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**ART AND CREATIVITY FOR HIV/AIDS AWARENESS,  
PREVENTION, AND EMPOWERMENT OF YOUNG  
PEOPLE IN UGANDA**

Robert Ssewanyana

**THESIS SUBMITTED FOR THE DEGREE OF DOCTOR OF PHILOSOPHY**

2022

**Department of Geography  
Durham University**

“... The purpose of art should not be to provide aesthetic pleasure or an escape from reality, but to contribute to society’s ongoing attempts to solves its problems”

(Boneh & Jaganath, 2011, p. 455)

## ABSTRACT

Art, youth engagement and informality in the context of HIV prevention have been generally ignored by most researchers and stakeholders within the HIV programming and policy arenas, thus silencing the plight of urban youth infected with and affected by HIV/AIDS. In response, this thesis draws on the case of peri-urban settings of Kampala, Uganda to bring geographies of applied sculpture, HIV/AIDS prevention, and youth empowerment into dialogue, informed by the notions of art having the capacity to move beyond the spaces of galleries into an expanded field, and thus, beyond the visual and into the social spheres. In liaison with local NGOs (The Uganda AIDS Support Organisation - TASO, National Guidance and Empowerment Network for People Living with HIV/AIDS - NGEN+ and Lungujja Community based Health care Organisation – LUCOHECO, it adopts a mixed methodological approach, including applied art and participatory techniques - observation, video, storytelling, and interviews, to understand the lived experiences of young people (15-24 years) in marginalized spaces in Kampala. The thesis first examines the general context of using ethnography and applied social sculpture to explore every day experiences by facilitating the engagement of young people in open communication about the epidemic. This is intended to enable them to act in confronting stigma, taboos, and their precarious existence, while raising their awareness about HIV/AIDS. The thesis then explores the everyday precarious existence of young people in informal settings in Kampala. It proceeds to examine how workshops with these young people allowed collective engagement which, in turn, influenced the creation of artworks envisioned to act as communication tools for raising awareness of HIV/AIDS with the potential for livelihood benefits. Finally, the thesis examines young people's active involvement in participatory workshops for HIV/AIDS prevention, providing ethnographic evidence regarding the artmaking process, the conversations that ensued as they worked, and the creation of applied objects/forms that enabled them to build their confidence to freely express about the precarities affecting their lives, countering taboos, and encouraging them to change their behaviours and practices while potentially acting as change agents in their own communities. It highlights the significance of stimulating open conversations about HIV/AIDS - as a starting point towards confronting stigma and other aspects of precarity, while advocating for the incorporation of the approach into practice by public health experts, policymakers, and development practitioners. The thesis shows the strengths of applied sculpture as an approach that has potential for making sense of ordinary everyday experiences, finding meaning and crafting clarity of young people's lived experiences in the context of HIV/AIDS. It concludes that applied sculpture is potentially an important tool in tackling HIV/AIDS and its attendant problems by engendering and facilitating open conversations and social economic development through an engagement with the voices and agency of young people in Uganda and beyond.

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## LIST OF ABBREVIATIONS

ABC	Abstain, Be Faithful and Use condoms
AIC	AIDS Information centre
ART	Antiretroviral Treatment
AIDS	Acquired Immunodeficiency Syndrome
ARVs	Antiretrovirals
CBO	Community-based Organisation
CEDAT	College of Engineering, Design, Art, and Technology
CHW	Community Health Workers
EMTCT	Elimination of Mother to Child Treatment
GCRF-CDT	Global Challenges Research Fund-Centre for Doctoral Training
ICWEA	International Community for Women Living with HIV/AIDS, Eastern Africa
JCRC	Joint Clinical research council
IDI	Infectious Disease Institute
ISPs	Inadequately served populations
LCs	Local Councils
LUCOHECO	Lungujja Community-based Healthcare Organisation
MAK	Makerere University
MTSIFA	Margaret Trowell School of Industrial and Fine Arts
NGEN+	National Empowerment Network for People Living with HIV/AIDS in Uganda
NGOs	Non-Governmental Organisations
PLHIV	People Living with HIV/AIDS

PEPFAR	Presidential Emergency Plan For Aid and Relief
PMTCT	Prevention of Mother to Child Treatment
PrEP	Pre-Exposure Prophylaxis
TASO	The Uganda AIDS Support Organisation
UNYPA	Uganda Network of Young People Living with HIV/AIDS
UAC	Uganda AIDS Commission
UNAIDS	The Joint United Nations Programme on HIV/AIDS
VCCM	Voluntary Male Medical Circumcision



## DECLARATION

The material contained in this thesis has never previously been submitted for a degree in this or any other institution

## STATEMENT OF COPYRIGHT

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## ACKNOWLEDGEMENTS

It is with profound gratitude that I acknowledge people who have helped me throughout this research process. Indeed, several individuals and organisations that have made contributions to this research and unwaveringly supported my academic journey to completion. I do acknowledge them as follows.

Firstly, my heartfelt thanks go to my supervisors, Dr. Lilian Nabulime, my mentor, and colleague, who was been at the heart of seeing me through the fieldwork in Uganda which was largely interrupted by Covid-19 between 2020 and 2021. The interest that you show in my success and development is something for which I feel very grateful. I am equally indebted to Professor Cheryl McEwan (Geography Department) and Associate Professor Hannah Brown (Department of Anthropology) of Durham University for their unconditional support and guidance from the very beginning of my PhD study in 2019 until now. You have not only been supervisors, but an inspiration. Introducing me to concepts I had never even envisaged; they have drawn me into a new world of cultural diversity, discovery and learning which has delighted, challenged, and inspired me. Thank you very much.

I greatly appreciate the financial support from the funder of this project – the UK government, through the Global Challenges Research Fund–Centre for Doctoral Training (GCRF-CDT) – for having awarded me this studentship, in the first place, and for continuing to provide the support, until its completion in 2022. Without the studentship, I could not have done this doctorate. I am grateful not only for all the living out facilitation, but also for the funding provided for the fieldwork and training as a complete researcher for three years in Durham University. Special thanks also go to Douglas Halliday, the Director of GCRF-CDT, and the Administrator, Abir Van Hunen, for making my stay and study in the UK memorable. Our cohort of 26 PhD colleagues has given me a firm foundation for scholarly support and rich cultural diversity that provides a sense of international solidarity and shared goals. Here in particular, I wish to extend my heart-warming thanks Martin Kandeh for his selflessness in sharing PowerPoint skills with me during my second year of study. Otherwise, I salute them all.

The administrative staff at the Department of Geography, whose work has not gone unnoticed, have not only been invaluable to my experience at Durham University, but have made dismal days brighter. A special thank you to Kathy Wood, who even before I came to Durham was already helping with travel arrangements through the numerous emails I sent; The requisitions for funding through your office were often handled expeditiously to my satisfaction. A vote of thanks to you. To Mervyn Brown, who never flinched at my endless request for technical support and information about tools and equipment for fieldwork, I am deeply indebted. Finally, Orton Chris of the cartographic Unit of the Geography department, whose great help in preparing my study site maps has been priceless. Most importantly, however, all this was

done with convenience and a smile, something which meant a lot to me, especially at those times I appeared to be in the middle of nowhere.

The timely role played by the ethics committees both in Durham and Uganda was a giant leap towards the success of this research in Uganda. My special thanks therefore goes to Leshem Noam, Durham University ethics committee and Andrew Mijumbi Ojok, TASO Ethics committee (TASOREC). I am also particularly grateful for the financial support from Makerere University and the assistance and information I received from various HIV/AIDS organisations, their staff members, and clients. These include Mr Nkabala Robert, the Centre Manager (AIDS Support Organisation (TASO), Mr Richard Kawooya of the AIDS Information Centre (AIC) and Retired Major Rubaramira Ruranga of the National Guidance and Empowerment Network for People Living with HIV/AIDS (NGEN+). I am also immensely grateful to Ms Maxensia Takilambule, the CEO of LUCOHECO- Lungujja Community Health-care Organisation along with Councillor Grace Kabubi (KCCA) and Immaculate Kamahoro, who are part of the village health teams in Kampala, for their support during the identification of HIV/AIDS/COVID-19 participants for the first lockdown art and creativity workshops in Lungujja. I owe the greater part of my fieldwork success to the role played by Mr. Tom Mark Ssebunya, the Chairman for Ndeeba carpentry Group, Mr Faisal Kawuki, the former Chairman for Bwaise Furniture Maker's SACCO and Mr Paul Mulangila (primary contact for welders in Katwe industrial area) as research gatekeepers in mobilizing young artisans for co-production activities between January and November 2020.

Thanking the research participants, some of whom are also my friends, is certainly not enough: you are at the heart of this research. Special thanks go to all those who consented to take part in the creativity workshops and whose participation contributed significantly to the success of this project. For their remarkable enthusiasm and dedication during the workshops, I wish to aptly recognise the following individuals; Mapenzi Bonny, Nabasiye Jane and Mangadda from Ndeeba industrial area, Tony Kasozi, Catherine Kemanzi and Trevor Ssemwogerere from Lungujja, Peter Sserugemu, Byekwaso Sam and Namigadde Nusurah from Katwe industrial area. Lastly, Tina Namwanga, Latif Walusimbi and Hussein Sebata from Bwaise industrial area, among others. Their unwavering involvement gave the project the much-desired publicity among the communities in which the research was conducted.

My great appreciation also goes to Prof. George Kyeyune in his capacity as the Director of the Makerere Institute of Heritage conservation and Restoration (MIHCR) for his guidance and support in the preparation of my research dissemination exhibition at the Makerere Art Gallery. The part played by Davis Harrison Watsala, the Gallery Administrator/Curator, Makerere art gallery during the dissemination exhibition is also immeasurable. Without forgetting, I would like to express my special thanks to Ms Victoria Nabacwa for her supporting role in collecting data and information during field work.

Mr Elvis Basudde, a senior journalist (features writer) of the New Vision newspaper, Kampala is also much appreciated for the time, information, and media attention he offered to this

research project. Dominique Muwanguzi, a freelance journalist with The Independent magazine, is also appreciated for his immense role in drawing media attention towards the dissemination exhibition in 2021 and I also duly recognise the noble contribution of Kanuge John Bosco of the Department of Industrial art and Design (DIAAD), Makerere University towards the designing and production of the project's exhibition catalogue. Additionally, I want to extend my sincere thanks to Tusiime Mathias of UCASDR for his wide-ranging insights and contacts for grass-roots community participation and visual activism in advocating the plight and empowerment of vulnerable young people/populations in the informal spaces of Kampala.

To my lovely friends and colleagues at Durham, who have made my experience so much richer. Lucy Szablewska, in particular, and Marek, your friendship, endless scholarly insights, encouragement, sightseeing trips and special contacts for services, and giving me a second family in Durham, are not things that can be expressed in words. Kind thoughts also go to Nigel and Heather on Claypath street in Durham city for their open hospitality. I will always treasure our friendship forever. Cynthia Kamwengo, your friendship has meant so much to me. I am lucky to know you and to have shared this experience with you. Wherever you are right now, thank you for your advice, help and for just being there when I needed.

