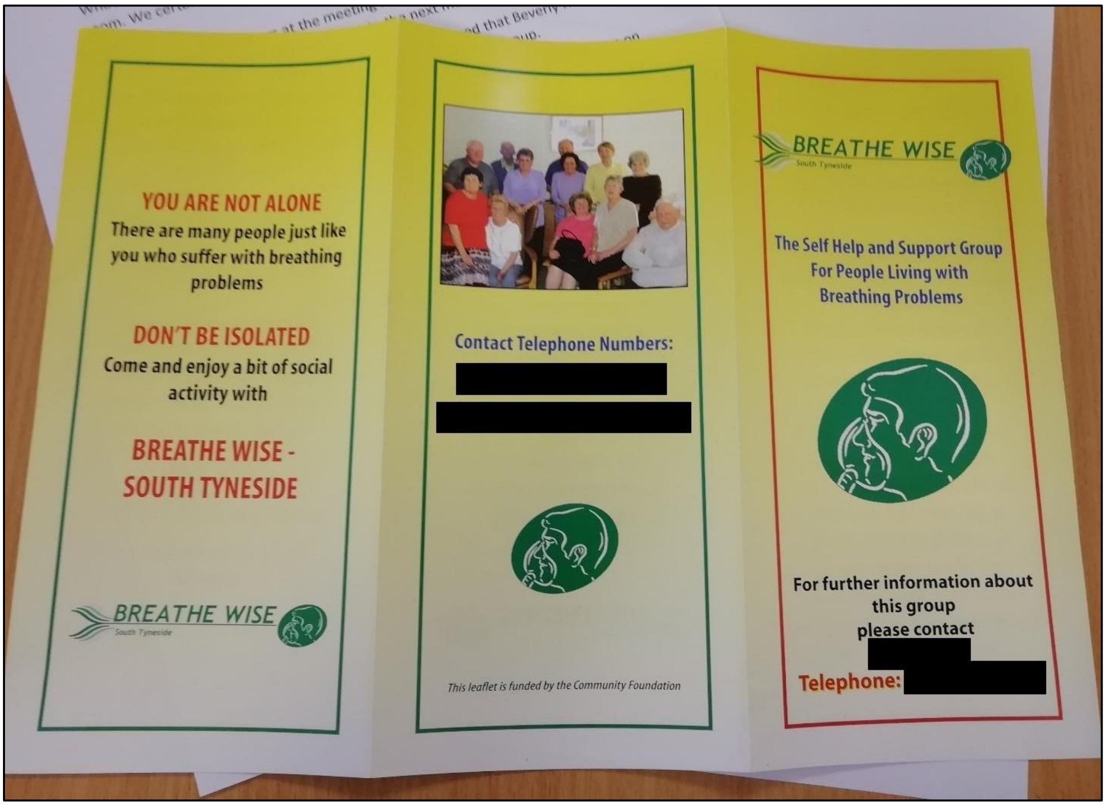
In contrast to Burnley and Halifax, the three Breathe Easy groups on which this dissertation focuses are well-attended support groups in their local communities. In Darlington, for instance, member Olivia (62) told me about how she and acquaintances of hers were approached by a local respiratory nurse to set up their Breathe Easy group.

> *It all started with… There were four or five of us—William being one and then myself—and then also Oakley, whom I believe you've met. We were approached by one of the senior, leading respiratory nurses (in the whole of the North East) and asked to start the Breathe Easy group, which is obviously part of the British Lung Foundation, but there wasn't anything around here [in Darlington]. And for some reason, we said 'yes'! [laughs] That was about nine years ago, I think. And… we got quite a bit of publicity at the start, and we also did quite a lot of active fundraising from the start. I think that's what has gotten us… out there—the name and all. And our membership went up to… on paper, 60-odd people—fairly quickly, that is. But I don't think we've ever had more than low twenties—a day like today. And if you think back like a year ago, it was probably just the four of us. You know, I'm quite glad to see it back to being… growing again. I mean, there were two new members here today, so that's always a good sign. And there are also people who joined recently who keep coming back. So that's encouraging—being back to where we were.*

Said nurse was, in fact, Olivia's practice nurse back then (later on becoming a community respiratory nurse) and had early on shown a clinical interest in respiratory disease. Thus, 'egged on' by the British Lung Foundation (in the words of Olivia), she had started to look for volunteers interested in establishing a Breathe Easy group in the town of Darlington. There have even been times when members' lives have been put on hold in order for them to help in setting up a group. In truth, William (65), who was mentioned earlier by Olivia, was supposedly asked by said nurse to vacate his place on an ongoing pulmonary rehabilitation course (Alison & McKeough, 2014; Spruit et al., 2015; Oxley et al., 2019) in order to prioritise the instatement of BE Darlington. In light of this, it is also interesting to note that due to his commitment to Breathe Easy, William has not been able to (re)register for and attend pulmonary rehabilitation ever since.

(ii) South Tyneside

Breathe Easy South Tyneside had come together under similar conditions to those of the Darlington group. However, in terms of community-based respiratory health support, South Tyneside had a predecessor to Breathe Easy. I was informed by one of the nurses at South Tyneside District Hospital that a support group named *Breathe Wise South Tyneside* had been set up in the early 2000s through financial support from NHS South Tyneside and other local funders. Amongst them were the Community Foundation in Tyne & Wear and Northumberland, a philanthropic charity and generalist grant-maker which support a wide range of community groups predominantly in the areas of Tyne & Wear, Tynemouth, and Northumberland. The group had a pamphlet, amongst other things (Figure 4.4).



YOU ARE NOT ALONE
There are many people just like you who suffer with breathing problems

DON'T BE ISOLATED
Come and enjoy a bit of social activity with

BREATHE WISE - SOUTH TYNESIDE

BREATHE WISE
South Tyneside

Contact Telephone Numbers:
[redacted]

This leaflet is funded by the Community Foundation

BREATHE WISE
South Tyneside

The Self Help and Support Group For People Living with Breathing Problems

For further information about this group please contact
[redacted]
Telephone: [redacted]

Figure 4.4: A leaflet from the former *Breathe Wise* self-help and support group in South Tyneside. Although out of date, the image has been edited so as to remove and anonymise all personal information.

(Photo taken by the author)

While not historically connected in any sense, Breathe Wise had, in fact, functioned in a similar manner to that of the current Breathe Easy support group network. Namely, it was promoted as a "self-help and support group" with a clear focus on providing space for people with breathing conditions to meet and socialise so as to prevent isolation—a common issue amongst people living with respiratory disease (Fraser et al., 2006; Williams et al., 2007; Ek & Ternestedt, 2008). To my understanding, however, Breathe Wise lasted only a few years. Nevertheless, its previous existence had left a stable ground for NHS South Tyneside to aid the British Lung Foundation in establishing a Breathe Easy group in the local area. Although the current group is named *South Tyneside*, the group is, in fact, based in South Shields. The name, needless to say, is meant to cover and include people living in the overall borough, stretching from South Shields to Jarrow, Harton, Hebburn, and the villages of Boldon. One of the group's current key members, Jon (65), told me the tale of how he was recruited to sit on the group's committee.

> *Jon: When the group was first set up back in 2009… I had been on rehab then. The exercise class…*
>
> *Fredrik: Pulmonary rehabilitation?*
>
> *Jon: Yeah, that one. It sounds bad that I've had 'rehab', doesn't it? "I was in rehab!" [laughs]… Anyway, this woman from the British Lung Foundation…… Not "B", though—some older lady…*
>
> *Fredrik: …the one who held the position before?*
>
> *Jon: Yes! [laughs] She came along to one session and said, "This is the British Lung Foundation, et cetera…", and that she'd like to set up a support group called 'Breathe Easy' in the South Tyneside area. And we all said we were interested. So… I think there were a couple of people from the rehab group, but anyway… We all went—I think there were about 20 people or so—and the lady, Margaret, which was her name, gave us the talk again. And she asked, "Are you interested?". And we were, like, "Yeah, oh yeah"… You know, we were this group of people, and people don't always say much. She then said: "I'll need some volunteers." For Chairperson, Secretary, and the like… "Would anyone like to volunteer?"… Not a soul! [laughs] "But we'll need a Chair!" she repeated… Not a soul! So, I thought… [sighs] And you say this, time and time again… But I volunteered to be Chair and that was it!*

Pulmonary rehabilitation (PR) is a programme of exercise and education for people with a long-term lung condition (lifeofbreath.org, 2016), and is specifically designed for those who are severely breathless. While people with asthma or chronic obstructive pulmonary disease (COPD) are most commonly referred to PR (much due to the high prevalence of these conditions in the United Kingdom), PR is recommended for all individuals living with a lung condition and chronic breathlessness (Troosters et al., 2013; Oxley et al., 2019) and may even come to benefit people living with bronchiectasis, pulmonary fibrosis, or even *lymphangioleiomyomatosis* (LAM). On the whole, PR is well recognised for its benefits in improving “quality of life, enhancing functional exercise capacity, reducing symptoms of anxiety and depression and preventing hospital readmissions in those who attend and complete” (Oxley et al., 2019: 2), and is a fundamental practice (and regime) in the management of chronic breathlessness.

Comprehensive PR programmes are supervised by a multidisciplinary team (habitually respiratory nurses and physiotherapists) and run for a minimum of six weeks with two sessions per week for groups of about 14 people. The sessions are about two hours in duration, wherein the “first hour of the class consists of a supervised exercise programme”, while the “[…] second hour of the class covers a series of talks designed to help” people manage their conditions (ARAS, 2018: 2), covering topics from inhaler techniques to healthy diets. While I was in South Shields for fieldwork, I was invited to observe a few PR classes held at South Tyneside District Hospital. Here this programme has been renamed the LEEP, i.e., the Lung Exercise and Education Programme. Several hospitals and NHS Trusts in the UK have followed suit and rebranded their PR programmes, much likely due to the unhelpful and unintended ways in which the name ‘rehabilitation’ may impact experiences, especially in terms of the “unfortunate and unwarranted stigma held by drug or alcohol rehabilitative services” (Oxley et al., 2019: 4).

In South Tyneside, the LEEP is supervised by the Acute Respiratory Assessment Service (ARAS) team. This selected team of respiratory nurses has always been close to and maintained a strong relationship with Breathe Easy (BE) South Tyneside, some of whom have, in fact, even been involved and assisted the BE group with its administration or in organising different activities (such as fundraising). This may explain why the investiture of the group itself stems from a session of the LEEP. Not only is the programme a common venue for people living with respiratory conditions and the management regime of said conditions, but it also acts as a catalyst for community building and a sense of belonging. Facilitated by local nurses (and, by extension, the hospital itself) in this case, it shows how South Tyneside District Hospital acts as an anchor institution (Vize, 2018), a large organisation whose long-term sustainability is tied to the well-being of the populations whom it serves. Thus, through the hospital, the LEEP (or PR) becomes fundamental to the members of Breathe Easy in South Tyneside, not only in improving their health but also in building stronger rapport with the wider community. This becomes especially evident in how the LEEP continues to remain BE South Tyneside's foremost way of advertising themselves, their activities, and recruiting new members to the group. This is something to which I will return to discuss later in the dissertation, as it is fundamental to the overall contribution that I seek to advance.

(iii) Bishop Auckland

In contrast to the groups in Darlington and South Tyneside, Breathe Easy Durham Dales was officially launched in August 2011 (and turned eight years old in 2019). Although the group and its members had, in fact, been holding meetings since November 2010, they were not officially launched by the British Lung Foundation (BLF) until a year later in 2011. The official opening was performed by Councillor John Lethbridge, the Fifth Mayor of Bishop Auckland (between May 2011 and May 2012), whose great-uncle had, in fact, lived with respiratory disease due to inhaling coal dust during his working life as a miner. As Councillor Lethbridge disclosed in an interview with the Northern Echo:

> *[My great-uncle] could barely get out of his chair but I [Lethbridge] can still remember sitting and listening to his stories. He would be gasping for breath but he would still tell me about what they (the miners) had done and how they got through those difficult conditions. I feel for anyone with lung problems and extend a welcome to all the members [of Breathe Easy].*
>
> (Newspaper article from 2011; in author's possession)

Back in 2011, there were about 30 active Breathe Easy groups in the North East region (four of them in County Durham) and the installation of Breathe Easy Durham Dales was yet another step in the network's expansion across the UK. In fact, "B" told me that groups in this specific region were particularly important to the British Lung Foundation because of its "high smoking rate and mining and shipbuilding history". Early on in my fieldwork I interviewed one of the Durham Dales' former committee members, Daniel (in his 70s), who was able to provide me with more details regarding the group's history and his personal involvement. Daniel is, in fact, a carer for his wife, who lives with emphysema (COPD), but enrolled onto the committee due to a lack of interest from the other members.

> *Fredrik: ……for you, it all started with you going with your wife?*
>
> *Daniel: Oh yes, yes. We both went to a meeting. The people from the BLF regional office were there that day… and they came through and said: "Right, we'll have to form a committee." There had to be a Chairperson, a Secretary—and hands went up. There also had to be a Treasurer, and everybody went: "Meh"… You know [laughs]. I didn't put myself forward, because, naturally, I don't suffer from a respiratory disease. And I personally thought that only members who suffer from a disease should be on the committee. So…… in the end, they said that "Well… if we can't elect a Treasurer, we can't start the group". That's it. So, I said, "Look, I'll do it", because I had been Treasurer before in one or two… things. So, I knew about accountancy and that. So, I said, "I'll do it", and I stayed on for six months.*

In a similar manner to that of its fellow group in South Tyneside, the name *Breathe Easy Durham Dales* is meant to incorporate a larger geographical area. In truth, the group meets in Bishop Auckland, a central market town and civil parish in County Durham that is located about 12 miles (19 km) northwest of Darlington. However, the name *Durham Dales* refers to a large area of landscape in the west of County Durham, consisting primarily of the Durham portion of the North Pennines, in England (thisisdurham, 2020). There are a few market towns within this area, such as Barnard Castle, Consett, Middleton-in-Teesdale, Stanhope, Tow Law, and Wolsingham.

The geographical scale, however, is rather disputed, with the far eastern towns of Bishop Auckland and Crook sometimes being excluded. There are also a number of small villages around Durham Dales, albeit sparsely populated and spread out, in great contrast to much of the rest of County Durham (thisisdurham, 2020).

SETTING THE SCENES: "BREATHE EASY"

Breathe Easy groups are often characterised by their members' active engagement not only in local community events but also in nationwide campaigns for improved public awareness of respiratory disease, the negative effects of smoking, or environmental health in 'fighting for clean air'. Nevertheless, Breathe Easy groups' most fundamental activities are their monthly support group meetings. According to Schwartzman, a meeting is a "blank-slate phenomenon useful as a *tool* for such functions as making decisions, solving problems, and resolving conflicts, but having no impact on behavior in and of themselves" (1989: vii). Anthropologists have for years studied meetings and gatherings in all forms. Some argue that meetings may be "the most important and under-theorized phenomenon that ethnographers encounter" (Sandler & Thedvall, 2017: 1), while others have conceptualised them as 'rituals' (Olsen, 1970; Starker, 1978; Nyqvist, 2015). In the simplest of terms, meetings are "prescribed spaces for coming together" (Brown et al., 2017: 10), that is, social contexts in which two or more people come together to discuss one or more topics (Schwartzman, 1989: 149); they are often in a formal or business setting, but also occur in a large variety of other environments. These extend to therapeutic settings and communities such as self-help, mutual aid, and peer support groups.

While the forthcoming sections advance Breathe Easy group meetings as 'meetings'—*as tools for decision-making*—they do so in the context of biosociality and biosocial formations. Specifically, I am interested in how support groups can be understood as being (self)technologies through the framework of biosociality. Drawing inspiration from Brown and colleagues (2017: 10 ff.), I seek to advance a distinctively ethnographic focus, illustrating how

> […] the negotiation of relationships ‘within’ meetings is germane to the organization of ‘external’ contexts, including in relation to time, space, organizational structure, and society.

For Breathe Easy groups, these relationships refer not only to the groups’ engagement (and negotiation) with other institutional structures or agents but also to individual members’ interaction with one another both inside and outside of the prescribed support group settings. The notion of ‘external context’ extends far and wide, incorporating not only how each Breathe Easy group serves its own community but also relations with other groups in the wider Breathe Easy network, as well as healthcare professionals and the British Lung Foundation (BLF) itself.

It is important to note that Breathe Easy groups overall are partially autonomous and inherently diverse; thus, every group is very much organised so as to fit the needs of its members. Given that reduced pulmonary function often leads to limitations in mobility (making even the most trivial of tasks physically challenging), Breathe Easy groups usually hold their meetings in venues located in the midst of their respective communities. These venues can be understood as being *third places* (Oldenburg, 2001; Dolley & Bosman, 2019), that is, environments that are characterised as being neither *home* (first place) nor *work* (second place). Dolley and Bosman (2019) argue that third places have grown to be especially significant in postmodern times. More specifically, third places offer space for interaction that promotes social attachment and ‘togetherness’ (Dolley & Bosman, 2019: 1) between people in a globalised world characterised by constant mobility and rapid change. This is key for members of Breathe Easy groups, especially considering how finding and maintaining a sense of belonging (and community) is at the forefront of why the Breathe Easy groups came into existence in the first place. Yet, the overall process very much entails a negotiation of space in times of constant mobility—wherein universal accessibility is the ideal scenario for each individual member and the group as a whole.

The centrality of a venue's location, however, does not necessarily come first for a Breathe Easy group. It is quite the opposite, actually, as in my experience the question of accessibility seems to be more fundamental. That is to say, an accessible venue may very well be chosen before one that has a proper, central location. Chronic breathlessness is, after all, determined and treated as a disability and people suffering from it qualify for certain social benefits (Calverley, 2017; Faull et al., 2018; Johnson et al., 2018; Macnaughton et al., 2018). In light of this, Breathe Easy meetings are often organised in venues with close access to parking or central bus routes, as well as with no (or few) stairs or similar obstacles, since for people with chronic breathlessness, climbing stairs can feel like climbing 'a mountain' (Dreher et al., 2008; Dubé et al., 2017). In case the latter condition is difficult to adhere to, groups aim for venues in which their members at least have access to lifts or other aids. Venues that fit these criteria are usually churches or church halls, community centres or local health centres. In fact, BE Durham Dales holds its monthly meetings in a Methodist church and BE South Tyneside in a Catholic church. Both of these groups have met in these church halls since they were initially set up in the late 2000s and are able to rent them monthly at reasonable prices in accordance with their own budgets.

In my interview with "B", I was told that several Breathe Easy groups had at an early stage organised their meetings in local hospitals. These groups had, in fact, been set up directly by or in collaboration with clinical staff and, thus, managed to gain access to venues inside of hospitals, be they community rooms or other spare rooms. However, as I was later told, (evidently) people found it increasingly difficult to either get to the hospitals themselves or gain access to parking, especially once hospitals in the UK started to charge visitors for parking (Rye & Ison, 2005; Macmillan Cancer Support, 2013). Thus, groups eventually started to look for smaller and more accessible venues, often ending up in libraries or even in police stations that accommodate public community rooms (e.g. northyorkshire.police.uk, 2020).

Breathe Easy (BE) Darlington had previously held their meetings in one of the community rooms at Darlington Memorial Hospital. However, as one of their committee members once told me, this came to an end when many of the group's members started to express discontent about meeting in a clinical environment. While the venue was accessible, indeed, I was told that as members already spent much of their time on visiting either GP surgeries or respiratory specialists directly in the Memorial Hospital itself, Breathe Easy engagement was not something that they wanted to further associate with the institution. Unlike other groups with which I met, BE Darlington have changed their venue several times over the years, much due to difficulties in finding a proper one that suited all of their needs. Besides the Memorial Hospital, the group have previously organised meetings at King's Centre (now King's Church) in Darlington, Darlington Community Fire Station, as well as a local *Beefeater* restaurant.

The reasons behind these relocations have varied, including issues surrounding inaccessibility, noise pollution, and expensive rental agreements. Since 2011, however, BE Darlington have stuck with their current venue and now meet in a local Darlington pub, which has a function room available for larger crowds. The benefits of meeting in this pub are many. First of all, the group are able to reserve this room on a monthly basis at no cost. The manager sympathises with and supports BE Darlington's resolve and very much acts as one of the group's sponsors. Moreover, as the group meet around lunchtime, they habitually combine their meetings with having lunch; thus, the manager is still able to make a profit by providing BE Darlington with this room. Alongside this mutual arrangement, the pub has a rather central location, being reasonably close to Darlington Market Square and the train station. Furthermore, the pub has a large parking lot and is located next to many local bus routes.

The growing membership of BE Darlington, however, is one shortcoming of holding Breathe Easy meetings in this pub. Ever since the group was set up, members have come and gone (and passed away) and BE Darlington at times consisted of only about eight to 10 full-time members. This number later increased to 15, but for the past three years the group has experienced a massive upturn in new members and currently holds monthly meetings for about 20–25 members (even 30 at their annual Christmas lunch). While this is an incredible turnabout for the group itself, the situation has at times put BE Darlington in a rather awkward situation with the pub management. A crowd of more than 20 people would normally require a pre-order of meals, to which the group cannot adhere, due to the unpredictable nature of living with respiratory disease and chronic breathlessness. For instance, because people need to "consider so many things before [they] go out, sometimes the day just has to be cancelled" (British Lung Foundation, 2015a). This may also refer to times when members take a sudden turn for the worse and either needs to make an emergency trip to the hospital or remain at home to recuperate.

While the pub manager has agreed to let BE Darlington abstain from pre-ordering their monthly meals, this arrangement comes at the expense of rather slow service and long waiting times. This does not always sit well with some of the group's members and has led to quarrels with the pub manager. As these issues grew in scale, I started hearing rumours that the BE Darlington committee was thinking about seeking out a new venue. Nevertheless, as all of this happened around the time that my fieldwork was coming to an end, I was unable to follow up on any potential decisions being made.

(i) How the meetings proceed

On the whole, Breathe Easy meetings habitually last for approximately two hours. The exact length depends on the set agenda and whether the group in question has managed to arrange for a speaker to attend, which usually is the main event of each meeting. With regard to the latter, as I have observed it, this is not as easy as one might think. In talking to many committee members (both formally and informally), I have been told that there are many details that need to be considered. All three Breathe Easy groups with which I met regularly tended to hold between 10 and 11 meetings each year (not mentioning all of the other activities in which the groups engage). There was much planning involved and the committees try to schedule each event as far ahead as they possibly can. This bears not only the speakers in mind but also the groups' members. While speakers may need time in which to prepare and make room for the talk in their schedules, so do the members of Breathe Easy. Considering how rushing anywhere may "leave [them] gasping for breath, and the stress it causes can make [them] feel even more breathless", it is important for people with chronic breathlessness to plan every detail of what they do (British Lung Foundation, 2015a). Fundamentally, it is not uncommon for Breathe Easy members and invited speakers alike to cancel their appearance, be it far in advance or rather at the last minute.[36] When this happens, or when groups have been unable to find a speaker, they usually just hold a simple 'social'—either playing bingo or holding a quiz—or give time for another cup of tea or coffee.

From my observations of several Breathe Easy meetings, I can draw the conclusion that some speakers tend to be more popular than others. For example, respiratory nurses and physiotherapists habitually draw large crowds, as do organisations like Age UK[37] and St Cuthbert's Hospice.[38] Furthermore, local historians are much appreciated, especially Chris Lloyd from the Northern Echo,[39] who has given several talks at both BE Darlington and BE Durham Dales. As I wanted to gain a clearer understanding of what this whole planning process may entail for the groups, I interviewed Olivia (62, asthmatic), who has been her group's Secretary since they were first set up by the British Lung Foundation (BLF). Olivia told me that members' interests are not static, but rather very much change over time.

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[36] While Breathe Easy members usually cancel because of poor health, speakers can cancel for a number of reasons. It may be due to sudden illness, shortage of staff, conflicting schedules, or previous commitments, to name a few.

[37] *Age UK* is a registered charity in the United Kingdom, formed on 25 February 2009 and launched on 1 April 2009, combining the operations of the previously separate charities *Age Concern* and *Help the Aged* to form the UK's largest charity for elderly people.

[38] *St Cuthbert's Hospice* are based in Durham and provide a wide range of end-of-life, health, and well-being services for local people. They began to offer services to the community of Durham in September 1988 and have since developed their services to meet growing and changing needs and have become well respected for the impact that they have had on many lives.

[39] Chris Lloyd is a journalist, author, and chief features writer at the *Northern Echo*, a regional daily morning newspaper based in the town of Darlington in North East England. The paper serves the North East of England, covering national as well as regional news.

> *In the beginning, people didn't like the health-focused talks… I mean, so we've got the respiratory nurses from the hospital and whatever… Our members didn't like them—it didn't work, and the attendance always went down when we had one of those health-related talks. And, theoretically, [Breathe Easy groups] are supposed to run a health talk—and a "fun" talk, as you might say—alternatively…… So, we kept off those health talks, but just over the last three years, perhaps, it's changed around again. And they now like those talks, so we try and invite as many as possible… and we've got some good speakers who'll come regularly, actually, from the hospital…… And we have, in our usual way, a bit of a laugh—but we also learn a lot and our members also get a chance to ask a lot of questions. So those've been successful… Local history talks are also usually successful… But, yes, it's just who we can think of [inviting to give a talk].*

When Olivia states that groups are to supposedly run health talks and 'fun talks' (like when Chris Lloyd attends) alternatively, this is merely a suggestion set out by the BLF. The suggestion does, however, stem from established clinical mutual-aid and self-care practice (Kurtz, 1997; Drebing, 2016) and patient activation (Hibbard et al., 2005; Greene & Hibbard, 2012; Hibbard & Gilburt, 2014), through which chronically ill people are systematically trained to attain a better understanding of their bodies. These activation practices parallel what Foucault writes on docile bodies: a body "is docile that may be subjected, used, transformed and improved" (1991 [1975]: 136), which refers to human bodies becoming objects of imperious and pressing investments in the grip of social constraints, prohibitions or obligations being imposed upon them. Judging from some of the educational material put together by the BLF (2015b, 2017a, 2018), (allegedly) these transformations cannot be achieved by solely employing socialisation as a self-care technique. Needless to say, I stand alongside Boyce (2016) in stating that social aspects of self-help should never be neglected or underappreciated. Ultimately, humans are social beings, which, by extension, means that support groups are inherently social, and as Grodner and colleagues write: social support is an important mediator of "health status and survival in chronic illness" (1996: 139).

Ultimately, it is the Breathe Easy group committee's responsibility that all details surrounding planning a meeting come together. This means that the committee members often have to meet prior to the monthly group meetings. There is no set format with regard to how this is done; both BE Darlington and BE Durham Dales, for instance, schedule for the committee to meet on days that do not clash with other events, while BE South Tyneside's committee always meets one hour prior to each monthly meeting. A committee habitually consists of about five or six members, wherein the key roles are the Chairperson, the Secretary and the Treasurer (blf.org.uk, 2018). Moreover, each Breathe Easy group is also required to have a main person of contact, who can be either one of the three key post-holders or someone else. As I have described it, what we can see here is a process of holding meetings to plan for other meetings to take place. Nyqvist writes that meetings (2015: 344)

> […] can have decision-making purposes or aim at the exchange of ideas, experiences or knowledge; and a meeting can have as a goal to solve a problem or to come up with a collective proposal.

Ultimately, arranging all that may come with running a Breathe Easy group is all about *decision-making*. Nyqvist argues that decision-making in and of itself can be understood to be a ritual—a "ritualized, legitimizing and trust-building corporate performance" (2015: 342). However, this also means that, as Nyqvist writes, "while a meeting can have an explicit decision-making function […] much more than decisions are at stake at these gatherings" (2015: 344). That is to say,

> […] meetings are legitimizing and trust-building events not merely since individuals with decision-making capacity have gathered and decisions are in fact being made at the meetings, but also because the meeting form in and of itself is legitimizing and aim at building trust for the [organisation and its members]. (Nyqvist, 2015: 346)

This illustrates how Breathe Easy meetings are permeated with negotiations of relationships (Brown et al., 2017) germane not only to the individual groups and their members but also to socioeconomic conditions which may be out of the groups' control, that is, how the relationships within these spaces are linked to "[…] transformations beyond them, including of institutional structure, time, space, and society" (Brown et al., 2017: 15). Here the notion of 'transformation' may refer to a wider number of social aspects and facts (Dumit, 2006; Andrew et al., 2011; Jiang et al., 2017), whether it may be structural changes within the British Lung Foundation or within the NHS as a healthcare system on the whole—or even shifting conditions within a group's local community, or the deteriorating health of one of their members. In terms of shifting conditions, Olivia told me during our interview about the struggles that may come with organising a Breathe Easy meeting—whether arranging for a speaker to attend or simply setting a social event in motion.

> *We like to try and keep a year in advance—well, publish [our plans] in the beginning of the year, so people know what's going on. That can have its disadvantages, though, because people say "yes" and then… three months later, they realise, actually, they're going to be on holiday…… So we've had a few… when we've gone for the few months we've heard that we've [had to cancel]… We had one last month. Actually, it wasn't supposed to be, but people who came, they came at the last minute! [laughs] But, yes, it's about fine-tuning, really, about three or four months in advance… it's probably the best we can do.*

One of the yearly Breathe Easy gatherings is always an Annual General Meeting (AGM), habitually held at either the beginning or the end of the year. Like for any business, charity or corporation alike, for Breathe Easy groups the AGMs "not only have a decision-making function but it also marks the end of one financial year […] and the beginning of a new" (Nyqvist, 2015: 344). Moreover, as Nyqvist writes, it is at AGMs that all actors "meet face-to-face and it is here that decisions are made and positions performed" and that power structures are made visible (2015: 344). This would explain why AGMs have been studied as decision-making events with a particular focus on accountability (Hodges et al., 2004; Codery, 2005; Carrington & Johed, 2007; Catasús & Johed, 2007; Nyqvist, 2015; Nyqvist, 2016).

I managed to sit in on two AGMs: one for BE Darlington (May 2018) and one for BE South Tyneside (March 2018). Both of these meetings predominantly consisted of the Chairperson summarising the year and highlighting certain significant events or achievements that the group had either attended, accomplished or organised. Furthermore, the Chairperson mentioned other potential events for the upcoming year. The AGMs (or at least those two that I observed) tend to be longer than usual meetings; thus, external speakers were rarely invited to attend.

(ii) Physical activity and fieldtrips

While physical activity (in the widest sense) is a challenge for people with chronic breathlessness, “getting breathless is actually really important. It can be tough, but getting exercise is good for [them]” (British Lung Foundation, 2015a). In light of this, many Breathe Easy groups organise different community exercise groups for members to enjoy when they are not undergoing pulmonary rehabilitation. These are oftentimes named BE Active classes (blf.org.uk, 2018) and all Breathe Easy groups that I visited attend some form of community-based exercise activity. Ultimately, Breathe Easy is also concerned with helping people to remain active.

Besides exercise, Breathe Easy groups also regularly arrange fieldtrips, either to substitute one of their monthly meetings or to be enjoyed on other days. These fieldtrips may involve many different activities—including visits to the theatre or a museum, attending pub quizzes, or going to the seaside or the races. Some groups even schedule longer trips spanning two or three days; for instance, BE Durham Dales has made regular trips to both Liverpool and Blackpool over the past few years. In terms of my fieldwork, I went along on a few of these fieldtrips. For instance, I joined BE Darlington on a daytrip to Newby Hall[40] in North Yorkshire (where, unfortunately, we were struck by heavy rain), and on three other occasions I went along with them to watch a musical at the Darlington Hippodrome (formerly Darlington Civic Theatre). Moreover, I joined BE Durham Dales for an evening at Sunderland Greyhound Stadium and attended two Christmas lunches with BE South Tyneside (both of which were scheduled outside of their regular meeting times) and went along to watch a musical at the Westovians Theatre in South Shields.

What I found to be most intriguing about these trips was that they illustrated a whole-new dimension of the groups and the interaction between the members—aspects that I had not noticed during the monthly meetings. For example, when we went away for a longer daytrip, members did not interact much outside of their smaller ‘friend circles’ (cf. Driessen, 1998). That is to say, from my point of view,

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[40] Newby Hall is an 18th century country house situated beside the River Ure at Skelton-on-Ure, near Ripon in North Yorkshire, England.

while the groups in question went away together, members were not ‘there’ together. As I rarely stuck with one ‘friend circle’ at all times, I managed to observe certain dynamics of the groups that had previously gone unnoticed. It grew more evident, for instance, who got along with whom (and vice versa) and where internal conflicts were more likely to take place. This proved to be especially significant in those cases in which certain committee members did not work well together, which often resulted in tenacious and uncomfortable atmospheres for all members to observe. This clearly illustrates, I believe, the negotiation of relationships that takes place within the groups.

CHANGES FROM WITHIN: REGIONAL AND NATIONAL OPERATION

As I previously mentioned in passing, several of the British Lung Foundation’s (BLF) regional offices closed down in 2013. Prior to this, the BLF had organised its operation from seven offices across the length and breadth of the United Kingdom (Figure 4.5). The South and South East regions of England were served by the charity’s headquarters in London, while the branch covering the South Central and South West regions was based in Bristol. Meanwhile, the branch serving the Midlands operated in Leicester and the North West branch (Isle of Man included) was based in Liverpool, while the North East and Yorkshire combined operated from Wallsend in facilities that previously had belonged to the Breathe North Appeal.

In contrast to England, Wales has always been served by a single branch based in Cardiff, whereas Scotland and Northern Ireland have shared a managerial assembly operating from Glasgow. Since 2013, however, three of the offices in England have been shut down: Bristol, Leicester, and Wallsend. Thus, all operations previously active in these regions have now been relocated to the BLF’s headquarters in London, while the office in Liverpool has assumed a completely new role in managing the charity’s helpline services. The offices in Cardiff and Glasgow continue to be in operation but, as always, serve only the constituent countries of Wales, Scotland, and Northern Ireland.

Figure 4.5: A map showing where all the offices of the British Lung Foundation—past and present—are (or were) located.

(Imagery ©2018 Data SIO, NOAA, U.S. Navy, NGA, GEBCO, Landsat / Copernicus)

What this administrative (and, indeed, geographical) alteration has meant for the overall operation of the BLF is manifold. Nevertheless, one fundamental aspect is that the charity has now moved from operating in a federal manner (through their semi-sovereign constituent branches) to a more centralised, national focus. That is to say, as "B" informed me, the regional branches had always operated rather autonomously, especially in terms of community fundraising (which is a localised activity). However, following the closure of the regional offices in England (with the exception of London and Liverpool), the BLF now have divided their primary operations between their headquarters in the South (London) and the North (Liverpool): one focuses on the charity's online services (primarily the helpline), while the other focuses on more actual 'offline' (cf. Boellstorff, 2015) services such as advocacy, fundraising, patient support, and policy work.

Following the closure of the regional offices across England, the British Lung Foundation subsequently underwent another fundamental amendment to its administration a mere five years later in March 2018. This time, rather than targeting selected work space (Kingma, 2019), the amendment terminated the workforce itself. More specifically, it made all of the Regional Administrators, the Service Development Managers, and the Breathe Easy Development Officers employed by the charity redundant. This was equivalent to about two or three staff members based in each regional branch—including one of my key respondents who had been with the BLF for 22 years. The news of "B" being made redundant came as an unpleasant surprise to many of the support groups across the North East and Yorkshire which they had not only helped to instate but also personally supported throughout the years. Given that my fieldwork was in its final stage and soon to end, I was first informed about these redundancies on 16th March 2018 in an email from one of the groups in the North East. In the words of said group's Chairperson, the email read:

> *[…] I have just found out that "B", the Senior Development Manager for the BLF in the North East, has been made redundant along with all the other regional Development Managers. It seems as though they are undergoing some form of re-structuring. This is very sad news for me as I believe "B" was the one link regionally that we and the NHS had with the BLF. Most of you will know "B" well and will be most appreciative of the work they have done for respiratory patients […] I have taken the opportunity to thank them on behalf of the support group for all the help they have given the group right from inception, throughout, and to wish them […] everything of the best in their future endeavours. A great loss to all concerned.*

According to "B", the whole process was "[…] quite an emotional one". Moreover, as they further explained, not only did these redundancies result in fundamental structural changes for all Breathe Easy groups (in terms of them losing their sole, central point of contact with the BLF), members of staff whom the groups had known for many years were now losing their jobs. Needless to say, this had a very personal impact on the Breathe Easy groups and their members. In fact, as I told "B" during our interview, said 'personal impact' was something that I had been able to observe on more than one occasion. Namely, the whole process of losing, firstly, the regional BLF office and, secondly, the main point of contact with the charity itself had been a sudden, major blow for the members of Breathe Easy and something that had left all of them feeling upset and disoriented. This response, "B" said, was probably testament to

> *[…] the good relationship that we did have with the Breathe Easy groups. We'd worked hard at…… I don't know, that 'relationship' thing and trying to get the groups in communication with each other so that they would hopefully be able to support each other and share ideas.*

Only time will tell what is next to come for the British Lung Foundation and its network of Breathe Easy groups. Nevertheless, while "B" and their colleagues are gone ("[…] and will be missed"), Breathe Easy groups will continue to run and function as they always have, and will remain in communication with the office in Liverpool and its new workforce of Group Support Officers (blf.org.uk, 2018), as they have already done for the last four or five years. When I inquired about the underlying reason behind these two fundamental changes to the British Lung Foundation's managerial structure (incorporating downsizes in both activity and administration), I was provided with the same forthright answer by different people affiliated with the charity. On the whole, the reason had been a financial one. Whether a business or a charity ("B" told me), "your expenditure cannot exceed your income". Any registered charity in the UK is

> *…monitored by the Charity Commission and you can't spend more than you bring in. So, we're reliant upon… either donations or a good fundraising team to bring the money in that we need to carry out the activities that the Trustees determine that they want to do. And whether that's perhaps a change in focus on where the charity is heading…… I mean, the BLF has always been interested in research and I think it will always continue to be a research-focused organisation.*

In light of this, I think back to what Martin (at the British Lung Foundation) voiced with regard to consolidating fundraising activities in a country like the UK, where "charity is such a huge sector… [and] a lot of people are very supportive of charities, from very local ones to national ones, to UK-wide ones". That being said, charities in the UK are subjected not only to the Charity Commission but also to their donors. Martin informed me that the British Lung Foundation often has to navigate through situations in which donors, specifically, have instructed the charity regarding what they want the donations to be spent on. For instance, research grants are (more often than not) restricted by donors to funding research; sometimes they are even restricted to being delegated towards research into a specific disease area. As Martin stated:

> *When you look at [the British Lung Foundation] as a whole, we get some donations that are restricted to do specific things. Quite often that is to fund research—not always, but quite often. So, there are these funds that sit there that are restricted to go to research. Then we get donations from people who say, "You can do whatever you want with this", and we then have to decide internally how we cut that cake up. You know, some of it has to pay for our buildings, pay for all our overheads, pay for staff costs, and so on. Then we make decisions on how much of it is allocated to specific activities. Now, because research is such a popular cause for people who make restricted donations, whereas some of our other activities aren't, we will probably put more of that unrestricted funding into doing the things that we don't get restricted funding for—just because we have no other way of funding it.*

What I draw from this statement is that while the decision to close down the regional offices in England had been a financial one, on the whole the recent restructure of the British Lung Foundation's (BLF) regional and national operations also stems from the charity (especially their Board of Trustees) taking a look at how they can maximise their reach and impact. While the BLF had a number of Service Development Managers who worked to influence and make an impact on more local levels, the charity had to (as Martin put it) "[…] weigh up about how much impact these people made on a local level compared to the reach that [the BLF] has around developing or changing policy on a broader national level". Ultimately, the research funding that the BLF amass remains rather stagnant with each passing year, amounting to "around just over £1 million" (Martin). Thus, considering what both "B" and Martin disclosed to me, (supposedly) the BLF conceive that the recent operational restructure is something that may enable the charity to support more people in the future—through research and innovation, as well as through further development of their national services.