I am extremely indebted to my family that has stood with me in my absence from home, in particular my wife, Nash Agaba Ssewanyana who has endured the trials and tribulations of handling family matters almost single-handedly. Last but not least, I am also highly indebted to my mum Nalongo Kaggwa, my sons and daughter, Kent, Kith, Kimi, Faith and Sandra for their patience, love, and prayers. This has been especially reassuring and energising for the greater part of my continued stay in the UK and during the fieldwork in Uganda this year.

# CHAPTER ONE

## 1.1 INTRODUCTION

In the early 1990s, HIV/AIDS reached a peak in Uganda – 14 per cent of the population was infected with the virus<sup>1</sup> (Jane Fallon Griffin, 2017; Slutkin et al., 2006). However, rapid action by Ugandan-founded NGOs such as the Aids Support Organisation (TASO), as well as the Ugandan government's public campaigns promoting abstinence, monogamy and condom usage through the ABC campaign (Abstinence, Be faithful and Condom use) brought the rate to 8 per cent by 2000 (Kyotalengerire Agnes, 2019)<sup>2</sup>. Uganda has demonstrated that an early, consistent and multisectoral control strategy can reduce both the prevalence and the incidence of HIV infection (Kiwanuka-Tondo, 2022). From only two AIDS cases in 1982, the epidemic in Uganda grew to a cumulative 2 million HIV infections by the end of 2000. The AIDS Control Programme (ACP) established in 1987 in the Ministry of Health mounted a national response that expanded over time to reach other relevant sectors under the coordinating role of the Uganda AIDS Commission (UAC). The national response was to bring in new policies, expanded partnerships, increased institutional capacity for care and research, public health education for behaviour change, strengthened sexually transmitted disease (STD) management, improved blood transfusion services, care and support services for persons with HIV/AIDS, and a surveillance system to monitor the epidemic (Low-Beer & Stoneburner, 2003; Okware et al., 2001). This remarkable achievement put Uganda at the forefront of championing the global fight against the deadly epidemic.

Unfortunately, today, infection rates are rising unabated (Murphy et al., 2006; Mushengyezi, 2003; UAC, 2016) and according to Uganda's Ministry of Health (2017), an estimated 1.3 million people were living with HIV, and an estimated 26,000 Ugandans have died of AIDS-related illnesses. Women and young girls, in particular, are disproportionately affected. The available statistical information from the Uganda National Bureau of statistics (UBOS) shows that:

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<sup>1</sup> <https://www.irishtimes.com/news/world/africa/how-uganda-got-results-in-its-fight-against-aids-1.2986417>

<sup>2</sup> [How HIV/AIDS fight started in Uganda - New Vision Official](#)

“Uganda’s population was estimated at 34.6 million in 2014, having risen from 9.5 million in 1969. It is a population that is largely very young, with 56.7% of the population below 18 years of age. Many households have a high dependency ratio making it harder to exit poverty. Currently, Uganda has one of the youngest and rapidly growing populations in the world: approximately 70 per cent of the total population of 34.6 million is aged below 30 and 56 per cent below age 18 and as such, the country is experiencing a youth population explosion”

(UBOS, 2016, p. 8)

Nonetheless, a large young population also has potential to contribute to economic development as an emerging labour pool. However, the low levels of educational attainment, the skills gaps between education and the labour market and inadequate levels of job creation combine to create high levels of unemployment, with the attendant development problems that arise from this<sup>3</sup>. Better still, a large youth population could be a great potential for socio-economic development, especially if these young people are given the right education, skills, and livelihood opportunities (United Nations Population Fund 2014). In this way, the country would benefit from what economists have termed the demographic dividend (Madsen, 2010). The demographic dividend can only be achieved when a country boosts its economic productivity using a youthful population, but the current gaps in the education system, skills development, and limited research into the current causes of rising HIV/AIDS prevalence among Ugandan youth and how this might be tackled are severe constraints on realising this dividend. This adds particular urgency to research into HIV/AIDS prevention and youth empowerment.

The rising rates of HIV/AIDS, the colliding Covid-19 pandemic, and their related social problems among the young people in Uganda are being fuelled by high levels of unemployment, low levels educational attainment and the skills gap between education and labour market, and escalating poverty levels. Complacency, taboos on discussion of sexuality and stigma surrounding HIV/AIDS are other likely factors in higher youth prevalence rates. These factors are known to shape the increase in the levels of HIV transmission across the population. Sociologists, anthropologists, and economists alike, have often argued that HIV flourishes in two distinct contexts, (i) the micro level and (ii) the macro level. Research suggests that sexual

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<sup>3</sup> <https://www.irishaid.ie/media/irishaid/allwebsitemedia/20newsandpublications/FINAL-Uganda-CSP-print-version.pdf> (Irish embassy, 2016, p. 11)

behaviour, which is one of the main avenues for HIV transmissions, is a micro level factor usually linked to the individual's cognitive processes and attitudes which create personal vulnerability (O'Brien & Broom, 2013; Okware et al., 2001; Staten, 2014). Researchers have also drawn attention to macro level factors such as poverty, gender inequalities and global capitalism that have shaped contexts within which the epidemic flourishes (Brown, Sorrell, & Raffaelli, 2005; Campbell & International African Institute, 2003; Hladik et al., 2017; Hunter, 2010; Mills, Beyrer, Birungi, & Dybul, 2012). Extensive research has been carried out on all fronts, particularly into biomedical, sociological, and cultural factors that influence HIV prevalence. The latter have also included engaging with arts-based practices in navigating factors that shape the continued spread of HIV. However, no single study exists around the use of arts-based approaches in tackling escalating prevalence rates among young people, especially those living precarious lives. To try to fill this gap in the context of Uganda, this thesis explores the utility of applied social sculpture (ASS) in raising awareness about HIV/AIDS among young artisans in informal peri-urban locations. Young people are, conspicuously, one of the long-ignored demographic groups in Uganda's national HIV/AIDS prevention interventions. With the exception of a few studies (e.g. Campbell's (2003) exploration how HIV/AIDS shaped the lives and occupational spaces of marginalised migrant miners in Summertown, Kwazulu Province in South Africa, and Kate Wells' research on the impacts of HIV on the lives and wellbeing of traditional Zulu craftswomen) there is a dearth of research that might inform efforts to stem HIV/AIDS in peripheral urban areas of sub-Saharan Africa. Even where research has focused on economically and geographically marginalised people (e.g., the Siyazama project that was the focus of Wells' research), this has not tended to engage with marginalised young people who show some of the highest increases in prevalence rates, especially those working as industrial artisans across sprawling peri-urban geographies around African cities. Reports continue show that young people in marginalized peri-urban communities are at a higher risk of HIV/AIDS infection because of high levels of poverty, population growth, and unemployment generated by rural-urban and cross border migration among regional diasporas (Baker & Pedersen, 1995; J. Campbell, 2002; Unwin, 2018; Young, 2019).



## 1.2 Uganda's HIV/AIDS Prevention: The A, B, C strategy and Politics

As already mentioned, Uganda is one of the few countries in the world that has experienced a significant reduction in Human Immuno-deficiency Virus (HIV) during the first two decades of encountering the epidemic (1990-2010). In contrast to the rest of the Sub-Saharan region, Uganda had steered past the HIV peak with an explicitly comprehensive multisectoral policy against the tide of the disease. This policy includes: The Abstinence, Be faithful, and Condoms, abridged as the ABC strategy which, later, was globally accredited as the efficacy of abstinence-based sex education especially in the United States of America (Blum, 2004, p. 429). The national HIV policy reviews over the years have affirmed the immense contribution of the popular ABC strategy in reducing the rate of HIV infection among key populations in the country while the new biomedical approaches, which include the EMTCT<sup>4</sup> and VMMC<sup>5</sup>, have also been highlighted as a modern-day breakthrough to tackling the HIV epidemic across the various demographic divides. The combined engagement of the biomedical and behavioural strategies - combination prevention (e.g., De Zaluondo et al., 2010) - clearly had a significant impact on the downward trend of the HIV infections (Doshi et al., 2018; Jane Fallon Griffin, 2017; Slutkin et al., 2006) especially among younger populations. However, several gaps still point towards the changing landscape (mainly due to the social factors) in which the epidemic thrives, curtailing the impressive record set in the previous decades by the Ministry of Health (MOH) through the Uganda AIDS commission (UAC) and NGOs such as The AIDS Support Organisation (TASO), National Guidance and empowerment Network for Persons Living with HIV/AIDS (NGEN+), Joint Clinical Research Centre (JCRC), and MILDMAY at the centre of fight in HIV in Uganda. Policy initiatives, such as the Presidential Fast Track Initiative (PFTI, 2017) which spells out plans to tackle HIV/AIDS in Uganda through a five point plan,<sup>6</sup> seemed to further augment the likely potential to turn the ebb of HIV infections among young people,

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<sup>4</sup> Elimination of mother to child transmission

<sup>5</sup> Voluntary Medical Male Circumcision

<sup>6</sup> To engage men in HIV prevention and close the tap on new infections particularly among adolescent girls and young women; Accelerate implementation of Test and Treat and attainment of 90-90-90 targets particularly among men and young people; Consolidate progress on eliminating mother-to-child transmission of HIV; Ensure financial sustainability for the HIV response; and Ensuring institutional effectiveness for a well-coordinated multi-sectoral response) <https://www.afro.who.int/news/president-uganda-launches-fast-track-initiative-ending-hiv-aids-uganda-2030>

especially young men in Uganda but, again, to no avail (Management Science for Health, 2017; Nicholas, 2010). This is because there are some major gaps that still exist in the response such as limited functionality of the decentralized coordination structures, human rights violations (including GBV), teenager pregnancies, inadequate integration of HIV/AIDS in district plans, understaffing/missing HIV Clinic staff like counsellors, poor mechanisms for human resource retention, heavy reliance on donor funding HIV/AIDS response (GOU contribution to HIV/AIDS response budget is low), limited private sector engagement and inadequate evidence based programming (ICWEA, 2020)

Additionally, while several HIV/AIDS activists and advocate agencies have voiced concerns over domination of biomedical interventions without broadening the scope to include comprehensible social and human rights avenues in the fight against HIV/AIDS, a number of national health discussion fora have argued that HIV/AIDS has been over-medicalised, and HIV is not necessarily a medical problem. In response to the comments by Uganda's Dr. Stephen Watiti about what happens to the people living with HIV/AIDS (PLHIV) who are faced with severe depression when their viral load has been suppressed, Maurine Murenga from Kenya stressed that:

“... unless we stop medicalising HIV responses, we will be mopping the floor with the tap open’, and therefore there is need for programmes to focus on looking at the whole comprehensive aspects to the response and taking into consideration; that just having drugs in the facility and people taking it and supporting is not enough to get us where we want to go and to get back on track”

(Maurine Murenga, CEO of ‘Lean on Me’ Foundation in Kenya, Launch of the UNAIDS World AIDS day report, 26<sup>th</sup> November 2020)

Murenga calls for a shift towards addressing social-economic aspects of PLHIV, and in line with UN shared goal of ending AIDS by 2030<sup>7</sup>. In response, this participatory project attempts to demonstrate the efficacy of applied sculpture as a social practice (using ethnographic accounts, every-day personal experiences, everyday objects, and local materials) whilst building sustainable partnerships with young people with the intention of enabling them (as change agents) to confront rising HIV infection rates and social challenges that may not necessarily be

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<sup>7</sup> [https://www.unaids.org/en/resources/documents/2014/JC2686\\_WAD2014report](https://www.unaids.org/en/resources/documents/2014/JC2686_WAD2014report)

addressed by biomedical interventions. This also resonates with the UNAIDS (2010) strategy that recognizes the importance of empowering and facilitating young people as change agents in activating their communities to redress harmful social injustices, including norms governing sexuality, gender roles and other behaviours.

Today, the emerging Covid-19 crisis has prompted UNAIDS (2021)<sup>8</sup> to raise global concerns over the imminent need to tackle growing social economic inequalities (gender-based domestic violence, prohibitive laws, and restrictions such as home confinements and travel restrictions) with the projection of more young people being at high risk of HIV/AIDS infection over the next 10 years. These limitations are also reported to include key populations which continue to be marginalized and criminalized for their gender identities and expression, sexual orientation, lifestyles, and livelihoods. Indeed, UNAIDS further warns that if the transformative measures needed to end AIDS are not taken, the world will also stay trapped in the colliding HIV/AIDS and COVID-19 crisis with indications of remaining dangerously unprepared for the pandemics to come. With a call to ‘action against inequalities’ that are exacerbating the epidemic, the UNAIDS Executive Director reiterates that;

“Progress against the AIDS pandemic, which was already off track, is now under even greater strain as the COVID-19 crisis continues to rage, disrupting HIV prevention and treatment services, schooling, violence-prevention programmes and more. We cannot be forced to choose between ending the AIDS pandemic today and preparing for the pandemics of tomorrow. The only successful approach will achieve both. As of now, we are not on track to achieve either”

(Winnie Byanyima, UNAIDS, Geneva, 29<sup>th</sup> November 2021)

Byanyima’s concerns echo the growing levels of complacency and drop in the political will to fund comprehensive engagements to fight HIV/AIDS across the globe and, in particular, rising HIV infection levels among the youth in Uganda and beyond.

### **1.3 Peri-urban geographies of Kampala**

There has been much research on issues concerning Uganda’s AIDS control strategies and its distinguished success in the last two decades (Blum, 2004; Genuis & Genuis, 2005; IRIN, 2014; Slutkin et al., 2006). However, I focus on exploring the under-researched questions concerning

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<sup>8</sup> <https://www.unaids.org/en/resources/documents/2021/2021-global-aids-update>

the everyday life and lived experiences of/with young people in potentially marginalized peri-urban industrial areas of Kampala with the intention of empowering them towards transforming their attitudes, perception and practices for better health and wellbeing in the context of HIV/AIDS. These intentions cohere with national HIV/AIDS policy (UAC, 2015) and the shared global commitment to end AIDS as a public health threat by 2030 (UNAIDS, 2019).

As part of the growing peri-urban spaces around Kampala, townships such as Ndeeba, Bwaise and Katwe (E.g., *Plate 1*, *Plate 2* and *Plate 3*) are home to sprawling industrial zones of poorly-educated/trained artisans, many of whom are school drop outs and migrants involved in casualized activities. These marginalized industrial spaces are poorly planned with inadequate social amenities, limited opportunities for formal education, and a surfeit of dilapidated buildings and makeshift structures which double as a business points during day and dwelling places at night for both industrial workers and city hoppers (people who reside in squalid spaces within a city in or near its centre, or in geographies associated with poverty, unemployment, substandard housing or slums/informal settlements).

The research aimed to explore the everyday lived experiences of young artisans to understand how the issues of marginalisation, gender inequalities and urban masculinity have shaped and exacerbated the continued rise in HIV infections among young people in Uganda. As mentioned earlier, over the years, there has been growing literature documenting social injustices, economic, social, and cultural issues in the context of HIV/AIDS in Uganda and sub-Saharan Africa. This includes research on the effectiveness of arts-based approaches in tackling these injustices, such as body mapping in South Africa (Brett-Maclean, 2009; MacGregor, 2009; Orchard, 2017; Solomon, 2007; Wienand, 2016); poetry, music, dance, drama (Barz & Cohen, 2011; Marschall, 2004; Nalubwama, 2019), as well as sculpture as a social practice (Heila Lotz-Sisitka, 2013; Kuhanen, 2010; Mushengyezi, 2003; Nabulime, 2007; Nabulime & McEwan, 2011). Drawing inspiration from such approaches, this project sought to explore the potential of applied sculptural practice in improving HIV/AIDS awareness, prevention interventions, and empowerment for better health and improved youth livelihoods. Notably, a number of major national reports have called for a more comprehensive and integrated approaches to research and practice in public health, but still with no significant impact towards reduction in infection rates. These highlight the need for (i) increased attention

to the complex issues that compromise the health of people living in marginalized communities (ii) more integration of research and practice; greater community involvement and control, for example, through partnerships among academic, health practice, and community organizations (iii) increased sensitivity to and competence in working within diverse cultures and (iv) the expanded use of both qualitative and other methods, whilst focusing more on health and quality of life, including the social, economic, and political dimensions of health and well-being (Altman, 1995; Israel et al., 1998; Wallerstein & Duran, 2006). It is difficult to generalise research findings across the Sub-Saharan Africa even when some scholars such as Thornton (2008, p. 2) attest that:

“In Southern Africa today, it has become a truism that when one is not infected by HIV, one is affected by it: With most of the young people dying at their prime as a result of HIV infection”.

However, many young people’s lives in this region share at least one important characteristic: what Thieme (2017, p. 529) identifies as:

“The everyday agentive struggle of a group of young people who self-identify with ‘hustling’ as a way to navigate precarious urban environments beyond the ‘paid job’ and advance their own (sometimes individual, sometimes shared) interests against the odds.”

This highlights the glaring institutional neglect of young people who are habitually relegated to the margins of formal urban spaces, such as the peri-urban fringes of Kampala (See *Plate 1* and *Plate 3*). Most HIV programmes and interventions in Uganda have been focused on key populations (fishermen, sex workers, men who have sex with men (MSM), people who inject drugs (PWID), and long distance truck drivers (see UAC, 2018), disregarding the already marginalised youth living and working in the industrial areas around Kampala’s outskirts. These areas attract myriad young people seeking employment in casual jobs as migrants, poorly and non-educated residents and, in particular, vulnerable young women and adolescent girls trying to subsist in highly exploitative and volatile male-dominated informal spaces. All these groups live in precarity, which increases their susceptibility to the HIV risk. These disadvantaged young people are thus part of the larger most-at-risk populations (MARPs) in Uganda that need urgent attention. This research was focused on Bwaise, Katwe and Ndeeba as typical informal urban spaces occupied by young people trying to hustle for a living in one of the less developed

economies of the world, where issues of creative artistic engagement for the youth in the context of HIV prevention has so-far been under-researched at a time when the reversal of Uganda's HIV/AIDS success story is under severe scrutiny. Ostensibly, today's changing epidemiological profiles and the emerging health threats posed by the Covid-19 outbreak call for new and creative ways of working with socially and economically marginalised youth who are most at-risk of contracting HIV/AIDS in Uganda.

#### **1.4 THE PROBLEM**

There have been significant efforts to fight HIV/AIDS through engaging creative approaches in the visual arts (Artivists 4 life, 2013; L. Nabulime & McEwan, 2011; Norton, 2009; Wells, 2012) and theatre (Barz & Cohen, 2011; Mushengyezi, 2003; Nalubwama, 2019) in Uganda, particularly after the 1990s. In particular, research by Nabulime (2007)<sup>9</sup> has shown that art can transcend social and cultural boundaries in disseminating knowledge and impacting positively on lives of people, especially women, living with or affected by HIV/AIDS in local communities in Uganda. However, one question that remains is whether this participatory research using applied social sculpture can go beyond a focus on improving HIV awareness to increase prevention and economic empowerment, particularly among young people in Uganda. Currently, there is a dearth of research into the causes of rising HIV infection rates among young people, and specifically, how applied sculpture (and other creative approaches) can be used as tool for raising HIV awareness and prevention while also tackling underlying causes, particularly in marginalised informal peri-urban settings. The growing number of socio-economic precarities (such as poverty, low esteem, limited literacy, misinformation, or lack of information about HIV prevention, and gender injustices<sup>10</sup>) that continue to shape the landscape in which HIV/AIDS flourishes, warrant further investigation of appropriate youth-centred creative solutions in informal contexts.

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<sup>9</sup> Nabulime's research focused on exploring the use of sculpture, developed through research in to the lives and experiences of Uganda women living with HIV/AIDS, as tool of for raising awareness about the illness. It developed new areas of sculptural practices and strategies of presentations and explored the practical application of these in communicating about HIV/AIDS awareness to literate and illiterate people form diverse ethnic groups.

<sup>10</sup> Including sexual abuse, sexual exploitation, assault, rape, and other forms of gender-based and domestic violence at home and work.

The primary concern of this thesis, therefore, is the exploration of the factors affecting the ability of marginalized peri-urban youth (mainly young artisans/craftsmen) in industrial urban locations to respond to the precarity and informality that shape the landscape in which HIV/AIDS flourishes. Particular concern is centred around understanding the everyday experiences related to stigma, discrimination, unemployment, gender inequalities, domestic violence, which are escalated by poverty, mis-information, and the absence of formal education opportunities or adequate youth-centred skills development and HIV awareness programmes. These factors make it extremely difficult for young people to speak about risk factors, access information, or navigate towards better decision-making and practices that boost their health and wellbeing. Evidently, these factors have not been sufficiently addressed by either the existing biomedical or behavioural interventions championed by the Ministry of Health (MOH) and other stakeholders such as NGOs involved in the fight against HIV/AIDS among vulnerable communities and, particularly, the youth in Uganda (see Bell & Aggleton, 2013; Evans, 2015; Kuhanen, 2010; Nicholas, 2010). Several approaches have been taken to prevent and reduce HIV and AIDS transmission: medical (counselling and prevention initiatives), behavioural (condom distribution, health education messages, media), familial (parent awareness, establishment of personal norms of moral behaviour), and of course school interventions (De Lange et al., 2004). However, despite the many prevention efforts from a variety of players, certain populations, most particularly young people in informal settings, continue to be the most vulnerable (Bell & Aggleton, 2013). Thus, finding alternative approaches – in this case applied sculpture as a social practice with an integrated visual participatory methodology<sup>11</sup> - to improve HIV/AIDS awareness and prevention, and the empowerment of young people in marginalized peri-urban geographies becomes a matter of critical concern and urgency. Some scholarly writers refer to these approaches and methods as enabling people to express, enhance, share and analyse their knowledge of life and their circumstances, and to plan and act upon it as well (Boneh & Jaganath, 2011; Chambers, 1994d; Kindon et al., 2007; Oakley, 1991). It is against this background that the engagement of applied social sculpture as a visual approach and socially engaged practice is considered to be