While these narratives do not provide us with the whole picture, they do shed light on why the British Lung Foundation at times struggles to fund certain activities or aspects of its operation. As this chapter has illustrated, overall, this has led to severe alterations with regard to how respiratory research in and of itself is financed; furthermore, it has had many direct consequences for how the Breathe Easy support group network is able to prosper and perform for its many members and service users around the United Kingdom. Although the network was formed and launched around one purpose in 1991, the vision has now changed. In a neoliberal fashion, responsibility for health and well-being is now placed on the individual—rather than on institutions, or on society as a whole. This can be observed in respiratory care in the clinic as well, which is now very much individualised (Jackson, 2009; Trnka, 2017; Kenner, 2018). Nevertheless, the relationship between the British Lung Foundation and the Breathe Easy groups is in many ways strained (and stretched to its limit), which I exemplify further in the forthcoming chapters. In the next chapter more specifically, I attend to individual members' experiences of attending a support group for people with breathlessness due to a respiratory condition.

CONCLUSION

In this chapter, I have described the historical conditions which led to the establishment of the Breathe Easy support group network. The chapter, I argue, acts as a clear example of biosociality in practice. It shows how people come together in distinct ways to respond to not only gaps in medical knowledge but also to serve social needs otherwise left unattended to by the healthcare system. The series of events to which this refers are directly tied with the history of the British Lung Foundation, which is self-proclaimed as being "the only UK charity looking after the nation's lungs". When the British Lung Foundation was set up in the mid-1980s, there was a systemic lack of funding and focus regarding respiratory research in the United Kingdom. That being said, the situation has very much remained stagnant, as respiratory research continues to be consistently underfunded by Her Majesty's Government 30 years later. As history shows, HM Government has never sought to place the same focus upon respiratory research that it has upon cancers or cardiovascular disease—despite the three medical conditions being on par with one another in terms of nationwide mortality rates. The premise that this draws out is that respiratory health, as such, is neglected on the overall UK public health agenda. This can be observed in the lack of research funding allocated to this disease area, as well as in the absence of specific patient-centred community care for people with respiratory conditions.

As mentioned earlier on in the chapter, this is the main reason as to why Breathe Easy came to be: to provide a venue enabling people with similar respiratory conditions to get together on a regular basis to support one another. The dissertation foregrounds the value of social support in chronic disease management, especially in light of how increasing neoliberal governance individualises respiratory care and relocates responsibilities for health and well-being from institutions to the private citizen. In terms of the premise at stake in this dissertation, how are communities formed around respiratory disease and chronic breathlessness? In this instance, the chapter illustrates this through the specific case of biomedical needs or—phrased alternatively—the biomedical need to elevate respiratory disease to the level of public health urgency that it so demands. Especially given that respiratory disease is one of the three biggest killer disease areas in the UK, wherein mortality rates have remained stagnant for the past decades.

~ CHAPTER FIVE ~

THE FORM AND FUNCTIONS OF BREATHE EASY GROUPS

PARTICIPANTS' VIEWS

"Breathe Easy [should] provide a network of friends, advisors, events and activities that support and empower people affected by lung disease."

BRITISH LUNG FOUNDATION

INTRODUCTION

"You alone can do it, but you cannot do it alone" is a very common expression in literature on self-help and mutual aid (Silverman, 2004: 86). The growing popularity of support groups around the world has led some to suggest that self-help interventions may soon rival all other forms of treatment (Jacobs & Goodman, 1989; Goodman & Jacobs, 1994; Barlow et al., 2000; Barlow et al., 2002; Harwood & L'Abate, 2009; Kramer et al., 2019). However, "mutual-help experience can take many forms" (Silverman, 2004: 85). This chapter takes a closer look at the form and functions of Breathe Easy groups, specifically how group members respond and adjust to the circumstances that active participation in Breathe Easy may involve. The illnesses themselves may play an active role in this and form a significant explanatory backdrop to the narratives described.

The chapter draws inspiration from meeting ethnography—predominantly Schwartzman (1989) and Brown *et al.* (2017), illustrating how social interaction within Breathe Easy group meetings can be understood as a negotiation of different relationships that provides individuals with a place for making sense of what it is that they are doing, which is germane to the underlying structure of the groups themselves.

Based on the interview materials and other ethnographic materials presented, I identify three central aspects of what it means to be a ‘Breathe Easy’ group. These are *sociality as support*; *support as sociality*; and *advocacy*. *Sociality as support* refers not only to the actual social interaction that goes on within the groups, but to how the groups may be understood as *safe spaces* (Boyce, 2016; Boyce et al., 2018) in and of themselves, where individuals can socialise free from judgement and stigma. The notion of a safe space (or ‘safe place’) derives from psychotherapy and counselling (Hartmann, 1995; Emerson, 1996; Steen, 2017; Crago & Gardner, 2019) where it functions as a therapeutic setting: “an emotional sanctuary where a person can internally go to recover stability when feeling stressed” (Van der Veer & Van Waning, 2004). By extension this means that support groups can be understood as mutual-aid therapeutic settings, an argument explored further in Chapter 7.

Support as sociality likewise entails more than mere mutual support and understanding between members. It refers to the process of acquiring specific skills in how to cope with one’s chronic breathlessness *through* the means of sociality. As I explain further on in this chapter, *sociality as support* and *support as sociality* can be understood as the same process—just reversed. For group members, the overall engagement in Breathe Easy revolves around achieving a sense of belonging through self-improvement, achieved by means of self-improvement through a sense of belonging. I argue that this stems from the helper therapy principle (Riessman, 1965), which suggests that when an individual provides assistance to another, the “helper” may benefit from the process as well.

Advocacy refers to the activities the groups engage in that may fall under the category of patient and service-user activism (Aggleton et al., 1997; Epstein, 1998, 2008) such as fundraising, awareness raising, and lobbying for health service development and so on. This chapter addresses how the aspects of sociality and support interact within Breathe Easy groups. The advocacy practices these groups may come to engage in will be the subject of Chapter 6.

The current chapter is organised as follows. *Sociality as support* is illustrated through interviews with Jon and Elinor; Adam and Elsa; and Quinn; *support as sociality* through interviews with Taylor, Jill, and Kim. All these narratives act as examples of how individual members approach their Breathe Easy membership differently, where sociality either is seen as the main supportive aspect or where support is seen as inherently separate yet derived from sociality. Following these sections, I provide three examples of members' differing values concerning the form and function of Breathe Easy groups, thus questioning their usefulness. The examples come from interviews with Lake; Anthony, Charlotte, and Marcus; and Sandra. These narratives exemplify Bell and colleagues' argument (2010) that there is no magical formula for an 'ideal' support group. While the previous chapter illustrated biosociality in practice, this chapter shows how biosociality is understood and enacted in daily lives by those taking part. What is more, the chapter also illustrates more clearly how support groups can be viewed as *technologies of the self* (Foucault, 1988) whereby self-management becomes practice of bodily autonomy (Willems, 2000). That is, in terms of *techne* (Behrent, 2013) the chapter shows how the support group turns into a resource (*know-how*) and enables one to perform a certain number of operations on their own bodies and semis.

SOCIALITY AS SUPPORT

> *"We basically get together and have a good laugh!"*
>
> — Kim, severe asthmatic (62)

Although therapeutic in nature and purpose, support groups are inherently social (Maton, 1988; Wann, 1991; Hitch et al., 1994; Davison et al., 2000; Potts, 2005; Van Uden-Kraan et al., 2009; Bell et al., 2010; Southall et al., 2019). Nyqvist writes that meeting up is an "intrinsically and fundamental human activity" (2015: 344) that is part of the everyday lives of people all over the world. In doing so meetings not only provide organisations with a form for making themselves visible, but that they also offer the individuals involved "a place for making sense of what it is that they are doing and saying […] and what their relationships are to each other in this context"

(Schwartzman, 1989: 9). In doing so support group meetings become sites of political positioning and negotiation" (Brown et al., 2017: 16), venues of biosocial interaction for "the alignment and negotiation of distinct perspectives" (Brown et al., 2017: 15). I will illustrate this argument by attending to three narratives, giving my interlocutors' views on the social interaction that plays out within their respective groups.

Though inherently social, Breathe Easy groups (as autonomous entities) demonstrate different forms and function with regards to their monthly meetings. While my experiences have been with groups located in the north of England, I have been told of other patterns amongst groups in the south. In London, for instance, there are Breathe Easy groups that very much value interaction outside their prescribed group meetings—usually directly after, where they occasionally go to a nearby pub. I did not observe this type of interaction within the Breathe Easy groups I primarily focused on, but group members socialised outside of the prescribed group meetings in other ways. However, in the meetings I observed how members planned their time merely around these prearranged situations, rather like with a doctor's appointment in which one is 'in' and then 'out' (Blanco White & Pike, 1964; Brahimi & Worthington, 1991). People came for the meetings and then left when the meetings were over (Schwartzman, 1989: 124, 151). Some venues cleared more rapidly than others, however. *Sociality-as-support* can itself take many forms within different Breathe Easy groups and members adapt accordingly. One group that largely seemed to function around their invited speaker session was BE Durham Dales, an aspect that very much adheres to the 'in-and-out' approach to meetings. This group's members seemed not to 'linger' as much as the other groups after the meetings had come to an end. This could have been due to several reasons; members often had medical appointments scheduled, while others attend to family matters.

I observed a similar social pattern on the few occasions I met with BE Sheffield. Unlike the other three groups I visited, BE Sheffield holds their meetings in conjunction with a 'Singing for Lung Health' session (British Lung Foundation, 2015d; Lewis et al., 2016; British Lung Foundation, 2017a; Lewis et al., 2017) that takes place an hour before the official Breathe Easy meeting. Although the group's committee has repeatedly stated that they would prefer if only Breathe Easy members attend the singing session (and thus also attend the subsequent meeting), it seems that people do not always adhere to this request. The preceding singing session habitually drew a large crowd (20-25 people) but as soon as it ended about half of the group left, leaving a much smaller crowd for the Breathe Easy meetings. While it was difficult to speak to everyone, the members I managed to talk to during my few visits to BE Sheffield informed me that although several members often have other prearranged engagements, many of them just come for the singing and I was told that some members find the singing sessions more beneficial than the regular meetings—where people 'just talk' (cf. Davison et al., 2000). This comment is interesting, as it highlights a desire for something tangible in terms of support. It may be that the singing sessions offer a sense of accomplishment, while the Breathe Easy meetings themselves, for these members, do not.

There is another perspective to be considered, however. Like there is a stigma to living with respiratory disease (O'Neill, 2002; Gysels & Higginson, 2008; Harrison et al., 2015), similarly there is a stigma to therapy and help-seeking (Sibicky & Dovidio, 1986; Owen et al., 2012; Shechtman et al., 2018). As Shechtman and colleagues write, "Stigma associated with seeking help has been found to be a key help-seeking barrier [...] Overall, participants reported more negative perceptions of group therapy than individual therapy" (2018: 104). Thus, people who have not undergone therapy before may feel embarrassed to participate. Singing, on the other hand, requires a person to follow instruction. They have the words, notes and parts in front of them, and they do as the conductor directs. They can, therefore, in many ways 'switch off' from their experience as an ill person while just enjoying the experience of singing and listening to the music around them (Dillon, 2001; Thomasson, 2004; Reagon et al., 2016). A support group would in itself require people to give and share more of themselves as a person (Davison et al., 2000), and this experience may feel more emotionally burdensome to some. Intrinsically, in and of itself, the experience of stigma may lead to feelings of a shared identity (Crocker & Major, 1989; Jacoby et al., 2005; Crabtree et al., 2010), which foregrounds the group identification found amongst patient communities and movements. As Crabtree and colleagues write, “Research into the relationship between stigmatization and well-being suggests that identification with a stigmatized group can buffer individuals from the adverse effects of stigma” (2010: 553). While stigma (as a theme) did not take centre place in my research participants’ personal narratives of being in a support group, I still maintain that this aspect was still made apparent (although implicit and unspoken)—especially considering how Breathe Easy groups function as safe spaces (Boyce, 2016) where people could, i.e., burst out in a violent coughing fit without risking judgement from their surroundings (Bush et al., 2001). However, stigma can also complicate social identity. In this domain, people with respiratory disease and chronic breathlessness face a number of threats in how they construe their identity (Gysels et al., 2007; Gysels & Higginson, 2008; Gysels & Higginson, 2010); “both in navigating stigma and maintaining access to needed support” (Read et al., 2015: 1162). After all, people are typically stigmatised due to attributes that set them apart from others and which mark them out as in some sense inferior—having what Goffman (1990 [1963]) referred to as a “spoiled identity” (see also: Crabtree et al., 2010). Being chronically ill people living with an invisible disease (one often seen as self-inflicted, as well) this very much describes the members of Breathe Easy.

Although the other groups apparently follow this ‘in-and-out’ pattern, members of both BE Darlington and BE South Tyneside were more inclined to ‘linger’. Some even took time to engage in conversations with people they had not managed to speak to during the meeting. This may relate to the size of each group, which in turn reflects each group’s underlying social structure and dynamics. BE Durham Dales is the smallest of all Breathe Easy groups I met with (10-15 members each month). In contrast BE Darlington, BE Sheffield, and BE South Tyneside all had about 20-25 each month. Ultimately, members approach their groups differently, all with their individual reasons. To illustrate this, I will now move on to provide three narratives detailing how sociality may act as support in Breathe Easy groups.

(i) Jon and Elinor

The first narrative comes from two participants who swiftly became key interlocutors of mine: Jon (65) and Elinor (78). When I asked them whether they would be willing to be interviewed, they kindly invited me to their home. Jon and Elinor are married and have been together for over 40 years. Jon has a lung condition, while Elinor (although living with health issues of her own) is his primary caregiver. However, as I have come to appreciate from engaging and talking with people living with respiratory disease, the spheres of care giver and receiver are very much entangled (Cossette & Lévesque, 1993; Brewin, 2004; Seamark et al., 2004; Butow et al., 2007; Sampson et al., 2015). For instance, as Brewin writes, “carers’ lives [are] severely restricted, all carrying a heavy emotional burden of frustration, depression and isolation” (2004: 906). That is, respiratory disease affects not only the lives of the ‘breathers’ (Choy, 2011) but also those of their families and friends (e.g., Cossette & Lévesque, 1993; Schulz & Williamson, 1994; Bergs, 2002; Goodridge et al., 2008; Lindqvist et al., 2013).

Jon and Elinor live in a suburban village in the metropolitan county of Tyne and Wear, not far from where their group meets. As Jon cannot exert himself too much, Elinor drives him to and from the meetings (and elsewhere). While Elinor herself is a key member of the group and very much enjoys the interaction, she does not always attend as she takes care of household matters that Jon is unable to see to. On the day of our interview, seeing the heavy rain and worrying that I might get lost, Elinor kindly offered to pick me up from the bus stop. As this was the first time Elinor and I met in person (having previously only spoken over the phone), we almost missed one another. Jon greeted us at the door, and I was shown into their comfy sitting room. At first Elinor seemed hesitant about whether she should stay, but Jon encouraged her to do so. I joined him, saying that I would be grateful to hear her experiences of caring for someone living with chronic breathlessness. I started by asking Jon about his condition:

> *As I child, I went to the hospital about every year or so. I had always gone, since I was very young. I was never told how my condition works. My parents might have [been], but it was never explained to me; or at least, nothing more*

> *than that the bottom part of one of my lungs had been damaged. It was not until about 2008, when I saw a new consultant – who was just brilliant – and she told me about how my condition actually works. When she had explained it to me, I said to her, ‘You have told me more about my illness [in] these past fifteen minutes, than anybody else in my entire life.’* (also in Nyman, 2018)

Such experiences are familiar to people living with respiratory disease (Gysels et al., 2007; Gysels & Higginson, 2008; Gysels & Higginson, 2010; Gysels & Higginson, 2011; Gysels et al., 2015). Respiratory disease has an insidious onset, “often attributed by those who experience it to ageing, lack of exercise, or smoking” (Macnaughton & Carel, 2016: 298). Alongside misdiagnosis, delayed diagnosis is far from uncommon (Jagana et al., 2015; Mujeeb Rahman & Samaria, 2016; Molina-Molina et al., 2018; Hoyer et al., 2019). Jon has bronchiectasis, which developed after he contracted pneumonia as a child, which left scarring on his lungs. Unlike other respiratory conditions, bronchiectasis is not caused by smoking. The airways are scarred and inflamed with thick mucus, becoming widened and thus unable to clear themselves properly. Mucus continues to build up and so the airways can become infected by bacteria (British Lung Foundation, 2016: 34).

Jon and Elinor have both been involved with their local Breathe Easy group since it was first initiated back in the late 2000s. Their explicit commitment has fluctuated over the years, in line with their declining health. Although poor health has restricted them in some senses, they continue to live their lives to the full. They both had a lot to share with me in the course of a four-hour interview. This included several breaks, and I had advised them both that they could stop the interview whenever they wished. Initially I had been non-specific about how long I expected the interview to take, but Jon and Elinor were both very good at keeping the conversation flowing. They did most of the talking and I did not want to interrupt, out of politeness, but also due to my own research interests.

About halfway through, Jon excused himself to use the facilities and I continued my conversation with Elinor. In retrospect, listening to our interview I find it thought-provoking to note Jon coughing in the background and his habitual laboured breathing, part of everyday life with respiratory disease and chronic breathlessness.

Breathing for individuals with respiratory disease can require extra energy and thus be very physically challenging (Nyman, 2018). While we were waiting for Jon to return, I asked about Elinor's experiences of attending a Breathe Easy group.

> *<u>Fredrik</u>: Do you feel you've gained anything from attending Breathe Easy?*
>
> *<u>Elinor</u>: ……Apart from the social side of it, I mean, it's a nice group of people. It's nice to chat to them, and things like that… And as I said, once it was set up, someone else was Treasurer from the first meeting, but as soon as they could they said, "I don't want to be Treasurer!" Then Jon said "Elinor, you can be Treasurer!" So… I was sort of involved that way, helping them out, but… It's interesting. And it's… good to see them, and sort of see how they're doing, how they're coping. We've lost some nice people, which is… unfortunate. But that's… that's the name of the game, basically. That's, that's… Because of, obviously, [Breathe Easy] is for people that've got those problems. So, you can't do anything else. But… we've lost some nice members of the group, who were good… But… as far as I'm concerned, it takes my mind off me, basically! [laughs] But as Jon said, when you get involved with something else, like now there's other people… and sort of, see what they're coping with—the problems they've got and things like that—it puts things into proportion, really. It's been…*

While I attentively listened to Elinor, I could clearly hear Jon coughing in the adjacent bathroom. His cough is very distinctive even in the recording.

> *<u>Elinor</u>: …I can think of three ladies that we've had [in the group] that… that had really, really bad problems, to do with their [conditions]… They were in quite a bad way already when they came, when they started coming to the group… And…… They were nice, I'm glad I got to know them, you know… But… They're a big miss, as well. But I think it's just nice to be involved with Breathe Easy, just to… have something to do with it. They're a good crowd…… It's just, we're missing out now, though, as Jon said, we've not been able to go on the trips, and things like that, because… That was good. Once we went up to Alnwick Castle,[41] and… the Alnwick Garden,[42] and… things like that. We went to Beamish Museum[43] a couple of years ago. And it was just nice to have that, sort of, outside social involvement with [Breathe Easy]… But… As Jon said,*

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[41] Alnwick Castle is a castle and country house in Alnwick in the English county of Northumberland. It is the seat of the 12th Duke of Northumberland, built following the Norman Conquest and renovated and remodelled a number of times.

[42] The Alnwick Garden is a complex of formal gardens adjacent to Alnwick Castle in the town of Alnwick, Northumberland, England.

[43] Beamish Museum is an open-air museum located at Beamish, near the town of Stanley, in County Durham, England. The museum's guiding principle is to preserve an example of everyday life in urban and rural North East England at the climax of industrialisation in the early twentieth century.

> *we've been so restricted [with his condition], so we've missed out on that part of it. But… It's good, it's a nice group to be involved with.*

At this point, Jon returned from the bathroom. Although the bathroom was just next door, this physical activity left Jon very breathless, and it took him quite some time to recover. He was eager to get back on his home-oxygen concentrator; a device (Figure 5.1) that concentrates the oxygen from a gas supply (typically ambient air) by selectively removing nitrogen to supply an oxygen-enriched product gas stream.

> *<u>Elinor</u>: Is it still on? [referring to the concentrator]*
>
> *<u>Jon</u>: Yes…*
>
> *<u>Fredrik</u>: […] we can take a break, if you want?*
>
> *<u>Jon</u>: No, I'm fine! Honestly, I'm fine. [takes several deep breathes] …It's all this fussing about.*
>
> *<u>Fredrik</u>: …well, I just asked Elinor about if she feels she's gained anything from attending the group.*
>
> *<u>Jon</u>: Alright! Okay…*
>
> *<u>Fredrik</u>: …and I mean, socially, and so on… Because I imagine that there's a lot of… that the group is about mutual support, as well…*
>
> *<u>Jon</u>: …yes. I think it's good to just know other people, isn't it, really? [turns to Elinor]*
>
> *<u>Elinor</u>: Yes.*
>
> *<u>Jon</u>: And it's useful to have…… the strange thing is, that… I wouldn't necessarily know what other people's conditions are… Because we don't…*
>
> *<u>Elinor</u>: Well, they don't, sort of, openly discuss [them]…*
>
> *<u>Jon</u>: …No! I mean, they just…*
>
> *<u>Elinor</u>: …it's just, sort of, they've accepted that… something… their problems…*

Figure 5.1: A home-oxygen concentrator. It is possible to attach oxygen tubes of different lengths, which can stretch all over the floor.

(Photograph taken by the author)

> *Jon: …I think it's more…… I think it's* social*, first of all… I mean, when I do the talks at the hospital, after they've had their exercise [pulmonary rehabilitation]… I sort of say, that it's a "Breathe Easy* support *group"… And like the name 'pulmonary rehab,' I don't like the expression '*support group.*' Because I think… I know that's what they've always been called—but it's kind of… personally speaking… it just seems… I don't know, a misnomer, maybe, there's…… I mean, some people, over the years, who've been going have seen it—maybe—as a support group… I know one lady, who did that—she passed away a few years back… The very first time she came—she was on oxygen when she came… when we opened up, and she arrived—she was the first person to come…… And she came in… I think I was in the kitchen when she arrived… And when I came through, she was sitting—she was crying! And I went over there, and said "Are you okay?" And she said, "a bit breathless"—"Oh, I'll get you a drink of water" I said… […] And in the end, she said, "I'm so pleased I was able to make it!" Because she lived not far from here, actually—and she said, "I've walked around…" from where she lived, and she said "…my husband said that I couldn't make it, but now I have, and I'm pleased!" She'd been down with this condition—I can't remember the name of it—but it was a very serious condition. And… She said, "When I was diagnosed… we were all in complete shock." Her family, that is. And she said, "What's happened is that I'm supporting them, because they're so shocked… They're all supporting me, but I'm the one that's being strong." She said that "I just felt that I needed… I heard about the group, and I wanted to come." So…… She was great—and she was Chairperson for a while, wasn't she?*

> *<u>Elinor</u>: Yes, she was… Very involved…*
>
> *<u>Jon</u>: She was great, wasn't she? She had a great sense of humour. A lovely person… And that's all stuck in my head, this…… She was the one who's being strong, but it shouldn't have been like that. Her family should have been there for her… But it was completely flipped on its head, and… And I think, when she said she wanted to come, and her husband just said, "You're not well enough to do that type of thing," she was determined to do it. And she came, as I said, for a good time—she was on the Committee, and everything—and then she just deteriorated. Because… I thought it was going to happen, her condition, and…… So, that was all awful! But I think for some people it is seen as a support group, but I wouldn't… I would guess… the majority see it more as a social group.*

I am intrigued by Jon's description of the 'support group' label as a misnomer. For him, the Breathe Easy groups are more like social groups and other members seem to share his view. It is important to note that Jon does not criticise or misrepresent either the social or supportive aspects that come with his group. What he finds problematic is, perhaps, the habitual conceptualisation of what a support group may or may not entail. I wonder—does this friction stem from the allegory and latent inadequacy of the term self-help? As Humphreys and Rappaport suggest, the term self-help (habitually used to describe mutual-aid support groups) is inaccurate in some respects, "because one important feature of groups is that people help each other. "Self-help" does not capture the mutually supportive atmosphere of groups, suggesting instead an ethos of rugged individualism" (1994: 218). The term 'mutual aid' is said to be more apposite as it captures the egalitarian and communal nature of the groups more accurately, Breathe Easy groups included (Katz, 1981; Borman, 1984; Humphreys & Rappaport, 1994; Pistrang et al., 2008; Pretto, 2012; Watts & Higgins, 2016).

On another note, not all individual members may benefit equally from support groups (Gage & Kinney, 1996: 31) and I deem it significant to note, as Davison and colleagues write (2000), *who talks* during a meeting? What illness experiences prompt people to seek each other's company? The forms, functions and values and hence 'inequality' in support groups may be explained (partially, at least) by each disease condition and its treatment trajectory. In looking at attendance patterns Bell and colleagues reveal that in breast cancer support groups benefited some members more than others, particularly members “who were in the ‘survivorship’ phase, or those for whom cancer had become a long-term, chronic disease” (Bell et al., 2010: 446).[44]

What I propose is that the misnomer Jon mentions may derive from a limited view and understanding of support groups as nothing but intransigent therapeutic settings. This is what Jon seems to find problematic as it does not characterise what Breathe Easy stands for. In terms of sociality vis-à-vis support in Breathe Easy groups, something that also became clear in my conversation with Jon and Elinor is that these aspects interlink with one another. As Jon and Elinor both state, mutual social support is central to managing chronic illness. Jon thinks it is important to get to know people who share one’s illness experience, and both he and Elinor spoke of the benevolence they have been shown from the rest of the members. Support may come in all forms, as Elinor says. In her experience people rarely openly discuss their declining health, as if they all have come to accept their current situation (and what is to come). All the same, it is interesting to note that the interaction that comes with the group helps Elinor in her position as Jon’s carer, with all the attendant stress and strain that is likely to involve. Especially in taking her mind off herself and putting “things in proportion” in relation to both Jon’s health and her own.

(ii) Adam and Elsa

The second example of how sociality may act as support comes from another couple: Adam (67) and Elsa (72). Again, Adam has a lung condition while Elsa acts as his primary carer. As with Jon and Elinor, Elsa has non-respiratory health issues of her own and in principle Adam acts as her carer too. Elsa opened my eyes to the lack of recognition and support for full-time carers and this was one of the reasons for her eagerness to participate in the interview.

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[44] This argument stems from research by Mok and Martinson (2000) and Krupnick *et al.* (1993).

> *Elsa: As a carer I find it…… I don't mind doing it the slightest. But the government doesn't appreciate you. Because… as I'm on a State Pension, I can't have any money for looking after Adam. You can only qualify for a Carer's Allowance if you're not on a pension, and not working fulltime… Our daughter has a disabled husband as well—he's in a wheelchair—but she works fulltime. So, her family cannot have any Carer's Allowance either.*
>
> *Adam: Yeah, they're in the same position. She's in fulltime work, acting as a carer…… The government doesn't recognise the fact that…… Overall, there's no recognition for carers.*
>
> *Elsa: They don't recognise her as a carer because she's a fulltime worker… But she has to do it when she comes home at night.*

Although there is a social benefit called Carer's Allowance for people who spend at least thirty-five hours a week providing regular care to someone who has a disability, the criteria under which it can be received are restrictive. First of all, the person being cared for must already be receiving a relevant benefit due to their disability, which in many cases has to be paid at a certain rate (turn2us.org.uk, 2019). While carers in paid work still qualify for Carer's Allowance, they cannot earn more than £123 in take-home pay each week. As Elsa said, this excludes anyone in fulltime work. Moreover, one does not qualify for Carer's Allowance if one is in fulltime education or if someone else is already claiming Carer's Allowance for looking after the same person (turn2us.org.uk, 2019). Furthermore, the restrictions which come with being a carer extends beyond mere financial aid and may require many personal sacrifices, as Adam and Elsa told me:

> *Elsa: We never expected that this would happen to us. We used to have a lovely big house, with a big garden. But Adam's condition has changed our lives completely.*
>
> *Adam: It has.*
>
> *Elsa: …but now… As I said, we've now moved into a one-bedroom flat. In a big, detached house. I miss my garden in the summer. I don't miss doing the gardening—I've never liked doing it. But I love gardens; to look out at them, and sit in them… So, it [respiratory disease] changes your life, really, in so many ways.*
>
> *Adam: But you don't realise it, at all.*

> *Elsa: No, you don't realise it. But it does. I mean, now I've had to become Adam's carer, which I never ever thought would happen…… But you've got to get on. It's what your life has been dealt. It could be worse.*

Adam has idiopathic pulmonary fibrosis (IPF), which is one of many types of interstitial lung disease, meaning that it "affects the interstitium, a lace-like network of tissue that supports the air sacs" in the lungs (British Lung Foundation, 2016: 43). Scar tissue builds up in the lungs, making them thick and hard. This is called 'fibrosis' and it becomes more difficult for the lungs to take up oxygen from the air one breathes (British Lung Foundation, 2016: 43). The term 'idiopathic' denotes that the cause of the condition is unknown. While IPF is the most widespread interstitial lung disease in the UK, there are cases of pulmonary fibrosis where the cause is known. For instance, it is common amongst people in occupations commonly exposed to dust from wood, metal, textile or stone, or from cattle or other farming-related exposures (British Lung Foundation, 2016: 43). In talking to several BE group members living with IPF, I often heard stories about frustration with misdiagnosis. While not uncommon in respiratory disease, it seems to be especially prevalent in cases of IPF (British Lung Foundation, 2015c; Mujeeb Rahman & Samaria, 2016; Molina-Molina et al., 2018; Hoyer et al., 2019).

Idiopathic pulmonary fibrosis (IPF) is not treated in the same way as asthma or chronic obstructive pulmonary disease (COPD). To begin with, inhalers are not habitually used and there are only two drugs licensed for use in IPF: *pirfenidone* and *nintedanib.*[45] Both these drugs are taken in the form of capsules. They are considered anti-fibrotic drugs that help to reduce new lung tissue scarring. However, while pirfenidone and nintedanib represent a significant improvement in the treatment of IPF (especially in delaying its progression), they do not represent a cure and both drugs have "significant and sometimes intolerable side effects" (Khalil et al., 2018). These side effects are so severe that some patients are unable to remain on them. Other medications that have shown improvements in treating

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[45] In the UK, licences are granted by the Medicines and Healthcare products Regulatory Agency (MHRA) and the European Medicines Agency (EMA). Due to its recognised status of expertise in IPF, the Royal Victoria Infirmary (RVI) in Newcastle upon Tyne is currently the only hospital in the North East of England that has permission to prescribe *pirfenidone* and *nintedanib*.

symptoms of IPF include anti-acid therapy (for gastroesophageal reflux) and opioids, such as morphine (in treating shortness of breath) (The Mayo Clinic, 2019). Other ways of managing IPF include supplemental oxygen, pulmonary rehabilitation, and even lung transplants.

Like Jon and Elinor, Adam and Elsa held fundamental roles in their Breathe Easy group. In fact, they helped set it up and are now considered *founder members*.

> *Adam: […] I was what they call a 'founder member' and Chairperson…*
>
> *Elsa: …and Albert was… Secretary, and the lady who left the legacy—she was the Entertainment [officer]… or…*
>
> *Adam: …yes… the Event Organiser.*
>
> *Elsa: …the Event Organiser, yes. And I was actually Treasurer! When we first started off…*
>
> *Adam: Yes.*
>
> *Elsa: …but then, unfortunately, Adam had all his heart problems… He was in and out of hospital, and he felt that he really couldn't give it all the time it needed…*
>
> *Adam: …yes…*
>
> *Elsa: …and then the lady took over as Chairperson, but it hasn't worked out…*
>
> *Adam: …it didn't work out, and she left.*
>
> *Elsa: She's left. And now… Officially… you're just a 'founder member,' but you do take on the Chairperson's [role]…*
>
> *Adam: …Yes. I do the work of a Chairperson, and I'm…… They've all been very good in nominating us as 'founder members,' and I'll be continuing the role as 'founder member'—irrespectively of whether I continue as… locum Chairperson, or whatever you want to call me… And we'll always be here; Albert has said he'll always carry on as Secretary, for as long as he's able to… And with help from other… members of the group, when necessary, we continue to function. And we continue to provide the support that we feel the group needs…… And, as you've seen, over the last few weeks, people will attend—they seem to enjoy themselves, and it seems we give them what they need… Otherwise they wouldn't keep coming back.*
>
> *Elsa: I think everyone also enjoys having professional speakers here…*

> *<u>Adam</u>: …yes, they do…*
>
> *<u>Elsa</u>: …but also, they enjoy more of a social—like today. Sometimes people just want to sit and chat to one another…… They don't want to hear medical details.*

Adam and Elsa reflect on how, while their fellow Breathe Easy members both enjoy and benefit from listening to invited speakers, at times people just want to socialise and talk to others who can relate to their personal illness experience. This recalls what Kirsten Bell and colleagues (2010) say about perceived benefits of participation in cancer support groups:

> I get out of the group other people's experience which I can bring home, which I can relate to. ... [I]t sounds probably cliché but there is an element of not feeling completely alone. Because it's a pretty lonely experience, you know, being at home. ... And neighbours don't want to hear about it, they really don't. Some of them, it's "How are you doing? Oh great. You're going to be just fine!"... Some of them [group members] really are willing to listen, probably because they've been there; they probably know what you're talking about. (Bell et al., 2010: 444-445)

I take this to mean that, while support groups are indeed therapeutic in how these settings foster patient activation (Hibbard et al., 2004; Greene & Hibbard, 2012; Hibbard & Gilburt, 2014) through members' mutual exchange of self-management strategies (Taylor & Bury, 2007; Guo & Harris, 2016), therapeutic measures are also found in the sociality: that is to say, social bonds based on mutual understanding that emerge between members. Again, turning to Bell and colleagues, "[…] in the support group it [the illness experience] will be understood. This is very important, the issue of understanding" (2010: 445). By means of biosolidarity (Bradley, 2019, 2021), support groups become public spheres "where life-world concerns can be discussed in the language of the life-world" itself (Kelleher, 2013: 115). Support groups are thus complementary to medicine and remain significant in modern healthcare practice because, as self-technologies, they retain the possibility for seeing things differently while enabling that medical practice be challenged and interrogated.

(iii) Quinn

Unlike the previous people I have referred to in this section, Quinn (68) had only attended a few meetings by the time I met her. Nonetheless, she was quick to volunteer to be interviewed about her experiences attending a Breathe Easy group. We scheduled the interview an hour prior to one of the group's monthly meetings—a practice I employed more than once as convenient for respondents. Quinn has chronic obstructive pulmonary disease (COPD), which she was diagnosed with in 1994. COPD is an umbrella term "used to describe a number of conditions including emphysema and chronic bronchitis" (British Lung Foundation, 2016: 37). Emphysema affects the air sacs (alveoli) in the lungs, whereas chronic bronchitis affects the airways (bronchi). There is no cure for COPD and thus current treatment practices emphasise on relieving symptoms and preventing further complications, to generally slow disease progression.

While Quinn currently lives in the North East with her husband, she was born and grew up in the Midlands. They had moved to their current house about a year before we met, having lived abroad for about six years. Quinn told me that she and her husband had made the decision to move away from the UK not long after they retired, in search of a warmer climate. However, the warm climate actually had a negative effect on her health, and they moved back to the UK. This is not out of the ordinary, according to the BLF website (blf.org.uk, 2018):

> Summer heatwaves and hot weather can affect anyone. But if you have a long-term lung condition like asthma, bronchiectasis or COPD, you're more at risk of the heat affecting you. And hot weather can cause your symptoms to flare up too. This could be because you're dehydrated and too hot, making you feel worse. Or it could be because strong sunshine has caused the level of ozone in the air to rise. High levels of ozone and other air pollutants can cause breathing problems and trigger symptoms if you have a lung condition like asthma, bronchiectasis or COPD. Humid, hot weather can also make your breathing problems worse.

Ingold writes that a "living, breathing body is at once a body-on-the-ground and a body-in-the-air" (2010: 122). This is yet another unavoidable aspect of the everyday life of those people managing a chronic respiratory disease. Air quality refers to both outdoor and indoor environments (Spengler & Sexton, 1983; Smith, 1993; Lin et al., 2007; Kurmi et al., 2010; Smith et al., 2011). In the words of D'Amato and colleagues, "This is part of a wider problem, relating to air quality in indoor environment, such as homes or offices, where people spend more than 90% of their time" (2018: 1). This is nothing new, Ingold would say, as the experience of climate and weather "lies at the root of our moods and motivations; indeed it is the very temperament of our being" (2010: 122). This is an epistemic gap and there is a need to better define the significance of repeated exposure to changes in weather and temperature (D'Amato et al., 2018), especially in terms of exposures that may affect the outcomes of patients with pre-existing airway diseases.