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<sup>11</sup> Visual participatory approaches refer to participatory methodologies for engaging and mobilizing people at grassroots level, using the research process itself as a means of empowerment through using the visual means (for example, drawing, collage, photographs, video work, and so on) as a focus for discussion (N. de Lange, 2008a)

potentially valuable towards improving interventions meant for HIV awareness, its prevention and empowerment among young people in Uganda. This thesis thus explores how applied sculpture, as an art and social practice, offers the means to do this by engaging collaboratively with local youths to explore the social, economic, and cultural experiences of young people in dealing with the challenges of HIV/AIDS and its associated problems. It draws on the notion of art acting as a social practice, which sees artists taking their practice into the expanded field to engage the public in their works to facilitate social, economic or political change (Barz & Cohen, 2011; Berman, 2018; Krauss, 1979). Globally, research has demonstrated that art can be effective in breaking down taboos, enabling dialogue about sexuality and challenging HIV/AIDS stigma, with potential to change sexual behaviour within communities. Art has been shown to transcend social and cultural boundaries in disseminating knowledge and impacting positively on lives of people, especially women in Uganda (L. M. Nabulime 2007; L. Nabulime & McEwan, 2011). Similarly, art can also affirm indigenous knowledge and skills as well as disseminating vital information about HIV/AIDS amongst and by the most marginalised and vulnerable groups (Diamond, 2007; Johansson, 2010; Moletsane et al., 2007; Stupples & Teaiwa, 2017; Teti et al., 2017; Thompson, 2012). Declining levels of awareness and rising complacency among youth about HIV/AIDS in Uganda, after a considerably successful period of a downward trends in HIV infections, makes research with high-risk groups crucial to promote HIV/AIDS awareness and prevention. This thesis, therefore, focuses on using applied sculpture as a social practice in engaging with young people working as artisans in the informal sector. It explores how social sculpture can facilitate observing, sharing, and learning from their lived experiences in order to (i) improve their confidence, awareness, and ability to minimise the stigma associated with HIV/AIDS among young people; (ii) equip young artisans with the social, moral, and economic capacity to improve their lives, reducing the economic dependency that makes them vulnerable to risky behaviours and practices that perpetuate HIV/AIDS infection.

## **1.5 AIM AND OBJECTIVES**

The overarching aim of this study is:

To examine the potential of applied sculpture in enabling young people (15-24 years) infected with and affected by HIV/AIDS to confront the everyday precarious experiences that allow the epidemic to flourish in the peri-urban spaces of Kampala.



Specifically, it sought to:

- i) To identify, articulate, document, and share knowledge about the everyday experiences of young people infected with and affected by HIV/AIDS in marginalised informal settings in Kampala.
- ii) To initiate collaborative partnerships with young people to co-create applied art forms as tools of communication about HIV/AIDS awareness and its prevention whilst building capacity for social-economic empowerment among young people in marginalized informal settings.
- iii) To demonstrate the value of applied social sculpture as a new approach for advocacy and information for public health policy decision makers and provider of health services concerning HIV/AIDS awareness, its prevention and empowerment of young people in Uganda

## **1.6 RESEARCH QUESTIONS**

- i) How might applied social sculpture be used to facilitate open communication and self-expression, increase HIV/AIDS awareness and prevention, and encourage behavioural change among young people in marginalized spaces of Kampala?
- ii) In what ways can applied social sculpture enable collaborative partnerships for the co-production of functional/usable art forms that are communicative about tackling HIV/AIDS for social transformation and remain relevant to economic empowerment of young artisans in Uganda?
- iii) How might applied artistic practices inform policy makers and providers of health information, and advance new approaches to improve HIV/AIDS awareness, prevention, and empowerment among young people/artisans in Uganda?

## 1.7 THESIS OUTLINE

Having introduced the central focus of the thesis in the first chapter, the Chapter 2 outlines in more detail the conceptual framework. It sets out the importance of the concept of taking art from galleries into the expanded field – transcending creative approaches from the visual into the social (L. Nabulime & McEwan, 2011) – as the conceptual framework for the research and the implications of this for the methodology employed in the research process. It explores the importance of using visual approaches in Global South contexts and advocates a multidisciplinary process that interlaces anthropological and geographical approaches with applied social sculpture as an inclusive creative approach to tackling rising levels of HIV/AIDS infections among young people. Chapter 3 explains and accounts for the methods employed in carrying out the fieldwork in Kampala. It provides details of the data collection methods used, including ethnography, participant observation, interviews, photography, audio and video recording, group discussions, field note-taking, and explains the creative technique of co-producing artwork as communication tools for HIV/AIDS awareness and prevention. The chapter not only describes the research process, but also explores the limitations and ethical aspects emerging from such research. Chapter 4 explores urban informality in relation to youth vulnerability and HIV/AIDS, explaining aspects of everyday experiences in the selected peri-urban spaces that are important in understanding the lives of young people infected with and affected by HIV/AIDS, such as social injustices, poverty gender inequality, cultural attitudes, inter/cross generational sex, urban masculinities, low education, and high levels unemployment, which all affect young people's lives. Chapter 5 focuses on the ethnographic accounts related to using applied social sculpture to explore deep seated issues connected to gender injustices, masculinities, and sexualities that shape the landscape in which HIV flourishes. Chapter 6 aims to demonstrate the efficacy of applied sculpture through participatory workshops in contributing towards HIV preventions and youth economic empowerment. Chapter 7 brings together the key findings and the discussions in the previous chapters to explore the agency of the research participants towards tackling HIV/AIDS and its associated ills. It also explains how these findings and co-produced works were disseminated to the wider public. It ends with a case for advancing engagement with creative practices, such as applied social sculpture, by policy makers and providers of health information and services in Uganda. It argues that as an alternative approach to HIV prevention and youth emancipation

for improved health and livelihood, creative practices such as applied sculpture can be valuable in peri-urban contexts. Finally, Chapter 8 summarises the key findings of the thesis in relation to the research questions. It concludes with suggestions for benchmarking applied social sculpture for improving development of HIV prevention policies and practices by engaging with the voices and agency of young people in informal urban spaces.

## CHAPTER TWO

### ART AS A SOCIAL PRACTICE: FROM THE STUDIO INTO THE EXPANDED FIELD

#### 2.0 INTRODUCTION

Emerging as new genre of public art, socially engaged art (participatory art), often activist in nature, and created outside institutional structures such as galleries or studios, became synonymous with engaging directly with an audience or publics (Jordan, 2013). For purpose of this thesis, I draw specifically on the contributions of two important figures: Joseph Beuys (Borer et al., 1997; Ermen, 2007; Jordan, 2013), who inspired a generation of new artists motivated by notions of art having the capacity to move beyond the spaces of galleries into an expanded field, and thus beyond the visual and into the social (Nabulime and McEwan 2014); the American artist, educator, and writer Suzanne Lacy.

#### (i) Joseph Beuys (1921–1986)

German artist Joseph Beuys used social sculpture definitively to embody his understanding of art's potential to transform society. He argues that social sculpture is based on the concept that everything is art, that every aspect of life could be approached creatively and, as a result, everyone has the potential to be an artist (Tate and National Galleries of Scotland, 2019). The central idea of a social sculpture is to create structures in society using language, thoughts, actions, and objects (Ermen, 2007). Beuys' art was purely based on concepts that could promote the creation of objects, encourage dialogue and political activism.

The social application of the creative process was Beuys' main idea and he coined the term "social sculpture" in the 1960s and 1970s. Beuys demonstrated his idea in his last major work, "7,000 Oaks" (See *Plate 4*), a city forestation and sculpture project in Kassel, Germany, designed to heal the deep psychic scars of the Third Reich and help renew German, European, and Western culture over hundreds of years. Beuys achieved this objective with remarkable simplicity: in the giant plaza at the city's centre, Beuys piled 7,000 irregular, human sized basalt columns in a formation, exactly as thousands of bodies were piled after the 1943 bombing of Kassel. Over the next five years, donors purchased the stones one by one. As each stone was

purchased, it was moved to a different location in the heart of the city, where it was placed upright, sticking at least a meter out of the ground, next to a tiny oak tree: a symbol of death and a symbol of life. One of the forms would remain static, while the other would change and grow over time. One dwarfed the other at first; as the oak tree grew, it would match the basalt column in size and eventually tower over it.

Beuys' concept of 'social sculpture' originates in the anarchist wing of the Socialist International arising from the work of Kropotkin and Reclus and was influenced by Steiner's "threefold social order" (David Adam, 1992, p. 26). In 1973, he stated:

"Everything human being is an artist who...learns to determine the other positions in the total artwork of the future social order. Self-determination and the participation in the sculptural sphere (freedom); in the structuring of laws (democracy); and in the sphere of economics (socialism). Self-administration and decentralisation (threefold structure) occurs..." (Bellman, 1995, p. 190).

The connection between the idea of art as a social practice and social sculpture arose from Beuys' educational, ecological, and political activism. He taught monumental sculpture at the Dusseldorf Academy of Fine Art from 1961 until dismissed for refusing to countenance entry qualifications. His work remained explicit on the role of art as a communicative medium to and about society (e.g., his Documenta series of artworks, the Honey Pump at the Workplace, Documenta 6, 1977), and 'accounted for his ideas about how art and society had necessarily got to change supported by extensive use of blackboards' (Gerhard, 1997). For Beuys, art was a pedagogical platform.

## **(ii) Suzanne Lacy (born 1945)**

Suzanne Lacy attempted to redefine a type of public art that was not just a sculpture situated in a park or a square but a form of social involvement of the environment and society. She was predominately concerned with bringing both social and aesthetic purpose to her work (e.g., see Silver Action 2013), making her, in many people's eyes, both an artist and an activist. Inspired by Beuys' conception of social art, her concept of "Between the Door and the Street", in which 400 mostly female participants decked out in lemon-yellow scarves took over a brownstone-lined block in Brooklyn to discuss issues of gender, race, and class with passers-by

(the live performance in Prospect Heights, Brooklyn, NY, 2013 is detailed in Miranda, 2014) is typical of Lacy's work. It is also influenced my involvement with young artisan in Kampala in a people-centred and public driven way. Lacy, working in a variety of media, (including installation, video, performance, public art, photography, and art books, in which she focuses on social themes and urban issues), defined new genre public art as being activist, often created outside the institutional structure which brought the artist into direct engagement with the audience (i.e. public engagement), while addressing social and political issues (e.g., Lacy, 2006). Her conception of art as a social practice simultaneously seeks social change, maintaining a certain instrumental attitude toward art as a means to facilitate policy changes or to correct social injustices. While such efforts challenge conventional power dynamics and hierarchies that sustain the contemporary art world, more often than not the democratic mode of communication that new genre public art envisions is for a unified public sphere. At the same time, it often maintains a certain protective attitude toward the "collaborating" participants (Kwon, 2002; Rooney, 2014).

The idea of art as social practice has gained the most traction in academia. Several artists, social scholars and institutions began offering social practice as a pedagogic necessity in education, public outreach programmes and social responsibility engagements through field activities that are tailored to benefit society (Kapoor & Jordan, 2009; Moxley, 2013; Walls et al., 2016). My prime concern here, in particular, is using Beuys' and Lacy's overlapping notions and perspectives of art in the wider social context to shape and inspire applied artistic engagements with young people in Kampala's informal spaces with the aim of tackling the restrictive marginalities of life and HIV/AIDS in Uganda. This relates simultaneously to participatory engagement processes and the adoption of multidisciplinary methods to co-produce new knowledge about youth empowerment, and HIV awareness and its prevention in informal urban contexts.