Quinn's relation to her support group is unusual in several ways. For instance, most members of Breathe Easy I met had either been directed to a local group by their GP or a respiratory nurse, pulmonary rehabilitation, the BLF or even a newspaper advert. Quinn, however, found out about Breathe Easy through the Internet.

> *Quinn: ……I think something popped up on the Internet, and it had something to do with a lung association, or something… And I just started poking around, and then…… We [my husband and I] don't know anyone in this area—we don't have family here. And… I looked in and I saw that there was a meeting, and I said, "I just live down the road" and I said to my husband "Oh, they have a Breathe Easy group! I might pop along to that! Because I will meet other people… share experiences, and you don't feel quite so alone"… and whatever. So that's what I did—just came along. So, I've only been to… I think four meetings. I'm one of the newbies! ……Everybody there was friendly, and, you know… But, like, they had a walk a couple of weeks ago—and I knew I couldn't do it. And I said to one of the ladies I'd met here, "I might come along to support you, and sit on a bench—but I can't do the walk." I knew I wouldn't be able to go. Not very far……*
>
> *Fredrik: …but, of the few times you've been there, at Breathe Easy, do you feel it helps? Do you feel that you get support that you can't get elsewhere?*
>
> *Quinn: ……… [thinking]*
>
> *Fredrik: I mean it's still very early to say, of course…*
>
> *Quinn: Yes, it is. It's still very early. And I've only seen a couple of presentations [from invited speakers]…… But just swapping stories with other people, and… You know, they say "Oh, I've had that… And I find so and so helpful"… So, you're just exchanging ideas—I think it's a marvellous group! I really do.*

Unlike Jon and Elinor or Adam and Elsa, Quinn evidently does not have years of experience to look back on in describing her encounter with Breathe Easy. Nevertheless, I find it interesting that she initially situated the meaning and usefulness of Breathe Easy participation in the invited speakers and their talks. This may suggest that although the groups are inherently social and rely on their members' active contribution, support (in the widest sense) is predominantly understood as an external service provided by a professional (rather than internally from and between the members themselves). This would also explain why some speakers tend to be more popular than others. For example, respiratory nurses and physiotherapists able to offer professional advice on how to manage one's lung condition habitually draw very large crowds across all Breathe Easy groups. However, having that said, Quinn still finds the mutual exchange and understanding between members essential. As this dissertation seeks to illustrate, there are many supportive features in attending Breathe Easy and Quinn has yet to discover and explore what it may bring her.

SUPPORT AS SOCIALITY

> *"How can I say this…… Nobody moans about what's wrong with them, but… People know if you're not very well—that's it! You're not very well. And that's what I like about [Breathe Easy]."*
>
> — Jill, COPD/emphysema (70)

In their recent paper on support groups for adults with hearing loss in North America, Kenneth Southall and colleagues (2019) describe the benefits of self-help and peer-support groups. Three themes they draw particular attention to are:

(a) "Practical and accessible information about [one's condition]"
(b) "Social belonging leading to personal transformation"
(c) "A new and mutually beneficial direction" (Southall et al., 2019: 29)

These are themes I very much recognise from my own work with Breathe Easy groups in the UK. Moreover, they align well with Alfred Katz and Eugene Bender's renowned definition of self-help groups, which reads (1976b: 9) as follows:

> […] self-help groups are voluntary, small group structures for mutual aid and the accomplishment of a special purpose. They are usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem, and bringing about desired social and/or personal change. The initiators and members of such groups perceive that their needs are not, or cannot be, met by or through existing social institutions.

The quote still remains highly relevant, particularly 1) how members seek to satisfy 'common needs' in bringing about desired change, where the group formation process is a direct response to the fact that 2) these 'needs' are not (or cannot be) satisfied by the existing social institutions. In the words of Ann Richardson and Meg Goodman, support groups are "groups of people who feel they have a common problem and have joined together to do something about it" (1983: 2). Thus, I argue that the formation of peer-support groups can be understood as a public response to "political failures in responding to biomedical misconducts" (Kasstan, 2019: 10). In terms of respiratory health, this may be due to practices of neoliberal governance where respiratory care regimens are individualised (Trnka, 2017; Kenner, 2018).

This argument ties together with the advocative practices often found in support groups; what Joseph Dumit (2006) sees as a process that allows people to live and cope better within current social institutions (like healthcare). Chapter 6 will delve deeper into advocacy and what this might mean for Breathe Easy groups, while the next section will focus more on mutual understanding and its role in transforming oneself "in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality" (Foucault, 1988: 18). This is what I call *support as sociality,* and I will illustrate it through three examples.

(i) Taylor

Taylor (in her 70s) kindly offered to meet with me prior to one of her group's meetings. Taylor is a former smoker, diagnosed with asthma in 2006 and then told in 2007 that the condition had developed into COPD. She told me how she often coughs at night and, worried that she might disturb her wall-to-wall neighbours, she used to go and sit on the stairs. Taylor told herself that she had to give up smoking, which she described as the "hardest thing I have ever, ever done to myself".

However, the damage was already done, and she got gradually worse. Taylor is divorced and lives alone, a situation that makes her anxious. For instance, the thought of suffering an exacerbation during the night is

> *[…] very, very scary. Because sometimes…… You cannot breathe! So, you cannot pick up the phone to tell someone… You know, one of the services, what is wrong—there is nobody there to help you. That is the most frightening bit; being on your own when you have an attack.*

Taylor told me how she had initially read about Breathe Easy in a local newspaper. It is evident that the group has come to fill a certain void in her life. Initially there were not many members attending, but Taylor told herself that if she kept going, she would, in time, "meet people who share the same condition as [her] and sometimes pick up tips and advice" on how to better care for her lung condition. Over the years the group flourished and is now a steady, well-informed gathering for people living with all sorts of respiratory conditions. As Taylor described it:

> *Taylor: …I think we've got… something about 24 or 26 [members]… We don't get them all in every occasion, but we've got quite a big group… That's nice… So it works for a social group, and a fundraising group, and… raising awareness [about respiratory disease] to people. We go to the hospital, have a table, and have a 'Big Breakfast.'*[46] *And… people have a chat, and all that. So, that's good.*
>
> *Fredrik: Even though it's called a 'support group', do you see it as a support group?*
>
> *Taylor: Yes…… I do find it a support group. If someone has a problem, and they're talking about it, there's always someone who has had a similar problem. And advise them on that. And, as I said, when we get somebody in from the hospital, and… they're telling them—telling people—well, "There's aids available… You can get this, and that"—that's supporting you! And… No, we do [support each other], we get people in who explain about… how your lungs work, how this happens, and… everything. And you just get so much more information, which helps you to cope with it. I think it's excellent… I'm glad I joined.*

---

[46] This 'Big Breakfast' that Taylor mentions is a campaign set in motion by the BLF. It is a breakfast event that revolves around raising funds for and awareness about respiratory disease as well as getting people "involved in the fight for healthy lungs" (blf.org.uk, 2018).

In just this brief extract Taylor managed to cover several different aspects and activities that are characteristic of a Breathe Easy group, including both social and advocative aspects. Although my question to Taylor may seem odd, I had Jon and Elinor’s interview fresh in my mind and I found it interesting how Taylor’s view of her group very much speaks to Jon’s of his, even though Taylor evidently identifies with the notion of a ‘support group’, whereas Jon does not. For Taylor it simultaneously acts as both a social and a support group, where the support stems from the social interaction between members. This acts as a clear example of how members may perceive and approach Breathe Easy groups differently, although the resulting benefits remain similar. Later, I will provide examples of members that feel that Breathe Easy groups have perhaps turned ‘too’ social, at the expense of the support and mutual exchange the groups are known for.

(ii) Jill

Jill (70) has COPD (emphysema) and, like Taylor, lives alone: she is divorced, with two grown-up children and several grandchildren and great-grandchildren. Jill was married for 23 years when her partner had what she described as an obvious midlife crisis. Their relationship came to an end and Jill moved closer to her daughter. Listening to her talk about her recent life changes, it is obvious that Jill is proud of herself for making this decision, given that she did not know anyone other than her daughter in the north-east. Jill managed to make lots of new friends and create a new life for herself.

Jill was diagnosed with COPD in 2013 but had felt that something was wrong for some time, which she attributed to issues with her weight, rather than her actual respiratory health. Around the same time she had moved up north (in 2007 or 2008), Jill was diagnosed with Barrett’s oesophagus, “a condition in which there is an abnormal change in the mucosal cells lining the lower portion of the oesophagus” (Shaheen & Richter, 2009: 850). She struggled to eat and lost a lot of weight. After treatment she regained the weight and initially thought the weight gain had caused her declining respiratory health. This speaks well to what

Macnaughton and Carel write, especially regarding the hidden burden of lung disease: chronic breathlessness "is a condition that usually has an insidious onset and is often attributed by those who experience it to ageing, lack of exercise, or smoking" (2016: 298). Jill's respiratory condition flared up in 2012 after a trip to Cuba. Jill described coming home "really, really ill with a chest infection", later diagnosed as a Cuban strain of pneumonia (Medell et al., 2013), leading to her having to undergo combination antibiotic therapy (Baddour et al., 2004). Following that treatment and several chest CT scans, she was referred to a respiratory specialist. Jill was diagnosed with COPD at South Tyneside District Hospital (in South Shields) in 2013.

Like Taylor, Jill is also a former smoker. She gave up in 2008, soon after relocating. Jill told me about this journey:

> *I know it [COPD] gets worse, so… that's why I keep active and things. But I did smoke, and I stopped that in 2008. I had a cough… and I had to go for a 'blow test' [spirometry] and they showed me: 'That's where you are. And that's where you should be.' From there on, I stopped smoking. So…… I won't be going back to it. One, I cannot afford it. And two—[laughs] I think it's stupid! I keep telling my grandchildren: 'Don't let me catch you smoking!' You know… And when I see people out on the street, I just want to go over and say: 'Look. This is what happens to you.' [she points to herself]*

In the words of Andrew Russell, with COPD "it is not so much a question of whether you will acquire it as a long-term smoker, but when" (2019: 261). Russell refers to a study by Lundbäck and colleagues (2003), which shows that the prevalence of COPD (particularly amongst smokers) is considerably higher than previously reported. Yet ignorance about COPD "and its debilitating effects" (Russell, 2019: 261) is commonly expressed by regular smokers in the north-east of England. Because of this "agnotological lacuna, the North East has the worst rates of COPD in England" (ibid.). The nature of this public health issue has been further discussed by the BLF, especially in their *Battle for Breath* report (2016).

Like many members of Breathe Easy, Jill was introduced to this mutual-aid network through pulmonary rehabilitation classes at her local hospital. As I observed, pulmonary rehabilitation (PR) is a central activity for people living with chronic breathlessness, not only for its health benefits (Williams et al., 2010; Rugbjerg et al., 2015; Mesquita et al., 2017) but also the social and mutual support that comes with meeting new people. As Halding and colleagues discovered in their extensive study of PR in Norway, the sense of *belonging* was an overarching theme (2010: 1272). That is to say, with regards to PR, "participants emphasised social integration […] as well as support from peers and health-care personnel as important dimensions" in rehabilitation groups (Halding et al., 2010: 1272). Jill agreed:

> *<u>Fredrik</u>: You said that you were put into contact with [Breathe Easy] through pulmonary rehabilitation?*
>
> *<u>Jill</u>: Yes, the rehabilitation class… which is one hour of exercise. And then… well, let's say one hour afterwards, you get speakers in. So you get the physiotherapists who come in one week, and then a dietitian comes in next week… well, the Breathe Easy comes in one week, to tell you [about them]…… But, that's how I got to know them, and I thought "that sounds"…… You know, at least I might be able to get some information… 'cause at that point I hadn't got any information, except what [my GP] had given me. And I thought "well, at least I might be able to talk to people." So, I started going, you know, and I find it…… Let's put it this way—the difference—I'm also a member of [another outdoor group]… and I do gardening, and we go for walks, which I can't do much now, because they walk too fast…… And if you're ill, you've got to start explaining. Which I'm not very good at… But at Breathe Easy, you're all in the same… situation, so if you say "I really can't do it this week, because… I can't breathe"—that's all the explanation needed, and they understand. Whereas the other group, they go "well, why?"…… "Well, you know, I just can't, it's too warm for me." "Oh, don't be silly!" they tell me. Breathe Easy is completely different. They know, so you don't have to do the explanation. And that's what I like about [Breathe Easy], because……*
>
> *<u>Fredrik</u>: There's a mutual understanding between the members?*
>
> *<u>Jill</u>: Yes, yes. You know, it's…… That's what I get out of it, I was thinking about it the other day, and I thought "Yeah, that is… one reason why I like going." You know, plus I've made some nice friends… You know, one bloke and I were doing the same, in pulmonary rehab, and I got talking to him and his wife and they now supply our garden with compost manure, 'cause they've got an allotment! [laughs] You know, the couple I sat next to…*

> *Fredrik: Yeah, yeah.*
>
> *Jill: Yeah, yeah. Well, that's where I get my manure from…… But I've made some good friends, you know… I've been going three years now, so… Plus, I also think that with the fundraising and everything, it's helping…… our community. The hospital. You know, the people who're involved with COPD, or other breathing problems. It's helping them. Rather than the [other outdoor group] who're raising money just to put the bands on. You know, so…… I enjoy going.*

Another statement from Jill has stayed with me: "Nobody moans about what's wrong with them, but… People know if you're not very well—*that's it*! You're not very well. And that's what I like about Breathe Easy". This, I believe, perfectly, sums up what Jill wants to convey about attending a Breathe Easy group: mutual understanding. This notion is fundamental to comprehending why support groups exist and continue to grow in popularity (Adamsen & Rasmussen, 2001; Adamsen, 2002). Mutual understanding is noticeable in Katz and Bender's definition from 1976 (p. 9): support groups are formed by people "who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem, and bringing about desired social and/or personal change". This extends beyond the members themselves into the wider local community that they serve and support.

Jill also emphasises an aspect of Breathe Easy (and support groups in general) that may go unnoticed: socio-economic exchanges or *gift-giving*. For example, how Jill obtains manure from her friends in Breathe Easy. Gifts are, in the words of French sociologist Marcel Mauss, like spiritual artefacts: tokens of appreciation in the widest sense of the word. Gifts are irreversibly tied to the giver: "the objects are never completely separated from the men who exchange them" (Mauss, 1990 [1950]: 31). Mauss argues that because gifts are so tightly linked with the giver and receiver, the act of giving implies an important *social bond*, obligating the receiver to reciprocate with another gift. Thus, "each gift is part of a system of reciprocity in which the honour of giver and recipient are engaged" (Douglas, 1990: xi). Not acting on this obligation results in loss of honour and status, and Mauss argues that in some cultures this may even have detrimental spiritual implications.

Mauss also writes that it is not individuals “but collectivities that impose obligations of exchange and contract upon each other” (1990 [1950]: 6). The parties are legal entities, who confront and oppose one another, exchanging not just property and wealth as represented by the gifts themselves, but acts of politeness. Drawing from my interviews (particularly the interview with Jill), I contend that these reciprocal acts and social bonds, apply to entities such as support groups as much as to clans, tribes, or families like those Mauss describes. That is, the social bonds that foreground the groups are founded on the members’ reciprocal obligations towards one another, which further enable mutual understanding between them. Jill fits in as a single woman without many other reciprocal ties.

(iii) Kim

Kim (62) has been severely asthmatic since he was a child. Asthma is a common, long-term inflammatory disease that requires ongoing management and medical attention (British Lung Foundation, 2016: 31). Asthmatics have very sensitive airways and in the UK, over 8 million people have been diagnosed with asthma at one point in their life, which means “more people have had an asthma diagnosis than have been diagnosed with all other lung diseases combined” (British Lung Foundation, 2016: 31). Kim also diagnosed with bronchiectasis later in life, a condition potentially brought on by his asthma (an association between asthma and bronchiectasis has been reported in many studies [Kang et al. 2014]).

Kim’s interview stood out from the others. He has been a prominent figure in his group from the start, which came across well in our conversation.

> *Fredrik: What has the group come to mean to you? What do you feel you get out of [attending Breathe Easy]?*
>
> *Kim: ……The satisfaction of saying… you know that people, hopefully, are doing well, or are coming out of their shells. You know, we have seen some people come out of their shells, like we talked about today, and also physically flourish, as you might say…… Quite regularly, you get the plus of that. The minus, of course, is that it’s a lot of work. But I also believe that there is this problem with respiratory disease… that it is… I suppose, from a political front, really, you know, someone gets a ‘big say’ in…… You know, everybody knows*

> *about how Macmillan[47] comes in and they do everything for you… So, my next-door neighbour gets cancer, and Macmillan are in there and they are doing all the care, and everything they can for them… But if you get something like we've got [respiratory disease]… where the survival rates are less…… You don't get anything, there's no charity out there that can help. That's why I'd like the British Lung Foundation to prosper, but it's got a long way to go to do that… So, it's partially a political statement.*
>
> *[Kim raises his tone suddenly]*
>
> *I think it's because heart attacks and cancers tend to be… well, if you look at, sort of, British politicians, I don't know… They tend to be from… it sounds wrong to say, but higher class… heart disease, stroke, and so on, tend to be… Whereas respiratory disease, and this might be a north-eastern thing to do with engineering, shipbuilding and so on, tend to be… It's more a working man's problem, respiratory disease, because of things he's come across in his working life in many cases……*
>
> *Fredrik: Have you read the 'Battle for Breath Report' that the British Lung Foundation released [in 2016]?*
>
> *Kim: I will have done, yes.*
>
> *Fredrik: Because that's where they map out where respiratory diseases are most common in the UK. Like in the North East…… And most of them are localised in former mining regions, and again, what you just said…*
>
> *Kim: Well, yes, exactly. And I think… Well, we used to keep clear of all these sorts of things, but the British Lung Foundation is putting out more and more figures that say, what I've been saying just now… I'm glad to see this change, because you won't win the fight unless you go to it, so to say.*

This segment from the interview with Kim is politically loaded, as Kim himself points out. He illustrates how biosociality and patient activism are correlated practices, expressing that he would like to see the BLF "prosper". This reminds me of Joseph Dumit and his writing on illnesses "you have to fight to get" (2006: 577), especially these words: "when emergent uncertain illnesses are also highly contested, [biological] facts function differently" (2006: 587). In times of struggle, Dumit writes, people turn to collective action and perseverance; or *contra-tactics*, which he describes as "creative use of existing categories, and deploying available counter-facts within the rules of the system" (2006: 578). This is evident in how Kim

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[47] Kim is referring to *Macmillan Cancer Support*, one of the largest UK charities who provide specialist healthcare, information, and financial support to people affected by cancer.

draws parallels between chronic illnesses and socioeconomic status, noting that respiratory disease (in comparison to, say, cardiovascular disease) has a higher prevalence amongst the more socially deprived communities in the UK.

In addition to portraying Breathe Easy membership as a political statement in and of itself, Kim also offers an insight into how the *helper therapy principle* (Riessman, 1965; Roman et al., 1999; Pagano et al., 2011) comes into play in these interactions. That is, the principle which reads that an individual who provides help or support to another may themselves benefit from the act of helping. I am especially intrigued by the statement that there is “satisfaction [in] saying… that people, hopefully, are doing well, or are coming out of their shells”. This was Kim’s response to the question of what he personally gets out of his Breathe Easy group, which in one way also shows the difference between mutual aid and self-help as analytical notions. That is, self-help is insufficient in describing support settings (like Breathe Easy) because it reads like an oxymoron (Humphreys & Rappaport, 1994; Nelson et al., 1998; Pretto, 2012); it focuses more on self-satisfaction, rather than the social bonds and mutuality between people. Kim seems to draw from his experiences of helping others (which in turn helps him) and how he gains an improved self-image by shifting his “focus from self-concerns and problems to assisting others (and thus distracting oneself from ongoing difficulties)” (Riessman, 1965: 31).

The helper principle also compares to a gift economy; especially in terms of the relationships and reciprocal obligations that are founded on gifts and gift-giving. As Mauss argues (1990 [1950]), there is no such thing as selfless gift-giving. “Far from being selfless gestures” (Goldhill, 2016: para. 1), giving gifts creates a personal debt between the giver and receiver which results in a debt-balance “that people keep, silently, with each other, within their relationships” (Goldhill, 2016: para. 4). Thus, emphasis is on the selfless gifting that *earns merit* for the giver rather than on the relief of the poor or the recipient of the gift (cf. Bowie, 1998). While benefitting from helping other members in a support group setting does not in and of itself have to come with ulterior motives, it still rests on the same principles and social obligations that we find in the archetypal gift economy described by Mauss.

DIFFERING VALUES IN ‘BREATHE EASY’

In the months I spent with primarily three Breathe Easy groups, most members I spoke with expressed positive feelings about their respective groups and the overall support group network. These comments very much reflect the ‘front of house’ experiences of the groups and thus may neglect what goes on ‘back stage’ (Goffman, 1990 [1956]; Nyqvist, 2014; Jacobsen & Kristiansen, 2015). Kirsten Bell and colleagues write that “there is no ideal support group. Nor is there a ‘magical formula’ for attracting and retaining a diverse audience” (2010: 447; cf. Ussher et al., 2006; Butow et al., 2007). In their study of caregiver support groups, Gage and Kinney write that they “aren’t for everyone”—especially as “not all individuals might benefit equally from support group participation” (1996: 31). Gage and Kinney conclude that “future research might seek to better understand the motivations underlying support group participation” (1996: 32).

If we continue to look at everyday life as a theatrical production (Goffman, 1990 [1956]) what sort of performances might we find in Breathe Easy group members’ interactions with each other? Following Bell and colleagues’ (2010) argument, I note that members might not agree how a support group should function. To illustrate this, the next section will focus on some members’ frustrations and differing views of what a Breathe Easy group is meant to uphold and convey to its members.

(i) The Annual Meeting of *LAM Action*

There was an ‘ethnographic moment’ (Ohm, 2013) where I was introduced to the unhelpful connotations (Oxley, 2017; Oxley et al., 2019) that may come with the term *support group*. I use this to illustrate potential mismatches between expectation and reality that people (or potential members) may experience when it comes to self-help, mutual aid, and peer-support groups.

Is our language rich enough to fully describe the experience of breathlessness? Is there a mismatch between the language doctors and patients use? Rebecca Oxley asks, “Do some of the words and descriptions used have unhelpful connotations?”

(2017). I feel this applies to peer-support groups as well as breathlessness itself. I attended the annual meeting of LAM Action in Birmingham in 2017. LAM Action is the UK charity for those living with LAM, their families, and the health professionals caring for them. LAM (or *lymphangioleiomyomatosis*) is a rare condition that occurs almost exclusively in women, with the average age of onset in patients in the UK being 34 years old (LAM Action, 2019: 2). The disease mainly affects the lungs, where abnormal cells build up around the airways, blood vessels and lymph vessels. It is estimated that approximately 350 women in the United Kingdom live with LAM, with around twenty-five new cases diagnosed each year (LAM Action, 2019: 2).

One section of this annual meeting was devoted to smaller focus groups, where the trustees of LAM Action wanted to hear people's views on aspects of the charity's work. One group addressed the regional support groups LAM Action hosts across the country. Unlike Breathe Easy, these groups only meet once or twice a year (lamaction.org, 2017) and the predominant concern in the focus group was how to develop the support groups further. Given that there are only about 350 women with LAM in the UK, spread all across the nation (although the majority are in London and the Midlands), LAM Action is not able to sustain a larger network of support groups in the same manner as the BLF. Hence, LAM Action relies very much on their members to keep these groups active. I was able to acquire a lot of interesting information and material on support groups from this exercise (as well as hearing several women's experiences of living with LAM), but there was a particularly striking sentiment expressed by one of LAM Action's most senior trustees. She regularly attends one herself in London and seems to be pleased with how that group functions. She said several times that she did not like the thought of "throwing support groups in people's faces, as some might not want to be confronted with their disease all the time or constantly talk about it." Another participant was quick to emphasise that "that is not what all groups do; they are very much social, as members meet up for lunch or coffee and talk about whatever people feel like talking about", suggesting that these groups act more like social groups than support groups (in the traditional, therapeutic sense).

Trustees and members alike agreed on that the overall goal of LAM Action (and their support groups) should not be to establish a group in all regions of the UK, but that every member who wants to attend a support group should be able to do so. This ethnographic moment brings us back to what Kirsten Bell and colleagues say about the lack of an ‘ideal’ support group (2010), a conclusion reached by Kelleher (1990) and Gage and Kinney (1996) as well. However, this discussion at LAM Action made me think about whether there may be unhelpful connotations in the notion of ‘support groups’ themselves. Breathe Easy member Jon evidently thinks so, which is why he thinks of it as a misnomer. Could, then, the concept of a ‘support group’ keep people away, if it makes them think of, for instance, Alcoholics Anonymous or similar settings? Do people stop attending because some of the groups are just too social and do not function as support groups? I will now attend to some of my interlocutors’ statements that display frustration with Breathe Easy groups and how they are habitually organised.

(ii) Lake

Lake (in his 70s) has COPD, which he was diagnosed with in 2002. Like other Breathe Easy members I met, Lake is a former smoker (“at least 60 cigs a day” in his words). Lake started to suspect that something was the matter when he experienced a series of chest infections where he coughed up “this awful green phlegm”. Shortly afterwards he received his COPD diagnosis, and he gave up smoking in 2007. Unlike many of my interlocutors, Lake was blunt and straightforward. He did not hesitate to say when he thought my questions were poorly phrased, but he was also very self-reflective and expressed that while he cannot praise the NHS enough for all the care and wonderful nursing he has received, “Nobody has touched upon what goes up there”, pointing to his head. There is a lot more to living with chronic breathlessness than adjusting to an abnormal pulmonary capacity. Specifically, Lake stressed the moment when he realised the barriers COPD places upon him.

> *If my wife says to me: "You know… that bush will have to come out of the ground"… Instinctively, I go towards the garage to get a spade and dig it out. And I've actually gotten to the stage where I've gotten to the place and realise that I cannot do it. Whereas now, a mind-set sets in, and you think "I cannot do that".*

Lake and his wife live in a two-storey house with a large garden, the maintenance of which had been occupied much of Lake's leisure time. As can be observed, people with severe COPD and similar conditions experience a shrinking life-world shaped by breathlessness, which "diminishes the predictability and automatic nature of their bodies and their perceived effectiveness as a person" (Gullick & Stainton, 2008: 605).

Lake's own interest in and dedication to Breathe Easy and its cause has fluctuated over time. While he still supports the system as an ideal, at the time of writing Lake is no longer an active member of his group, due to his view of how a 'support group' is supposed to work and what services members are meant to enjoy.

> *<u>Lake</u>: I thought, "I need to do something." And that's why I joined Breathe Easy. And I was the Chairman there for a couple of years, and Secretary as well. I don't go as much now, because…… God forgive me, I find it a bit boring! They're mainly very verbal, middle-aged women… elderly women… who I don't get along with anyway! [laughs] Although I do love the current Secretary and Treasurer, and people like them, but… I don't go as much. I attend the coffee mornings to help out, I do things like that, but I don't… I'm not so involved anymore as I was. And it isn't…… Oh dear. It isn't the great self-help group that it advertises itself as.*
>
> *<u>Fredrik</u>: Could you give examples of this?*
>
> *<u>Lake</u>: Not really, no...... My idea of a self-help group would be people who sit around, having a cup of coffee, and say: "Have you tried this? Have you tried that? Ask your GP about this…" and things like that—but they don't. It's just a gossip shop. Which is not for me, I'm not a gossip person. That's all. That's why I don't go as much. But I still support it. I still support the British Lung Foundation. It's one of the charities we, my wife and I, contribute to, you know…… So that's my involvement with Breathe Easy.*
>
> *<u>Fredrik</u>: But how was it when you started to attend these meetings? And when you were more involved as a Secretary and Chairman? How did you feel about the group and attending it, did you feel it… gave you anything?*

> *Lake: Well, I've always naturally been… This is going to sound pretentious, but I've always been a bit of a leader. I was in the Army, so being Secretary or being Chairman, was no challenge to me at all. I quite enjoyed it. I quite enjoyed, if you like, [when] sometimes I was given some jobs to do that involved meeting other professionals—which was quite good. But having said all that, I decided that after… I was Secretary for about three years and Chairman for about three years, and then I decided that I wanted a break from it. I wanted less involvement. To me, it had run its course. It wasn't what I thought it would be, although I still support it and I support the current Committee, but… It's not for me anymore. To that level of involvement, you know. Although I still support it.*

There is a lot to unpack in this statement. Lake's term "gossip shop" to describe what he feels Breathe Easy has turned into is striking, something he appears to blame the female members of his group (whom he does not "get along with") for. Lake seems to think the group was female-dominated. Yet despite his description, from my observations it was not. Similarly respiratory disease is in itself not equally split between the genders. According to the BLF (2016: 14), men are overrepresented when it comes to mesothelioma and obstructive sleep apnoea, whereas bronchiectasis is more common in women. In contrast COPD and IPF are rather more common in men, while asthma and sarcoidosis are similarly more common in women (British Lung Foundation, 2016: 14).

Why, then, does he feel the way he does? Is the key in his word *verbal*? Perhaps some of these women he finds so frustrating dominate the conversation, and thus seem to be more numerous than they actually are? Or should one read his use of the word *gossip* as gendered? The commonly accepted understanding is that gossip is "idle talk, tittle-tattle, malicious tales, scandal and rumour" (Noon & Delbridge, 1993: 24). Besnier writes that, from an ethnographic perspective, "gossip must be defined from the ground up, an approach that is attentive to local conceptualizations and to cross-social variability" (2019: 101). Yet as can be read in Noon and Delbridge's paper, gossip "has been under-researched" (1993: 23) and is assumed only to have negative outcomes for organisations. This, Noon and Delbridge argue, "masks the role of the gossip process in preserving and perpetuating organizations" (1993: 35) to clarify an understanding of the social organisation of work. Noon and Delbridge understand gossip to play a significant part in the relationships and formal structures that protect organisations by “offering individuals both informal social mobility/influence and escapism” (1993: 35). Thus, while Lake’s group may be side-tracked by idle talk and tittle-tattle, these engagements may also be pertinent to how the group functions as a social entity.

I pushed further about Lake’s initial statement of his: that Breathe Easy “isn’t the great self-help group that it advertises itself as” and Lake struggled to respond. Clearly, he missed something concrete to walk away with i.e., a skill or an idea to try. Lake expressed dissatisfaction with a lack of advice from fellow members regarding how to cope with a respiratory disease. That is, Lake very much prefers *support as sociality* above the *sociality as support* that many of his fellow members seem to practice. This also brings us to the notion of support groups as *technologies:* tangible resources from which to draw, as Lake would have preferred. So, given that (as Bell and colleagues write [2010]), there is no such thing as an ideal support group, how should support groups act in a pragmatic sense members’ illness and treatment trajectories, where the need for information is gradually replaced by a need for “support and understanding” (Bell et al., 2010: 433). The group no longer suited or fulfilled Lake’s needs, which is why he decided to leave. While an acrimonious explanation it may also be that after long periods in a male-dominated environment (the army), Lake may not know how to talk to women and thus finds them trivial and irritating. It is indeed striking that he picks out women of a particular age as the cause of the problem but is then unable to explain how or why this might be the case.

(iii) Anthony, Charlotte, and Marcus

Anthony (in his 70s), Charlotte (in her 70s), and Marcus (in his 80s), form a typical ‘friendship circle’ (Driessen, 1998; Humphreys, 2003) and I always found them sitting together at their Breathe Easy group meetings. The interview took place in Marcus’s home. Speaking to three individuals at the same time very much changed the dynamics of the interview. Much like a focus group, the three of them talked amongst themselves while I took notes and prompted them with questions.

Anthony and Charlotte are married to each other, while Marcus is a close friend of theirs. Unlike Jon and Elinor (and Adam and Elsa), Anthony and Charlotte both live with a respiratory condition. Anthony has bronchiectasis, a life-long condition which is generally characterised by the airways being damaged and widened. Anthony relayed the rather vivid description he was given by his physician: "It's like a spider's web. And the infections—the *bugs*—get caught in the web, and that's why I get so many chest infections". Anthony is currently being treated with *azithromycin*; an antibiotic that can permanently damage the heart and the liver, as well as causing gradual deafness. Anthony expressed how pleased he was to be on the drug as he felt the most efficient alternative was a nebuliser tablet, which required "everyone to leave the room" as the vapour was potentially harmful to others. Moreover, the nebuliser (a machine that helps you to breathe in a medicine as a mist through a mask or a mouthpiece; Figure 5.2) would have required an exhaust pipe to go out through the window, an idea that Anthony described as an outright nightmare.

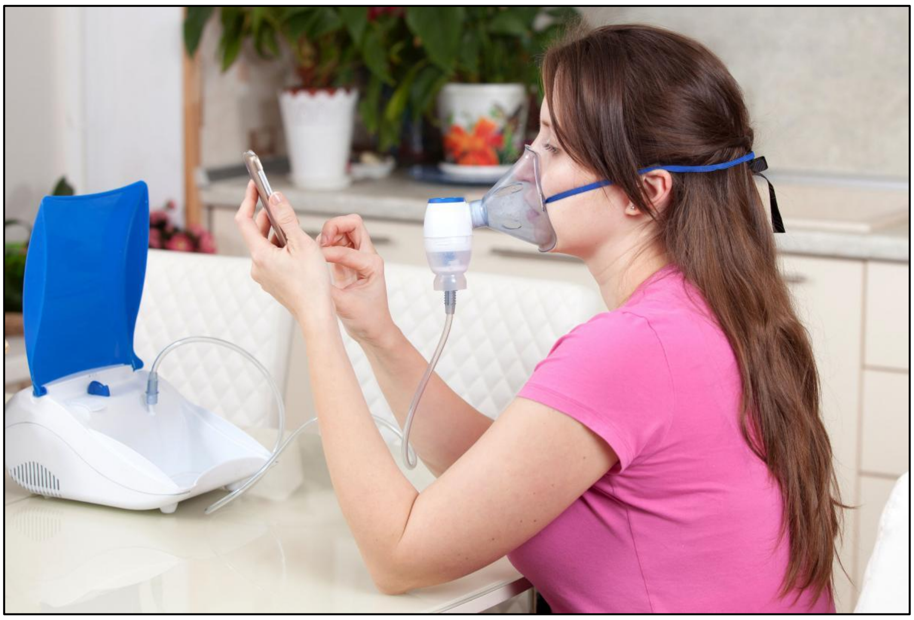

Figure 5.2: An example of a nebuliser.

(© British Lung Foundation)

Charlotte and Marcus both have asthma. While Anthony is Charlotte's caregiver as much as she is his, Anthony is usually the one whose condition takes a turn for the worse. Thus, the overall caretaking responsibility habitually falls on Charlotte. Charlotte told me that her father had developed emphysema (COPD) late in life, which she thought this was the result of him working as a coal miner for most of his adulthood. This may very well be the case, as increased coal dust exposure is associated with increased risk of death from obstructive pulmonary diseases (Coggon & Taylor, 1998; Santo Tomas, 2011; Laney & Weissman, 2014). Marcus said that he has always been *chesty*—sensitive to chest infections, but respiratory disease also seems to run in his family. This is a social condition he shares with Anthony, whose father contracted TB (and never fully recovered), and brothers and sisters all with various degrees of asthma. Anthony is also a former smoker and while tobacco smoke does not cause bronchiectasis, he believes it may have weakened his overall pulmonary health. Anthony and Marcus are also both former factory workers, a group at risk of several occupational diseases, much like coal miners (Sirajuddin & Kanne, 2009).

Anthony and Charlotte met Marcus at pulmonary rehabilitation classes, which is also how they were later referred to their local Breathe Easy group. When I first met them, they were had been part of the group for about six months and were still grappling with what to make of Breathe Easy.

> *Charlotte: …as Marcus said, there's recently been—rightly or wrongly—there seems to have been a drift away from… the core values of it [Breathe Easy]. It's alright in a way, but it more seems to be meetings for clubs and trips, and the…… If someone [new] was to attend a meeting, they wouldn't know it had any connections with lungs…*
>
> *Anthony: Well, you know, at that last meeting we had…*
>
> *Fredrik: Yes.*
>
> *Anthony: …there was nobody there… It was just, like, you know…*
>
> *Fredrik: There was no invited speaker, you mean?*

<u>Anthony</u>*: …Yes. There was just a raffle, and that's it. And I thought, "well"… You know, even, as we said, if they haven't got anybody to come in and speak to us… it's not all the time we do that… You know, even if we all got in a discussion about, well, "How are you doing? Any new medication?"… You know, just…*

<u>Marcus</u>*: …Well, it did the first week, didn't it? When we started going?*

<u>Anthony</u>*: Yes, the first week. Yes…*

<u>Marcus</u>*: …and that's where you get your help from, isn't it? When people are talking… But that just disappeared, didn't it?*

<u>Charlotte</u>*: It just seems… Like I said, I repeat myself, if someone was to come in from the street to that meeting, they wouldn't realise it was a lung foundation…*

<u>Marcus</u>*: No, no. They wouldn't.*

<u>Anthony</u>*: Breathe Easy, you mean.*

<u>Charlotte</u>*: Oh, sorry—I mean Breathe Easy! A Breathe Easy meeting…*

<u>Anthony</u>*: Yes…*

<u>Fredrik</u>*: Yes, I've noticed, you don't have this huge sign, or banner, that other Breathe Easy groups have. They always put, whenever they meet, this huge banner next to the door, like to say, "Here's this Breathe Easy group meeting"… But you don't have one of those?* [48]

<u>Anthony</u>*: No, no.*

<u>Fredrik</u>*: I don't know… Would that make a difference?*

<u>Marcus</u>*: Well, I think it should be…*

<u>Anthony</u>*: …it should be advertised more, shouldn't it? Definitely… If they put it, like, as you said previously, at doctors' surgeries, any type of… public place, really, where people go. Libraries, even…*

<u>Marcus</u>*: Well, I've suggested, like… because I'm a Catholic, and that's a church [where we meet], and we have a bulletin there every week… Even if they'd put it in the bulletin—in big letters—if we put all the churches together… At least people would see it, and put in the meeting times when they're due, and things like that… That would get through, because people read the bulletins, you know…*

---

[48] It was later brought to my attention that the group does indeed have a banner, but they choose not to put it up for their meetings.