## **2.1 ART AS A SOCIAL PRACTICE**

Theorizing art practice is much-contested in arts-based contexts, but art has often been viewed as having a critical social work aspect with wide-ranging sociological concerns. Nonetheless, social work or social practice as a genre has been around in one form or another for a long

time, though it hasn't always had that label, or been quite so lauded. Davis (2016, p. 5) argues that:

“Social practice”—both as a form of art making and as a theory of art making—grows out of a dispirited reaction to the commercial art industry’s complicity with capital, and a corresponding, and altogether wholesome, hunger for an art that actually makes a difference. The questions it raises are real. Its limitations are worth assessing and criticizing, but it would be a mistake to say that it is simply to be denounced”

Viewed as a reactionary divergence against the excesses of individualism and studio confinements, the popularity of art as a social practice among scholars and artists, in particular, reflects a significant shift from the art market to one that prioritises society (Rooney, 2014). Also known as participatory art (e.g., White, 2009), the social practice of art has been described as the ‘practice skill’ that combines both knowledge and subjectivity in working with human beings; the ability to see the *other* beyond the science and incorporate creativity and imagination in meaning-making (Seana Moran, 2003). It involves embracing the importance of human relationships, community and congruence with self in practice (Samson, 2014). As stated by Sánchez-Camus (2011), art in social work/practice recognizes potential and insights that can be incorporated into the relationship between the social worker/artist and participant, in a way that is open and multifaceted. The most influential component of the helping process identified by participants is often the relationship between the artist/facilitator and performer. This relationship can best be viewed as a partnership for change which helps provide effective therapy that incorporates attitudes, behaviours and values, all of which encompass the critical components of practice wisdom (Samson, 2014). It is also documented that:

“Currently, in the social sciences, visual and artistic stimuli are prominent in both research and practice. This manifestation includes areas such as arts-based research, visual culture, visual anthropology, community art, photovoice, action methods arts therapy, outsider arts, arts in conflict negotiation, and arts in social change”

(Huss & Sela-Amit, 2019, p. 722; also see Mitchell, 2006)

Social practice has been slow to embrace those aspects, hence, defining arts more as a theme illustration or as a generally romanticized concept of creativity. Art-making, therefore, may emerge within a group as its principal source of pleasure, interpretation of the world, and coping (Enge et al., 2011; John Clammer, 2014b; Lindqvist, 2003).

### 2.1.1 Utilizing art through desire and circumstance

Like performance itself, more recently, art has also been understood as a way of engaging directly with social reality, the specifics of space and the politics of identity. For instance, Kate Wells led the Siyazama Project, which enables rural, traditional craftswomen from KwaZulu-Natal to express their concerns about AIDS and all of its complexities through the creation of cloth dolls and beadwork. The Siyazama Project communicated and spread awareness of HIV/AIDS through creative workshops, local and international exhibitions, museum collections, publications, and other research activities. Jackie Guille and Kate Wells transferred Siyazama to Uganda in a bid to help local communities confront their own social difficulties and HIV/aids in Particular (Wells, 2012). Similarly, several other scholars have argued that artistic social practice is not as a medium nor artwork, but rather, a set of questions and concerns about how art relates to people and the wider social world' (Graham et al., 2013; Stuart, 2010). Sometimes, "social practice" can seem like little more than aestheticized spin on typical non-profit work. Several other scholars remind us of how art forms from struggle to liberty and disadvantaged people realising democratic ecstasy (Moxley, 2013; Strong, 2002). Interestingly, (Moxley, 2013, p. 236) adds that:

"Those who experience struggle in society may revert to invention in art-making as a way of transcending harsh treatment through portrayal and representation no matter what medium the artist chooses. Helping people whose status is diminished struggle effectively and overcome the causes and consequences of the social issues they face becomes essential to what the author calls the cultural practice of social work and art-making is central to such practice."

Literally, here the process of art-making centres its concern on socially engaged processes (collaboration or social interaction) intended to challenge debate and address people's lived experiences. Similarly, Suzanne Lacy (2006) describes art as a socially engaged practice that is collaborative, often participatory and involving people as the medium or material of the work. The participatory element of this practice is key, with the artworks created often holding equal or less importance to the collaborative act of creating them.

Researchers and visual performers/artists have used the arts to address and express pain and adversity so as to enhance their resilience through symbolic interaction and self-expression (Chambers, 1994d; Hagman, 2009; Wallace-DiGarbo & Hill, 2006). In effect, this means that art potentially provides a personal interpretation of a social context that connects to problem-



solving and resilience. It can easily recreate connection among cognition, emotion, and the senses. In doing so, it creates a unique, embodied configuration of the person's interpretation of her or his reality (Csikszentmihalyi, n.d.; Seana Moran, 2003) – a situation that relates so well with storytelling and memorisation of lived experience and past circumstances. Sometimes, art-making may emerge within a group as its principal source of pleasure, interpretation of the world, and coping (Moxley, 2013).

Additionally, art may help to produce new, more enabling meanings and solutions at both the personal and the community level: symbols and metaphors form a much broader hermeneutic base that might contain multiple and conflicting meanings in comparison to words that tend to be more linear, clearly enabling conversations about critical and sensitive aspects of life such as HIV/AIDS, sexist experiences, and so on (Hewson & Hamlyn, 1985; Laura Nyblade, 2005). Thus, the use of the arts enables systems to negotiate shifts from homeostasis (same and steady) to mobilization of change in a system that is stuck. This works by gradually shifting traditional symbols to contain new meanings and thus behaviours or role divisions, thereby concretely expressing and re-envisioning new social organization. Because the arts are primarily a communicative medium, they can enhance communication between participants and the facilitator (Berman, 2018; N. de Lange, 2008a). The arts can also be recognised for helping communicate marginalized experiences because they provide participants a space to explore and define their experience. Experience is expressed in form and content that demands exploration and self-definition of one's experience to decide how to communicate it to others. Compositional elements of images, such as shapes, size, colour, brightness, intensity, location, position, contours, lines, movement, shading, omissions, and texture within the image, together with objects, symbols, and metaphors, enable the excavation of experience of the self in context – a pedagogical approach to aimed at fostering a critical analysis of society and one's status within it using democratic, empowering, and interactive methods (Moxley, 2013). The aim is social change as well as learning, which makes these ideas especially relevant to the structural and social injustices faced by marginalized people (Dugga, 2015; Freire, 2021). In her book "Finding a voice: A visual arts approach to engaging social change", Kim Berman (2005) views the arts as a space of agency in which we can look back, and at one another, naming what we see and argues retrospectively that:

“Art is directly relevant to resilience because it is participatory and inclusive: it emerges from the deepest layers of human beings; involves an implicit recognition of shared humanity and creativity; evokes imagination and creates alternative visions in collaboration with others; is spacious in accommodating mystery and spiritual aspects of people; and contributes to healing, empowerment, and self-esteem for individuals and groups”

(Berman, 2018, p. 101)

Clearly, art and the creative process are the centre of concern in understanding their role as social practice—not simply in terms of the aggregate potential in generating tangible visual products, but also in terms of the larger and broader potential to bring about meaningful change among individual and communities. This change can be achieved through a reconsideration of the goals and methods in designing arts-based undertakings (Bunn et al., 2020; John Clammer, 2014b).

### **2.1.2 Art and creativity: The meaning making process**

Creativity is the process of bringing something new into being. It brings to our awareness what was previously hidden and points to new life (Cunningham, 2007). According to Linda Naiman, a renowned educator and coach, creativity is characterised by the ability to perceive the world in new ways to find hidden patterns, to find connections between seemingly unrelated phenomena, and to generate solutions. Additionally, creativity requires passion and commitment. It brings to our awareness what was previously hidden and points to new life; it cultivates the ability to connect and incorporate ideas, disciplines, ways of resolving problems and relating experiences (Naiman, 2015, 2020b). Today, we are living in the age of creativity where having the ability to connect and incorporate ideas, disciplines, and developing critical thinking can lead to innovation and comparative advantage by adding social and aesthetic value to our work (Pink, 2005). The prevalence of diseases like HIV/AIDS pose significant threats to many economies in world, especially in sub-Saharan Africa, and points to the greater need for creative minds. Creativity itself cannot happen without the existence of creative brains or artistic minds. It borders on elements of aesthetic experience which give form, meaning and most importantly value to everything we are, all we experience and everything

we do (Hagman, 2009; Urdang, 2018), and this aesthetic experience achieves its most refined form in the fine arts<sup>12</sup>.

Art and creativity create a bonding experience that facilitates collaboration and accelerates the ability to get to the heart of and solve problems (Naiman, 2015). Creative engagement has been essential in the world of discoveries because it is always at the heart of innovation; such engagement can be used as an instrument of team building, communication, problem solving and innovative processes (Lacy, 1995; Sánchez-Camus, 2011a). The creative process sometimes manifests through the production of art forms/works. Art therefore becomes a core component of creative engagement that allows innovations to succeed. In the modern era, creative (or arts-based) practices provide a platform upon which the fine arts and visual arts collectively use both traditional and non-traditional methods to communicate and interact with broad and diversified audiences about issues that are directly relevant to their lives. This is no more obvious than in the fight against HIV/AIDS. For instance, art has been at the forefront of raising funds through auctions, which literally save lives while keeping the HIV/AIDS epidemic on the public health agenda (Clift et al., 2016; Maimi Times, 2018; Wells, 2012; Wells et al., 2004). Art-based practices have been described by some scholars as transformative because they have been used as an avenue for empowering people within their local communities through the harnessing of creative capacities for improved economic production and well-being. Such was the case for the introduction of Theatre for Development in many Sub Saharan countries (Diamond, 2007; Kiguli Susan and Okot m Benge, 2000; Low, 2010; Thompson, 2012) – a participatory theatre practice which allows communities to write their own stories, perform and participate in a culturally-appropriate and transformative storytelling process. Such practices have been used successfully in HIV/AIDS prevention and empowerment of young people. Creative engagement through arts-based practices, alongside other interventions, has often provided the spark of inspiration that has enabled innovative processes to bear fruit, particularly where communities have been at high risk of HIV/AIDS and other disasters. Examples are the ‘Body mapping’ and Siyazama projects in South Africa (MacGregor, 2009; Wells, 2012). In Sub Saharan Africa, both projects have been widely

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<sup>12</sup> Fine arts is a collective term that refers to the creative art, especially visual art whose products are to be appreciated primarily or solely for their imaginative, aesthetic, or intellectual content. It includes such traditional disciplines as drawing, sculpture, painting, graphics, ceramics, art criticism and appreciation.

acknowledged as a successful artistic innovation that has helped reduce social stigma and discrimination of people living with HIV/AIDS (CATIE, 2006), while also improving their economic well-being.

The notion that taking art from the galleries or museums to the expanded field is responsive and generative, with the capacity to enliven individuals and communities (Berman, 2018) is further explored below through (i) reviewing existing creative engagements towards addressing challenges related to HIV/AIDS (ii) advancing applied social sculpture as an alternative approach in tackling HIV/AIDS related challenges.