> *<u>Anthony</u>: …yes.*
>
> *<u>Marcus</u>: …and the doctors' surgeries, it's… It should be in there, it's down our own lane.*
>
> *<u>Anthony</u>: It should be.*
>
> *<u>Marcus</u>: There's all this rubbish in there, already, that they don't take in…*
>
> *<u>Anthony</u>: I think I'll mention it the next time I go down… And see if we can get some kind of… paper made, you know, for the display…*

This conversation very much speaks to my previous example (Lake). Anthony, Charlotte, and Marcus all express frustration at leaving meetings without a 'take-home message'; something concrete, whether it be advice or information. While they do not label the group a "gossip shop" or similar, evidently, they feel that the sociality tends to overtake other aspects of the group, especially when it comes to sharing and learning from experience. I find it interesting how they draw parallels between the absence of explicit support (between members) and the lack of advertisement the group does for itself within the community. I take this to mean that for Anthony, Charlotte, and Marcus, Breathe Easy engagement does not merely revolve around the group and its members: engagement also extends to the surrounding community.

(iv) Sandra

Unlike the other Breathe Easy members I interviewed, Sandra (in her 70s) does not live with a lung condition herself. She is caring for her husband (who is asthmatic) and she was the only carer I interviewed without their spouse. Sandra has been more involved with the Breathe Easy group than her husband. While seats on the committees are habitually left for people living with a lung condition, an exception was made for Sandra. She acted as her group's Treasurer for a long time because in the early days of the group, there were not enough members who had expressed an interest in being on the committee. Sandra told me that this had nearly brought the group to an end, as it had been a requirement of the British Lung Foundation that each group had at least a Chair, Secretary, and Treasurer. Sandra decided to take on the role, which made it possible for the group to thrive and grow.

At the time of writing both Sandra and her husband have withdrawn (or *retired*, as Sandra puts it) from the group. Although Sandra still keeps in touch and may attend meetings when she is able to do so, the last time she attended one was in 2019 when I was invited to update the group on my research. While the decision to retire from Breathe Easy was primarily due to her husband's declining health and her own lack of energy (and loss of interest), looking back at our interview it seems that there were other reasons as well, some of which speak to previous examples that illustrate people's frustration with how Breathe Easy groups are run.

> *<u>Sandra</u>: …I mean, to be quite honest, in one sense… my husband and I feel as if we're outsiders, you know. I mean, the Chairperson is very good with us; we liaise a lot with him and his wife, and so…… But… I don't know. I think if I'd leave [my position], nobody would be doing this, you know. And… I'm not saying the group would fall apart, 'cause our Chairperson would try and keep it all together, but I say… It's difficult for him, because he has a lot on his plate, to do…… I mean, I don't want to take on the Chairmanship, and having to write a paper, and whatnot, and all that…… It's a pity really, that the members do not want to take up more* interest*, in the group itself…*
>
> *<u>Fredrik</u>: In the organisation of it? That which keeps it running?*
>
> *<u>Sandra</u>: Yes, that's right. Exactly. Some of them are there just to, you know, listen to the speakers, and see what they can get out of it… I mean, like, the speakers that come, that relay about their own topics, like the weatherman, and so on… Well, some members can say something like "Oh, we're not interested in that", you know…… Like, once we had a lady that came and talked about… what she made; chutneys… you know, jams and chutneys, and so…… And there was a chance to buy some [at the meeting], and some went like "Oh, that's interesting!" So, that was a more interesting forum, I suppose… But that's a theory of mine… I shouldn't be [complaining too much]… But that's all there is.*

Sandra offers clear examples of internal issues that may arise within Breathe Easy groups—especially when it comes to management and leadership. I observed similar conflicts across all the groups I visited. Sandra's frustration primarily stems from the lack of interest and engagement from the other members, whom she sees as mostly concerned with self-preservation and what they can gain from the group rather than what they can contribute. This is a recurring narrative that often places a huge burden on the Chair and other committee members. I can name several occasions where I observed a Chair asking for help in keeping the group afloat. People never refused to offer their assistance, but I also observed that no-one tried to take on more responsibilities unless asked directly. It seems that a majority wants the groups to remain active, but they do not want to be in charge of actually *keeping* them active. As a result, Breathe Easy group committees habitually remain static, with members feeling compelled to act in roles of responsibility. If these individuals were to step down, the groups would fold.

CONCLUSION

In summary, the rapid popularity of support groups worldwide has led some health professionals to suggest that self-help interventions might soon rival other forms of treatment. Taking this to mind this chapter has delved into Breathe Easy groups' form and functions, looking particularly at how group members respond and adjust to the different circumstances that active participation in Breathe Easy might come to entail. Ethnographically speaking, social interaction within a Breathe Easy group can be understood as a negotiation of various relationships that offers each individual with a 'safe place' for making sense of what it is they are saying and doing. Drawing from both interviews and fieldwork observations, I came to identify three primary aspects of what it means to be a Breathe Easy group. These are *sociality as support*, *support as sociality*, and *advocacy*.

Sociality as support refers to the actual social interaction within the groups. More specifically, it refers to how the groups may be understood as safe places in and of themselves, where support derives from members socialising free from judgement and stigma. Sociality equals self-improvement, where sociality and support are seen as correlated. Bluntly put: "You alone can do it, but you cannot do it alone". In contrast, *support as sociality* entails more than just mutual social support and understanding between members. It refers to the process of acquiring specific skills in how to cope with one's chronic disease in a group setting through sociality.

Sociality is more seen as a means to an end (towards self-improvement), and where sociality is understood as distinctive from support (which inclines a 'take-home' message). These aspects are very much entwined, where members' engagement with each other primarily revolves around attaining a sense of belonging *through* self-improvement, which parallels with achieving self-improvement through a sense of belonging and mutual understanding with other members.

Last of all, *advocacy* refers to activities the groups engage in that might fall under patient and service-user activism, such as fundraising, awareness raising, and lobbying for health service development. The following Chapter 6 will discuss and illustrate in more detail how advocacy may play out in Breathe Easy groups. It does so by looking specifically at the borough of South Tyneside, where the local Breathe Easy group made significant changes to its practice and operation—all in support of the South Tyneside District Hospital which has been heavily affected by major changes to local healthcare and service provision.

~ CHAPTER SIX ~

"GIVING BACK TO THE COMMUNITY"

BREATHE EASY AND PATIENT ADVOCACY IN THE BOROUGH OF SOUTH TYNESIDE

"All advocacy is, at its core, an exercise in empathy."

S. POWER

INTRODUCTION

> "What is becoming very clear is that the [UK] government agenda is already reducing safe access to vital health services for whole swathes of the population in the North East and across England and this agenda is being further pursued in the present deconstruction of local [South Tyneside] District Hospital acute services and the local GP services across England. We know that if people fight to save their services they can win as demonstrated by recent examples such as at the Huddersfield Royal where the Secretary of State […] has been forced to admit that the closure of this hospital is 'not in the best interest of the people of Calderdale and Huddersfield'."
>
> — *Save South Tyneside Hospital Campaign*[49]

This chapter follows on from where Chapter 5 came to heel. More specifically, in this chapter I address the way in which Breathe Easy groups and their members may come to be involved with patient activism and advocacy. In this regard, Breathe Easy becomes a patient advocacy organisation (PAO), whereby members may advocate for "increased research funding and policy changes and provide services to patients and their families" (Rose, 2013b: 680). On the whole, I draw out and illustrate these practices in conjugation with issues regarding neoliberal deconstruction of local healthcare services across the United Kingdom. The above-mentioned quotation acts as an example of this, which I detail further on in this chapter. The chapter focuses especially on healthcare services across England and the North East, where it sheds light on the current situation of the District Hospital in South Shields (Figure 6.1), which serves the whole borough of South Tyneside.

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[49] This quote comes from communication with the campaign management (21st May 2018).

The hospital opened in 1880 under the name *Harton Institution and Hospital*, where it was originally built by the South Shields Poor Law Union as a workhouse hospital. It was not until 1st April 1937 that the institution became a separate General District Hospital (nationalarchives.gov.uk, 2020).

Figure 6.1: South Tyneside District Hospital (Ingham Wing).

(©Dunwoodie Architects)

In this chapter I focus more specifically on the Breathe Easy South Tyneside support group (based in South Shields), which has maintained a close association with the said District Hospital ever since the group was initially founded. This can especially be said for the hospital's Acute Respiratory Assessment Service (ARAS) team, which consists of several senior specialist nurses who often attend meetings and other local events hosted by the Breathe Easy group. This relationship is key to not only this chapter specifically but also the dissertation as a whole, as it speaks to the question of how communities are formed around breathlessness. The chapter looks closely at the biosociality around biopolitical needs (where especially biological and patient citizenship are of interest), and further illustrates how a hospital can mould into the actual backbone of a community. More specifically, I look at this through the lens of hospitals as *anchor institutions* (Stewart, 2019)—a concept which emerged in the 2000s "as a new paradigm for understanding the role that place-based institutions could play in building successful local economies and communities" (UK Commission for Employment and Skills, 2015: vii). I parallel this with how my interviewees talk about the hospital services as a *safety net*, which in itself speaks well to the understanding of Breathe Easy groups as safe spaces. Through the empirical data presented, this chapter sheds light on where biosociality and biological citizenship intersect. As Rose and Novas write (2005), biological citizenship also has a collectivising moment. Looking back to Rabinow's work (1992, 2008), he shows that new forms of biosociality and new ethical technologies are being assembled around the proliferating categories of "corporeal vulnerability, somatic suffering, and genetic risk and susceptibility" (in: Rose & Novas, 2005: 442). Biosocial groupings have a long history (Ingold & Pálsson, 2013) and as Rose and Novas write, medical activism by those who refuse the status of mere 'patients' long predates recent developments in biomedicine and genomics (2000; 2005). This deliberation is at the heart of the chapter, where it further illustrates how biosociality can be applied, analytically, to bridge dialogues between subjective and collective bodily experiences of health, illness, and wellbeing.

The chapter is organised as follows: following a theoretical introductory annotation, I briefly draw out the significant history and socio-economic conditions of the metropolitan borough of South Tyneside. I do this in light of the effects that neoliberal practices have on public health and health care in the UK (King & Wood, 1999; Fuchs, 2016), where for many reasons South Tyneside is considered a vulnerable community. Additionally, South Tyneside is also considered a 'hotspot zone' when it comes to respiratory disease (COPD and mesothelioma, especially) which plays further into the area's socio-political vulnerability (British Lung Foundation, 2007b). In the section that follows I attend to what is known as the *Path to Excellence* programme. This is a government-led transformation of healthcare provision throughout the borough of South Tyneside and the neighbouring City of Sunderland, which due to its nature has been named the *Pathways to Closure* by locals in these two communities (Pollock, 2019). While framed as a ‘partnership’ this programme acts as a modern example of neoliberal deregulation in UK health care, where vulnerable communities have been promised improvements but experience nothing but closures and downsizes in their local hospital services.

This is especially true for the South Tyneside District Hospital, where major services have been relocated to Sunderland. The chapter details this transition, where it specifically focuses on how Breathe Easy South Tyneside made significant alterations to its operation to further support the District Hospital. I illustrate this journey in the later sections of the chapter where I first detail people’s experiences of the hospital services, and then draw out the shifting conditions (Caldeira, 2015) which were set in motion by the Breathe Easy group itself.

***ADVOCACY* AS POLITICAL PROJECT**

This chapter seeks to examine the meaning of *patient advocacy*, and how this practice parallels with Breathe Easy groups and their multifaceted undertakings. The chapter does so, more specifically, by looking at the Breathe Easy group in South Tyneside and the role this group holds within its community. However, as Hyland (2002) writes, there is still no clear consensus as to the meaning of patient/client advocacy and autonomy. Moreover its compatibility with nurses’ “proclaimed role as patient advocates is questionable” (ibid. 2002: 472). As a result, “it remains unclear what advocacy actually entails and what values it ought to embody” (Schwartz, 2002: 37). For a patient advocacy organisation (like Breathe Easy) advocacy may come to revolve around empowerment and protecting personal autonomy, “where patients representing themselves benefit from enhanced autonomy and informed consent” (ibid. 2002: 39). However, service-users are in varying states of vulnerability and may be unable to represent themselves in adequate ways.

On the other hand, for a nurse in their role as patient advocate, “advocacy is described as an act of informing and supporting individuals so that they may make the best decisions possible for themselves” (Boyle, 2005: 250). While the nursing profession may hold conflicts of interest in this area, research does support the need for external patient advocates; “especially where patients cannot advocate for themselves” (Schwartz, 2002: 40). Schwartz argues that advocacy embodies two related tensions. The first one is in regard to expectations: what can be deemed reasonable to expect from a healthcare professional, vis-à-vis what goes beyond a reasonable expectation. For example, as Schwartz writes:

> If advocates choose to represent patient perceptions unconditionally, they may find themselves going against their better judgment and being faced with professional or personal compromises that they aren’t prepared to make. This can create burdens, such as conflict with other professionals and may be supererogatory. (2002: 38)

In contrast, the second tension concerns the difficulty in distinguishing between “what is an actual representation of patients’ wishes, and what is an assertion of what the advocate believes to be in the best interests of the patient” (Schwartz, 2002: 38). If we are to assume that healthcare professionals ought to act as advocates, Schwartz asks “…would this invite paternalism?” (2002: 38). Patient advocates are more often than not described as those professionals who assist patients through the clinical event by providing clarification, education, and advice. However in this context “…it is not as a representative of the patient that the advocate acts, but as a representative of the system” (ibid. 2002: 38). Since the days of Florence Nightingale, patient advocacy has been put forward as an important nursing responsibility. Nightingale laid the foundation for patient advocacy by consistently insisting on quality of care, including a safe and clean environment and basic human rights for all. In line with the way in which the hospital has been understood as a therapeutic institution (Main, 1946) in healthcare research, the nurse-patient relationship has similarly been described as a therapeutic one. Moyle writes that the therapeutic notion has “received a great deal of attention, particularly in the psychiatric nursing literature” (2003: 103). What is more, it is a *caring* relationship (Granados Gámez, 2009), one which involves elements of person, health, surroundings, and nursing. In the words of Granados Gámez, the nurse-patient relationship is distinct in that it “provides nursing with an identity and differentiates it from other professions” (2009: 126). However, a therapeutic relationship does not necessarily come instinctively. In her study of mental health nurses, Moyle (2003) illustrates that there may be a dichotomy of expectations between nurses and their patients. As she writes,

> …there was a dichotomy between the close relationship expected by patients and the distant relationship provided by nurses. It is unclear whether nurses' distancing behaviour was as a result of the participant's depressive illness, [was] a normal part of nursing practice, or whether other [factors] such as nurses' workloads were an influencing factor. (Moyle, 2003: 103)

While the positive benefits of a maintained nurse-patient relationship have previously been reported (e.g. Carol Ramos, 1992; Stuart, 2001; Hagerty & Patusky, 2003; Moyle, 2003; Mok & Chiu, 2004; Granados Gámez, 2009; Davoodvand et al., 2016; Gerber, 2018; Nsiah et al., 2019), this knowledge "has not previously been synthesized" (Strandås & Bondas, 2018: 11). In their meta-ethnography of the nurse-patient relationship, Strandås and Bondas illustrate that the bond between client and practitioner may in fact enhance patients' health "…not only with regard to illness, physical condition and treatment but also physical, emotional, mental and social well-being" (2018: 11). What is more, Strandås and Bondas also contend that the nurse-patient relationship has the potential to strengthen the "…patient's own resources towards maintaining health" (ibid.). This argument feeds well into the understanding of self-management practices (and the practice of autonomy), where "patients become less dependent on their physician for important decisions... [and] obtain the competence to intervene in their own treatment regime" (Willems, 2000: 27). Moreover, I argue that this also extends to cover self-help support groups, where the group settings themselves become a collective resource (or *technology*) for maintaining health and wellbeing through self-improvement. Or as Foucault (1988: 18) would have phrased it: a technology which permit

> …individuals to effect by their own means or with the help of others a certain number of operations on their own bodies [...] so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality.

As I came to observe at several Breathe Easy meetings, people's individual self-management practices not only drew from other members' but also established medical practice, which were taught to them by the nurses who visited regularly to give talks on respiratory health and medicine. This certainly applies to the Breathe

Easy group in South Tyneside, where selected nurses have been integral parts of the local group from the very beginning.

(i) Biological citizenship

The notion of *patient advocacy* is evidently far from clear cut and may come to involve several agents and actors on different levels of the system. Nevertheless, these tensions noted by Schwartz (2002), however sound they may be, refer solely to the conditions that apply to an external patient advocate rather than to the patient *as* advocate. I find this intriguing and problematic, almost as if the patient simultaneously cannot be an agent as well. My approach towards patient advocacy in this chapter centres on the patient as an advocate for their own benefits, using their own voice. The phenomenon of patient advocacy (where the *patient* is the advocate) parallels well with what Petryna defines as biological citizenship: "a massive demand for but selective access to a form of social welfare based on medical, scientific, and legal criteria that both acknowledge biological injury and compensate for it" (2002: 6). Through biological citizenship, health becomes a "political project" (Petryna, 2002: xxv) which speaks to a failure of "politics and science to account for human welfare, compounding vulnerability for citizens whose practices of survival have never fit neatly into our efforts to conceptualize them" (ibid.). This aligns with my argument for why self-help and mutual-aid support groups continue to grow in numbers. Namely, due to increased neoliberal deregulation of health care systems across the world, whereby healthcare services are continuously individualised (Trnka, 2017; Kenner, 2018), the number of support groups grow as collective biosocial responses to "political failures in responding to biomedical misconducts" (Kasstan, 2019: 10).

Petryna locates the notion of biological citizenship as a particularly post-socialist phenomenon in which, as Mulligan writes, "citizenship claims were being radically transformed in the wake of state building projects in the former Soviet Union" (2017: para. 2). She first introduced the term in her ethnography of the aftermath following the Chernobyl disaster, named *Life Exposed* (2002). Nevertheless, the term has not remained static but been developed and reconceptualised by several scholars following in Petryna's footsteps. One such scholar is Nikolas Rose (2007), who together with Carlos Novas wrote a paper reflecting on global transformations in citizenship and contending that new forms of biological knowledge are increasingly connected to citizenship projects (Rose & Novas, 2005). This speaks well to Rabinow's thoughts on the transition from sociobiology to biosociality (1992, 2008), which I have outlined more thoroughly in Chapter 2.

Other scholars who also have examined the rapport between biology and citizenship are João Biehl (2009) and Vinh-Kim Nguyen (2010). Both these authors offer novel ways of looking at "changes in people's identity resulting from their biological condition" (Russell et al., 2016: 1448) and particularly in interactions with institutional bodies (governmental or otherwise). Biehl examines the political economy of pharmaceuticals in Brazil, looking specifically at the universalised access to life-saving HIV/AIDS therapies (2009). While Brazil has been the first developing country in the world to implement such a policy, Biehl illustrates how it in fact proved difficult to implement the policy amongst the more underprivileged subpopulation, who are "often stigmatized as noncompliant or untreatable, becoming invisible to the public" (2009: 376).[50] Biehl's use of the patient and pharmaceutical citizenship notion is directly informed by Petryna's work on biological citizenship, and especially draws from the context of struggle for care and

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[50] This parallels with the concept of so-called *hard-to-reach* groups, which has an extensive body of literature behind itself (e.g. Freimuth & Mettger, 1990; Flanagan & Hancock, 2010; Kovandžić et al., 2011; Lamb et al., 2012; Bonevski et al., 2014; Kasstan, 2019). These groups may include "drug users, people living with HIV, people from sexual minority communities, asylum seekers, refugees, people from black and ethnic minority communities, and homeless people" (Flanagan & Hancock, 2010: 1). However, as Flanagan and Hancock write, "defining the notion of the 'hard to reach' is not straight forward" (2010: 1) and remains a highly contested and ambiguous term. In many ways, the groups often named "hard-to-reach" may not be as hard to reach as they habitually are profiled to be, but rather they are rendered hard-to-reach and subjected by the structural violence and social inequalities that permeates society. In a Foucauldian (and draconian) sense, hard-to-reach groups are rendered hard to reach because they are deemed abnormal (Foucault, 2003a)—or even pathological (Canguilhem, 1989 [1966]). As Kasstan writes, hard-to-reach groups "at the margins of society can be likened to being socially, economically, or politically disenfranchised—or what is also termed 'underserved'" (2019: 6). The stigma, as Biehl writes (2009), lies in that the noncompliant behaviours (making the groups "hard-to-reach") are seen and understood as self-inflicted rather than a consequence of already existing social inequalities, which renders the groups even more invisible (*and* hard-to-reach) from what they already were.

accountability following Chernobyl (Biehl, 2009: 411). In a similar manner, Nguyen (2010) draws on his experiences as a physician and anthropologist in Burkina Faso and Côte d'Ivoire (specifically the period between 1994 and 2000) around the time that global health organisations around the world acknowledged a right to treatment of HIV, thus making antiretroviral drugs more accessible. In times when being "able to talk about oneself became a matter of life or death" (Nguyen, 2010: 87)—in this case, access to life-saving HIV medications—Nguyen shows how the notion of therapeutic citizenship contrasts with other forms of citizenship also mediated by biomedical categories. More specifically, while therapeutic citizenship is also conditioned by biological knowledge and biomedical practice, it "differs from the 'biological citizenship' […] in that it arises where large, stable institutions that can grant access to life-saving therapy are absent" (Nguyen, 2010: 109).

In making sense of these patient-citizen practices (and especially in relation to the current events around the North East of England), I return to Foucault's political philosophy which details how in the pronounced (post)modern world, economic productivity is closely associated with political powerlessness and docility. Nowadays these said practices of economic productivity are equated with neoliberal governance (Lemke, 2001; Peters, 2007; Cotoi, 2011; Lemm & Vatter, 2014), whereby Foucauldian theory specifically refers to neoliberal governmentality as a particular form of post-welfare state politics where the state essentially outsources the responsibility for ensuring the well-being of the population (Hamann, 2009; Dilts, 2011). I contend that this economic productivity can be said to go hand in hand with the global phenomenon of support groups and their increasing popularity. Yet such economic productivity also coincides with contemporary practices of respiratory care in the UK, where individualisation is key and has led to several shifts in both collective and institutional responsibility across the healthcare system (Worth et al., 2011; Geddes, 2016; see also Kenner, 2018). My argument stems from observations made around South Tyneside especially, which grew out of interactions with the local Breathe Easy group and their relationship with the South Tyneside District Hospital. That is to say, the hospital's changing circumstances had a direct effect on the ways in which this particular support group organised themselves on an everyday basis in relation to the hospital itself, the local community, and the British Lung Foundation.

(ii) The hospital in ethnographic description

In this section I deliberate on how hospitals have been conceived from an ethnographic point of view. That said: where do we place the hospital vis-à-vis notions of biological and patient citizenships? Hospitals; only buildings "until you hear the slate hooves of dreams galloping upon its roof" as Richard Selzer writes (1987: 238), are united by their mission and by a long history of caring for communities (cf. Risse, 1999). Rural hospitals, in particular, are vital parts of their small communities and South Shields provides a contemporary example of this.

In *The Birth of the Clinic*, Foucault (2003 [1973]) chronicles the rise of the medical industry in the eighteenth and nineteenth centuries, linking its growth directly to the expansion of medical knowledge (see also: Hancock, 2018). In detail, Foucault writes about the development of *la clinique*—the teaching hospital—as a medical institution, where he also identifies and describes the concept of *Le regard médical* (what we call "the medical gaze") as well as the epistemic re-organisation of the research structures of medicine in the production of medical knowledge. In the genealogy of medicine (knowledge about the human body) (Wang et al., 1999; Coslett et al., 2002; Daneski et al., 2011), the term *Le regard médical* identifies the doctor's practice of objectifying the body of the patient; separate and apart from his or her personal identity, or "the medical separation between a patient's body and his identity" (Hancock, 2018: 443). As Hancock writes, this detachment or dehumanisation of the body into an object of analysis (to be isolated, probed, analysed, examined, and classified) "became the basis on which medical knowledge was developed" (ibid.: 443). As such, this 'gaze' stands significant in understanding not only the role of the hospital as an institution throughout history—but also the social expectations maintained between medical professionals and their patients (i.e., service-users). In the treatment of illness and disease, Foucault writes (2003 [1973]), the intellectual and material structures of *la clinique* made possible the inspection, examination, and analysis of the human body. Having that said, the clinic was also part of the socio-economic interests of power (Daneski et al., 2011; Stewart, 2019). Consequently, when the patient's body entered the field of medicine, "it also entered the field of power where the patient can be manipulated by the professional authority of the medical gaze" (St. Godard, 2005: 1072). In sum, while hospitals invite "mankind to heroism" (Selzer, 1987: 238), the development of these institutions allowed for the essential part of a new art of medicine "through the observation of patients in their beds and the extension of the doctor's gaze into the 'field of signs and symptoms'" (Daneski et al., 2011: 372). It turned patients into subjects; setting out hospitals to become the disciplinary institutions (and institutions of confinement) they are to this day (Finzsch & Jütte, 2003).

These interests of power notwithstanding, hospitals attracted little attention from ethnographers when the discipline was still young, where social scientists "who were interested were mainly sociologists [...] focusing on structural and organisational aspects of hospitals as institutional systems" (Long et al., 2008: 71). Nevertheless, Long and colleagues write (2008: 71) that the first bidding to conduct hospital ethnography may have come from Michael M. Davis in 1930. Through his comments on the public investment in U.S. American hospitals, Davis placed the hospital under three categories. To patients and their families the hospital becomes "a battlefield between life and death, the focus of intensive anxieties and hopes" (quoted from Coser, 1962: 3). On the other hand, to a medical practitioner the hospital is an institution for the practice of medicine; "a central agency through which the study of disease is pursued, the boundaries of medical science widened, and medical skill increased" (ibid. 1962: 3). Yet from the view of capitalists, businessmen or taxpayers, the hospital "represents a financial enterprise" (ibid. p. 3). This last category becomes especially interesting in light of the current NHS funding crisis in the United Kingdom (Gorsky, 2008; Appleby, 2019); which is, in fact, said to be the underlying reason behind the creation of the Path to Excellence programme affecting South Tyneside and the City of Sunderland.

The notion of the hospital as an enterprise folds well into the practice of neoliberal governance—a framework also known as the *neoliberal project* (Larner, 2003). Neoliberalism is, undoubtedly, "one of the most powerful concepts to emerge within the social sciences in the last two decades" (Springer et al., 2016). In anthropology, neoliberalism denotes a "wide array of political contexts and socioeconomic phenomena" (Ganti, 2014: 91). Looking beyond the anthropological scope, Thorsen and Lie write that neoliberalism is "the dominant ideology shaping our world today" and further suggest that we now perhaps live in "…an age of neoliberalism" (2007: 33). Neoliberalism comprises of three core principles: "individualism, free market via privatization and deregulation, and decentralization" (McGregor, 2001: 82). Within the context of globalisation, neoliberal reforms have led to deep changes in healthcare systems around the world "on account of their emphasis on free market rather than the right to health" (Sakellariou & Rotarou, 2017: 1). Even global institutions such as the World Health Organization and the World Trade Organization, having been consumed by neoliberalism, "fail to act decisively to reduce poverty and inequality and thereby do all too little to promote population health at a global level" (Mooney, 2012: 383). As such, McGregor writes, we must broaden our analysis of health care by understanding and challenging the neoliberal mind set (2001: 82). This dissertation offers such an analysis precisely by looking at the political economy of respiratory disease.

In their review article of the hospital ward as an ethnographic field, Long and colleagues (2008) draw out numerous significant discrepancies detailing how the hospital takes (or is given) its place in human society. From a postmodern view, the hospital can be understood as a system of practices which come to act outside the scope where other social institutions (governmental or otherwise) habitually come to maintain their functions (Risse, 1999; Griffin, 2011). Irrefutably hospitals serve their communities (and their societies), yet they also serve in the name of 'the greater good' (cf. Kirkwood, 2009). Where one draws the line between who is (and who is not) eligible to access care is ultimately a political decision (cf. Blendon & SteelFisher, 2009; Khan & Hashmani, 2018)—rarely a moral or idealist one. There are several analytical lenses which would provide further insights to these queries:

the hospital-as-island and the hospital-as-culturally-embedded (Long et al., 2008: 72), for instance.

The notion of the hospital as 'an island' was initially framed by Coser, who in her work turned the hospital 'exotic' by calling it a "tight little island" (1962: 3). As Long and colleagues write, "as an island, [the hospital] cuts its inhabitants off from the 'continent', the world where 'normal life' takes place" (2008: 72). The hospital-as-island metaphor parallels well with the concept of *non-places* coined by Marc Augé (1995), which refers to spaces where issues of relationships, history, and identity are erased. Augé contends that non-places are defined on precisely as what 'place' is not. These concepts are opposed polarities, where place "is never completely erased" whereas a non-place is "…never totally completed" (Augé, 1995: 79). Like palimpsests, identity and relationships are ceaselessly rewritten. In contrast, Tim Cresswell defines 'place' as

> how we make the world meaningful and the way we experience the world. Place, at a basic level, is space invested with meaning in the context of power. (2014: 12-13)

Power relations play a central role (much as we can see in the relationship between doctors and patients), and Cresswell is on-target when he defines place through a context of power—especially as "somebody, at some point, has decided that a space becomes a place worth stopping for" (Egeler, 2020: 28). While the stop points, as such, are temporary in nature this very much extends to hospitals as well, as much as it does to any places of worship or pilgrimage. As Augé contemplates, there is a break or discontinuity between "the spectator-traveller and the space of the landscape he is contemplating or rushing through" (1995: 84). On the other hand, Merriman (2004, 2009) looks at this relation differently. In acknowledging that spaces or landscapes of travel and mobility often are portrayed as *non-places*; being placeless, or even ageographical (Sorkin, 1992), Merriman examines the ways in "which the design, construction and use of a specific motorway led to its 'placing' in very particular ways at different times" (2004: 146). In truth, Merriman

> …attempt[s] to utilize a more open, relational and inclusive working of place… in which the movements of travellers are not seen to be movements *across* the landscape; rather these flows and associated frictions and turbulences are integral to the construction and performance of landscapes and places. (ibid.: 146)

Place, or ‘anthropological place’ (meaning how *place* is applied within anthropological practice) (Augé, 1995: 52), Merriman writes, “is seen to be localized, familiar, known, organic, occupied and meaningful (to its occupants and observers)” (2004: 148). That is to say, “a space where identities, relationships and a story can be made out” (Augé, 2000: 8). A *non-place*, on the other hand, effects a certain detachment between the individual and the spaces he or she traverses, Merriman argues. In the words of Augé, they are “the spaces of circulation, communication and consumption, where solitudes coexist without creating any social bond or even a social emotion” (1996: 178). Augé (1995, 1996) maintains that users (travellers or visitors) are unable to fully recognise their presence in non-places; while they may “encounter others and witness past and present events in these spaces, supermodernity has the effect of paralysing the individual, who becomes ‘merely a gaze’” (quoted from Merriman, 2004: 148). Having that said, while a person may be unaware of its presence (non-place or not), consciousness is not necessarily fundamental to receiving the benefits provided (*health benefits*, when referring to hospitals). As Kearns writes, “the taking of health care into communities both enhances the wellness of the population and positively enhances the experience of place for local residents” (1991: 519). Thus, as wisdom sits in places (Basso, 1996) so does health. As such, hospitals are also understood as *therapeutic institutions* (Main, 1946) and *geographies of wellbeing* (Schwanen & Atkinson, 2015), where the immense power of lived emotional experience is harnessed in the service of helping patients (Buechler, 2008). However, does health (in the widest regard) require *placeness* of its own? Not necessarily, from where I stand at least. Health sits in places but also in people, and their actions (Brown, 2007)—and as Kearns maintains (1991, 1993), one does not need to be conscious of the geographies to actually benefit from them. I reiterate what Merriman writes: rather than coining a new species of space/place (which is how many define ‘non-place’) we need to “rethink ‘place’ as open, dynamic, inclusive, relational and in process, rather than as closed off, organic, static and localized” (2009: 10).

Hospitals, much like airports and train stations (Augé, 2000), are often placed under the descriptor of ‘non-places’. They are transitory spaces where humans pass through, where the ‘poetics of a dwelling’ (Meljac, 2008; Shokouhi, 2019) does not exist, and residues from human practices do not accumulate. This further explains the principle of *medical neutrality* where alongside the physician’s code of ethics, “the clinic is a protected space” (Benton & Atshan, 2016: 151). In times of armed conflict and civil unrest physicians must be allowed to care for the sick and wounded, and soldiers must receive care regardless of their political affiliations. With this in mind, I read the concept of ‘non-place’ differently than most perhaps would. That is, I do not see a non-place (like a hospital) as not-a-place, lacking any kind of ‘placeness’ or meaningfulness that sits in (or are assigned to) spaces (Basso, 1996; Cresswell, 2011, 2014). Instead I differentiate ‘non-places’ from ‘places’ in terms of their temporality, or discontinuity, as Augé would say (1995: 84). As previously stated, these places are transitionary spaces and function according to mobility within (and across) society. Dwelling is not possible; forbidden even—or at least, not meant to be enacted and would, much like squatting, be a violation against social order (Höjdestrand, 2011; Vasudevan, 2014). This works well with Merriman’s (2004, 2009) definition and understanding of places (geographical), which considers how the *usage* of places affects their said ‘placeness’.

That being said, there are those scholars who have sought to turn this hospital-as-island (*non-place*) notion on its head. One of them is Zaman (2003, 2013), who in his ethnographic work of an orthopaedic ward in Bangladesh set out to analyse and understand the ward as a *microcosm* invaded and shaped by the values, rules, and ideas of the outside world. Zaman argues that in contrast to the assumed universalism in biomedicine, “biomedical practice is in fact a product of particular social conditions” (2013: 45) where the hospital comes to reflect the features of the society in which it is embedded. Van der Geest and Finkler conceive a similar viewpoint, where they write:

> First, contrary to a commonly held notion that hospitals are nearly identical clones of a global biomedical model, anthropologists are beginning to describe and interpret *the variety of hospital cultures in different countries* […] Second, and related to the first, *is that biomedicine, and the hospital as its foremost institution, is a domain where the core values and beliefs of a culture come into view* (2004: 1996, original italics).

As such, the hospital can be understood in manner of different ways. Culturally embedded or not, when push comes to shove there are two fundamental viewpoints (where hospitals are regarded) to which I would like to draw special attention in this section. In one way, they are opposed polarities—yet this interaction also illustrates the social conditions wherein biomedicine (as practice) has become a product (Lock & Nguyen, 2010). First, from a Foucauldian point of view, the hospital is seen as a *disciplinary institution* (Foucault, 1991 [1975]) where people are turned into subjects, made useful and obedient through the repression of any deviation from the norm (cf. Foucault, 1982). That is to say, a 'good' patient is an obedient patient (Jadad et al., 2003; Campbell et al., 2015)—and an obedient patient is a good patient citizen (Biehl, 2009; Nguyen, 2010; Heinemann, 2016). Yet from the view of a functionalist, the hospital also falls under the category of *anchor institution* (Birch et al., 2013; Goddard et al., 2014; Vize, 2018). An anchor institution is an organisation that comes to play a significant and recognised role in its locality by making strategic contributions to the local economy and the wellbeing of its population (Centre for Local Economic Strategies, 2015; UK Commission for Employment and Skills, 2015). The concept emerged in the 2000s as a "new paradigm for understanding the role that place-based institutions could play in building successful local economies and communities" (UK Commission for Employment and Skills, 2015: vii). Anchor institutions are usually not-for-profit and tend to remain stagnant in their geographical settings even as conditions change around them. Ethnographically speaking the hospital can be many things, and ethnographers are not short of metaphors to describe its wide array of underlying conditions. Different, yet the same, it is important to understand and recognise that hospitals are *complex adaptive systems* which "exist in a dynamic state with multiple interacting agents" (Barasa et al., 2017: 104). Furthermore, in regard to political interventions Barasa and colleagues write that policy makers ought to

> …proactively think about and anticipate the likely effects—positive or negative—of policies on the various components of the system as well as the full range of actors and stakeholders. (2017: 112)

Reading this quote, I cannot help but to think back on the Path to Excellence programme: were these aspects neglected? Nevertheless, while perhaps trivial, what this chapter has set out to disentangle is the question as to what a hospital may actually come to mean for its local community and service-users. As Stewart contends, by asking *what hospitals are* we are able to "rethink the gap between organisational narratives of healthcare, and the everyday lived experiences of users and staff within healthcare facilities" (2019: 1253). The chapter asks this question in light of the current situation in South Tyneside. Looking closely at the relationship between the South Tyneside District Hospital and its service-users (where the SSTHC has come to act as a communal voice), it is evident that the District Hospital can be understood as an anchor institution. In supporting the wider community that is South Tyneside, this hospital now acts beyond healthcare practice—which is where my argument takes its shape. The hospital as anchor institution speaks to the uniqueness of its 'placeness'. While perhaps an island (Coser, 1962) the hospital is not 'less of a place' merely neutral ground; a refuge in discontinuity, which allows for the medical neutrality to persist. Moreover, universal access to health care (without discrimination) is a human right enshrined in the Universal Declaration of Human Rights and the International Covenant on Economic, Social and Cultural Rights (OHCHR & WHO, 2008). By contrast, human rights in patient care specifically address "stakeholder rights *inside* health care settings—be they hospitals, clinics, outreach facilities, places of detention, or private homes—and in the particular context of patient care" (Cohen & Ezer, 2013: 7 ff.), which may be defined as services rendered by health providers for the benefit of patients.

Following this deliberation, in the next section I attend to the history of the community of South Tyneside in more detail where I particularly focus on the borough's professed socioeconomic vulnerability. In a sense, this vulnerability speaks to the 'placeness' of South Tyneside and further explains the relationship that now exists between the borough, its people, and the said District Hospital.

SOUTH TYNESIDE: A VULNERABLE COMMUNITY

> South Tyneside is dominated by the seaside town of South Shields, east of Jarrow, a town built on coal and shipbuilding. Although all the coal mines have now closed and ships are no longer built there, the Tyne is still busy with ship repairs and offshore oil platforms, but light engineering and electronics companies have replaced some of the heavy industry. (British Lung Foundation, 2007b: 47)

While doing fieldwork I was told a numerous time by locals how South Tyneside (Figure 6.2) is a "vulnerable community". This can be likened to the concept of a *vulnerable population* (Flaskerud & Winslow, 1998; Sutton et al., 2003; Alexander, 2010; Quesada et al., 2011; Waisel, 2013; Bain et al., 2016; Óskarsdóttir et al., 2016). That is to say, groups of people (or *communitas*) which include

> …patients who are [from] racial or ethnic minorities, children, elderly, socioeconomically disadvantaged, underinsured or those with certain medical conditions. Members of vulnerable populations often have health conditions [which] are exacerbated by unnecessarily inadequate healthcare. (Waisel, 2013: 186)

What is more, as Waisel writes, vulnerable populations are often "at risk for disparate healthcare access and outcomes because of economic, cultural, ethnic or health characteristics" (2013: 186). Nevertheless, while undoubtedly applicable to this specific case study, this statement may be interpreted in a number of different ways. Nevertheless, the people I engaged with primarily seemed to refer to the community's socio-economic status—in conjunction with the health of the overall population (cf. Metcalfe, 2015). As research shows, socio-economic status (assessed by income, education, or occupation) intertwines and is linked to a wide range of health problems. More specifically it underscores three major determinants of health: health care, environmental exposure, and health behaviour (Adler & Newman, 2002). This is especially true for respiratory health in the United Kingdom and the various diseases that may affect the respiratory system, all of which "continues to be a major factor in health inequalities" (Marmot, 2016: 3).

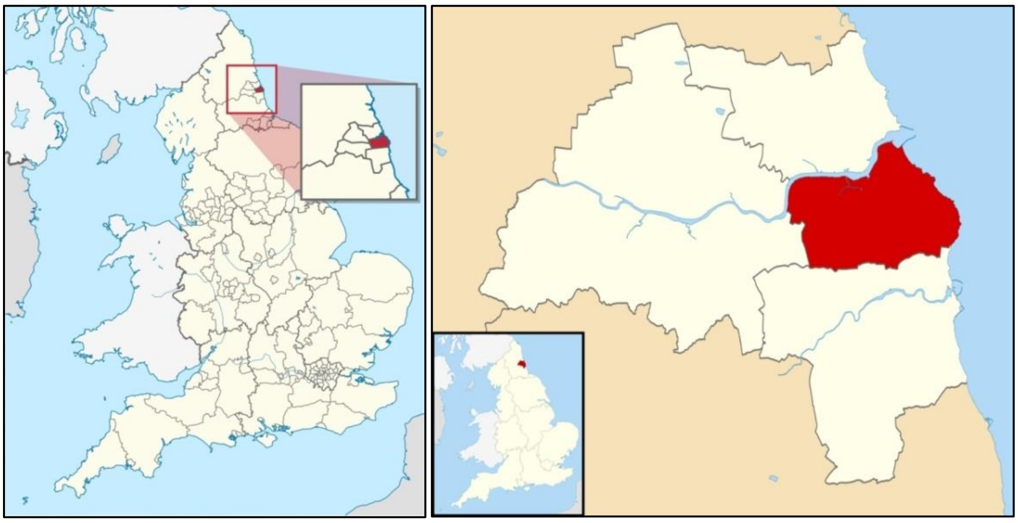

Figure 6.2: The metropolitan borough of South Tyneside.

(© Wikimedia Commons)

In regard to neoliberal governance and its effect on communities around the United Kingdom, the borough of South Tyneside is a region which has seen a "decline in its traditional industry and suffers from significant socio-economic deprivation" (South Tyneside Council, 2017: para. 4). This deprivation can be traced back to former Prime Minister Margaret Thatcher and her politics, whereby the deregulation of certain key industries resulted in a decline of the North.

> When Britain's first female prime minister was in her pomp, northern football fans travelling to away games in London would be taunted by home supporters waving wads of £10 and £20 notes. The brutal repartee of the terraces expressed a fundamental truth of the Thatcher period: the north suffered the worst of the deep recession and high unemployment of the early years; and it benefited least from the eventual boom of the late 1980s. (Coman, 2013: para. 8)

Historically South Tyneside's main industries have been shipbuilding and coal mining, similar to the rest of the North East of England (Thirlway, 2015; Perry, 2019). However the last shipbuilder (Readheads Shipyard) closed in 1984 and the last coalmine (Westoe Colliery) closed in 1993 (South Tyneside Council, 2017). Readheads Shipyard (initially *John Redhead and Sons*) was founded as a business back in 1865 and was a major influence in the social and economic development of South Shields, the main administrative centre and largest town in South Tyneside. The Westoe Colliery opened in 1909 and was at that time one of many coal mines in the local area. When the colliery closed in May 1993 it was, however, the very last pit of its kind around the Tyneside area (The Durham Mining Museum, 1999-2019). The decline of these industries around Tyneside resulted in mass unemployment. In more recent years, however, this trend has reversed, and South Tyneside now attracts new industries, most notably in the service sector. In 2001 the service industry was the largest sector of South Tyneside's local economy "employing 63% of all workers" (South Tyneside Council, 2017: para. 4).

(i) Respiratory health in South Tyneside

When it comes to respiratory health, South Tyneside is a so-called "hotspot zone" (British Lung Foundation, 2007b: 47) for diseases of the chest and lungs; a position it shares with e.g. Greater Glasgow, Lanarkshire, and County Down in Northern Ireland (Figure 6.3). In disease epidemiology, hotspots (or spatial clusters) are "areas of elevated incidence or prevalence, higher transmission efficiency or risk, or higher probability of disease emergence" (Lessler et al., 2017: 1270). However despite being increasingly applied in policy making, the term itself remains "vague and rarely defined precisely" (ibid. 2017: 1270), and this obscurity continues to generate confusion amongst professionals. For example, Lessler and colleagues write (2017: 1270) that at the December 2014 Cholera Round Table in Kinshasa (DR Congo) the focus was on targeting cholera hotspots. However

> …attendees expressed considerable confusion about precisely what a hotspot was and how it differed from previous concepts like cholera "sanctuaries." Such confusion can have significant repercussions, potentially leading to misinterpretation of policy recommendations or misallocation of resources in countries that can ill afford to do so. Hence, clarity and precision are needed in the use of this evocative term.

The ambiguity of the term notwithstanding, with regards to the borough of South Tyneside this region is particularly a hotspot zone for two respiratory conditions: chronic obstructive pulmonary disease (COPD) and mesothelioma (British Lung Foundation, 2007b, 2016).

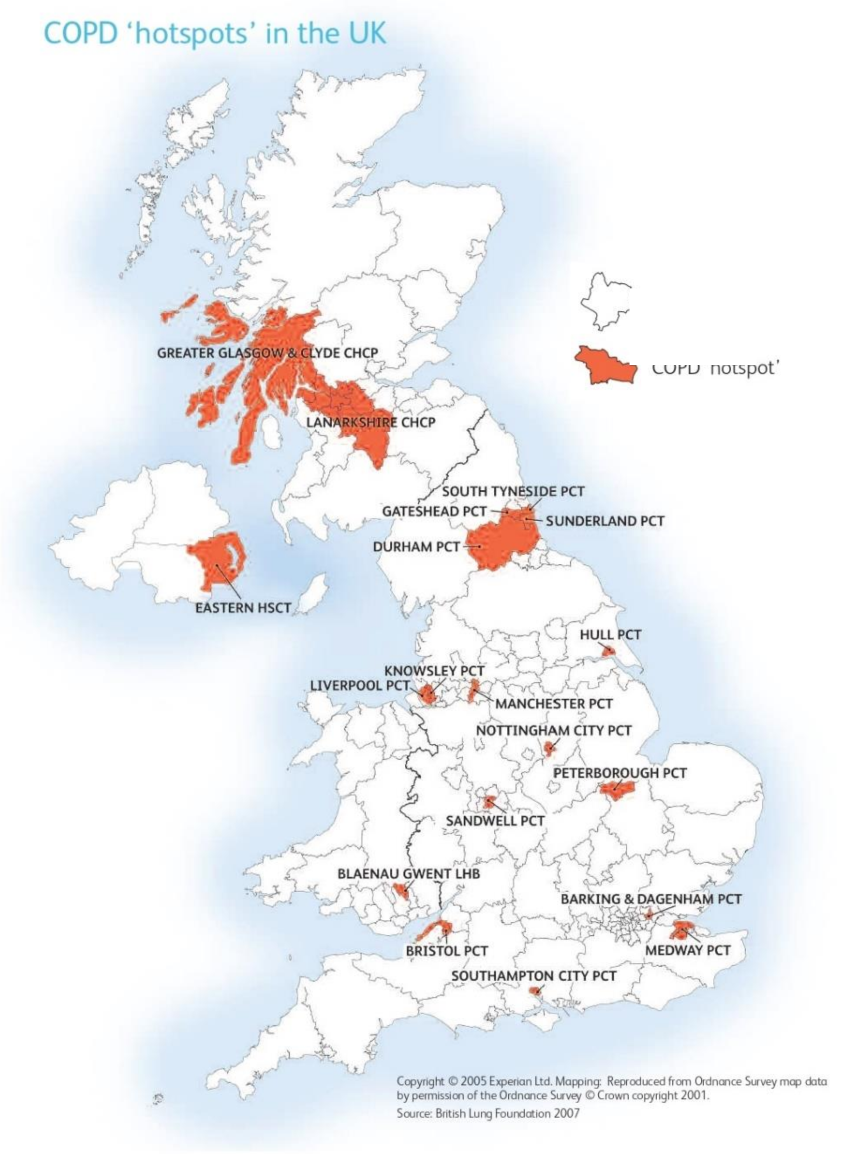

Figure 6.3: COPD hotspot zones in the United Kingdom.

(©British Lung Foundation, 2007b: 40; edited by Nyman)

Mesothelioma is a type of cancer[51] which grows in the pleural membrane. This is the name for the "two thin layers of cells (the pleura) that line the outside of the lung and the inside of the chest" (British Lung Foundation, 2016: 49). The main cause of mesothelioma is breathing in asbestos[52] dust, which makes it an occupational disease due to exposures in certain workplaces (Waldman, 2011). As such, the high rates of mesothelioma in South Tyneside can most likely be explained by the borough's strong history of steel and shipyard industries, where exposure to asbestos was especially prevalent throughout the 1950s during the conversion of steam ships to oil and diesel (Leigh Day, 2019). This process involved "large quantities of asbestos lagging being removed from the pipework" (Leigh Day, 2019: para. 3) where asbestos dust ended up on the floor and then dry swept away.

Mesothelioma often has a poor prognosis, where typical survival rate is between 12 and 21 months depending on the stage of disease at diagnosis (British Lung Foundation, 2016). Nevertheless, while "mesothelioma is incurable, with a median mortality of only eight months after discovery" (Rose, 2016: para. 1) statistics are mere abstractions which explain variation. Yet, as Rose writes, "[…] we tend to treat these abstractions as if they were real" (2016: para. 1) which may be more or less useful when it comes to understanding the disease condition. I have never personally met anyone living with mesothelioma or someone who has lost a loved one to the disease, thus this dissertation addresses mesothelioma only in terms of the context and mapping of the epidemiological landscape of South Tyneside.

More people are dying from mesothelioma in the region of Tyneside than almost anywhere else in the UK. "Alarming new figures reveal death rates in South and North Tyneside are more than twice the average for the rest of the country" (Thompson, 2015: para. 2) and according to the Office for National Statistics, the two boroughs "[…] have the second and third highest rates of mortality for the

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[51] Nevertheless, it is important to understand that cancer is not a single disease condition. There are many different types of cancer of which mesothelioma is just one (cf. Manderson, 1999).

[52] *Asbestos* is a term used to refer to six naturally occurring silicate minerals which were commonly used in buildings and as fire proofing from the 1950s to the mid-1980s. When fibres from damaged or disturbed asbestos are inhaled into the lungs, there is a risk of developing serious or even fatal diseases (Johnston & McIvor, 2000; Kazan-Allen, 2005; Waldman, 2011).

asbestos-related lung cancer in England and Wales" (Thompson, 2015: para. 3; see also Office for National Statistics, 2016). Overall, the North East of England holds one of the highest rates of mesothelioma in the world—largely because the UK permitted the use of asbestos long after other countries around the globe outlawed its use in 1991. In the UK, blue and brown asbestos materials were banned outright in 1985 whereas the import, sale, and second-hand reuse of white asbestos were not outlawed until 1999 (Johnston & McIvor, 2000; Kazan-Allen, 2005; Waldman, 2011). To further confirm this tendency, the British Lung Foundation writes in its *Battle for Breath* report (2016: 49)

> Incidence rates for mesothelioma increased over the last four decades. However, they were steady during the period 2008 to 2012, suggesting that they have, as expected, begun to plateau. This reflects the tail-off in asbestos use in the 1970s, before the complete ban on asbestos products in 1999.

When it comes to COPD, South Tyneside "has a higher proportion of people at risk of future hospital admission […] than anywhere else in the UK" (British Lung Foundation, 2007b: 47). Specifically, people are 62 percent more likely to be admitted to hospital with COPD than the UK average. Generally speaking urban areas in the North of England have higher hospital admission rates than the rest of the country (British Lung Foundation, 2016: 28), and lung disease mortality overall is highest in the North East together with the North West, urban Scotland, and parts of south Wales (Figure 6.4). These numbers are heavily influenced by the deaths from COPD and lung cancer, "[…] over 80% of which are smoking-related" (British Lung Foundation, 2016: 27). They also align well with the respiratory disease and COPD hotspot zones which I previously mentioned.

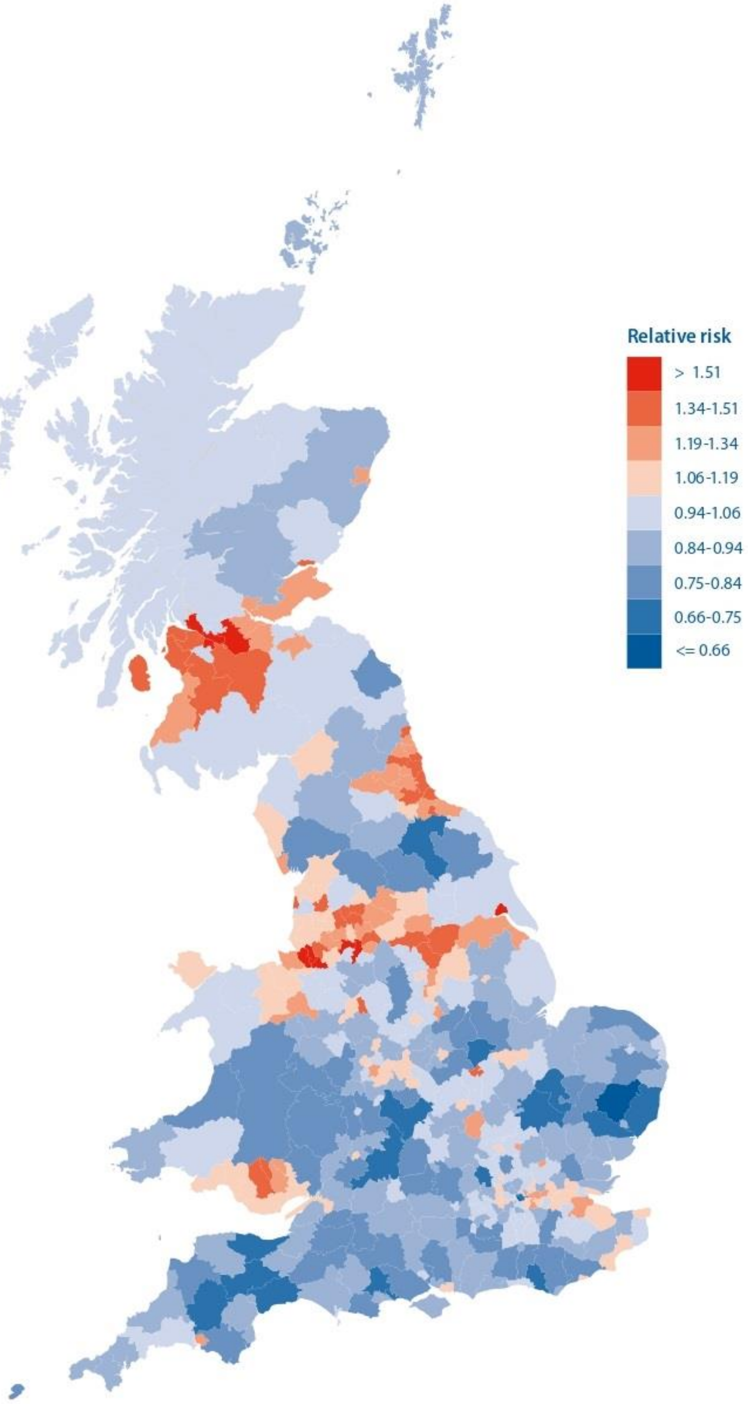

Figure 6.4: Adjusted all-cause respiratory mortality in Great Britain, 2008-2012.

(©British Lung Foundation, 2016: 29)

The need for respiratory services for local people in South Tyneside specifically has been stressed in “several Department of Health documents in recent years” (South Tyneside Council, 2017). Pulmonary rehabilitation is particularly emphasised as an intervention in these cases, due to its well-established effectiveness in helping people with chronic breathlessness. In fact, the NICE[53] guidelines recommend pulmonary rehabilitation as an important part in the management of several respiratory diseases—including but not limited to COPD, “in conjunction with optimal treatment and smoking cessation” (South Tyneside Council, 2017). These guidelines cover, for example, the diagnosis and management of COPD (including emphysema and chronic bronchitis) “in people aged 16 and older” (South Tyneside Council, 2017), where they more specifically aim to help people to receive a diagnosis earlier “[…] so that they can benefit from treatments to reduce symptoms, improve quality of life and keep them healthy for longer” (South Tyneside Council, 2017).

PATH TO EXCELLENCE: A TRANSFORMATION OF HEALTHCARE PROVISION

Having drawn out the wider context of South Tyneside, I will now return to a specific point in time for analysis in this chapter. I will examine certain reforms in healthcare systems across England and their implications for healthcare provision in South Tyneside. I am referring to the (now rather disreputable) NHS *Path to Excellence* which is being implemented across the metropolitan borough of South Tyneside and the City of Sunderland. As advertised on its webpage (pathtoexcellence.org.uk, 2019) the Path to Excellence is branded as a *five-year healthcare transformation programme* across South Tyneside and Sunderland, which has been set up to

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[53] The *National Institute for Health and Care Excellence* (NICE) is an executive non-departmental public body of the Department of Health in England. This public body was established “in an attempt to end the so-called postcode lottery of healthcare in England and Wales, where treatments that were available depended upon the NHS Health Authority area in which the patient happened to live, but it has since acquired a high reputation internationally as a role model for the development of clinical guidelines” (Timmins et al., 2017).

> […] secure the future of local NHS services and to identify new and innovative ways of delivering high quality, joined-up, sustainable care that will benefit the population both now and in the future. (ibid. 2019: para. 1)

The ambition, simply put, is to build "[…] outstanding future hospital services" and offer the very highest "[…] quality of patient care and clinical excellence" for each and every resident of South Tyneside and Sunderland (pathtoexcellence.org.uk, 2019: para. 1). However, the response from the local people living in these areas has been far from satisfactory, which I will illustrate throughout this chapter.

The Path to Excellence programme was first put into motion in March 2016 when the NHS Foundation Trusts of South Tyneside and City Hospitals Sunderland committed to "working more closely together as part of a strategic alliance to transform local healthcare services" (City Hospitals Sunderland and South Tyneside NHS Foundation Trusts, 2018: 1). This was just the first step however, and soon a merger of the two NHS Trusts was proposed. The reason behind the merger being put on the table (enabling the Path to Excellence programme to take form) allegedly stems from the current struggle within the NHS to cope with record-high demands, and where social care services are stretched to the limit (cf. Appleby, 2019). The overall strategic alliance rests on four pillars:

- **Changing hospital care alone** will not solve the pressures facing the NHS
- **Care in local communities** needs to expand and develop as that is where the vast majority of care takes place
- **More needs to be done to improve the health and wellbeing of the population** with a focus on preventing people becoming unwell in the first place
- **This needs to happen while we balance our finances** and plan for the future of services to support the growing population demands.

(pathtoexcellence.org.uk, 2019)

Taking this to heart, while the Path to Excellence programme was allegedly designed to improve healthcare services across the two boroughs—and as a result lessen the pressure on an already burdened NHS system—the proposals made were not taken well by the local populations in South Tyneside and Sunderland. Daniel (in his 60s), part of the local opposition, said early on:

> *If the [UK] government and NHS England approve the merger [of the two NHS trusts] […] it will show that they want the people of South Tyneside to have even less control over the fate of our hospital—that is what the merger is all about.*

The consensus, as I gathered from informal conversations with people at different Breathe Easy events around South Tyneside, was that the majority of people living in the region opposed the merger of the NHS Foundation Trusts of South Tyneside and City Hospitals Sunderland. Hospital staff were seemingly in agreement as well. One of them was Karen (in her 40s), a Respiratory Nurse Specialist at South Tyneside District Hospital, who told me that:

> *The fear for us [nurses]—and for other people as well—is that because the first three services under review [in Phase 1] have all been downsized, that's why people think: "What else is going to happen to this hospital?" But… we [my colleagues and I] think we're a pretty strong respiratory team, the consultants, and us [nurses]… and the amount of patients we're seeing, the things that we cover. So, hopefully… and we know the nature of the situation, we know that Sunderland [the hospitals] couldn't cope with all our patients, and we couldn't cope with Sunderland's… so maybe respiratory is one of the services that we might have to tweak. Some think so, but who knows? But, yeah, it's worrying for everybody.*

In terms of localised resistance, the most prominent movement against the Path to Excellence programme—the *Save South Tyneside Hospital Campaign* (SSTHC)—came into being in May 2016. This was two months after the agreement on a shared strategic alliance between the regions of South Tyneside and Sunderland. The campaign brought together residents from not only the town of South Shields but also Hebburn, Jarrow, and the Boldon villages (savesouthtynesidehospital.org, 2018b). However, in December 2018, despite local resilience and opposition against the forthcoming decision, the boards of South Tyneside NHS Foundation Trust (STFT) and City Hospitals Sunderland NHS Foundation Trust (CHS) agreed on a merger. With positive feedback from the overseeing public body, NHS Improvement, the hospital trusts officially merged on 1st April 2019 and became *South Tyneside and Sunderland NHS Foundation Trust* (STSFT) (Sunderland Echo, 2018/12/5).

As has been seen and advertised (Figure 6.5), the words ‘alliance’ and ‘partnership’ and their implication are significant in understanding how this healthcare transformation programme (Path to Excellence) has been portrayed and communicated to the locals of both South Tyneside and neighbouring City of Sunderland. Moreover, it is important to note that the SSTHC does not oppose collaboration across the two boroughs. On the contrary, the members welcome the possibilities it could bring about. However, as Daniel has stated repeatedly:

> *[…] the campaign is not and has never been against an alliance, or further collaboration of clinical services [between South Tyneside and Sunderland]. But we believe what is proposed [through Path to Excellence] is not based on strengthening vital services for the people of South Tyneside, but downgrading the hospital and moving services to Sunderland with the least opposition.*

Thus, Daniel believes that the merger was merely the first step in a meticulous plan to remove the layers of obstacles that comprise the two NHS Trusts, and their governors. By removing these obstacles, one would remove opposition to the closure of vital services at South Tyneside District Hospital.

Figure 6.5: An example of how the Path to Excellence was advertised locally around South Tyneside and Sunderland.

(©NHS South Tyneside and Sunderland)

(i) Phase 1 and 2: the relocation of hospital services

When it comes to changing the policies in relation to hospital practices, the Path to Excellence programme has been structured and scheduled in two phases, both of which focus and profile different “innovative ways of delivering” certain selected hospital services (pathtoexcellence.org.uk, 2019). The said targets have all been identified and designated by the Governing Bodies of South Tyneside and Sunderland clinical commissioning groups (NHS, 2019). Briefly speaking, a clinical commissioning group (CCG) is an NHS organisation set up by the Health and Social Care Act 2012[54] to organise the delivery of NHS services in England (NHS Clinical Commissioners, 2015). In turn, NHS hospital trusts are commissioned by the CCGs to provide secondary health services across England.

While neither of the two phases specifically addresses respiratory care services, they target other crucial hospital services. Phase 1 is marked for stroke, maternity, women’s healthcare (gynaecology), and emergency paediatric services (NHS South Tyneside and Sunderland, 2017). In contrast, Phase 2 involves emergency care and acute medicine, emergency surgery, and planned care (including surgery and outpatients) (NHS South Tyneside and Sunderland, 2018). Needless to say, while the initial programme itself is communicated as “Working together to improve hospital services in South Tyneside and Sunderland” (pathtoexcellence.org.uk, 2019), this healthcare transformation has so far unreservedly focused on relocating services from the South Tyneside District Hospital to the City of Sunderland. This is set out in the Path to Excellence Phase 1 Report (NHS, 2019), which provides an update on the issues raised in the advice accepted by the Secretary of State for Health and Social Care:

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[54] “The Health and Social Care Act 2012 is an Act of the Parliament of the United Kingdom. It provides for the most extensive reorganisation of the structure of the National Health Service in England to date. It removed responsibility for the health of citizens from the Secretary of State for Health, which the post had carried since the inception of the NHS in 1948. It abolished NHS primary care trusts (PCTs) and Strategic Health Authorities (SHAs) and transferred between £60 billion and £80 billion of ”commissioning”, or health care funds, from the abolished PCTs to several hundred ”clinical commissioning groups”, partly run by the general practitioners (GPs) in England but also a major point of access for private service providers” (Wikipedia contributors, 2020, January 11).

> 1. While the three options are being implemented, there needs to be further consultation and engagement, with a view to developing a better understanding about the bigger picture for healthcare in the area;
> 2. All inpatient stroke services should be consolidated at Sunderland Royal Hospital;
> 3. All obstetrics, inpatient gynaecology and special care for babies should be consolidated at Sunderland Royal Hospital with a free-standing midwife-led unit at South Tyneside Hospital;
> 4. Further work is required on long term options for paediatric emergency care as part of considering the future of the whole urgent and emergency care system for the area. In the meantime, emergency paediatric care overnight should be consolidated at Sunderland Royal Hospital. (*emphasis added*)
>
> (NHS, 2019: 3)

Simply put, all services included in Phase 1 will be relocated from South Tyneside District Hospital to Sunderland Royal Hospital leaving nothing but a midwife-led unit to cover some of the services previously provided. This decision has received much criticism from inhabitants of both South Tyneside and City of Sunderland (Pollock, 2019). People living around South Tyneside (my interlocutors included) are reportedly upset because, from their point of view, the overall process results in nothing but a downgrade of their local district hospital. In a similar manner, people living in Sunderland are anxious that this relocation of services will do nothing but overload the already stretched local services (Ledwith, 2019a; Pollock, 2019).

The public consultation for Phase 2 of the programme took place in early 2020. Responding to previous concerns raised throughout the implementation of Phase 1, Dr Shaz Wahid, Medical Director at South Tyneside and Sunderland NHS Foundation Trust, has stated that:

> Our aim [with Path to Excellence] is to create outstanding hospital services which provide the best working environment for our staff and offer the best possible care to our patients [in South Tyneside and Sunderland].
>
> To do this, we must look at transforming the way our services are arranged, whilst also meeting the challenges which the NHS currently faces.
>
> I would like to emphasise, once again, that both South Tyneside District Hospital and Sunderland Royal Hospital will continue to be here, but we must change the way we deliver services in order to protect them for many future generations to come.
>
> (Ledwith, 2019a: para. 5-7)

Nevertheless, Professor Allyson Pollock writes that these plans “are driven by deficits not local needs” (2019: para. 11). As she explores through personal anecdotes:

> I visited the South Tyneside DGH on a sunny evening last month. Even at first glance it is clear that it is a well-loved and well cared for hospital. The large multi hectare site has an up-to-date emergency A&E, an Urgent Care Centre, the Children's A&E, outpatients diagnostics, a maternity wing with birthing pool, and theatre suites, all upgraded within the last decade. The trust has a rich estate; it owns Palmer Community Hospital, Clarendon, and Primrose Hill Hospital in Jarrow. These are valuable assets, which Sunderland Royal was keen to get its hands on, not least having sold off a great deal of its own land and buildings. (2019: para. 15)

Known for opposing the continuous privatisation of the NHS throughout the UK (Pollock & Leys, 2005; Mandelstam, 2007; Niemietz, 2016), Pollock has been a prominent contributor and supporter of the SSTHC in South Tyneside. She has, for instance, made numerous appearances and contributions to public debates and discussions across the borough (as well as the UK overall) in support of the hundreds of campaigners who work to safeguard the future of health services. This despite, as she has said, these campaigns are largely being “[…] ignored by the national and even local media” (*Personal communication*, 2019/07/26).

Determined to follow the Path to Excellence programme in all respects, Pollock (2019) has worked to expose the whole corporate direction towards which the UK government is driving NHS Trust Boards across the country (cf. Pollock & Leys, 2005; Mandelstam, 2007). What supposedly are on the agenda in particular, according to Pollock, are mergers (as with South Tyneside and Sunderland) which all go hand in hand with deregulation and the reduction of services, as well as the conception of private companies that are increasingly involved with the NHS (Pollock & Leys, 2005). In a meeting with the SSTHC at the Brinkburn Community Centre in South Shields (July 2019), Pollock pointed out how the government proposals to switch to alternative ways of funding the NHS. Rather than through the habitual *private finance initiative* (PFI), the UK government now aims to persuade county and borough councils across the UK to raise bonds to finance hospitals—while at the same time councils themselves are facing cuts to the services they aim to provide (Joseph Rowntree Foundation, 2015).

This process has taken place in South Tyneside and Sunderland, where the local South Tyneside Council and Sunderland City Council have been asked to provide financial support to Phase 2 of the Path to Excellence programme. As the SSTHC details on their website:

> Health chiefs are hoping to get a cheap loan from our council, but we think that this will also force the council to 'buy into' this second phase without knowing what it really entails, and if they buy into it then the council will be less likely to oppose the loss of services. Phase-1 was referred to the Secretary of State by the Joint South Tyneside and Sunderland Health Scrutiny Committee, but they may feel that they have less freedom to do something similar again if they are involved in funding phase-2. (savesouthtynesidehospital.org, 2018a)

Pollock agrees with this argument, stating that the financial reserves held by the councils should not be tied into new forms of project funding for hospitals and NHS services across the country (*Personal communication*, 2019/07/26). Labour MP for South Shields, Emma Lewell-Buck, is also against these proposals:

> I wrote to the leader of the council on the 28th of May 2019, asking specific questions about this loan being sought by the hospital Trust from the council. I received no reply to any of those questions.
>
> […] It is my opinion that [Path to Excellence] will downgrade our hospital, and the evidence is stronger than ever to demonstrate that. It concerns me greatly that the Labour Group statement mentions none of these losses. The prospect of the council giving a £35-million loan to the Trust to enable it to continue with this 'path to disaster' beggars belief! A loan of this magnitude will need sign-off from the councillors. The smoke and mirrors around this are - as always - obfuscating the reality. If the loan is granted by the council, then that becomes the responsibility of South Tyneside council-tax payers, in the same way that if you act as a guarantor, you are responsible if the loan is not repaid.
>
> Do we actively want to facilitate the downgrading of our own hospital services? I certainly do not support it in any way and I urge councillors to do the right thing, with the interests of the people of South Tyneside at the forefront of their minds, by voting against this loan – because if the loan does not go ahead, the "Path to Excellence" is dead, the government won't pay for it.
>
> (savesouthtynesidehospital.org, 2018a)

The NHS was created in 1948 with a budget of £437 million (Sheard, 2011) born out of an ideal that good healthcare should be available to all regardless of wealth. Since its launch the services have been "98.8% funded from general taxation and National Insurance contributions, plus small amounts from patient charges for some services" (The King's Fund, 2021). The NHS has three core principles at its heart: the services should meet the needs of everyone, be free of charge at the point of delivery, and based on clinical need rather than ability to pay (Sheard, 2011). While the NHS was one unitary system at its launch in 1948, the current form of devolution was enforced in the late 1990s. In 1997 voters chose to create a Scottish Parliament and a National Assembly for Wales (Denver, 2002; Duclos, 2006). In Northern Ireland devolution was a key element of the Belfast (Good Friday) Agreement, which was supported in a referendum in 1998 (Ruane & Todd, 2001; Muldoon et al., 2007). Thus there are now four systems in place, one for each of the four countries of the United Kingdom: NHS England, NHS Scotland, NHS Wales, as well as *Health and Social Care Services* in Northern Ireland (Greer, 2004). In England, local government lost its control of hospitals in 1948 but retained responsibility for a range of community and public health services until 1974. The Health and Social Care Act 2012 returned to local authorities the responsibility for commissioning of many of these services, such as those dealing with sexual health and substance misuse (Heath, 2014). Under the Act, each local authority is required to “take such steps as it considers appropriate for improving the health of the people in its area” (Cronin, 2012: 55).

(ii) Court appeals and local resistance

In addition to providing a range of community and public health services, in the United Kingdom local authorities are also responsible for scrutinising local health organisations to ensure they are providing effective, efficient services and to encourage improvement (Department of Health, 2014). The Path to Excellence programme fell under such scrutiny as it proposed a substantial reconfiguration to local NHS services. Nevertheless because the programme affected the borough of South Tyneside and the City of Sunderland, the South Tyneside and Sunderland borough councils were both “required by law to form a joint committee to carry out their duty to scrutinise these proposals” (savesouthtynesidehospital.org, 2018b). Thus, the Joint South Tyneside and Sunderland Health Scrutiny Committee was formed and comprised of elected councillors appointed by the two councils. The primary aim of health scrutiny is to strengthen the voice of local people,

> […] ensuring that their needs and experiences are considered as an integral part of the commissioning and delivery of health services and that those services are effective and safe. (Local Government Association, 2015: 4)

This speaks well to the SSTHC and their allies, whose manifesto is built on bringing people together into an organised campaign—“regardless of differing political and other views” (savesouthtynesidehospital.org, 2018b). Following the scrutiny of the proposals made in Phase 1, the Joint South Tyneside and Sunderland Health Scrutiny Committee agreed to refer the matter to the Secretary of State, with the response that the proposed reconfigurations were not in the best interests of the people living around South Tyneside and the City of Sunderland (savesouthtynesidehospital.org, 2018b; see also Shields Gazette, 2018; Ledwith, 2019c). The referral was submitted in May 2018. With this decision the SSTHC followed suit in support and took their demonstration to Westminster, saying

> Our aim for this trip is to further take this fight to save our hospitals services [sic] to Westminster and demand that these services are protected and guaranteed as everyone has a right to health care and equal access to those services in their towns and cities. (*Personal communication on 2018/05/21*)

Nevertheless, the referral was in the end rejected by the UK government. Lady Theresa May, the Prime Minister at the time, responded:

> […] it is for the local NHS to make decisions about the future of local health services; these matters are not determined in Whitehall […] Local commissioners did consult the public and they agreed a number of service changes in February, which will improve services for patients. (*Personal communication on 2018/05/25*)

While met with great disappointment, the SSTHC and its followers did not back down. In response, supported by the law firm Irwin Mitchell, they filed an application for a High Court Judicial Review[55] which was granted in August 2018. Granting permission, His Honour Judge Andrew Saffman had declared he believed

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[55] “Judicial review is a kind of court case, in which someone (the ‘claimant’) challenges the lawfulness of a government decision. This can be the decision of a central government department, another government body such as a regulator, a local authority, or certain other bodies when they are performing a public function. If the claimant wins then the government decision can be declared unlawful or quashed. That will sometimes mean that the decision has to be made again. Alternatively, the court can order the government to do or not do something. The law which applies in cases of this kind is sometimes called ‘public law’ or ‘administrative law’. In very important cases which concern fundamental rights or the relationships between democratic institutions, it is sometimes called ‘constitutional law’” (Institute for Government, 2020: para. 1).

the grounds put forward by Irwin Mitchell were “sufficiently arguable such as to justify the granting of permission” (The Shields Gazette, 2018b). Needless to say, the decision was met with joy across South Tyneside even at a political level, where Labour Party MP for South Shields, Emma Lewell-Buck, said to Shields Gazette:

> The news that a High Court Judge has now approved a Judicial Review of the decisions taken earlier this year by South Tyneside CCG with Sunderland CCG to remove and downgrade some of our key South Tyneside Hospital services has strengthened the resolve of those of us fighting to retain them. (2018a)

Taking their campaign to save the South Tyneside District Hospital services to the court in Leeds, spokespeople for the SSTHC claimed this would be a vital legal case not just in challenging the downgrading of services proposed in Phase 1, but also because of what was to come next in Phase 2. The Judicial Review was scheduled to take place over a three-day period from December 18-20, 2018, and to be held at the Leeds Combined Court Centre on Oxford Row. Campaigners in their legal challenge stated that they especially thought the consultation process (apropos the merger and Path to Excellence) had been *fundamentally unfair* and *unlawful*. As a legal representative of Irwin Mitchell has stated (National Health Executive, 2018):

> Our legal challenge raises questions around the decisions taken by the CCGs because of a potentially flawed consultation process, which breached the principles of procedural fairness, and decisions made on the basis of potential flaws in the transport analysis […] Our clients believe the proposals to transfer the NHS services to Sunderland were based on a flawed assessment of the impact on patients and that the criteria to assess the cost of this was also flawed.