## **2.2 RETHINKING CREATIVE ENGAGEMENT IN CONFRONTING HIV/AIDS**

Creative practices that involve art-based engagements have been central to HIV/AIDS prevention, providing knowledge and raising awareness among young people in local communities for their social and economic well-being. According to Berman, the visual arts are universal forms of expression and have been practiced in many communities globally (Berman, 2018). There are numerous examples of the use of music, dance and drama (MDD) as an education-entertainment strategy to promote HIV/AIDS awareness and prevention campaigns in sub-Saharan African (Vaughan et al., 2000). In what follows, I discuss two specific creative interventions in more detail. Body mapping is well known as a visual artistic intervention into HIV/AIDS awareness and prevention. I also make the case that sculpture has an equally important role to play in HIV/AIDS prevention, education, and empowerment, yet is relatively neglected. While public and social sculpture has long been recognised as having transformative possibilities, applied sculpture remains a neglected but, as this project demonstrates, important approach in HIV/AIDS prevention.

### **2.2.1 Creativity through body maps**

First seen as an advocacy tool South Africa, body mapping has brought significant attention to HIV/AIDS prevention and empowerment among young people both infected and affected by HIV. Through practical exercises directed by a facilitator, using pictures, symbols and words, the path one's body has taken through life is mapped visually (Solomon, 2007). This may include visual marks (scars, stretch marks, etc.), body parts or areas of emotional significance such as hands and wombs, current status of well-being and illness, as well as visualising artistic

symbols of personal power and visions of the future. Then the resultant body maps illustrate the impact of HIV/AIDS on the body as well as personal struggles and triumphs of living with the disease. The body mapping exercise aims to assist participants to recognise and understand how their life story and HIV have affected their body, within and without (Gastaldo et al., n.d.; MacGregor, 2009; Solomon, 2007). The participants involved in body maps experience a heightened awareness and appreciation of the various threads and storylines making up their lives. They notice that sometimes it is not limiting ways in which they narrate their stories, and they increase their confidence, courage, integrity, and hope. In addition, they experience a renewed commitment to promoting increased acceptance and understanding that helps reduce the stigma of HIV (Brett-Maclean, 2009). One of the most provocative works of art was showcased by Canadian AIDS Treatment Information Exchange (CATIE) in partnership with the Regional Psychological Support Initiative (REPSSI) and produced by women from Tanzania and Zambia. This delivered powerful lifesaving awareness information and the associated challenges described through body mapping (CATIE - Canadian AIDS Treatment Information Exchange, 2006). Some of the startling and beautiful artworks (E.g., *Plate 5*) were sold, and proceeds were given to the artists and their communities. This and other body mapping projects the world over have demonstrated how art has creatively promoted awareness, instigated political action (MacGregor, 2009) in the lives of vulnerable communities, and contributed significantly to well-being, while promoting treatment, therapy and social transformation. However, body mapping has not been without critics; some researchers suggest that those who have suffered trauma may become further distressed by increased awareness of embodied experience and there is now greater awareness of the need to screen participants who wish to take part in body mapping workshops (Chalcraft and Churchill, 2011:22).

### **2.2.2 Photovoice in HIV/AIDS prevention and awareness**

Photovoice is an important and creative art-based approach that is increasingly being used as a way to view social and economic worlds of young people (Wilson et al., 2007). It is a participatory action research methodology based on the notion that people are experts on their own lives owing to the fact that they can freely express their personal and community concerns (C. C. Wang, 2006; C. C. Wang et al., 2004). Photovoice has been broadly engaged in many recent youth-related social research projects because it is one of those unique creative

learning approaches by which people can identify, represent, and enhance their personal lives and community through photography. As with all the other arts – sculpture, painting, and so on – photovoice allows participants to take pictures about their lives and community (Moletsane et al., 2009), and to represent their worlds with their own photographs, which they analyse to surface their meaning. The format for reflecting on the photographs is to respond in writing (a ‘free-write’) to questions such as: what do we see here? What is really happening here? How does it relate to our lives? Why does the problem exist? And what can we do about it? (C. Wang & Burris, 1997; C. C. Wang et al., 2004). Central to this creative practice is the ability to engage people in critical thinking through ‘freewriting’ which expands both individual and group awareness of their personal and social challenges in life.

Photovoice as a creative art has been at the forefront of promoting positive living among people suffering not only from HIV/AIDS and its associated problems (Teti, French, Kabel, & Farnan, 2017), but also other forms of chronic and terminal diseases such as cancer and TB . It has been deployed to help people with HIV/AIDS to manage their ailment and symptoms in new ways thereby enabling them rebuild their self-esteem and communication with others in a society. In one of the HIV/AIDS funded project by the South African National Research Fund – “Learning together: Integrated and Participatory Methodologies in the fight against HIV/AIDS (2006)”, photovoice was engaged as a research and development methodology which explored possibilities of doing social research and having fun as part of the process with young people in Kwazulu-Natal, South Africa. This research saw the development of a social group called *Amavulandlela*, also known as ‘Ground-Breakers,’ who aimed to challenge stigma among young people concerning HIV/AIDS. They used photovoice to develop short play scripts which were then performed in schools (Moletsane et al., 2009). This was done alongside setting exhibitions of a collection of drawings and photographs which participants had made and taken during the sessions. The overarching benefit from this approach was the heightened sense of awareness of HIV/AIDS within the community and consciously generating strategies for reducing stigma and social discrimination amongst the infected and affected in the larger Kwazulu province in South Africa. In what follows I focus on the significance of social sculpture and proven impact in socially transforming communities affected by HIV/AIDS.

## **2.3 SOCIAL SCULPTURE AS A COMMUNICATION TOOL FOR HIV PREVENTION**

In this study, I attempted to explore social sculpture as one of those creative art-based approaches that brings together individuality, subjectivity, and creativity as a potential platform for social change among people affected by and infected with HIV/AIDS. While awareness of the disease in Uganda is often high, having the capacity to openly discuss and act upon this awareness is often problematic, largely because of fear, stigma and taboo, and the unequal gender relations that determine the nature of men and women's sexual lives (L. Nabulime & McEwan, 2011). Authors generally place an emphasis on the potential of social sculpture as a communication tool for raising awareness about HIV/AIDS as well as an enabling avenue for enabling men and women to confront their harmful social inequalities, taboos and stigma that allow the disease to flourish in their communities. Before discussing how social sculpture has been used to socially transform lives among local communities affected by HIV/AIDS in the diaspora, I briefly explore some of the harmful social issues such as taboos about sex and sexuality and silences that continue to hamper the efforts intended to stem the tide of the HIV/AIDS among young people in Uganda.

### **2.3.1 Tackling taboos and silences within the Ugandan cultures**

In Uganda, silence on issues related to sex may be a social norm, but in the face of the success stories around reducing the rates of HIV infections, there is a growing number of Ugandans who believe such a mentality is simply no longer an option. However, issues regarding norms governing sex and sexuality, gender, and persistent HIV/AIDS-related social stereotypes such as labelling PLHIV as promiscuous, denial of inheritance opportunities and fear to being rejected or discriminated by families and society continue to shape the negative mentalities and increased silence about the disease among the youth. Many young people have died of AIDS prematurely simply because of the growing fear to reveal that they are sexually active and about their HIV status openly. Many young are influenced by their peers to engage in sexual acts which arguably shapes their masculine construct of maturity (adulthood). Traditionally, the patriarchal constructs induce men to suffer secretly, suppressing or tucking their emotional and mental problems into self-denial (Wyrod, 2011, 2016b). It is also notable that young people in many areas of Uganda learn from their elders and peers about sex taboo

words as early as 10 year the sex taboo words are learned as early as 10 years of age (Obbo, 2020).

Due to patriarchal influences, many young people often use of metaphoric expression particularly in the local dialect, in Buganda for instance, that elude social realities and conceal meanings that relate to the act of sex and sexuality. Conspicuously, one easy gets lost in translating the meanings. For example, *Okulya ebisiyagga* in Luganda to mean Penile-anal intercourse (Homosexuality). Another word/metaphor is *okuzina* (To dance) which, at times, sounds ambiguous as it ordinarily refers dancing. Instead to the most youth it is figuratively used to mean sexual intercourse. Speaking such language in local context especially in central Uganda is abominable as the meaning sounds quite vulgar and unacceptable culturally. While Hewson & Hamlyn (1985, p. 32) emphasises,

“Metaphors are semantic structures that provide understanding and experience of one kind of thing in terms of another..... metaphors are not simply linguistic structures, they also influence the way in which we perceive, conceptualize, and act. Metaphors are important conceptual tools for explaining abstract ideas that cannot easily be explained or understood”.

Many young people acknowledge that some of metaphors are part of the culturally affirmed semantics, but they sound restraint and instil fear. They instead opt to introduce simple figurative words such as *Embwa* (dog) to refer to *Mukenenya* or slim and '*Okulya*' (To eat) to mean having sex in order to circumvent those terminologies that are deemed vulgar and socially unacceptable to communicate issues of relationships, love, sex, and sexuality amongst themselves. Such circumstances have forced many young people to remain silence about the sexual behaviours and that arguably distances them from confronting the social actions and behaviours that are associated with getting infected with sexually transmitted diseases including HIV/AIDS. Very often young people have fallen victim to HIV for failure to openly talk about their social and sexual experiences as they transition from adolescence to adulthood. The use of the term '*Mukenenya*' to refer to the sliming disease - HIV/AIDS - continue to harbour inhibitive traits that gag young people to openly reveal their status and have free conversations around the disease. The existence of a predominantly patriarchal society prevents young people from taking the lead in their lives and communities, as well as exercising their rights. This translates into stigmatised identities (characterised by fear, silence, social



isolation, and denial) among the youth which in turn allows HIV/AIDS and other infectious diseases to be transmitted unabatedly.

During one of my private projects and interactions with young artisans in Bwaise area in 2018, a young artisan friend revealed how one their workmates succumbed to death because of stigma and the silence associated with the reality of being infected with the virus.

“He spend the greater part of suffering and ailment in the workshop. He worked with us while complaining of regular headaches and fever. It seemed to have known his status, but he never told us for fear of being tormented with negative comments from his workmates. Sometimes he would spend nights in one of the carpentry workshops until one morning when his close friends realised that he was critically ill, and we decided to take him to Mulago Hospital for treatment. That is when we discovered that he was HIV positive. Unfortunately, our help was a little too late and he passed on.

(Informal conversation, Young artisan, Bwaise, 2019)

This is not merely a statistical account but a broader representation of many young people who have lost their live to HIV/AIDS related illness as a result of stigma and fear associated with the disease.