However, the SSTHC and its campaigners lost the Judicial Review as well, where His Honour Judge Mark Raeside QC found in favour of the clinical commissioning groups (CCGs) for South Tyneside and Sunderland. Namely, legal representation for the CCGs had argued that the prospect of “retaining the services on South Tyneside was not considered a viable option, and information was presented to the public about why things could not stay as they were” (BBC News, 2018). This position was accepted by Judge Mark Raeside, who declared: “My conclusion is this is not a case where it can be properly said information was not available to the public and the claims are rejected” (BBC News, 2018). Despite being defeated once more, the SSTHC and its allies did not give in to pressure. As a response they took their challenge against the overhaul of South Shields maternity and paediatric services to London's Court of Appeal[56] in late 2019 (Ledwith, 2019c, 2020). On behalf of the campaign, specialist legal representation from the firm Irwin Mitchell argued that

> […] the decision-making process over the transfer of some or all of these services to Sunderland Royal Hospital from 2018 onwards was essentially pre-determined before a public consultation process the previous year. (Ledwith, 2019c)

Campaigners also believe there was not enough information on the various options or the implications of the decision (Ledwith, 2019a, 2019c). South Tyneside and Sunderland Clinical Commissioning Groups (CCGs) contested this appeal, however, maintaining that the proposed changes were about "[…] doing what is right for our patients" (Ledwith, 2019b). Matt Brown, director at South Tyneside CCG, said:

> We [the CCGs] will of course defend the appeal and, while this legal process carries on, our focus remains on providing excellent care for patients by our hardworking fantastic clinical teams. (Ledwith, 2019b)

The Court of Appeal hearing took place at the Royal Courts of Justice in London on 19th November 2019. However, a decisive ruling was not made until 28th January 2020, where the SSTHC announced to its members that their legal challenge had been rejected once again. Lady Justice Nicola Davis, judge of the Court of Appeal of England and Wales, had ruled that (PublicLawToday, 2020):

> I am satisfied that there was sufficient reference to the 'retain services' option within the public documents produced at different stages of this process. […] The local public were well aware of this option as it represented the status quo. If it was felt that insufficient information relating to this option had been made publicly available, then more could have been requested. This was not done.

On the whole, the view was that there had been "[…] genuine engagement with the public and reasons were given as to why the retention of services option [in South Tyneside] was not viable" (LocalGovernmentLawyer, 2020). Lady Davis had also concluded that the CCGs had carried out a "[…] balancing exercise between identified risks as against anticipated benefits with no grounds to find these were irrational" (PublicLawToday, 2020), and that the policy changes did not amount to

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[56] "The Court of Appeal is the highest court within the Senior Courts of England and Wales and deals only with appeals from other courts or tribunals. It is divided into two Divisions, criminal and civil, and is based at the Royal Courts of Justice in London" (Courts and Tribunals Judiciary, 2021).

fundamental differences in the context of this case. Nevertheless, the Court of Appeal did criticise the Judicial Review in Leeds for "delays in issuing [its] judgment, which created a situation that did not comply with Civil Procedure Rules" (PublicLawToday, 2020). While greatly disappointed with the outcome, SSTHC spokesperson Daniel did publicly proclaim that: "The important thing is to say we all felt the Appeal judges listened to the case this time" (*Personal communication*, 2020/02/07). Nevertheless, while defeated in court the SSTHC remains active in campaigning for the protection of health services across South Tyneside.

SHIFTING CONDITIONS IN BREATHE EASY

The issues surrounding the Path to Excellence programme did not initially fall within the scopes of this dissertation. However, as a research interest it grew diffidently over time very much in line with the frustration expressed by some of my research participants. Initially I was told about Path to Excellence at my very first meeting with Breathe Easy South Tyneside in July 2017. This meeting took place about one year after the NHS Trusts in South Tyneside and Sunderland had agreed to move towards a joint management structure. At this meeting, the Breathe Easy group was visited by one of the respiratory nurses from the District Hospital. In light of the transformations that were to come, this nurse cautioned members of the group to be mindful of any changes to respiratory care which potentially could be implemented. Although I did write down "Path to Excellence" in my field-notes, I did not take much notice of it at that time, and rather dismissed this healthcare transformation as fairly irrelevant for my work on Breathe Easy groups. It was not until much later when several of the group's members started talking about "losing their hospital" that I fully realised its significance in understanding the function and meaning of this local South Tyneside support group. This became especially clear during interviews with some of the group's members. For instance, Sarah (in her 70s), who lives with bronchiectasis, told me that:

> *Last Christmas, I had a bad [respiratory] exacerbation. I called, and… well, I didn't want to go to the hospital. So, they sent out two [nurses] from the respiratory team… and they were absolutely fantastic. You know, they came and sorted it out. And it's like, if you're no better, if you feel worse, in about half an hour they'll come back. "You can't be doing that," I said. But they just said "Look, this is why we're here. All year round, 24 hours a day." They said: "That's our job"… and "You wouldn't believe how many people we're out to every day. We'll go, because that's our job," they said, "…and it's keeping us in a job, as well."*

This exchange illustrates the feelings of mutual hope and trust between hospital staff and their service-users in South Tyneside. Even more so, it reminds me of what Agić writes in that healthcare technology "represents 'hope' for the hopeless while their trust is invested in the expertise of the experts" (2012: 163). In studying mechanical help-heart implantation treatment in Sweden, Agić shows that hope is an essential element of modern medical care for people suffering from end-stage heart failure. Yet there are two sides to the maintenance of hope: one with the patients in mind, and the other for practitioners. In terms of the former, Agić writes that the creation and maintenance of hope is imperative in helping "…patients to deal with the uncertainty of their illness" (2012: 366). In truth, hope plays a crucial role in the process of recovery and self-healing (Arnaert et al., 2006; Acharya & Agius, 2017; Schiavon et al., 2017) were there is a growing recognition (in both theory and practice) that positive psychological functioning may influence health and survival positively. Also, as Petersen argues, it is a result of the ways in which an "attitude of hopefulness is increasingly viewed as a valued aspect of personal wellbeing and as manifestation of being in 'good health'" (2014: 113-114).

These perspectives mainly deal with the experience of the patient. However, what about the health professionals? Agić writes that the sense of hope "…helps the medical professionals' dealing with uncertainty in their risky business" (2012: 366). Simply put: hope makes their work meaningful, which in turn reinforces their sense of a professional identity (cf. Maynard, 2007). Without hope, patients would not only lack trust in their recovery process, but they would also not hold trust for the health system itself, its practices and the people it employs. Trivial as it may sound, as Agić suggests, without hope and trust in the system medical professionals would not be in business (cf. Douglass & Calnan, 2016). Hope is thus "…the main property of these new cultural forms that are embodied through" medical practice and treatment (Agić, 2012: 367). After all, how would society be able to preserve a communal function and service it does not trust?

Be that as it may, the interview with Sarah managed to open my eyes about a lot of things concerning her Breathe Easy group and its relationship with South Tyneside District Hospital. The following passage proved, in actual fact, staggering in making sense of the endeavour that BE South Tyneside felt when the hospital was threatened with a downsize of its services:

> <u>*Sarah*</u>*: I had to phone ARAS [because of an exacerbation]. I don't like bothering them, but… I phoned… and I spoke to Wendy—who's very good. She said "I can hear it over the phone. I can hear the [chest] tightness." […] So… she said, "Put in an extra* symbicort[57] *in your blue inhaler… and see how it goes for a couple of days." But she also said "…if you're no better, I want you up here [at the hospital]… tell them at the A&E to get somebody from ARAS and we'll get you straight through." I wouldn't have to wait or anything… they're fantastic. We don't want to lose that service, because they're so… it's like a cushion. You know, it's like a* safety net*. They're there, and it does put your mind at ease. I don't panic as much now, because I know I can call them.*

The notion of the hospital and its services as a *safety net* is crucial, and extends from and parallels well with the analytical viewpoint of Breathe Easy groups as safe spaces (Boyce, 2016; Boyce et al., 2018)—where members can listen and talk to each other free from judgement and dismay. As a *safety net*, the hospital acts as a rescue if all else fails—both socially and medically speaking. If we look to the literature, this understanding of hospitals is rather prevalent (although multifaceted). For instance Stewart argues that, whereas the specific valued characteristics of hospitals may vary, overall they can and should be "helpfully understood not as shells within which services are provided but as socially-constructed 'anchor institutions' which hold communities together" (2019: 1252). Taking this to heart, Stewart's argument is not that hospitals *should never change or close*, rather "clinically or managerially-driven efforts to change them should

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[57] Symbicort (*budesonide* and *formoterol fumarate dihydrate*) is a combination of a steroid and a long-acting bronchodilator used to prevent bronchospasm in people with chronic respiratory diseases, such as asthma or COPD.

acknowledge and offer alternative possibilities for these social roles" (Stewart, 2019: 1252). Efforts to understand the complexity of public perspectives on healthcare change may "…reveal scope for compromise", Stewart argues, both in shaping how the public values their health services, and in helping healthcare organisations to "…make decisions better-informed by the multiple 'everyday' roles of healthcare facilities" (ibid.).

(i) Changes: a support group in transition

The prolonged transformation of Breathe Easy South Tyneside first became noticeable in mid-January 2018 after I had returned to the UK from celebrating Christmas and New Year's Eve back home in Sweden. By then I was halfway through my research, and in the midst of thinking about potentially relocating my fieldwork to spend more time in South Tyneside with this group in particular. The initial plan was to ask the group members for advice on this matter at their January meeting. However, that day in particular I was running late and would not make it in time for the start of the meeting at 2:00 PM. I contacted my key contact person, Maureen (65), to inform her about the situation and ask that the group proceed as usual, that I would arrive sometime after the summary agenda and order of business. When I arrived, the meeting was already in full swing. It was a well-attended gathering, with at least 20 people around a table that had been set up in the midst of the room. In a manner similar to that of a late-arriving primary school pupil, I attracted attention as I stepped through the front door. As usual and likely due to not having seen them since the 2017 Christmas party, I received many greetings in the fashion one might expect from extended family (although fictive[58] in this case). In fact, some of the members did not hesitate to point out (in banter) the extra weight I

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[58] Fictive kinship is a term used by anthropologists and ethnographers to describe forms of kinship or social ties that are based on neither consanguineal (blood ties) nor affinal ("by marriage") ties, in contrast to *true kinship* ties (Ebaugh & Curry, 2000). In fact, Rae illustrates how fictive family ties may grow to become a "salient and meaningful component" (1992: 226) in social networks of elderly people. In her study, evidence was found to "[…] support the substitution principle, or the notion that individuals who have no kin tend to substitute for missing relatives by converting close friends into quasi-kin" (Rae, 1992: 226).

had gained while being home over Christmas—yet the same members laughed and smiled saying how “well” it suited me.

When all greetings had been said and done, I took my seat around the table, fully prepared to present the group with my query about possibly relocating to South Tyneside for the remainder of my fieldwork. However, in the end, due to circumstances which I will soon come to reveal, I was unable to bring attention to my query. Basically, within minutes of sitting down I was told that the group had just been informed that Maureen (my key contact) and her husband, Leon (also a member), had decided that they would be leaving the group and move to Newcastle upon Tyne (about 12 kilometres west of South Shields) to be closer to their two sons. Moreover, Maureen had bronchiectasis and I was told that her declining health had also played a part in coming to this decision, especially as the two of them would be living closer to the Newcastle Freeman Hospital and the Royal Victoria Infirmary (RVI), two institutions recognised all across the UK for their wide expertise in respiratory medicine.

This announcement came as a huge surprise— not only to me personally, but also the extended group. In fact, selected members were quick to speak of this as “the end of the group”. More specifically, these members were in fact referring to how Maureen (especially), but Leon as well, had both been at the forefront in getting the group up and running back in 2009 with the help of the British Lung Foundation. Moreover, many members credited Maureen with having (in practice) almost singlehandedly run the group for nine years straight—a resolve which would be difficult to substitute once she had gone. Nevertheless, the group’s Chairperson was quick to provide words of comfort and encouragement in saying that the group would live on and that they all wished Maureen and Leon the very best.

No one could have imagined the changes that would follow this announcement. Whether for better or worse is not up to me to decide (and out of the scope of my involvement) but one thing remains incontestable: Breathe Easy South Tyneside was about to fundamentally change the way in which they operated as a local support group for people with respiratory disease. Nevertheless, the situation with

Maureen and Leon very much speaks for the social dynamics in small community-based groups like Breathe Easy. That is to say, the way in which some individual members take "on a special role or set of roles which marks him or her out as different from everyone else in the group" (Sallis & Sallis, 1990: 172), whereby they grow more prominent than others and basically carry the responsibilities (or the group's direct survival) on their shoulders. As I illustrated above, rather immediately members of the South Tyneside group were inclined to assume that no one else would be able or willing to take on the responsibilities.

Sallis and Sallis write that for organisational success (whether in for-profit or not-for-profit), leadership is a key ingredient (1990: 179). Leadership stands apart from management, and while many managers "possess leadership qualities others do not, and people without managerial responsibilities can and do exercise leadership within organisations" (Sallis & Sallis, 1990: 179). Even though the situation within Breathe Easy South Tyneside may be explained through different measures, I do believe that when it comes to Maureen and Leon stepping down the group was seen to be without clear leadership. As Ellis and Ellis write, "Leadership is a key element in effective management. Leaders take charge, make decisions and inspire confidence in others" (1990: 179). Thinking back to the year I spent with this particular Breathe Easy group, it goes without saying that Maureen and Leon were seen as the backbone of their assemblage. Leaders can provide their groups with a voice—and with Maureen and Leon leaving, the Breathe Easy group in South Tyneside was seen to lose its communal voice.

(ii) Independence

The imminent departure of Maureen and Leon was, needless to say, an earthshattering moment for the group as a whole, and this incidence would ultimately contribute to changing how the Breathe Easy group fundamentally functioned *as* a support group. However, the announcement was only the first of several changes the group would go through in a short period of time. Firstly, at the following meeting in February 2018, the group ended up implementing a rather innovatory motion that would come to alter how the group itself worked on an everyday basis. In actual fact, the said February meeting was also the South Tyneside group's annual general meeting (AGM). At this meeting, I came to observe and personally experience how a mundane Breathe Easy group meeting (similar to any corporate meeting) may be understood as a highly "ritualized, legitimizing and trust-building… performance where the different roles… are played out in positioning procedures" (Nyqvist, 2015: 341) where the support group itself is enacted as an organisational and collective entity. The alteration surrounded Maureen and Leon—or more specifically, the roles they had held within the group. With the two of them soon to depart, their roles had to be filled, and all members of the group had previously agreed that this had to be addressed as a primary concern at the upcoming AGM.

In preparation for the meeting, however, another issue had been listed on the agenda, one that very much related to the overall function of the group as part of the Breathe Easy support group network. The issue regarded the relationship with the British Lung Foundation. Unlike the other Breathe Easy groups I had met with during fieldwork, this group had on multiple occasions openly expressed discontent with the lack of support the members had received from the British Lung Foundation over the years. During interviews with members, some of them had even explicitly uttered a disposition towards becoming an independent support group. Ultimately, however, the group's position had remained the same, as the process was thought to involve, as some put it, "too much hassle". Nevertheless, at the AGM held in February 2018, the question was raised once again—which ended in the Chairperson asking the other members upfront:

> *Okay… how many of you in this room would actually like to leave*
> *the British Lung Foundation? Hands up!*

Although I was quite taken by how casually this question (and vote) had been raised, I was less surprised about the outcome: a clear majority had voted to leave. I remember looking to my right, seeking to make eye contact. Not everyone had openly voted to leave however, but whether this meant they had preferred to remain an integrated Breathe Easy group or had simply abstained from voting (which I had done myself) was difficult to make out. I never approached people about it, primarily because I did not want to risk putting anyone on the spot or appear denunciative. While I held my own predisposition on the matter, whether the group wanted to remain part of Breathe Easy or not was entirely up to its members and not something an ‘observer-as-participant’ researcher (Gold, 1958; Davies, 2007; DeWalt & DeWalt, 2011) should interfere with.

While the South Tyneside group’s dissatisfaction with the British Lung Foundation was obvious and the overall issues surrounding the lack of services and support come to touch on several areas, the discontent which led to the aforesaid vote-to-leave primarily stemmed from recent policy changes regarding how Breathe Easy groups were meant to conduct their fundraising activities. These changes were enforced by the British Lung Foundation (which the Breathe Easy groups are officially and legally part of). Taking this to heart, I believe it would be useful to draw out the different ways in which support groups can be run. Looking back to the pioneers of research on support groups—for instance, Katz and Bender (1976a, 1976b) or Hatch and Kickbusch (1983), they all contend that there are two types of support group constellations: those run by professionals or larger organisations (like patient support groups in hospitals), and those run by the group members (the more ‘traditional’ self-help groups, so to speak). I would like to argue however that Breathe Easy groups are somewhere in-between, or a mix of both types—they are ‘semi-professional’ due to the fact that while the groups themselves are run by their members, the groups (as legal entities) operate under the wider framework of the British Lung Foundation. All fundraising activities are done under its charity numbers, with its logo and other copyrighted material.

While all Breathe Easy groups are initially set up by the British Lung Foundation through its internal funding, they are later allowed to continue operating as local autonomous entities. Initially the British Lung Foundation had intended to be more involved with the Breathe Easy groups (in the background of their operations), however due to financial constraints this was impossible to uphold in the longer term. Nevertheless, all Breathe Easy groups are still very much legal entities under the British Lung Foundation. In spite of this, the British Lung Foundation is itself very much financially dependent on the groups. As should be clear by now, Breathe Easy groups often organise diverse fundraising events to raise money for their cause and to spread awareness about respiratory disease as a public health emergency. Although it is not a requirement per se, many groups are in fact very successful in raising funds, often achieving between £200 and £300 from each event. In fact BE Darlington, BE Durham Dales, and BE South Tyneside have all been rewarded by the British Lung Foundation (in different ways) for their success in fundraising for the charity itself and the support group network.

What Breathe Easy groups can ultimately do with the raised funds however is very limited. Firstly, the groups are meant to be self-sustained. Thus, groups are allowed to keep whatever they need to cover their monthly costs and stay active. The rest, however, has to be split between the British Lung Foundation and whatever else the groups would like to fund. As the first edition of the *Breathe Easy Manual*, authored by the British Lung Foundation, reads:

> Groups are asked to make a contribution to the BLF – quarterly if possible. Over the financial year this amount should total at least 50 per cent of money left once group running costs have been accounted for. However, we recommend that you keep about £300 to £500 in your account to cover running costs. (British Lung Foundation, 2007a: 18)

The policy regulating this notion has however changed several times. As the manual states, groups were previously allowed to match whatever they donated to the British Lung Foundation. This meant that if a certain group donated £500 to the British Lung Foundation, they were allowed to donate £500 to another cause. Since its launch the group in South Tyneside has always aimed high at giving back to the local community, with South Tyneside District Hospital being of huge priority to the group members. Nevertheless, in 2017 the policy changed once again. Since 2017 Breathe Easy groups have not been allowed to match whatever they donated to the British Lung Foundation. Alongside keeping what they need to sustain themselves (which rarely extends £60, I have been told) groups are only allowed to donate a maximum of £200 to another cause. Matilda (65), a member of the South Tyneside group, told me that:

> *There's been a change in the rules, recently… and I think that's to do with the charity's guidelines […] It's like to do with… the British Lung Foundation kind of brought them out… these new financial guidelines, but I don't know whether they've been brought out by the charity's… committee, or trustees, or whatever they call them… like nationally, for all charities or just the British Lung Foundation, I don't know. But they're putting a limit on… what we [Breathe Easy] can spend on the hospital. We couldn't buy equipment that the NHS should pay for. Which kind of made sense… and anything we did give them, the equivalent amount had to be given to the British Lung Foundation as well. Which is what we did: we bought £500 worth of something, and then we'd give another £500 to the BLF. Which was fine—that all worked fine. But when these new guidelines came out… a year ago, I think… within them it says "Fundraising… only certain amounts" and it says approximately £200 is the limit… to what can be given to the hospital [in our case]… And, I'm not exactly sure why… I think why, is it because it's thought that the equipment that is bought… for the hospital, might be used by people who don't have a lung condition.*

This new policy very much dismayed the group in South Tyneside, to say the least. As I was told, £200 would not be of much financial help to the District Hospital. The group's dismay was further fuelled when after the group announced to the British Lung Foundation that they would like to become an independent support group, they were told to prepare to close the associated bank account. At the time of the AGM in February 2018 the South Tyneside group had a working balance of £2,879 in its account. After receiving a final refund for all the group's internal expenses, the members were only allowed to withdraw a further £200 to spend on whatever they wished. The remaining balance (over £2,500) later transferred back to the British Lung Foundation. Matilda told me in detail of the contributions the group had made to the hospital over the years, which the new policy would make impossible:

Over the years we've bought… I think originally, we bought some nebulisers, the proper nebulisers that is. And then… I think the next thing we bought… I think we've bought two sets of nebulisers actually. And then we bought some travel nebulisers—which do what it says on the tin. So, if people are going on holiday, and need nebulisers […] these are the much smaller ones, more compact… you can plug them [and charge them] in the car… or if you just need to take them abroad or something.

So, we bought some of them… and then we bought… I think the biggest thing we've bought… we bought three chairs for Ward No. 10… They are like recliner chairs, and they're used for… people staying overnight, mostly—the loved ones, if people are quite poorly. They're also for patients who cannot get comfortable in bed. I mean, for instance… if you cannot breathe, and you're laid quite flat in bed, it can easily get uncomfortable. But if they're sitting up in the chair, a recliner chair, then they can sleep in that… so we bought three of them. And I think they were about £500 each, so we got three for £1,500, which they [the hospital] were delighted about! And then we bought… the last thing we bought was a TV for the [ARAS] waiting room [Figure 6.6]*. Because the waiting room… hasn't got any windows. It's not very big… probably the size of a [regular sitting room]… and there's nothing in it, as usual.*

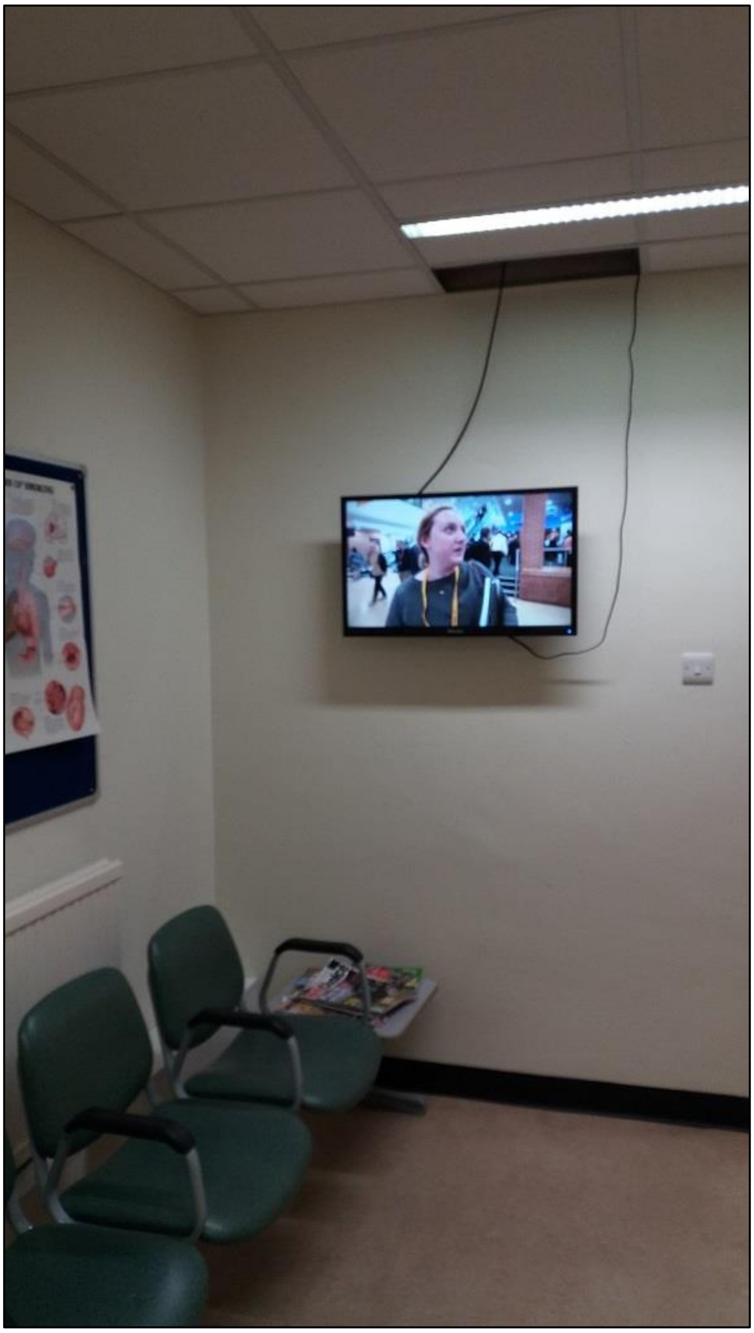

Figure 6.6: The ARAS waiting room at the South Tyneside District Hospital, with a TV donated by the BE South Tyneside group.

(Photo taken by the author)

Following the group's AGM in February 16th March 2018 marked the last day the members of Breathe Easy South Tyneside officially called themselves a 'Breathe Easy group'. On the whole, the meeting itself (a 'meeting' in name only) turned out very special. The group had invited a local ukulele band to come and perform, and members invited friends and families to attend. Speeches were made where praise was especially given to Maureen and Leon for their dedication over the years. Overall, the day very much functioned as a celebration of what had been and what was to come for the group and its members. Like a phoenix,[59] they would obtain new life (as a new group) by rising from the ashes of their predecessor (Breathe Easy). I remember thinking to myself that the celebration very much reminded me of a ritual process—or more specifically, a *rite of passage*. As dictated by Arnold van Gennep, rites of passage are rites "which accompany every change of place, state, social position and age" (quoted from Turner, 1977: 94). All rites of passage are marked by three phases: separation, margin ("threshold"), and aggregation. Turner writes that the first phase of separation comprises

> […] symbolic behavior signifying the detachment of the individual or group either from an earlier fixed point in the social structure, from a set of cultural conditions (a "state"), or from both. (1977: 94)

The notion of detachment from a social structure is very applicable in describing what I observed at this celebratory gathering. If anything, the gathering was organised to look back on the group's decade-long journey of advocating for the elevation of respiratory disease in South Tyneside as part of the British Lung Foundation, a social structure which this group had now outgrown, thus calling for a change of pace and structure.

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[59] In classical mythology, a *phoenix* is a unique bird that lived for five or six centuries in the Arabian Desert, after this time burning itself on a funeral pyre and rising from the ashes with renewed youth to live through another cycle.

IN PLACE OF CONCLUSION

This chapter has dealt with the notion of *advocacy* from a variety of perspectives—from patient activism outside the clinic (where biological citizenship turns health into a political project) to nurses in their role as patient advocates. What the chapter highlights more than anything is how biological citizenship, *through* the acts of advocacy, becomes an expression of autonomy and pastoral power (cf. Wilson, 2001). As such, by looking specifically at advocacy the chapter draws parallels between biosociality and biological citizenship, thus illustrating how biosociality can be analytically applied to bridge dialogues between subjective and collective bodily experiences of health, illness, and wellbeing. Placing the borough of South Tyneside in the limelight more specifically (where access to healthcare has increasingly been restricted through bureaucratic means), the local SSTHC succeeded in transforming its campaigners (i.e., patients and service-users) into *agents*. While ultimately unsuccessful in its legal claim, the campaign nonetheless managed to connect individuals otherwise isolated "to draw upon the collected experiences of others in order to navigate these sites of struggle, including courts […] mass media, and government" (Dumit, 2006: 585). This also extends to the (now former) local Breathe Easy group and its members—a scenario where an imagined 'lost autonomy' (cf. Siroky & Cuffe, 2015; Sampson et al., 2019) was reclaimed through an act of organisational separation.

In contrast to my analysis of chronic disease self-management practices (which I deem *technologies of the self*), analytically I approach advocacy practices more in terms of *technologies of production*—"which permit us to produce, transform, or manipulate things" (Foucault, 1988: 18). While this concept is often neglected apropos technologies of the self, it offers very significant insights into human behaviour. Rather than explaining direct transformations upon one's own body, it looks more to social transformations permitted upon one's external surroundings. For instance, while the development of a self-management practice (i.e. for chronic disease) would indeed be an 'operation' on one's body (Foucault, 1988: 18)—practising public health advocacy (whether inside or outside of the system) may certainly work in the manner of a *technology of production*, whereby an advocate (or activist) seeks to transform or manipulate prevailing practices at work within a healthcare system, or in the overall biopolitical agenda. Nevertheless, in view of the widespread anthropological literature on patient organisations and their biosocial movements (e.g. Aggleton et al., 1997; Epstein, 1998; Baer et al., 2004; Landzelius, 2006b; Robins, 2006; Sanford & Angel-Ajani, 2006; Epstein, 2008) there are three concepts which although similar in nature need to be distinguished from one another. These are a) *advocacy*, b) *activism*, and c) *lobbying*.[60] Overall, advocacy is often abstracted as social practices of

> […] publicly representing an individual, organization, or idea with the object of persuading targeted audiences to look favourably on—or accept the point of view of—the individual, the organization, or the idea. (Edgett, 2002: 1)

While often understood as a form of advocacy, *activism* has a less favourable reputation (cf. Sanford & Angel-Ajani, 2006) where it is described as taking direct action to achieve a desired socio-political change. By and large, as Sandra Kosik (1972) and James Paul (1977) write, advocacy has now come to stand for practices working ‘within the system’, whereas activism is more understood as ways of working ‘outside the system’ to implement change. *Lobbying*, on the other hand, may be seen as a step further, as a strategic means of influencing specific decision-makers on specific issues (Farris, 1979; Bourgeois & Nizet, 1993). All in all, lobbying also falls under the umbrella term of advocacy. However, while all practices of lobbying are also practices of advocacy, it is not the same in reverse—not all advocacy practice is to be understood as lobbying.

In terms of Breathe Easy and similar groups, how can these three concepts be applied? I contend that when it comes to implementing change within the nationwide Breathe Easy support group network—and by extension, the British Lung Foundation itself—Breathe Easy groups can be said to practise advocacy. When it comes to social conditions outside of this scope, for instance change in respiratory care regimens within the National Health Service (NHS), Breathe Easy groups can be said to practise activism. When it comes to practices of lobbying for

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[60] For the purpose of this dissertation, I have decided to exclude the concept of *campaigning*. By and large, I very much see the concept as synonymous with *lobbying* and it does not offer any further perspectives to the issues at hand.

change on the other hand, the political target has to be even more specific. Thus, if a Breathe Easy group were to seek change in their local community, for instance, regarding specific services offered at their respective district hospital, these practices could be understood as lobbying. This would apply to the group in South Tyneside, and especially if their activities are conducted with the South Tyneside District Hospital in mind. Nevertheless, while being a support group for chronic breathlessness, all advocacy practices are not necessarily carried out in the name of respiratory disease and health. They are, nonetheless, carried out from the point of view of being ill and living with respiratory disease.

What lessons can be learned from the situation that surrounds the South Tyneside District Hospital? How do *hope* and *trust* come into play in the engagements between service-users and hospital staff, and the initiative the local community now maintains in preventing the hospital from closing? This is where my argument takes its form. As I have drawn from the narratives presented throughout this chapter, I argue that notions of hope and trust both shine through when looking at the relationship between service-users and the medical professionals at the District Hospital. Drawing upon Stewart's work, I refrain from asking "how healthcare organisations can overcome public attachment to hospitals" (2019: 1252)—something the CCGs around South Tyneside and Sunderland deem a priority. Instead, taking Stewart as a prime example, this chapter attends to the question of *how* hospitals have meaning for their communities vis-à-vis "what roles communities play in their change and closure" (2019: 1252).

PART III

EPILOGUES

~ CHAPTER SEVEN ~

MEANING, IMPORTANCE, RELEVANCE

IDENTIFYING THE CONTRIBUTIONS MADE TO ANTHROPOLOGY (AND BEYOND)

"Participation changes the anthropologist and leads [them] to new observation, whereupon new observation changes how [they] participate."

P. RABINOW

INTRODUCTION

This dissertation has centred on support groups for elderly people living with chronic breathlessness in the United Kingdom. More specifically, what this dissertation has shed light upon is the expediency of *biosociality* as an analytical term in examining how communities are formed around pathological breathlessness, where understanding the support group as a technology (*techne*) in and of itself (rather than as a mere social setting) becomes substantial. In this chapter I delve into the meaning, importance and relevance of the findings that have been presented throughout the previous chapters of this dissertation. On the whole, the chapter focuses on explaining and evaluating the ethnographic material that is in the foreground of Chapters 4, 5 and 6, where it seeks to show how this material parallels the research inquiries presented in Chapter 1 and the literature on *biosociality* reviewed in Chapter 2. With the notions of biosociality, biocitizenship, and biosocial formation in the limelight, this chapter attends to all loose ends with the purpose of making an argument in support of the overall conclusion and contributions which this dissertation seeks to construe.

Structure is the most difficult part of writing, regardless of its genre. In terms of this chapter's disposition and dissemination, I draw much inspiration from Docherty and Smith (1999) as well as Skelton and Edwards (2000) in structuring and delivering my argumentation. As Docherty and Smith construe, in writing a discussion section (journal articles notwithstanding), authors often use certain rhetoric whereby the function of the discussion becomes to help 'sell the paper' (1999: 1224). Writing extensive text without subheadings, focusing on the strengths (rather than the weaknesses) of the study, as well as its generalities (rather than specifics), ends in authors going "beyond the evidence they have gathered and [drawing] unjustified conclusions" (Docherty & Smith, 1999: 1224). This is something that I seek to avoid, as my aim is to discuss and draw parallels between the different perspectives presented throughout this dissertation. In contrast to Docherty and Smith, however, Skelton and Edwards (2000) disagree and take issue with the line of argument posed by the former two. While they argue that the overall contribution is indeed timely, Skelton and Edwards contend that discussion sections already have a "fairly conventionalised structure" (2000: 1269). What is more, they further maintain that speculative phrasings are sometimes desirable—and even in cases in which they are not, these phrasings "would be impossible to get rid of by virtue of a tighter structure" (Skelton & Edwards, 2000: 1269). As they write:

> A discussion cannot simply repeat the results as they seem beforehand or it is tautologous. In this sense, every discussion is obliged to "go beyond the evidence." Every paper must reach a conclusion that is not contained in its results. (ibid.)

Then, what is the way forward? Skelton and Edwards write, rather wittily, that "one can take the science out of rhetoric but not the rhetoric out of science" (2000: 1270). In summary, they argue that the purpose of a discussion section is to discuss; therefore, it should be *discursive*. Words, as such, are not reductionist, nor is it possible to extract all of their rhetoric. Speculation cannot be contained by a mere simple structure, with Skelton and Edwards suggesting that there are other ways in which to "keep science in check" (2000: 1270). Having Docherty and Smith (1999) as well as Skelton and Edwards (2000) in the back of my mind when structuring this chapter, I implement designs and suggestions from both of them. First of all, I deliberate on the principal findings of the dissertation. Firstly, I discuss breathlessness and how it should be understood as being a 'very personal experience'. This is then followed by a discussion of the communities formed around breathlessness, identified throughout this dissertation. In this discussion I parallel two analytical standpoints: 1) how communities are formed around needs, and 2) how a support group can be understood as being a technology which bridges subjective and collective experiences of health and illness. What then follows is a section in which I detail personal reflections on the notion of biosociality, and how my approach towards this analytical framework changed throughout conducting this research. What follows is a vivid deliberation that details the overall meaning of the study at hand. Lastly, I come to discuss and deliberate on what questions remain unanswered and what further research is needed, much of which will be in relation to post-fieldwork events, such as the COVID-19 pandemic.

PRINCIPAL FINDINGS

What is breathlessness ethnographically? What is the role and structure of breathing within embodiment? While secondary in nature, these questions have still featured within this dissertation. Being a somatic condition that habitually has an insidious onset—such as in chronic respiratory disease, where breathlessness (dyspnoea) just keeps getting worse over time—breathlessness can be understood as a biographical disruptive event. As Michael Bury writes,

> […] illness, and especially chronic illness, is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted. Chronic illness involves a recognition of the worlds of pain and suffering, possibly even of death, which are normally only seen as distant possibilities or the plight of others. (1982: 169)

Simon Williams, on the other hand, having 'rescued' the concept from "recent postmodern and disability critiques" (2000: 40), has looked at Bury's analytical utility from a different point of view. Taking the notion of chronic illness as 'biographical disruption' as his point of departure, Williams sought to tease out both its strengths and weaknesses as an analytical tool; "not simply in the light of existing critiques […] but also in terms of some relatively new terrain and previously uncharted issues" (2000: 60). More specifically, Williams believes that we have come a long way; having displaced ourselves from the traditional concern with chronic illness as biographical disruption, to understanding biographical disruption *as* chronic illness. These broader series of reflections, he writes, lay on the "contours and existential parameters of life in late modernity, including the various pathologies of reflexive self-control it spawns" (ibid.: 60). Namely in detail, Williams argues that a biographical disruption rests on problematic foundations concerning the 'shattering' of our, what he writes, "taken-for-granted assumptions about our bodies, ourselves and the world in which we live" (2000: 60). In doing so, the analytical notion fails to account

> […] for a range of other possibilities in which illness may already be a central part of one's biography, either from birth, early childhood or in later life, including the notion of so-called 'normal crises'. (Williams, 2000: 60)

In truth, Megan Wainwright illustrates such a shattering assumption about the human body, ethnographically, by showing how the experience of breathing and breathlessness (through examples from South Africa and Uruguay) is "closely tied to perceptions of air outside the body—in particular humidity, temperature change, wind, and contamination" (2017: 332). More specifically, in conceptualising breath as "the mechanism and air the medium for environmental embodiment" (ibid.: 332), Wainwright brings together sensorial medical anthropology, anthropology of the body, and the anthropology of wind and climate in describing how breathing amounts to living—and living in an autonomous way (cf. Škof, 2018). Such an analysis draws on Luce Irigaray's ontology of breath (in itself based on a philosophy of air), which bethinks that air is at the groundless foundation of "metaphysics amounts to ruining metaphysics through and through" (1999: 5).

While this dissertation has evidently placed its focus on respiratory disease and pulmonary pathology, one simply cannot discuss these topics without mentioning breathing and, indeed, breathlessness; the first vital symptom of disease (Currow & Johnson, 2015). Few people are aware of the true power of breath; they take it for granted despite the fact that it is the most essential function for life (Irigaray, 2004a; Ramacharaka, 2007; Marmot, 2016). Even more so, while philosophically under-investigated (Williams, 2020) there is immense significance of breath, breathing, and pathological breathlessness in the context of philosophy of medicine. As Lenart Škof and Petri Berndtson write:

> What then, in today's world, can we do in philosophy with the breath? It is our wish […] to present the readers with a new genre in philosophy—namely, a respiratory philosophy—as an archaeology of breath, and think of respiratory philosophers as spiritual archaeologists excavating its hidden ontological, epistemological, ethical, religious, and political layers. (2018b: ix)

Human beings breathe to live. This remains an indisputable fact. Ever since the dawn of time, Edwards writes, this vivacious link between breath and life "has provided the foundation for various religions, philosophies, beliefs and practices related to survival, preservation and promotion of life in this world and in the afterlife" (2006: 1). This reminds us again of Irigaray, who writes that "breathing, in fact, corresponds to the first autonomous gesture of a human being" (2004a: 165). According to Irigaray, "it is our future task to become awakened to a new ethical constellation" (in Škof & Berndtson, 2018b: ix) in which we will be "…making awareness of the breath essential for an embodied ethics of difference in our globalized, ecological age" (Škof & Holmes, 2013: 1-2). In seeking to draw out and describe a hermeneutics of breathing, Kleinberg-Levin writes that:

> Breathing (in the primary sense of *psyche*) is not only essential for biological survival; it assumes a privileged function in the processes of developing self-awareness and deconstructing self-identifications: processes leading to, and constitutive of, an authentic "individuation," a never-ending dialectic, "going beyond" ego. (2018: 5)

Especially true, as Arthur Rose illustrates, in a more physiological (and less anthropocentric) sense, *breath*, as such, catches and brings together all those bodily processes by which beings with lungs take in and release air: the mechanical, the chemical, the affective and the metaphoric (2018: 1).

> The diaphragm contracts. It drops. A vacuum appears in the chest cavity, which allows the lungs to expand with air. While the lungs are surfeit with air, oxygen passes through thin membranes in the alveoli to bond with haemoglobin, which, in turn, releases its load of carbon dioxide. (ibid.: 1)

What, then, is breathlessness ethnographically? Moreover, as ethnography can mean and imply a lot of different things (Czarniawska-Joerges, 1992; Bate, 1997)—what happens when, as Prabhala and colleagues ask (2011), the same word means different things to different people? In attending to these queries, I reiterate once more: this dissertation is not a phenomenological study of people's lived and embodied experiences of breathlessness. As such, it does not seek to, through the philosophical study of the structures of experience and consciousness,

> […] momentarily erase the world of speculation by returning the subject to his or her primordial experience of the matter, whether the object of inquiry is a feeling, an idea, or a perception. (Thompson, 2004: 36; Palmer, 2019: 234)

In terms of its contributions, while the dissertation indeed does describe lived experiences of breathlessness, as they become a 'shared biology' in a sense (cf. Bornstein et al., 2006; Lee et al., 2015)—in this case, the dissertation shows how chronic breathlessness becomes less of a medical symptom or somatic sensation, and more of a biologically-based identity that enables the formation of biosocialities and biological citizenship (Petryna, 2002; Gibbon & Novas, 2008a). And as this dissertation shows, with biosociality comes "significant forms of sociality and signification, of enterprise and activism, both negative and positive" (Comaroff, 2007: 203) where biological citizenship sheds light on a fundamental practice of polity building in post-socialism: how one's biological identity enables

> […] a massive demand for but selective access to a form of social welfare based on medical, scientific, and legal criteria that both acknowledge biological injury and compensate for it. (Petryna, 2002: 6)

As such, in contrast to the phenomenological approach which does not go beyond describing lived experiences of breathlessness (e.g., as a 'mere' biographical disruption) before theorization by science, the biopolitical analytical framework used within this dissertation asks: How do people relate and engage further with this disruption? In sum, this dissertation illustrates how people who live with chronic breathlessness transition from being diagnosed and 'activated' as patients (Hibbard et al., 2004; Hibbard et al., 2005; Hibbard & Gilburt, 2014)—to becoming agents with legitimate claims (to citizenship) formulated in the context of fundamental losses (Petryna, 2002, 2004; Davidson & Orsini, 2013). What I do, beyond description, is explaining how people with breathlessness (in this case, members of *Breathe Easy*) enact in the descriptions (fact, categories, and codes) bestowed upon them, and develop counter-tactics (Dumit, 2006) that can be brought to bear against these descriptive frames and contested biological facts. As Dumit illustrates, “when emergent uncertain illnesses are also highly contested” (2006: 587) biological/medical facts function differently. This goes to say for chronic breathlessness as well, which according to Oxley and Macnaughton, suffers from “an evident disconnect between the way [it] is understood, assessed, and defined between clinical and lay perspectives” (2016: 257). Like we can read in Gysels and Higginson’s work (2008), people with breathlessness initially experience their ‘contested illnesses’ in the form of exclusion: i.e., “since there is no code for this, there is no care” (Dumit, 2006: 587). As such, in the form of biosocialities—as social movements (Brown et al., 2004; Epstein, 2008; Thompson & Tapscott, 2010), sufferers and service-users (‘breathers’) and those committed to helping these ill people “provide a community and offer alternative personal narratives, strategies for surviving” (Dumit, 2006: 588), and even emotional support.

In drawing things to a close, ethnographically speaking, phenomenology (at odds in this dissertation) simply understands breathlessness as a biographical disruption; a ‘critical situation’, where the taken-for-granted assumptions and behaviours are disrupted (Bury, 1982; Becker, 1998; Jowsey et al., 2014). While important insights, undeniably so, this dissertation takes a step further. Thus, bio-politically speaking, breathlessness is a biological fact which turns the point of communal identity (Gibbon & Novas, 2008a; Novas, 2008; Friedner, 2010) and enables a massive demand for access to social welfare (Petryna, 2002). Being that breathing and breathlessness, as phenomena, are pregnant with “historical, cultural and existential meanings that are often overlooked in the clinical context” (Macnaughton & Carel, 2016: 295), the phenomenological approach is not enough. As such, in this dissertation I not only look at what breathlessness *is* and what it *does* to people (the ‘breathers’)—I describe, explain, and analyse how these individuals (agents) make sense of their biographical disruptions (i.e., chronic illnesses) through the fundamental reconfiguration of human conditions and conditions of citizenship. As Williams writes whilst a distinction "…has been drawn between the analytical utility of biographical disruption as a concept, and its explanatory potential as an empirical datum" (2000: 60), theoretical speculation without adequate empirical checks (as often is the case within phenomenological research, as Sholl argues [2015]) is ultimately redundant—"particularly in a substantive domain such as ours" (Williams, 2000: 60).

(i) The communities formed *around* breathlessness

I now turn to the key contributions made in this dissertation. As such, I ask, how are communities formed around somatic phenomena? Whilst inquiring about people's understanding of breathlessness (as lived experience) has been central to this study, the question of community formation *around* the sensation of breathlessness has been even more crucial. In many ways, this approach responds to the call for a more sensorially engaged anthropology, wherein the study of healing modalities and idioms of distress stands to be significant (Nichter, 2008: 163). Nichter argues that a sensorial approach to anthropology can contribute to the study of "transformative healing and trajectories of healthcare seeking" (2008: 163), as well as patterns of referral in pluralistic healthcare arenas. As phenomenological literature (e.g. Katz & Csordas, 2003; Desjarlais & Throop, 2011; Dolezal, 2015a; Carel, 2016; Szanto & Moran, 2016) maintains, social relations are articulated at the site of the body through somatic modes of attention (Csordas, 1993). These modes can be better understood as an index in which "bodily ways of knowing learned through socialization, bodily memories, and the ability to relate to [other people]" (Nichter, 2008: 163) remain stored. As such, by understanding cultural interpretations associated with the senses, sensorial anthropology and the anthropology of the senses can both contribute to the study of transformative healing and trajectories of healthcare seeking and patterns of referral in pluralistic healthcare arenas (Nichter, 2008; Weisner, 2015).

For decades, anthropologists have been studying the interaction of cultural values and norms with regard to health-related issues, where sensations and symptoms are understood as being distinct expressions of disease (Hinton & Hinton, 2002; Hinton et al., 2008; Biehl & Moran-Thomas, 2009; Hinton & Good, 2009; Eriksen & Risør, 2014; Andersen et al., 2017). Inspired by the sensory turn in the humanities, anthropologists forged the terms *sensorial anthropology* (Hinton et al., 2008; Nichter, 2008) and an *anthropology of the senses* (Andersen et al., 2017) to better envision the study of sociocultural responses to the perceptual output of sense modalities, or sensations such as dizziness, chest and heart pain, and indigestion—even shortness of breath (Nichter, 2008: 164). Yet, as Nichter writes, the meanings and experience of bodily sensations are "biosocial and need to be studied in the context of social change" (2008: 186). If anything, this is what the dissertation contributes in terms of understandings that inform anthropology. This dissertation offers a glance at what happens to biosociality and bio-identity in times of biopolitical turmoil, wherein social change remains a key feature. It does so, more specifically, through the social transitions of Breathe Easy support groups.

When critically engaging with what we know to be (and call) *community*, there are two major distinctions to take into consideration. As Gusfield (1978) writes, (firstly) we have the territorial and geographical notion of community—be it a parish, neighbourhood, village, town or city. Secondly, we have the *relational* notion, which is concerned with the "quality of character of human relationship, without reference to location" (Gusfield, 1978: xvi). Nevertheless, Gusfield notes that the two usages are not mutually exclusive. As territorial notions are far from cut in stone and can shift over time and within the imaginary, territorial aspects of identity may also entwine with more relational aspects. However, as Durkheim (1997 [1893]) observes, "modern society develops community around interests and skills more than around locality" (quoted from McMillan & Chavis, 1986: 8). The argument for nation states, however, may also be understood as a merger of Gusfield's two distinctions. Nation states are territorial, geographical entities which you can locate on a map and are maintained by border controls. People's connections to such territories are, however, multifaceted—in the same way that nationalism is Janus-faced (Nairn, 1997; Wiese, 2006; Palonen, 2018). While insisting that nationalism is as inescapable as ever, Nairn (1997) shows how its forms and content are shifting, i.e. how the ethnic definition of the national is giving way to the civic, and the “natural” to the designed. National identity is, thus, relational—even imagined—and this applies to biosocial formations and biocitizenship, too (Gibbon & Novas, 2008a; Happe et al., 2018).

Thinking back to the several interactions that I enjoyed with Breathe Easy groups across North East England, I can definitely state that I observed both notions of community (Gusfield, 1978) in practice: the territorial/geographical and the relational. Needless to say, the expressed territorial notion predominantly revolved around people’s identity of being from the North—often contrasted with people from the South (especially Londoners and *Cockneys*). However, this territorial notion could itself also be split and diverse. For instance, when examining the group located in South Tyneside, there was indeed an expressed difference and divide in respect of whether people were from South Shields, Hebburn, Jarrow, or the Boldon villages. This became even more obvious when members were to pick a new logo for the group: being in the majority, members from South Shields voted for a lighthouse (much seen to be a local symbol), while the other members voted for a tree in the shape of human lungs.

Having that said, on issues concerning the borough as a whole (e.g. South Tyneside District Hospital), the notion of a territorial community and identity grew even stronger and wider. While not a segregated group per se, all members shared the wish to protect the status of the District Hospital—be they from South Shields, Hebburn, or Jarrow. One can argue, of course, that understandings of territorial and geographical identities are imagined and, thus, relational. They are, after all, social constructs as well—being the result of social practice (Hacking, 2006; Thompson et al., 2009). However, in terms of support groups like Breathe Easy, what really sets the boundaries for a relational community is the notion of biosociality, that is, the fact that people come together through shared medical or biological conditions—whether through imagined ones or through established diagnoses (Dumit, 2006). Breathlessness comes into play here, especially with regard to its somatic nature.

Group members do not necessarily share the same underlying condition—merely the same sensations, symptoms and somatic experiences, which (in terms of respiratory diseases) are more or less of a similar nature (Ambrosino & Scano, 2004; Balbi et al., 2010; Crisafulli & Clini, 2010; Jensen et al., 2016). All the same, communities are built on such fundamentals and while "imaginary" in a sense, they are not virtual communities—they are actual ones (Boellstorff, 2012, 2015).

Taking all of this to heart, *how* are communities actually formed around breathlessness? What are the pushing factors behind such a process? Firstly, we need to ask ourselves why communities are formed to begin with. What this dissertation proposes and conceives is that communities are formed around common, shared *needs*. This goes for biosociality in particular, and (in fact) parallels well with the definition of *self-help support groups* as provided by Katz and Bender, which reads (1976b: 9)

> [Support groups are] voluntary, small group structures for mutual aid and the accomplishment of a special purpose. *They are usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem, and bringing about desired social and/or personal change.* The initiators and members of such groups perceive that their needs are not, or cannot be, met by or through existing social institutions (italics added, not in original).

The dissertation sheds light on three distinct scenarios, all of which explicate where communities have been formed around needs rooted in issues that surround respiratory diseases and chronic breathlessness. Correspondingly, I have discussed these needs in three separate empirical chapters, all of which deal with different levels of biosociality in modern society.

(ii) Biomedical needs

At the outset in Chapter 4, I discussed biomedical needs where, historically speaking, communities can be said to have formed around a *cause* (cf. Black, 1992) and the need for advancement in medical knowledge due to the lack thereof. That is to say, the need in question revolves around a strive to elevate respiratory diseases as a priority on the public health agenda in the UK—a collective strive which ultimately led to the formation of both Asthma UK and the British Lung Foundation many years ago, and later even the Breathe Easy support group network. Dumit (2006) considers such processes while discussing *illnesses that one has to fight to get*. In his case, Dumit focuses on chronic fatigue syndrome and multiple chemical sensitivities, constituting two clusters of illnesses that are pervaded by medical, social and political uncertainty. Where these medical conditions struggle to attain proper recognition in terms of diagnostics, Dumit shows how sufferers (his word) describe “their experiences of being denied healthcare and legitimacy through bureaucratic categories of exclusion as dependent upon their lack of biological facts” (2006: 577). In a collective response, service users started to archive the systematic nature of these exclusions to work towards “developing counter-tactics” (ibid.: 577).

Although a different pathology altogether, I recognise breathlessness in the struggles depicted by Dumit. In interviewing people living with chronic breathlessness, I came to document numerous narratives of struggles with regard to having one’s condition not only diagnosed but also acknowledged. I remember one narrative in particular: a man in his late 50s, living in Sunderland, detailed how he started to suffer from recurring breathlessness and decreased pulmonary function. Meeting with his general practitioner time and again, he was first diagnosed with asthma; then it was COPD, then allergies, and, lastly, hay fever. However, his condition continued to worsen, and he was finally referred to the Royal Victoria Infirmary (RVI) in Newcastle upon Tyne, wherein he was diagnosed with idiopathic pulmonary fibrosis (IPF). This diagnosis stuck with him and (at last) he could get the medical treatment that he needed. Nevertheless, as he told me, he had to *fight* for this diagnosis, and still has to defend it whenever he meets with a new health practitioner who does not understand the nature of his illness.

While respiratory diseases are indeed difficult to both recognise and diagnose (e.g. Bednarek et al., 2008; Hayen et al., 2013; Dobson et al., 2014; Carel, 2015; Jagana et al., 2015; Ghadaki et al., 2016; Mujeeb Rahman & Samaria, 2016; Molina-Molina et al., 2018), the experiences that I have detailed above and those through Dumit’s study (2006) clearly illustrate the rift between objective measurement and subjective experience in living with chronic illness. In terms of breathlessness, there is a distinct difference between normal and abnormal breathlessness. Havi Carel, who herself lives with the respiratory disease known as *lymphangioleiomyomatosis* (or simply ‘LAM’), writes that:

> This debilitating, paralysing breathlessness cannot be compared to healthy breathlessness. They are qualitatively different. In healthy breathlessness, you are in control; you are far from that liminal space where life is squeezed out of you and death beckons. Healthy breathlessness might tell you that you are challenging yourself physically and getting a good workout. Many people describe it as exhilarating. But regardless of how much you exert yourself, healthy breathlessness never feels threatening. You decide how breathless you want to be; you control it, not the other way around. […] By contrast, pathological breathlessness descends on you, paralysing you. Until you get that breath in, nothing else can happen. Nothing else matters. Your world closes in on you and nothing is present except the terrible need to breathe, get more air in and out, and slowly regain control over the panting and panic that have taken over. (2018a: paras. 2-3)

Pulmonary function tests (like spirometry), while highly useful, measure only what is measurable—“the volume of air inhaled and exhaled, residual volume, rate of gas exchange, tidal volume, forced expiratory volume per second” (Carel, 2018a: para. 9). Needless to say, what is measured bears little resemblance to what really matters to a person living with chronic breathlessness, for instance, how their everyday lives will be affected by their illness and what they will have to give up because of it. While breathing is a universal physiological process (and all animals respire), it is also a “subjective and socially mediated experience” (Oxley & Macnaughton, 2016: 256). As such, the meaning of breathlessness for those who live therewith is poorly understood in respect of its subjective, cultural and experiential significance. This extends to diseases of the chest and lungs. Living in a day and age with so many competing public health priorities, chronic respiratory diseases have not received the attention that they really deserve (Forum of International Respiratory Societies, 2017: 5). Calling for an elevation of respiratory diseases in terms of the UK’s health priorities not only is a biomedical cause but also remains a biomedical *need*. This need is proclaimed by a (bio)sociality consisting of not only patients and their families but also researchers and educators, health professionals, charity and voluntary workers, and policymakers as well.

That being said, biosociality around socio-medical causes is far from being undocumented within anthropology (and cognate sciences), and this dissertation will stand proudly next to them. By all means, the AIDS Coalition to Unleash Power (ACT UP) and its work to improve the lives of people with HIV/AIDS by means of direct action and medical research, treatment and advocacy will forever be remembered amongst patient advocacy organisations (Christiansen & Hanson, 1996; Haldi, 1999). This movement has been widely documented by researchers across the humanities and social sciences; Whelehan (2009), Blythin (2000), and Schulman (2021) are merely a few vivid examples. Biehl (2009) documents a similar process in Brazil. In *Will to Live* (2009), Biehl writes about a group of AIDS patients (all unemployed, homeless, involved with prostitution and drugs) who successfully established a makeshift health service against the backdrop of a national policy that sought to universalise the access to AIDS therapies but failed the financially underprivileged and further stigmatised these groups as being noncompliant or untreatable. Novas (2008) also contributes to this literature, who illustrates the potential for biotechnology in developing new means of acting on the health of citizens. In detail, Novas documents the creation of substantial political economies oriented towards extremely rare diseases, where novel alliances are being forged between the life sciences and the capital market. As Novas writes, the creation and existence of these political economies demonstrates how biotechnology firms and the capital markets can, through proper legislation, be used as mechanisms to:

> […] correct a market failure and at the same time accomplish the socially and economically desirable objective of developing cures or therapies for populations affected by rare diseases (2008: 150).

As a final example, I want to mention Raffaetà, who suggests “that socialities may develop beyond biomedicine and around contested understandings of health” (2017: 22)—a perspective which has political consequences. While Rabinow (1992, 2008) argues that in biosociality, culture has primacy over nature, as it provides the model for nature in a biotechnological age, Raffaetà comes to challenge this representation of the relationship between biology and culture. In her study of parental groups critical of paediatric vaccinations in Italy, Raffaetà (2017) illustrates how these parental groups affirm the priority of nature over culture. This extends, Raffaetà argues (2017: 1), the notion of biosociality because it, instead, considers communal identities around shared understandings of health, wherein one's body and biology are deemed to be sacred and something to remain untouched. Such social outlooks are not unheard of, especially amongst religious movements such as Jehovah's Witnesses, who believe that the Bible prohibits Christians from accepting blood transfusions (Bram, 1956; Bisha, 1995; Rajtar, 2018). All the same, this opens up a debate: is biosociality a tautology or circular reasoning? How is the biological not sociocultural as well, and can the biological ever escape its political nature?

(iii) Biosocial needs

Following on from biomedical needs, the second scenario (considered in Chapter 5) concerns biosocial needs. I deliberate on this in reference to the forms and function of Breathe Easy groups in particular, and the question of why support groups have come to grow in popularity around the world. In many ways, however, this conception illustrates the biological determinism (Walsh & Wright, 2015) that habitually personifies biosociality theory and which ignores constructivist epistemology. That is to say, what I am referring to with 'biosocial needs' is sheer socialisation and the importance of human interaction (cf. Umberson & Karas Montez, 2010)—however, due to the social interaction being performed on biomedical grounds, it all becomes *bio*social. While the concept of biosociality was forged so as to stand in contrast to the concept of sociobiology (Wilson, 1975; Ruse, 2012), whereby capturing a "new kind" of social interaction due to developments within genetics (Pálsson, 2007; Gibbon & Novas, 2008a; Ingold & Pálsson, 2013), a question remains: is biosociality a new form of human interaction? All the same, putting the *bio* in *biosocial* carries potential in making important contributions to the humanities and the social and behavioural sciences for a number of reasons (Marsland, 2012; Harris & McDade, 2018). Humans are biological creatures, after all—"embedded in families, social networks, communities, and cultures" (Harris & McDade, 2018: 4). Context matters to human biology, and engagement with biological concepts and measures reflects this reality. Harris and McDade maintain that this becomes especially clear:

> […] in the case of human health, where the importance of social determinants is well established and widely known […] and where social impacts on underlying physiological processes are apparent and increasingly elaborated (2018: 4).

This, I argue, is from where biosocial needs stem: humans' embeddedness in and connection to families, social networks, communities, and cultures. Even more so, it parallels with why self-help support groups exist. In the words of Katz and Bender (1976b, 1990): due to a perceived shortcoming in having one's needs met, people come together for mutual assistance in satisfying or overcoming a common concern, disability, or life-disrupting problem. Again, we see this in Dumit's (2006) work on people living with contested illnesses, wherein direct action online is employed so as to track how the very systemic nature of healthcare denial can be archived, discussed, and used to create 'tactics of the weak' (cf. Scott, 1985) in response to symbolic domination and bureaucratic categories of exclusion. Biological determinism notwithstanding, the need for human interaction stands to be firm. As such, Harris and McDade write, a new generation of biosocial research is "poised to bridge the gap between community- and clinic-based approaches to understanding the dynamic interplay of biology and social context across the life course" (2018: 7). Whether or not we consider certain socialisation and interaction to be biosocial, Marsland argues that a "nuanced understanding of theories of biosociality requires us to take sociality and locality as seriously as we do 'bio'" (2012: 470). The prefix *bio*, Marsland writes, "invites us to think in terms of universals" (ibid.: 482). Thus, if we (instead) were to emphasise the social in reassessing the term as "(bio)sociality", then we would be able to observe how said *bio* phenomena play out in different social, political and economic contexts.

That being said, what are the biosocial needs in living with a chronic disease—breathlessness or otherwise? What becomes of the individual vis-à-vis the collective, especially when thinking about support groups? As Katz and Bender (1976b) point out, the needs derive from one's experience and understanding of a life-disrupting problem. As I mentioned earlier on in this chapter, Bury (1982) conceives chronic disease through the notion of *biographical* disruption. Moreover, a disruption to life, Bury writes, highlights the resources “available to individuals, modes of explanation for pain and suffering, continuities and discontinuities between professional and lay thought, and sources of variation in experience” (1982: 167). The anthropological perspective on disruption is further expanded upon by Becker, whose book entitled *Disrupted Lives* (1998) was the first to examine disruption in American life from a cultural (rather than a psychological) perspective. Through vivid and poignant stories of people throughout the life cycle (all of whom experience different types of disruption), Becker (1998) examines how people rework their ideas about themselves and their worlds—from the meaning of disruption to the meaning of life itself. Breathlessness, as such, falls under both the former and the latter categories: being both a symptom *and* a sensation. As has been discussed throughout this dissertation: in the contexts where breathlessness is considered abnormal, it is named a medical symptom found in many underlying medical conditions—especially in diseases of the chest and lungs (Lansing et al., 2009; Burki & Lee, 2010; Gigliotti, 2010; Johnson et al., 2014).

Although a medical symptom, breathlessness is also a somatic sensation and a mode of attention (Csordas, 1993) in both its normal and its abnormal states. Specifically, breathlessness is, in and of itself, an embodiment (Csordas, 1990)—a respiratory mechanism and physiological response experienced by humans, non-human primates, and other animals (Burki & Lee, 2010). Therein lies the problem: the rift between objective measurement and subjective experience. When it comes down to it, the collective experiences of being neglected, not listened to, and not cared for due to chronic breathlessness (which have been detailed throughout previous chapters) correlate with what this dissertation considers to be the ‘invisibility of breathlessness’. This analytical term stems from research construed by Gysels and Higginson (2008), who explore the experience of breathlessness in patients suffering from COPD through the patients’ accounts of their interactions with healthcare services. All told, the authors conclude that the poor service delivery and the low access to services for patients are due to the nature of breathlessness itself, “with its slow and surreptitious onset; patient interactions with the social environment assigning stigma to breathlessness; and the way the symptom is addressed by institutions" (Gysels & Higginson, 2008: 451). They apply the metaphor of *invisibility* to capture, illustrate and describe these illness experiences.

In sum, I argue that it is by reason of experiences like invisibility, exclusion, stigma and shame (Pattison, 2000; Dolezal, 2015a, 2015b; Harrison et al., 2015) that self-help support groups have come to increase in numbers worldwide. The groups respond to people's biosocial needs, providing "help and support [that they] were not able to get elsewhere" (Boyce et al., 2018: 5). The nature of this mutual support is multifaceted however, as illustrated in Chapter 5—it can be social, emotional or practical. Although (intrinsically) it is a reciprocal process which allows for peers to benefit from the support regardless of whether they are giving or receiving it (cf. Riessman, 1965), support groups often develop "organically from the grassroots in reaction against the stigma projected by others" (Boyce et al., 2018: 4), and grow to become safe spaces in which members can listen and talk to one another free from judgement and dismay. Taking this to heart, as Nichter proclaims (2008), it becomes apparent that the 'biosocial' needs to be studied in the context of social change. After all, a biosocial perspective draws on "models and methods from the biological, medical, behavioral, and social sciences" (Harris & McDade, 2018: 3). The biosocial perspective, Harris and McDade argue, enables the conceptualisation of the biological and the social as *mutually constituting forces* (2018), which blurs the boundaries between phenomena both inside and outside of the body. As such, it remains significant that one defines the 'biosocial' with a broad spectrum in mind, thereby referencing the "dynamic, bidirectional interactions" (Harris & McDade, 2018: 2) between biological phenomena and social relationships by means of different contexts throughout the life course.

(iv) Biopolitical needs

The third and final scenario, which I use to consider how communities may form around common needs, is grounded in the biopolitical sphere. I discussed this scenario in Chapter 6 in relation to patient advocacy as a political project. My argument, on the whole, is that biopolitical needs revolve around notions of citizenship (e.g. biological, patient, pharmaceutical) and one's civil rights in society. As such, expressions of biopolitical needs take the shape of claims through advocacy and direct action—as illustrated in Chapter 6 and in the campaigns against the Path to Excellence programme in the borough of South Tyneside. Being the last piece of the puzzle, this scenario illustrates the circular reasoning that underlies my overall contribution. That is to say, all needs are interrelated. As it goes to show, biomedical needs (*causes*) are built on and draw on biosocial needs—needs that are not (or cannot be) met by existing social institutions. Seeking to overcome such perceived shortcomings through contra-tactics, this extends to the biopolitical sphere in the shape of direct action in which one constructs a (biomedical) cause through medical research, treatment and advocacy, as well as working to change legislation and public policies.

Throughout this dissertation, I have drawn several parallels between themes that have emerged from the ethnographic material presented. Amongst these themes, we find not only debates surrounding the distinction between nature and culture, but also practices of neoliberal governmentality (Rose, 1999) in which biopolitics is seen to subjugate people and bodies to symbolic domination. Looking specifically at what I call *biopolitical needs*, it becomes all the more significant to note that in relation to biopolitics (the practice to 'ensure, sustain, and multiply life'), *biosociality* is to be understood as "something produced by and through, and not in spite of, the existence of power" (Friedner, 2010: 337). Namely, Friedner suggests that power is "productive of forms of community and subject formation" (2010: 339), and further argues that such processes of individualisation, medicalisation and classification have produced the "conditions of possibility" (ibid.: 339) that are conducive to the emergence of biosociality. Within this context, power should explicitly be understood as *bio*power. Biopower, simply put, refers to the control of human bodies through anatomo-politics of the human body and by means of biopolitics of the population (Rabinow & Rose, 2006; Macgregor, 2012), wherein people are subjected to, as Foucault writes, “an explosion of numerous and diverse techniques for achieving the subjugations of bodies and the control of populations” (1978: 140). If so, this means that biosociality can be conceived as a collective response to subjugation, as well as a pursuit of social change. Biosociality thus becomes an act of bodily autonomy, agency, and pastoral power (Wilson, 2001) as well as a process of expressing one’s biological citizenship—the individual and collective welfare claims made by a biologically damaged population (Petryna, 2002, 2004).

By means of biosociality being understood as an act of bodily autonomy, I come to argue that the global proliferation of support groups (like the Breathe Easy network) is not only a consequence of individualisation and of shifting responsibilities in modern-day healthcare (Trnka, 2017; Kenner, 2018). In truth, the phenomenon should also be understood as being a direct reaction to political failures “in responding to biomedical misconducts” (Kasstan, 2019: 10). While Kasstan refers to misconducts in terms of direct biomedical controversies—like with the measles, mumps, and rubella vaccine in the United Kingdom (2019: 10), I expand on the notion of biomedical misconducts to incorporate a more biopolitical sphere. That is to say, I look more closely at neoliberal governmental decision making that concerns healthcare organisations and which, in the views of its local service users, is deemed to be unlawful. Thinking back to Chapter 6 and the ordeals surrounding South Tyneside District Hospital, this is what actually played out: how the proposed Path to Excellence was not seen to strengthen vital services for the people of South Tyneside, but rather was seen to be a way in which to downgrade the hospital with the least opposition. As such, as this scenario shows, biopolitical needs stem from a biosociality that emerged via practices of (bio)power, as a response to people becoming subjected to anatomo-political subjugation and symbolic domination.

BIOSOCIALITY: REFLECTIONS ON AN ANALYTICAL FRAMEWORK

Many themes have been touched upon throughout this dissertation, but one in particular has come to dominate the discussion: how communities are formed and sustained around shared medical or biological conditions. This social phenomenon is considered through the use of *biosociality* (Rabinow, 1992)—an analytical framework that, simply put, refers to the process in which people diagnosed with a disease or condition form a self-identity around the diagnosis. Those afflicted can reflect on themselves as a "specific kind of person, find others with the same disorder, and even develop a sort of kinship with that group" (Halverson, 2015). Some even refer to biosociality as being a new form of communality and creating identity (Tomašovičová, 2015). In modern times, the concept now has a wide array of literature behind it. As Gibbon and Novas write:

> The widespread referencing of Rabinow's […] concept of biosociality during the [many years] since its original formulation illustrates its utility for many social scientists in mapping and investigating the transformations in knowledge and identity brought about by new genetic knowledge. (2008b: 1)

Many scholars have picked up and further developed Rabinow's notion of biosociality, using it for empirical research (e.g. Gibbon & Novas, 2008a; Lock & Nguyen, 2010; Hadolt & Hardon, 2017; Happe et al., 2018). For instance, Mohr (2018) applies the notion in examining what it means to be a man in our biomedical day and age. Through ethnographic exploration of the everyday lives of Danish sperm donors, Mohr (2018) illustrates how masculinity and sexuality are reconfigured in a time in which the norms and logics of reproductive biomedicine become ordinary, and intertwine with men's intimate sense of self. By contrast, heavily inspired by the biosocial framework, Biehl (2009) uses it to examine the political economy of pharmaceuticals in Brazil. For this achievement, being the first developing country to universalise access to life-saving AIDS therapies, Brazil has been hailed as a model worldwide. However, Biehl (2009) reveals the possibilities and inequalities that accompany this 'magic bullet' approach to healthcare, which has been difficult to implement amongst destitute Brazilians with HIV/AIDS (who are often stigmatised as being noncompliant or untreatable). Yet, rather than discussing *what* biosociality is, should we not perhaps deliberate on what it *does*?

This perspective is central to this dissertation. Rather than predominantly discoursing with regard to how Breathe Easy groups are, and act, in the form of autonomous biosocial constellations, the dissertation illustrates what happens to social engagement in view of biosociality—whereby biological citizenship is also sanctioned and further made possible (Hadolt & Hardon, 2017; Happe et al., 2018).

As might be expected, throughout the course of this study, my own views of and approach towards biosociality (as a theoretical paradigm) changed on multiple occasions. In the coming section, I deliberate on this journey. The reason as to why the concept of biosociality came to mantle the analytical framework upon which this dissertation draws stems from research on the growing position of genomics and genomes in modern society. This historical process is well documented by Rabinow (1992, 1996b, 1999, 2008) and has now been further advanced by other scholars—such as Petryna (2002, 2004), Pálsson (2007, 2013), Gibbon and Novas (2008a, 2008b), and Rose (2007, 2013a). What this body of literature considers and offers is a broad, fresh perspective on how genetic research redefines what it means to be human in our society. In their edited volume from 2008, Gibbon and Novas (and fellow authors) deliberate on biosociality from a wide array of perspectives. As they apply this concept in making sense of shifts in social relations and in ideas about nature, biology and identity brought about by progress in biomedicine, Gibbon and Novas write (2008b: 1):

> The growth and expansion of certain fields of knowledge within the biological and medical sciences, including those linked to genomics, have widened the scope and range of techniques, theories and tools that can now be used to understand and intervene upon ‘life’. Just as practitioners within these sciences have sought to develop new concepts and techniques by which to study and act upon vital biological processes, practitioners within the social sciences have also similarly engaged in the work of developing novel concepts and methods that are adequate to the task of analysing how potential transformations in understandings of ‘life’ may be involved in reassembling existing cultural, social, economic, ethical and political practices.

The growth of so-called ‘new genetics’ (Pálsson, 2007) has dramatically increased our understanding of health, diseases and the body (Petryna, 2002; Gibbon & Novas, 2008a; Gamlin et al., 2020). Anthropologists have thus come to argue that these scientific advances have had far-reaching social and cultural implications—

radically changing our self-understanding and perception of what it means to be human (Pálsson, 2007; Rose, 2013a). Such scientific advances have allegedly, in modern times, rendered us ‘bio-medicalised’, fragmented and commodified (Burri & Dumit, 2007; Lock & Nguyen, 2010), insofar as we have even come to redefine our notions of citizenship, social relations, family, and identity (Gibbon & Novas, 2008a; Gibbon et al., 2016). Taking all of this to heart, especially in relation to what Pálsson calls the ‘new genetics’, research on biosociality (the process in which people diagnosed with a disease or condition form a self-identity around their diagnosis) becomes significant when it comes to making sense of three themes in particular: a) increased understandings of health, disease and the body; b) cultural implications for self-understanding; c) redefinitions of citizenship and social identity. After all, Rabinow (1992, 2008) forged the concept of biosociality as a way in which to think through what kind of sociality might emerge as our knowledge of what a disease is undergoes a process of considerable change. In view of how a study of support groups for people with chronic breathlessness (inevitably) also comes to consider how members self-identify and make sense of their illness, the concept of biosociality was an obvious first choice for the analytical framework. After all, a support group is centred on people who come together through shared, common goals or needs—referring in this case to the symptom burden of living with breathlessness (Hayen et al., 2013; Carel, 2018c).

While undeniably applicable in terms of analysis, I still made sure not to let the notion of biosociality come for granted and potentially cloud how I would observe what could come about in the field. This is why at an early stage of this study I entered the field with the following question: *Is the concept of biosociality useful in looking at support groups for people with chronic breathlessness?* This question led me to a junction, where if the initial answer was “Yes”, then how was this expressed? However, if the answer transpired to be “No”, then how come and in what ways was the notion of biosociality insufficient in looking at these groups? As the research study progressed over time, I arrived at the inference that biosociality still made sense within this context and in trying to make sense of how people understood themselves in relation to both breathlessness (subjectively) and the support group as a whole (collectively).

Having that said, this approach did not come without its challenges. As senior colleagues at Durham University had commented, if one were to interpret biosociality as closely to its original phrasing (cf. Rabinow, 1992) as one could, then one would have to adhere to two principles: 1) people come together by means of sharing biological conditions, and 2) the same people take to ‘the streets’ and advocate for a common cause that relates to said biological condition (whereby giving a ‘voice to the voiceless’). I disagreed with them, however; thus, early on I came to take a step away from this contemplation. The primary reason for doing so was that I, on the whole, considered it to be an outdated perspective on what biosociality had to offer in terms of understanding the relation between health, disease and the body. However, such a proclamation is also rather ableist, as it considers (or supposes, more likely) that all bodies can and will act the same, despite not necessarily living under the same pathological conditions and circumstances. That is to say, older people with diminished pulmonary and cardiovascular function cannot engage in the same physical encounters that habitually may come to characterise global patient organisations and advocacy (cf. Epstein, 2008; Lemke, 2015) where cancer and HIV/AIDS have come to dominate the public and political scene (Aggleton et al., 1997; Epstein, 1998; Manderson, 1999; Gibbon, 2007; Biehl, 2009; Nguyen, 2010; Bausewein et al., 2013; Malik et al., 2013; Timmermann, 2013; Chou & Zeitzen, 2018). The AIDS Coalition to Unleash Power is an illustrious example (Christiansen & Hanson, 1996; Haldi, 1999) in which members demonstrated at Wall Street and Broadway to demand greater access to experimental drugs and for a coordinated national policy with which to fight the disease.

Much later, after having spent time in the field, I came to change my position once again. Instead of questioning whether the framework had to consider highly engaged advocacy in order to align well with biosociality, I started to question our understanding of what it actually means to *be* an advocate and how these practices come to take shape. That is to say, biosociality as an analytical term may very well always (or in the majority of cases) parallel identity making with advocacy, but *what* advocacy actually comes to mean in this context is far from being unilateral. On the contrary, advocacy incorporates a multitude of ways of establishing social scenes and making neglected voices heard. It was during this stage of my research journey that I drew my attention towards making sense of how Breathe Easy groups may enact activities that fall under the category of patient advocacy. After all, as I came to observe their engagements, these support groups were very much concerned with having their messages 'take to the streets'—which was ultimately done, needless to say, in a less literal and physical sense.