Notably, people living with HIV/AIDS (PLWHA) face not only medical problems, but also social problems associated with the disease. Clearly, one of the barriers to reaching those who are at risk or infected with HIV/AIDS is stigma. Stigma enhances secrecy and denial, which are also catalysts for HIV transmission. Recent studies show that HIV/AIDS stigma negatively affects seeking HIV testing, seeking care after diagnosis, quality of care given to HIV patients, and finally the negative perception and treatment of PLWHA by their communities and families, including partners (Mafigiri et al., 2017). It isolates people from the community and affects the overall quality of life of HIV patients. HIV stigma is shaped not only by individual perceptions and interpretations of microlevel interactions but also by larger social and economic forces. It is a social construct, which has significant impact on the life experiences of individuals both infected and affected by HIV. Stigma includes prejudice and can lead to active discrimination directed toward persons either perceived to be or actually infected with HIV and the social groups and persons with whom they are associated. Currently, there is an increasing number of research on HIV-related stigma not only in Uganda but also in the wider Sub-Saharan Africa. It is being increasingly acknowledged, however, that effective treatment and care strategies require an understanding of the cultural context in which stigma exists (Mbonu et al., 2009) –

an aspect that applied social sculpture potentially explores as it gives room for free expression and open conversations among diverse groups of young people in the context of health and social/economic wellbeing.

Research has shown that utilizing social sculpture as a tool for communication, young people are potentially provided with the means to share vital knowledge, information, about the HIV/AIDS, but also enabling them to speak openly with one another (L. Nabulime & Mcewan, 2014). It also offers the researcher an opportunity to listen, learn and familiarize with the language they understand in order to engender their participation in creative artistic production meant to empower them for better health and wellbeing. Understanding the language they use, and the social construct of their lives potentially enables open conversations intended to boost their confidence to express themselves about their everyday experience in the context of the disease which allows their perceptions to rise above negativity and to challenge misconceptions with the potential to outweigh myth and taboo born out of silence.

In the same vein, I remain cognizant of the insightfulness of Joseph Beuys in leading a generation of social artists and transcending the notions of traditional sculpture into making artistic productions for social awareness and economic benefit. They did this through the creation of works that involved participation, conversation, and civic action, all of which are central to this research. The notions of social sculpture are visible in the works of artists such as Shelley Sacks, particularly, through the 'Exchange Values' project that connected affluent consumers of bananas in the UK with poorer banana farmers in the Caribbean (Shelley Sacks, 2000) – and more particularly, Lilian Nabulime (L. M. Nabulime, 2007) who attempted to generate, situate and use objects and art works to address HIV/AIDS awareness and associated social concerns among women in Uganda through collective participation and conversation. The numerous experiments of sculpture projects have demonstrated that that art can facilitate the ability to question and change social situations (for instance HIV/AIDS pandemic and its related ills). In what follows, I discuss Lilian Nabulime's ground-breaking work in more detail. I explore how it demonstrates the role of sculpture as a creative tool of communication regarding HIV/AIDS prevention, awareness, and empowerment. I also explore the idea of

sculpture as a social practice, able to have positive and transformative impacts on local communities.

### 2.3.2 The social sculptures of Lilian Nabulime

Lilian Nabulime, a Ugandan educator, and artist has explored the potential for sculpture in playing a transformative role in HIV/AIDS awareness and prevention, and in transforming the gender relations that shape the dynamics of the spread of the disease. Her work is inspired by notions of art having the capacity to move beyond the spaces of galleries into an expanded field, and thus beyond the visual and into the social spheres of life (Nabulime and McEwan 2011). It explores the role of sculpture as a creative tool of communication regarding HIV/AIDS prevention, awareness, and empowerment, revealing sculpture as a social practice and how it has been able to impact on local communities. Evidence from findings in her research (L. M. Nabulime, 2007) demonstrated the power the soap sculptures (using symbolism) had in connecting with the participants (Garrido Castellano, 2018), breaking down social taboos and encouraging men and women to discuss both the disease and its prevention (*Plate 6*).

In *Plate 6*, Nabulime presents translucent soap forms with cowrie shells to symbolise femininity, currency, and traditional healing, whereas in *Plate 7*, Lilian uses beans communicate ideas about germination, life, and fertility; rotten beans suggested the sequential stages of infection, multiplication of the virus, infertility, and death. Both plates (6 and 7) provide salient evidence of the communicative nature of social sculpture and its creative process in expressing the bodily experiences of living with HIV/AIDS using simple everyday materials.

Having drawn from the tested potential of social sculpture for generating positive change in relation to public attitudes and knowledge (L. M. Nabulime, 2007) and the successful art-based interventions demonstrated by the Siyazama project in South Africa (Wells, 2012) and other art-based engagements, I now briefly present a case for the use of applied sculpture as multidisciplinary approach that is potentially capable of tackling challenges associated with HIV/AIDS and improving the livelihoods of young people through participatory actions.

### 2.3.3 A case for applied sculpture in HIV/AIDS prevention, awareness, and its potential for the empowerment of young people.

Integrating applied sculpture with social geography and social anthropology potentially brings together the researcher (sculptor) and artisans in efforts to generate economic empowerment, while also opening new pathways to dealing with HIV/AIDS challenges among young artisans in Uganda.

Distinctively, applied sculpture, also known as functional sculpture, is a branch of the art of sculpture that engages design and tactile decoration of everyday objects in order to make them aesthetically pleasing (Webster, 2014). It is a term used to distinguish from sculpture that solely produces forms for beauty and to stimulate intellect, but in practice the two often overlap. It enters the realms of social sculpture as it explores the very nature of functionality, utility value and social spaces while addressing notions of audience participation and rational art practice. In reality, applied sculpture works as a communication tool and abridges traditional sculpture as it engages the space between form and functionality, archiving ostensible ingredients of aesthetics and conceptual space as it transcends into social sculpture and social connectivity (Shelley sacks, 2000; Thompson, 2012) . Applied sculpture, like live art performance in theatrical practice, positions itself across and between the traditional sculpture and other fine arts which are purely conceived for aesthetic 2D and 3D productions, making it a hybrid practice that, like theatre, evades definition, refusing to be constrained by categorical frameworks (See *Plate 8*).

From my own experience, applied sculpture encompasses components of carpentry and general fabrication in a variety of tangible materials such as wood, metal, and glass. As we rethink the creative approaches – specifically applied sculpture – as not only a neglected field of aesthetic attraction but an avenue of knowledge dissemination, dialogue, socio-economic and cultural change as conceived by social sculptors, we attempt to transcend the visual parameters of fine arts and performing arts into the social and cultural spheres of life. This makes applied sculpture a potentially valuable tool in the fight against HIV/AIDS among young people in Uganda, specifically through its ability to evoke conversation, create dialogue and awareness about HIV/AIDS, as well as harnessing young people’s creative capacities in the world of work, particularly in the informal sector. Although it is a relatively under-researched

field, social sculpture can be engaged as a platform upon which applied sculptural practices can simultaneously be used as interdisciplinary techniques to address HIV/AIDS awareness gaps, prevention, and improving the livelihoods of young people. This research also draws on notions of performance as a socially oriented practice, designed to concurrently entertain and educate yet creating social-economic change through co-production in a fashion that can also inform the public about significant social problems such as HIV/AIDS.

The theoretical framework of this research is largely informed by previous arts-based practices, in particular social sculpture (Ermen, 2007; Heila Lotz-Sisitka, 2013; Jordan, 2013; L. Nabulime & Mcewan, 2014), photovoice (C. Wang & Burris, 1997; Wang, 1999), theatre (Semambo-Sempeebwa, 1996), and body maps using creative visual and tactile art forms to deliver HIV/AIDS awareness and prevention messages laden with symbols and metaphors to explicitly to communicate with local communities. However, I contend that most of these approaches have been less comprehensive in their reach and often times have been inaccessible to the most marginalised given the economic status of local communities, thereby paralysing their effectiveness in raising HIV/AIDS awareness messages at grassroots level. Their emphasis is placed mainly on inducing social/ behavioural change without addressing the economic aspects that continually aggravate the susceptibility of disadvantaged people to HIV infections in their local communities.

On the contrary, and in the interest of advancing applied social sculpture as an alternative participatory approach towards social and economic empowerment, I am inspired and informed by the works created and sold by Zulu women in South Africa in the Siyazama project (Wells, 2012; Wells et al., 2004). These involved the production of beaded craftworks (badges, so-called Zulu love letters, beaded dolls - *Plate 9*) and coloured wire 'imbenge' (wire baskets) containing HIV/AIDS messages (Marschall, 2004a). I borrow from such experience, in attempting to initiate and harness the creative capacities of young people forming the greater artisan community in Kampala and to improve their working experiences through collaborative vocational practices that are related to applied sculpture for HIV/AIDS awareness and socio-economic empowerment.

In summary, I wish to move beyond the overarching principles and methodologies of social sculpture into applied sculptural practices, borrowing practical elements from Nabulime's

research (L. M. Nabulime, 2007; L. Nabulime & McEwan, 2014) that translates sculptural forms into tools of communication in the lives of women living with HIV/AIDS in Uganda. I also sought to incorporate participatory actions into my approach as an empowering process, to enable people to take command and do things themselves (Chambers, 1994a; Kapoor & Jordan, 2009). Furthermore, in her study of why HIV/AIDS intervention programmes fail, an anthropological discourse about marginalised migrant miners in Kwazulu-Natal, Campbell (2003) argues that less attention was paid to the way in which the macro factors (poverty, gender inequality and global capitalism) and micro factors (individual perceptions, attitudes and instinctive behaviours leading to personal vulnerability), which shape contexts in which HIV flourishes, interact at community level. All these factors, she argued, often played a key role in restraining people from taking control over their health. She notes that;

“There is now widespread agreement that a key step in addressing the HIV epidemic is to get local people collectively to ‘take ownership’ of the problem, engaging in collective action to increase the likelihood that people will act in health enhancing ways...”

(C. Campbell, 2003, p. 3)

Her observation clearly suggests the potential need to support the sociological consensus around tackling the spread of HIV/AIDS by getting people to collectively engage in action to create space for health-enabling behaviours in their own contexts. However, Campbell underplays the significance and desirability of economic transformation among marginalised informal communities, which is vital in enabling social change in capitalistic developing contexts. In attempting to address this gap, this study adopted a participatory action path to engage with marginalized young artisans in such a way that permitted them to challenge the realities surrounding their social and economic lives in the context of HIV/AIDS. In the same vein, Chambers (1994b, p. 1) observes that:

"Participation" has three uses and meanings: cosmetic labelling, to look good, co-opting practice, to secure local action and resources; and empowering process, to enable people to take command and do things themselves. Its new popularity is part of changes in development rhetoric, thinking and practice. These have been shifting from a standardised, top-down paradigm of things towards a diversified, bottom-up paradigm of people. This implies a transfer of power from "uppers" - people, institutions and disciplines which have been dominant, to "lowers" - people, institutions and disciplines which have been subordinate. Participatory work"

Additionally, he continues, the rhetoric of participatory development widely favours putting people first – and in the case of this participatory research, putting marginalized young artisans in industrial locations of peri-urban Kampala, first.

## 2.4 YOUTH EMPOWERMENT AND SOCIAL TRANSFORMATION

According to Jennings (2012), empowerment is:

“a multi-level construct consisting of practical approaches and applications, social action processes, and individual and collective outcomes. In the broadest sense, empowerment refers to individuals, families, organizations, and communities gaining control and mastery, within the social, economic, and political contexts of their lives, in order to improve equity and quality of life. The concept of empowerment has been addressed at both theoretical and practice levels in specific reference to youth.”