What becomes of biosociality, as such, if the habitual image of this phenomenon persists as a large crowd of people with plaques, screaming their lungs out and demanding change for their cause? While ACT UP remains a cornerstone in not only HIV/AIDS politics but also patient activism and advocacy, generally speaking, continuing to perceive such an act to be 'the way' in which to do it will merely feed into ableism and neglect those groups whose circumstances demand for other methods in their practice. In my view, this remains the most crucial issue when it comes to research on biosociality. Thus, this dissertation acts as a call to action for approaches that seek to expand on and contribute novel understandings to biosociality theory, and that go above and beyond in considering what biosociality *does*—rather than merely what it *is*.

MEANING OF THE STUDY

Strathern writes that the value of anthropological, ethnographic research lies in its ability to present perspectives from which the world can be apprehended anew (1988: 91). As I demonstrate in this chapter, the dissertation provides a number of novel contributions. Most significantly, this dissertation provides several contributions and perspectives to anthropology—especially anthropological understandings of health, illness and disease where it bridges dialogues between subjective and collective embodied experiences. Yet, in turn, these perspectives also further inform understandings of other sociocultural phenomena, amongst them: advocacy, breath and breathing, biosociality, and support groups. The dissertation is, I firmly believe, the first of its kind to comprehensively and historically look at the support group as a phenomenon that extends beyond the social setting that it provides. Rather, this dissertation makes sense of the support group as a self-help resource—a *technology* on which service users can draw in seeking to expand on their knowledge towards self-improvement. The dissertation does this explicitly through the lens of biosociality (Rabinow, 1992; Gibbon & Novas, 2008a; Vrecko, 2008; Friedner, 2010; Raffaetà, 2017) and provides novel insights into what biosociality *does* and *becomes*—rather than merely deliberating on what it *is*.

Contrary to how it might appear, initially this doctoral research did not set out to study support groups. Although an independent study in and of itself, due to it being integrated within the larger project framework of *Life of Breath*, (rationally) the themes of breath, breathing and breathlessness were always to be at its heart. However, rather than following suit and further contributing to either the phenomenology of breathing (Carel, 2016; Oxley & Russell, 2020; Malpass et al., 2021), breath in the philosophy of medicine (Carel, 2018c; Williams & Carel, 2018; Williams, 2020), clinical cultures and diagnostic practices (Carel, 2015; Macnaughton & Carel, 2016; Oxley & Macnaughton, 2016), or the harmful industries that surround respiratory health and diseases (Russell, 2018, 2019; Rose, 2020) , the research design ultimately fell on a particular group of stakeholders. More specifically, the study came to focus on those who live with a breathing condition and each day have to navigate through the precariousness that accompanies chronic disease management (Newbould et al., 2006a).

Down the line, however, the study eventually took this perspective one step further. That is to say, rather than merely investigating the human subjects of illness in and of themselves, (in a true Foucauldian sense) the study emerged itself within the discourses that come to embody the subject *as* a subject (Hacking, 2004; Speziale, 2017). Namely, as such, Foucauldian theory rejects the search for a true self, as within this framework the self is understood to be a series of practices, rather than a predetermined matter (as often construed in psychology) (Foucault, 1988; Gutting, 2005; Smith, 2015). If anything, Foucault himself was primarily invested in how people come to think, feel, and act as certain kinds of selves (or subjects, as he called them), and dedicated his academic career towards examining the effects and consequences that such behaviours have on society (e.g. Deleuze, 1986; Garland, 1986; Martin et al., 1988; Barry et al., 1996; Danaher et al., 2000; Lemke, 2001; Gutting, 2005; O'Farrell, 2005; Cotoi, 2011; Behrent, 2013).

It stands to reason that the outcomes of this dissertation speak to this Foucauldian archetype, as it not only asks what breathlessness is and how people understand this pathology but also provides perspectives which inform understandings of how people understand themselves in relation to breathlessness and how the pathology *subjectivates*[61] them to certain kinds of social conditions (Foucault, 1982). However, as many of my interlocutors said to me: "I am more than my illness" (cf. Sontag, 1978; Bury, 1982; Leete, 1989; Heurtin-Roberts & Becker, 1993; Becker, 1998; Fleischman, 1999; Revenson et al., 2005; Carbine & Dolphin, 2012; Jowsey et al., 2014; Carel, 2018b). Indeed, these people do talk openly about living with a chronic illness—but they do not wish to be defined purely by being "ill". As one service user posted on a blog:

> I might be ill, but my illness doesn't define me. Having a lung condition is not the end of the world; we can go forward with a little help and understanding from friends and family. (British Lung Foundation, 2015a)

Although this doctoral project initially was designed to critically engage with the biopolitics surrounding respiratory health in the UK, the project later came to turn towards investigating instances in which patient advocacy intersected with notions of biological and patient citizenship (Petryna, 2002; Biehl, 2009). Namely, at an early stage I started to observe certain "anomalies", as one calls them (Merton, 1948; Barnett, 1985; Hakim, 2000), that is, abnormal social patterns that involve "the unanticipated, anomalous and strategic datum which exerts pressure upon the investigator for a new direction of inquiry which extends theory" (Merton, 1948:

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[61] I am aware that, grammatically speaking, this concept does not really work as a verb. Having that said, it draws on Foucault's writings (in French) and is now commonly used to describe the processes which I seek to analyse (Foucault, 1982, 1997; Ong-Van-Cung, 2011; Robbins, 2013; Foucault, 2014b; Rebughini, 2014; Smith, 2015; Oberprantacher & Siclodi, 2016).

506). While some scholars would perhaps consider it to be a knowledge gap (Lavrakas, 2008), I prefer the notion of anomalies because the observations to which I refer did not concern a discrepancy between what is known and what should be known. Rather, they concerned abnormal social patterns—or, as Kuhn (2012) would put it, social facts contradicting and challenging the prevalent paradigm.[62]

Butler writes that "telling the truth about oneself comes at a price, and the price of that telling is the suspension of a critical relation to the truth regime in which one lives" (2005: 121-122). In many ways, this relates to the overall (symbolic) meaning behind this dissertation. The aforementioned anomalies of which I had made a note concerned the actual practices of collective chronic disease management outside of the clinical environment—in support group settings, to be even more specific. However, the anomalies did not concern the management practices in themselves per se. Rather, the issue concerned the time period—a time of sociopolitical turmoil, to say the least (cf. Pollock & Leys, 2005; Mandelstam, 2007; Gorsky, 2008; Sheard, 2011; Hyde et al., 2016; Niemietz, 2016; Appleby, 2019; Pollock, 2019). That is to say, these nonclinical support group gatherings were taking place at a time when governmental deregulation of national healthcare services in the UK was at its highest—after almost a decade of underfunding, the NHS continues to struggle, and the money promised thereto does not allow for preparations for the future. In these times, the deregulation of healthcare services is normalised to the point at which the practice of *caring for one's self* (Foucault, 1986; Martin et al., 1988; DeFrancisco, 1995; Faust, 1998) not only becomes a necessity in living with a chronic illness (Furin, 1997; Trnka & McLauchlan, 2012; Larsson et al., 2016) but also the actual means of activating (Rademakers et al., 2012; Ashmore et al., 2013) and personifying citizens as ideal subjects. This is what Foucault (1982) calls *subjectivation*—the process by which one becomes a subject. Our understandings of advocacy, social formations, and support groups become crucial when examining the issues that come into play here.

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[62] Foucault would most certainly call this the *regime of truth*, referring to a discourse that holds certain things to be "truth" (2005, 2010, 2011, 2014a, 2014b).

That being said, what happens to the idea of culture under neoliberalism? Neoliberal reforms, like the deregulation and privatisation of key national industries, have led to severe changes in healthcare systems around the world (Sakellariou & Rotarou, 2017). In the United Kingdom, these reforms often emphasise how there are “no rights without responsibilities” (Owen & Harris, 2012)—a disposition which is said to reinforce the ideological preference for a free market system rather than (bio)citizenship and rights to health (Happe et al., 2018). However, owing to their distinctive healthcare needs and lower socioeconomic status, people with disabilities are especially disadvantaged by such neoliberal reforms, as they seldom have the energy (or the confidence) with which to challenge those in authority or campaign for improvements in care. One such vulnerable group is that of people who live with chronic breathlessness and respiratory diseases, who, in neoliberal ways, are further inundated with how respiratory care is increasingly individualised by public health responses that emphasise individual responsibilities over collective or institutional ones (Trnka & Trundle, 2014; Trnka, 2017; Kenner, 2018). As Kenner writes:

> While some modes of care […] mirror practices that have been written about through asthma’s history, other responses—both public and private—reflect unique circumstances of the contemporary epidemic as well as advances in biomedicine and pharmaceutical treatments. I join with other social science researchers in arguing that asthma care has been individualized in neoliberal ways; even public health responses have tended to emphasize the responsibility of individuals—taking medication, cleaning home environments, and monitoring pulmonary performance—over collective responsibility. (2018: 8)

While Kenner focuses on asthma in her research, these modes of care do not merely refer to asthma regimens—but rather to respiratory care on the whole. The burden that respiratory diseases place on health and health services is immense (Marmot, 2016). It is on par with non-respiratory cancer and cardiovascular disease, yet the amount of resources and attention invested in tackling respiratory diseases trails behind these other disease areas. Better diagnosis and disease management would reduce this burden (British Lung Foundation, 2016), particularly on emergency care. This underwrites why the practice of training and activating patients (Hibbard et al., 2004; Greene & Hibbard, 2012; Rademakers et al., 2012;

Ashmore et al., 2013; Hibbard & Gilburt, 2014) escalates around the world and why the responsibilities of individuals (such as monitoring one's own pulmonary function) now come before collective and institutional responsibilities. "The order is clearly worth saving, but the question is how" (Lind & Wohlforth, 2019: 70). As such, in order to 'save the system' the individual is sacrificed over the many (cf. Halbertal, 2012)—as in a neoliberal way, one is expected to strive for constant development and self-improvement. This is why, I argue, support groups need to be understood as entities that extend beyond their collective purpose and vision of sociality for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem. Ultimately, support groups are communal reactions to historical contexts of marginality that may continue to be at play (Kasstan, 2019)—or to political failures in responding to biomedical misconducts.

UNANSWERED QUESTIONS

Although extensive in themselves, all research projects are limited by a certain scope. Many questions have received adequate attention, whereas there are those only touched upon superficially—or perhaps not at all. Having that said, there are also those questions which have had to be left unmentioned, either because of time restraints or because of events that took place 'post-production' yet would come to affect the research questions at hand. In this section, I want to pay certain attention to some questions which have been left unanswered—much due to circumstances that ultimately were out of one's hands and, thus, impossible to predict. This will also intersect with questions that were brought to the surface once the project ultimately had come to an end.

I would like to start by attending to certain events that took place after fieldwork had come to an end, and thus could not be included in this thesis. More specifically, I refer to two events: 1) proposed changes to the Breathe Easy support group network, which were made public by the British Lung Foundation in July 2018; and 2) the merger of the British Lung Foundation (BLF) and Asthma UK in 2020. Needless to say, these changes will have a massive effect on *how* the Breathe Easy groups form and function. While it may be fair to suggest that the BLF side of the new partnership most likely will continue to oversee the Breathe Easy group network, the charities' newfound financial situation will come to change and, in all likelihood, improve. This will (undoubtedly) come to affect how these two charities (now merely *one*) engage in their benevolent and voluntary undertakings throughout the United Kingdom. Nevertheless, how this may come to affect the Breathe Easy groups is difficult to say at this time and would require an independent, novel research study in order to be fully explained. How many groups will ultimately stay fully integrated with the British Lung Foundation and how many will end up declaring themselves independent? What will this mean for the Breathe Easy support group network as a whole in functioning as a national patient service, and what will become of the collaborations that sometimes take place across individual groups? These are all questions that will remain unanswered for now.

Turning our attention to more local events throughout the borough of South Tyneside and the City of Sunderland more specifically, the controversial *Path to Excellence* programme has yet to reach its final stage. Being a five-year-long process that initiated in 2016–17, this doctoral project was never in a position to investigate this transition from start to finish. Having said that, as I have made clear in previous chapters, this political intervention (which local people have named *pathways to closure*) quickly grew to become impertinent for my research and for my overall argument regarding how to appropriately understand the forms and functions of Breathe Easy groups—especially in smaller towns, like South Shields. Furthermore, the whole incident that is Path to Excellence sheds further light on the role that hospitals play in contemporary society and how—though a rather well-researched topic even now (Main, 1946; Coser, 1962; Long et al., 2008; Rapport, 2008; Stewart, 2019)—our understanding of anchor institutions is still in need of further research. These questions grow to be particularly important in light of the *Keep Our NHS Public* movement (Cassidy, 2011) that is spreading all across the United Kingdom, committed to reversing what it describes as the ongoing privatisation of the NHS (Pollock & Leys, 2005; Mandelstam, 2007) and its services. South Tyneside is far from being the only UK borough that is, or has been, at risk of losing its district hospital or having a large amount of local services relocated or downgraded. In truth, pathways similar to Path to Excellence have been enforced all around the UK, resulting in local campaigns like Save Lewisham Hospital, Save Ormskirk and Southport Hospitals, Save Our Queen Elizabeth Hospital, and Save the Vale of Leven Hospital, to name a few (e.g. Dyer & Torjesen, 2013). In view of the current NHS funding crisis (Gorsky, 2008; Appleby, 2019), local health activism in the UK is more widespread than ever before, which enables many research opportunities.

As a final note, I want to turn the attention towards the 2019–20 coronavirus disease pandemic (COVID-19), which, needless to say, will continue to affect human life for the remainder of 2021 (Zeegen et al., 2020)—and perhaps even years to come. It is fair to say that not only does COVID-19 put the topics of breathlessness and respiratory diseases properly on the agenda, the outbreak also sheds light on global issues surrounding widespread health inequalities (Heymann & Shindo, 2020; Mehdi, 2020), while illustriously exhibiting a global transition from a health crisis to an economic crisis (Shoss et al., 2020). While this doctoral project had come to an end long before the pandemic witnessed its outbreak, the crisis certainly led to the arrival of questions crucial to the theme of this dissertation as well as to its outcomes. What is more, the pandemic has further illustrated the complex nature of breathlessness and its treatment. How does one treat a symptom? Even more so, how does one treat an *invisible* one (Carel, 2018c; Macnaughton, 2020; Williams, 2020), especially when we lack the language (Netuveli et al., 2007; Mahler & Baird, 2008; Petersen et al., 2008; Aggarwal, 2009; Malpass et al., 2021) with which to properly detail and describe this sensation? Breath is essential to life and any threat thereto is too frightening to be able to comprehend, let alone express.

As COVID-19 has shown us, our deepest and most primal fears relate to suffocation, drowning, or being unable to breathe. Having that said, the aforementioned questions posed by COVID-19 are not novel—at least not in and of themselves. These questions were (in fact) relevant years before in examining people's experiences of living with chronic breathlessness and respiratory diseases (British Thoracic Society, 2001, 2006; British Lung Foundation, 2007b, 2016). They will remain relevant, as will research on the respiratory system, for as long as breathlessness remains invisible (Gysels & Higginson, 2008) and respiratory research continues to suffer from neglect in terms of research funding (Hubbard, 2006; Macnaughton, 2016). The disruption caused by the pandemic will, however, forever become marked in the history books as something never previously experienced by mankind. I can only hope that anthropologists follow suit and document the disruption caused to healthcare and people's lives all across the globe. After all, the value of anthropological research lies in its ability to present perspectives from which the world can be apprehended anew.

IN PLACE OF CONCLUSION

Obstructive and inflammatory respiratory diseases, such as asthma and chronic obstructive pulmonary disease (COPD), are on the rise as killer diseases around the world. In truth, the World Health Organization has predicted that COPD, explicitly, will rank as the third-highest cause of death worldwide by 2030. In Europe alone, an estimated 300,000 deaths are due to COPD each year. Looking at the United Kingdom more specifically, as revealed by the British Lung Foundation in their 2016 report entitled *Battle for Breath*, respiratory diseases constitute one of the three biggest killer disease areas (alongside heart disease and non-respiratory cancers). Respiratory diseases kill 115,000 people each year—the equivalent of one person every five minutes. Whilst the physiology of breathing is well recognised, the subjective experience of breathlessness is poorly understood. Although far from being an invisible condition (statistically speaking), respiratory health is rarely discussed as the widespread public health issue that it really is. Thus, as a result, people living with respiratory diseases often feel invisible and seldom have the energy or confidence with which to challenge those in authority or campaign for improvements in healthcare.

This dissertation considers the problem outlined above, looking specifically at how people with respiratory diseases cope with and manage their conditions through participation in local self-help support groups. In this dissertation, which is a novel study of the somatic sensations of abnormal breathing and breathlessness, I conclude from the ethnographic data provided on Breathe Easy groups in North East England that self-help support groups can be understood as vehicles for bridging dialogues between subjective and collective bodily experiences of health and illness. This study contributes to widening the anthropological understanding of biosocial communities and their formation by shifting the emphasis from considering what communities are to considering what they do. With regard to the literature on biosociality and biological citizenship, the study contributes by illustrating how communities and citizenry (*communitas*) are formed around needs, wherein the ethnographic data centre their attention upon three needs: biomedical, biosocial and biopolitical. For further research, the study suggests that researchers foreground communities (in the broad sense of the word) and take them as objects of study—rather than, as has been the usual practice, treating them as non-interesting containers for socialisation and other communication processes.

~ CHAPTER EIGHT ~

CONCLUDING REMARKS

THE LESSONS LEARNED

“Almost all good writing begins with terrible first efforts.
You need to start somewhere.”

A. LAMOTT

A PANDEMIC OF BREATHLESSNESS

> Just as we are wrapping up our five-year project, we find ourselves in the middle of the COVID-19 pandemic and with it, a rapidly escalating fear of breathlessness. This is all the more strange, because a major theme of our project was the invisibility of breath: how as healthy individuals we take breathing for granted; how hidden are those who live with the daily fear of death that accompanies severe breathlessness; and how trustingly we rely on the air around us. (Life of Breath, 2020)

The year 2020 will, undoubtedly, go down in history as the year when the whole world was challenged with one *invisible enemy* (cf. Crawford, 2002) that came to change everything in human society. It is the modern pandemic that has shaken all aspects of human life, and it is clear that nobody in any field (be it ‘hard’ or ‘soft’) was prepared for what was to come when COVID-19 burst forth (Manderson et al., 2021). Having said that, the novelty of this phenomenon has given room for several qualitative research opportunities to help understand and address the social implications that pandemics have for human lives. This can especially be said about *digital ethnography* (Boellstorff et al., 2012; Horst & Miller, 2012; Boellstorff, 2015; Przybylski, 2020), which in the time of the pandemic has provided a complement to continue conducting research across the humanities and social sciences when one has not been able to access the ‘field’ regularly physically (Ghosh, 2020; Higgins et al., 2020). Given that the world is now predominantly being (re)shaped by humans and their activities (rather than by nature and natural processes) (Moser, 2010; Seymour, 2016), I will echo what has been said elsewhere: that the need for humanities and social science research is greater than ever before. With COVID-19 in mind, this is especially true for the knowledge surrounding the human respiratory system and the automatic yet controllable physiology of breathing.

The COVID-19 pandemic is a wake-up call, Godlee writes (2020). Even more so, it is a crisis of our own making, especially in light of the current fight against antibiotic resistance (Brown, 2019; Hansson et al., 2021a; Hansson et al., 2021b). The rapid emergence of resistant bacteria is occurring worldwide (Rossolini et al., 2014), which endangers the efficacy of antibiotics that have transformed medicine and saved millions of lives for generations. This crisis is strongly related to the overuse and abuse of antibiotics. Antibiotics are commonly used in the management of respiratory disorders such as cystic fibrosis (CF), non-CF bronchiectasis, asthma, and chronic obstructive pulmonary disease (COPD). O'Connor and colleagues write (2018) that there is an emerging consensus in the literature regarding strategies proven to reduce antibiotic consumption for acute respiratory infections. In the matter of antibiotic resistance and the overuse of certain drugs, the widespread adoption of these strategies in primary care remains imperative.

The work on this dissertation was struck by the pandemic in many ways. Even though its content suddenly became more relevant than ever before, personal health worsened as social isolation was taking its toll. However, as I listened once more through the interviews that I had held with people all across the North East, I was constantly reminded of how this pandemic perhaps affected them the worst—for pathological reasons, nonetheless. Due to people's medical vulnerability (and because of the social restrictions in place), physical contact was out of the question and in many cases I was not able to give proper farewells as I prepared to move back to Stockholm. It was not long before I started to receive messages which read that all upcoming Breathe Easy meetings and events had been cancelled, and would remain on hold for the foreseeable future. Being at high risk of COVID-19, members started to shield themselves from the outside world. Thankfully, measures were put in place and, soon enough, some groups started to hold their meetings via Zoom. With a new 'normal' ahead of us (Yanow & Good, 2020; Zeegen et al., 2020), perhaps one might say that society as it was prior to the lockdown no longer exists and never will again. As McLachlan writes: “After the lockdown, we will be faced by different social realities” (2020: para. 5). With the virus far from gone, I believe that we can already see signs of this happening.

In the end, what have we all learned from this ordeal? As infectious diseases continue to progressively pose major global health challenges to humanity, what can we draw from this catalyst of shifts (Kelly et al., 2019) that is a total social phenomenon? Although breathlessness is central to the diagnosis of COVID-19 and is a sign of disease progression, it remains not highly visible in the media—despite being a pervasive symptom of severe disease. In the matter of breathlessness and its treatment, there is now growing evidence for the use of both pharmacological and nonpharmacological interventions (Breaden, 2011). However, further research is needed in order to firmly establish the best way forward in treating the medical symptom of breathlessness and its underlying conditions. All the same, there is more to the sensation of breathlessness than meagre symptomology. If there is anything that this dissertation contributes, it is a framework for understanding breathlessness more broadly as a *lived experience*, rather than as a mere medical symptom. This further adds to the understanding of social disruption (cf. Becker, 1998) and how people manage to create meaning in a chaotic world.

Breathing is one of the most basic and fundamental functions of the human body, and when it all works well the typical respiratory rate for a healthy adult (at rest) is 12–18 breaths per minute. An important characteristic of the human respiratory system is its ability to adjust breathing patterns to changes in both the internal milieu and the external environment (Klocke et al., 2020). Yet, as breathing is an automatic and a rhythmic act alike (enacted by networks of neurons in the hindbrain), this physiological process very much comes for granted. Needless to say, as Marmot writes, for “millions of people across the UK, breathing is something they have had to think about” (2016: 3). For people living with a respiratory disease and chronic breathlessness, doing tasks and things often deemed to be trivial may take twice as long. The effort of getting up, washed and dressed, for instance, can leave these people needing 15 or 20 minutes in order to catch their breath. Sometimes it can take so long for them to get ready in a morning that the day does not start until noon. Moreover, due to their need to consider so many things before leaving the house, people sometimes even have to cancel the day that they had planned ahead of time.

This dissertation shows that respiratory disease can be a frightening and uncomfortable experience, wherein anxiety often arises in conjunction with exacerbations in patients with severely progressed conditions. The decline in physical activity is associated with increasing airflow limitation; thus, avoiding activities becomes a rhythmic strategy for avoiding symptoms. Pathologically speaking, abnormal breathlessness signifies a biological state or syndrome (Calverley, 2017) in which the human body becomes unable to properly transfer oxygen from the air that one breathes in to the blood and, later, the rest of the body. Habitually, the problem lies in the lungs themselves, as they start to lose their function in diseases such as asthma and COPD. However, issues of a similar nature are also found in people with cardiovascular disease, as well as in obesity, which further illustrates the importance of approaching breathlessness from a holistic point of view (Herigstad et al., 2011; Hayen et al., 2013). Yet, service users often ignore their symptoms because they appear gradually and progress over the course of years. This is the reason as to why breathlessness continues to remain invisible, being a condition that "[…] usually has an insidious onset and is often attributed by those who experience it to ageing, lack of exercise, or smoking" (Macnaughton & Carel, 2016: 298). Yet, while breath is invisible, it is ever present and vital for all living beings.

LIMITATIONS

It stands to reason that the strengths of this dissertation lie in its integrative approach to respiratory health and medicine, as well as in the thick descriptions that it provides of people's lives with chronic breathlessness. The overall narration gains further strength through its *emic* perspectives, wherein the focus remains on "how local people think [and feel]" (Kottak, 2006: 47)—the locals being, needless to say, my interlocutors all across the United Kingdom. As a whole, the study considers the symptom burden of respiratory diseases (cf. Barnes & Kleinert, 2004; Hubbard, 2006; Mannino & Buist, 2007; Izquierdo et al., 2009; Salvi et al., 2018; Johansson et al., 2019), although this is done from an anthropological point of view, that is, how breathless people's life-worlds shrink (Gullick & Stainton, 2008) and become severely restricted—especially in terms of stigma, mobility, and pulmonary function (Nicholls, 2003; Jones et al., 2004; Medina-Mirapeix et al., 2018). Having that said, all research studies come with their limitations and this ethnographic study is no exception. Nevertheless, limitations and restraints play important roles in the project outline as well and may often become positive in helping to frame the overall contributions of the research study as a whole.

(i) Non-comparative approach

At the outset, it is significant to note that (empirically speaking) this ethnography is not a comparative study. The rationale was never to investigate how support groups for people with breathlessness differ in their form and functions from other support groups that manage chronic illnesses—whether cancer, cardiovascular disease, dementia, or other disease areas. Namely, the purpose of this study was to gain further insights into how support groups (in this case, the *Breathe Easy* support group network) become resources in the self-management regimens of elderly people with respiratory disease and chronic breathlessness.

In a Foucauldian sense, I sought to conceptually approach "support groups" as a phenomenon that extends beyond the physical settings in which people meet and the meetings or gatherings themselves (as tools for decision making) take place. The support group is not merely a place that one 'goes to' as one attends a meeting (cf. Schwartzman, 1987), but rather is the result of continuous practice. Much like meetings, support groups are "moments of ethnographic momentum" (Garsten & Sörbom, 2017: 126). People *do* support groups; such groups do not exist independently of their members, but rather exist because people utilise them. As Tracy and Dimock write, meetings are "discursive sites for building and fragmenting community […]", wherein common practices are the "[…] frequent objects of derision and complaint" (2004: 121). Simply put, support groups are social constructs and, much like a nation state or government (cf. McConnell, 2016; Bryant & Hatay, 2020), do not exist as self-evident, physical shapes per se—rather, they are the result of practices, performances and rehearsals (Turner, 1982, 1986; Goffman, 1990 [1956]; Ahrne & Brunsson, 2010).

While a comparative analysis of different support groups' forms and functions would have been able to clearly illustrate each group's uniqueness vis-à-vis its similarities, what ultimately divides them is the pathology that underlies each medical condition. A support group for people with dementia, for instance, will work in a distinct, different way from a support group for cancer or respiratory diseases (Dunger et al., 2015). The nature of each medical condition demands its own regimens—in terms of both care treatments and self-management. All things considered, this is what shapes how each individual paces through everyday life, wherein rhythm becomes a way of coping with chronic diseases (You, 1994; Homma & Masaoka, 2008; Ek et al., 2011; Freer, 2015; Varga & Heck, 2017).

(ii) Demographics

Besides its non-comparative approach (which I deem to be an asset rather than a drawback), this dissertation also has its limitations in terms of demographics. While a conscious and intentional decision in terms of research design, it remains significant and warrants acknowledgement. First of all, the study focuses on elderly people with chronic breathlessness and omits the perspectives of children and younger people on the whole. Regardless of how one chooses to look at this condition or consider its implications, (while intentional) it is also the result of circumstances. That is to say, the members of the three support groups on which this study centres largely belong to a certain generation: aged 60 or above (with some even being in their 90s). Personally, I did not meet a group member who was below the age of 50. Although the Breathe Easy support group network welcomes all who live with a lung disease—regardless of how old they are—it is primarily older people who ultimately attend. This can (undoubtedly) be explained by a number of reasons, or even pathologically. Logistically speaking, considering that Breathe Easy groups usually meet in the early afternoon, it would make it difficult for people in full-time employment (or education) to attend. While most likely an individual decision made by each Breathe Easy group's committee, it does hinder certain people from attending.

Logistics notwithstanding, there are also underlying pathological conditions at hand that have affected demographics. The age of onset in chronic obstructive pulmonary disease (COPD), for instance, occurs most often in older adults and can also affect people of middle ages (British Lung Foundation, 2007b, 2016). It is not common in younger adults. Similarly, idiopathic pulmonary fibrosis (IPF) mainly affects people aged 50 years or above—approximately two thirds of people diagnosed with IPF are aged 60 years or above at the time of diagnosis (British Lung Foundation, 2015c; Harari & Caminati, 2015; Ferrara et al., 2016). Locating the study in the North of England (more specifically around County Durham and South Tyneside) also came with its limitations—especially in terms of ethnic diversity. That is to say, the population in these areas are homogenous and, by a large majority, White British. The numbers in question are as high as 90–95%, with the town of South Shields probably having the largest non-Caucasian population (with an Asian minority at around 3.2%) (UK Census, 2011).

While locating the study elsewhere in more urban, multicultural communities (like Birmingham, London or Manchester) would have come with its own sets of benefits, and differentials, (ultimately) the reason for remaining in the North East was always logically sound. As the British Lung Foundation sets out in many of its reports (2007b, 2015c, 2016, 2017b), the North East is one of the regions in the UK most burdened by a high prevalence of not only respiratory diseases but also air pollution, tobacco, and smoking—all of which are determinants that affect respiratory health across the UK population (Bush et al., 2001; Bryant et al., 2012; Small et al., 2012; Lewis & Russell, 2013; Thirlway, 2015; Measham et al., 2016). What is more, the North East is also widely recognised for its sociocultural history of harmful industries in which occupational diseases of a respiratory nature are highly prevalent (Coggon & Taylor, 1998; Kazan-Allen, 2005; Sirajuddin & Kanne, 2009;

Santo Tomas, 2011; Laney & Weissman, 2014). In summary, respiratory diseases amongst the elderly are common and characterised by underdiagnosis and undertreatment (Gibson et al., 2010). This may be due to ageing being associated with unique medical facets that modify the expression, recognition and treatment of respiratory diseases; for instance, both asthma and COPD overlap and converge in older people. This correlation, alongside the absence of precise diagnostic methods in medical practice, makes diagnosing respiratory diseases a challenging and complex process (Kinter, 1997; Bednarek et al., 2008; Gibson et al., 2010; Carel, 2015, 2018c). However, more research is required, as there currently are limited data on factors in young adulthood that could predict future cases of respiratory diseases (Kalhan et al., 2018).

(iii) Offline vs. online

As a final exclamation, I want to highlight that this dissertation does not consider the difference in form and function between offline (actual) and online (virtual) support groups. This dissertation examines only actual, physical self-help support groups. While the Breathe Easy support groups with which I met ultimately turned to partially using digital technologies for their meetings during the COVID-19 pandemic, originally (and principally) these groups met in person—and they aim to continue doing so. Besides logistical circumstances, the distinction between offline and online groups may also speak to the reason as to why Breathe Easy groups are primarily attended by elderly people and lack attendance from the younger population. Namely, as Ali and colleagues point out, "[o]nline peer-to-peer communication is popular among young people" (Ali et al., 2015: 1). Yet, simultaneously (and perhaps paradoxically), there have been few systematic reviews examining the effectiveness of online peer-to-peer support in improving the health of adolescents and young adults. Criticising this historical trend, Ali and colleagues write that there is an urgent need to "determine the effectiveness of peer support alone as an active intervention" (2015: 6-7), considering its growing popularity amongst young people. Having that said, considering how computers and associated technology have become so central to modern life (even ushering in a new era of mass media), Broady and colleagues write:

> In a society where the population is rapidly ageing, the acceptance and utilisation of developing technologies by an older population is becoming increasingly important […] leading to the conclusion that similar factors influence both [old and young people]—hence, older people could well be taught to use technology in a similar manner to younger people. (2010: 473)

This may suggest that, sooner or later, the older population around the world may very well turn to using online tools and technologies more often as active health management interventions in their daily lives. However, more research is needed in order to properly map out such a trend, alongside whether online peer support as a sole active health intervention is sufficient to improve the lives of people with different chronic diseases (regardless of their age group). Nonetheless, (generally speaking) online support groups have been used extensively in numerous areas of social and medical distress for several years (Potts, 2005; Barak et al., 2008) and while there is said to be a lack of evidence with which to support their presumed effect of empowerment, they are growing in numbers and popularity (Van Uden-Kraan et al., 2008a; Van Uden-Kraan et al., 2008b; Van Uden-Kraan et al., 2009). On the whole, the topic of virtual and online support groups has been widely researched (Hsiung, 2000; Potts, 2005; Bar-Lev, 2008; Barak et al., 2008; Mo & Coulson, 2008; Mo et al., 2009; Fortun et al., 2014; Ali et al., 2015) and its body of literature will continue to grow in size, especially in times in which social isolation limits physical interaction and renders virtual environments a necessity.

There may also be pathological reasons as to why online support groups are more popular amongst certain populations. For instance, due to the nature of cystic fibrosis (CF)—a genetic disorder that affects mostly the lungs, as well as the pancreas, liver, kidneys, and intestines (Boucher et al., 2000; O'Sullivan & Freedman, 2009)—people with this disease cannot meet (and are actively discouraged from meeting) in person. Namely, people suffering from CF are vulnerable to different bacteria which grow in their lungs. While these bacteria are usually harmless to people who do not have CF, they can settle in the lungs and be harmful to those who do (Festini et al., 2006; Waine et al., 2007; Conway, 2008).

Considering how the median age at diagnosis is 6–8 months and about half of the people with the disease live beyond the age of 40,[63] CF is most prevalent amongst the younger population. This, alongside the high risk of cross-infection, would explain why people with CF only meet online and why such environments are predominantly inhabited by a younger population.

FINAL WORDS

As I trudge towards the final words of this dissertation, I cannot help but think back to my very first fieldwork moment (an ethnographic momentum, if you may) in the North East, which took place on 11th March 2017 in Darlington. I was attending a gala night for the Mayor of Darlington's chosen charities, one of which was Breathe Easy Darlington. I remember the evening fondly, and the relations that I developed that night opened up doors that made it possible for me to later conduct fieldwork around Darlington. Looking back at my field notes, I found this rather amusing section, which read:

> *As I observed all the commotion going on—looking rather baffled and mislaid, I am sure—I was soon approached and welcomed by the Chairperson of Breathe Easy Darlington. Considering my young(ish) look and rather absent appearance, I imagine I stood out like a sore thumb. I was directed towards a table right in the centre of the room, where other personal guests of theirs had been seated.*

On the first day already, I was acting like the *clown* that Eriksen (2015) describes anthropologists to be while being in the field. In a sense, I never stopped acting like one—and I would not have it any other way. The strategy (if one can call it that) paved the way from me in developing relations and even in making friends, which by now I hope I am allowed to call many of them. Having said that, my now rather old field notes contain much more than warm, touching memories and funny anecdotes. Rather, they also contain personal narratives of an incredible nature.

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[63] Nevertheless, in recent years, people with cystic fibrosis have tended to experience a longer life expectancy and higher quality of life (Marson et al., 2015; Keogh et al., 2020).

One of them, in particular, draws upon the welcome speech from the evening of the Mayor's charities, given by the Chairperson of Breathe Easy Darlington.

> *Expressing my nervousness earlier on this evening, I was advised to "take a deep breath—you'll be fine". But therein lies part of the problem. Having less than wonderful lung function isn't always conducive to taking a deep breath. In fact, there are lots of things made a little tricky by being breathless. Even some of the things that cause enjoyable breathlessness may not be quite so enjoyable. Respiratory disease often isn't much fun at all. Appearances can be deceptive. Many of us who struggle with breathlessness look perfectly well. We are often round-faced and rosy on steroids. You can't tell that it took half an hour to get my socks on or know that I have my hair cut like this because I can no longer wield the hair dryer. In fact, respiratory disease is a killer, right up there with heart disease, stroke, cancer, and Alzheimer's disease. It is, unlike many of these, on the rise as a killer.*
>
> *Yet, for some reason, it isn't talked about as much. Research isn't as well supported—neither are those who are struggling with it. Those of us affected by it aren't sure why that is. Breathlessness can be isolating and lonely. It can be socially and physically limiting. It can be embarrassing and awkward—all that noisy breathing and coughing! It can be exhausting and frightening. The drugs can be unpleasant, with all sorts of side effects. There is often no cure, so those living with it constantly face life-threatening, life-limiting experiences with poor quality of life.*

On the whole, chronic disease not only impacts the social and economic lives of millions of people and their families, but also is a major contributor to healthcare costs. Breathlessness is hidden for many complex reasons, but it remains important to bring it into the open in order to relieve suffering and overcome stigma. As of now, when people go through the clinic door and are given a diagnosis of respiratory disease, there are still more problems to overcome. Breathlessness associated with respiratory disease very often becomes chronic, and even after maximum treatment has been offered, people are still left with significant issues. Some people deal with breathlessness better than do others, but when it comes down to it, medical doctors are trained to treat diseases—not symptoms. In chronic respiratory disease, however, breathlessness just continues to worsen. Eventually, doctors reach a point in time at which *there is nothing to be done*, where patients will stop complaining and put up with their precarious situation. This means that those living with chronic breathlessness will become even more invisible—or perhaps even forgotten. The problem of invisibility is thus deepened and intensified by a sense of helplessness. This is the point in time at which self-help support groups like Breathe Easy enter the scene, providing help and support that are otherwise unattainable. The support group phenomenon will hopefully continue to spread and rival all other forms of treatment, serving at the pleasure of the group and its members through free expression of thoughts and feelings. All told, support groups provide an environment in which one can learn new ways of coping with and managing one's chronic illness, such as breathlessness. They offer a space in which people can share self-help approaches that they have discovered, or even learned from others. Even more so, self-help support groups can help people simply by providing them with the knowledge that they are not alone in their hardships. "You alone can do it […]" might perhaps be true, but "[…] you cannot do it alone" speaks as much truth. Together, people can find purpose through pain.

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