(Jennings et al., 2012, p. 33)

Empowerment can also be seen as:

“A construct that links individual strengths and competencies, natural helping systems, and proactive behaviours to matters of social policy and social change. It is thought to be a process by which individuals gain mastery or control over their own lives and democratic participation in the life of their community”

(Zimmerman & Rappaport, 1988, p. 726)

Emphasising that empowerment is a multilevel construct that may be applied to organizations, communities, and social policies, *psychological* empowerment is the expression of this construct at the level of individual persons. Empowerment can thus be understood as psychosocial and/or economic.

### 2.4.1 Psychological and social empowerment

Psychological and social empowerment may develop more readily from activities aimed at influencing political decision making, but involvement with others, increased responsibility, and organizational problem solving are also expected to contribute to one's sense of empowerment. In this research, citizen participation is broadly defined as involvement in any organized activity in which the individual participates without pay to achieve a common goal. As illustrated in this research, this may include involvement in community-based activities for health concerns such as immunisation or epidemic prevention programmes at different levels of local government, voluntary organizations, mutual-help groups, and community service

activities. A broader definition captures the possibility that people find multiple avenues to engage with their community. My attempt here was to establish a link between participatory art with young people in marginalised settings in collaboration with community-based organizations to create a sense of empowerment, rather than to specify those settings that may best contribute to the development of empowerment. Ultimately it was envisaged that once the link is demonstrated, future work may proceed to examine the specific activities and organizational types that are most likely to lead to empowerment. Research from several domains suggests that participation may be an important mechanism for the development of psychological empowerment because participants can gain experience organizing people, identifying local resources, and developing strategies for achieving goals. For example, the involvement with a community-based organization called LUCOHECO in Lungujja helped young HIV participants to feel more competent and less alienated. This enabled sustained interest and increased responsibility and perceived control of the creative activities, which later translated into regular attendance and freedom to interact with the neighbours and residents. This was indicative of growing enthusiasm, liveliness, and more active and more alert residents (Langer, E. J., & Rodin, 1976)

As an applied sculptor, visual artist, and educator, I considered using applied sculpture to work collaboratively with young people to enable them to become agents in their own lives and in their communities. In other words, I attempt to share, learn, and facilitate the knowledge co-production process with young people as an artist in a democracy way. Many of the people who consented to participate in the creativity workshops have a poor academic record, as well as personal problems and significantly lacked financial support. They are often entangled with informality, exclusionary tendencies, and multiple social injustices – gender-based violence, rape, sexual assault, sexist male ideals, and so on – that shape the landscape in which HIV/AIDS flourishes. My challenge was to support young artisans to navigate the harsh realities of living and working in highly informal conditions in anticipation that this might improve livelihoods, and to facilitate their active dreaming so they can shape a better future for themselves. Working with these young people and fostering collaboration is an important part of defining creative process and, more so, elevating individual creative voices for the benefit of boosting confidence and empowerment that enables consciousness-raising and, ultimately, the engineering of positive change at the community level (Berman, 2013, 2018; Moxley, 2013).



This, in some way, positions me as an activist, and a semi-insider whose role is concerned with the plight of vulnerable young people and helping them realise their full potential in dealing with the effects of HIV/AIDS epidemic in informal spaces. Like Berman (2013, p. 8),

“By advocating for the artist as activist, I am not arguing for the social content of an artist's work but, rather, wish to consider how art can enhance civic agency”.

I strongly believe that creative engagement is vital for self-actualization - a critical dimension of freedom and democracy. It requires constant exploration of boundaries and every day experiences of chaos and HIV threat among young people in marginalised peri-urban spaces. Collaborative engagement through applied artistic practice as a pedagogic tool for disadvantaged young craftsmen has been helpful for instilling a sense of identity, confidence, and purpose. Several studies in Uganda and sub-Saharan Africa demonstrate this: for example, the *Siyazama* (Zulu for "we are trying") Project - (Wells, 2016), uses traditional and contemporary artistic expression to document the realities of HIV/AIDS and to open lines of communication about the virus (Wells, 2012, 2016), and body mapping exercises, later transformed in to expressive painting among women infected with HIV/AIDS in South Africa (Solomon, 2007; Wienand, 2016). Clearly, these projects attest to artists having potential to play an important role in maintaining the health of a society in transition.

#### **2.4.2 Economic empowerment of young people in peri-urban spaces**

It has been argued that women's economic vulnerability and dependence on men increases their vulnerability to HIV by constraining their ability to negotiate the conditions, including sexual abstinence, condom use and multiple partnerships, which shape their risk of infection. Worldwide, gender and poverty are two of the most important influences on health. This is particularly true in sub-Saharan Africa (SSA), the poorest region of the world, and the region most affected by HIV/AIDS, a highly gender-discriminatory epidemic (Sserwadda et al., 2010). In the face of escalating infection rates among young people, and particularly young women and adolescent girls, many have pointed to the potential importance of economic empowerment strategies for better HIV prevention responses. A few notable interventions by NGOs and government to stem the social economic impact of HIV/AIDS to local communities particularly among the youth were initiated. These include national programmes initiated by government to support the youth in general. For example, the National youth council 2020

(NYC), the presidential youth empowerment fund and the Youth livelihood programme under the Ministry of Gender, Labour, and social Development. Whereas many of such initiative are established with the intention of supporting the youth in the country, their mandate appears to focus on young people in general (Targeting social-economic areas - providing revolving funds to support youth groups in areas such as trade, industry, and vocational working) but not specifically to those infected and affected by HIV/AIDS. The National youth council, in particular, was established by the act of parliament as an umbrella organisation of all the youth in Uganda between the ages of 18 to 30 years mainly to organise, mobilize and engage the youth in development activities as well as protect them from any kind of manipulations (Also see, National youth council act, CAP 319 as amended 2020). Additionally, several other grassroots initiatives by some individuals and NGOS have attempted to tackle youth challenges including addressing key areas related to stemming HIV/AIDS among the youth. They include Siyazama Uganda project, Uganda Network of Young People Living with HIV (UNYPA), street lights Uganda and several others.

In particular, the siyazama model in Uganda (2019) was initiated by Kate Well in collaboration with Makerere University, School of Fine art in which they supported local HIV affected communities within the framework of other craft projects to improve their livelihood prospects while tackling stigma and other ills associated with the epidemic. Indeed, the project aimed to strengthen and enhance creative capacity together with knowledge on HIV/AIDS and other health complexities amongst the participating craftswomen from selected groups in Uganda sharing experiences gained within the Siyazama-rural crafts and HIV/AIDS project in South Africa. The project was conducted in collaboration with School of Design, Northumbria University, UK, School of Arts, Middlesex University, UK, Dept. Graphic Design, Durban University of Technology, South Africa as international partners. The Local Partners included Kalisizo Post-Test Club in Rakai District (Southern Uganda), Nalumunye Balikyewunya Women's Group, Wakiso District (Central Uganda), Learn and Do (LAD)–Group (Mildmay Centre), Wakiso District (Central Uganda) and the Margaret Trowell School of Industrial & Fine Arts (MTSIFA), Makerere University, Uganda (Sserunkuuma, 2019). The project targeted selected actors in the craft industry (cultural or creative industries, also known as Jua Kali) from both rural and urban spaces who use the traditional and indigenous technologies especially by use of the hands and simple tools. It involved HIV infected participants regardless of their age group.

Despite such initiatives, there still remain huge gap in the engagement of young people through participatory approaches aimed at reducing the social-economic impact of the epidemic particularly in peri-urban spaces in Uganda.

#### **2.4.2.1 Understanding the links between poverty and vulnerability to HIV infection**

Numerous cohort studies in sub-Saharan Africa, particularly in marginalised settings found that complacent tendencies such as reduced condom use among men from impoverished households, the changing biomedical landscape for HIV treatment - through ARVs and pre-exposure prophylaxis (PrEP), and poverty were the leading factors that allowed HIV to flourish in most informal settlement across Africa (Evans, 2015; Gysels et al., 2001; Michielsen et al., 2012). In Botswana and Swaziland, food insufficiency among women was found to be significantly associated with inconsistent condom use with a non-primary partner, exchange of sex for resources, intergenerational sexual relationships, and lack of control in sexual relationships. For men, food insufficiency was associated with only a 14% increase in the odds of reporting unprotected sex, and was not associated with other risky sexual behaviours (J. Kim et al., 2008; J. C. Kim & Watts, 2005). In Uganda, the links between poverty and vulnerability to HIV infection are thus clearly multidimensional and not easily explained by the more straightforward associations characteristically tested through epidemiological studies (Logie et al., 2020; D. Mitchell, 2003; Opio et al., 2008). It is increasingly apparent that other factors, including gender inequalities, condition the manner and circumstances in which poverty interacts with the risk of infection. Joseph & Joseph (2010) and Young (2019) have provided empirical evidence indicating that the world is increasingly becoming one characterised by informality and poverty and that a response to improving the livelihoods of residents in the developing world is especially critical.

Analogous to these circumstances are the rising rates of HIV infections among young people in marginalised peri-urban spaces in Kampala as the situation is linked to the high levels poverty, unemployment, gender-based violence, and informality. However, there are possibilities of tackling poverty, gender injustices, and every-day exploitative experiences at work through skills development and training, artistic production mobilization and co-production using participatory approaches, which are explored in the next Chapter.

## 2.5 CONCLUSION

This thesis situates its arguments about the possibilities of using participatory research methods in conjunction with sculptural practices alongside other similar art-based approaches to attempt to engage young artisans in building HIV/AIDS awareness and knowledge about prevention. It attempts to do this while harnessing the creative potential of individuals with the intention of improving their livelihoods.

Building on the synergies and platforms initiated by sculptors such as Nabulime concerned with raising awareness about HIV/AIDS in Uganda, as with body mapping and photovoice, access into local communities requires prescriptive understanding of the social-cultural context in which HIV/AIDS messages can be decoded, especially in communities where masculinity, poverty, taboos about sexuality and stigmatisation are deeply ingrained in the social fabric of life. Without ignoring the possibilities and present challenges formed around art-based research practices, I utilized creative sculptural approaches in engagements that stimulated and sustained participation of the young artisans in peri-urban spaces. Through participatory action strategies, the approach provided leisure and learning experiences at the same time reminiscent to theatre and performance (Low, 2010; Sánchez-Camus, 2011b). The theoretical framework of this research is largely informed by previous arts-based practices such as photovoice, theatre (Semambo-Sempeebwa, 1996), social sculpture (L. Nabulime & McEwan, 2011), and body maps which used creative visual and tactile art forms to deliver HIV/AIDS awareness and prevention messages laden with symbols and metaphors explicitly curtailed to support local communities. However, I argue that some of these approaches, particularly photovoice and social sculpture, have been less effective and oftentimes inaccessible with the poorest and most precarious groups (including young people in informal areas of the city) thereby inhibiting their effectiveness in raising HIV/AIDS awareness messages among populations at greatest risk. To counter this, I attempted to initiate and harness the creative capacities of young people forming the greater artisan community in Kampala and to improve their working experiences through collaborative vocational practices that are related to applied sculpture for HIV/AIDS awareness and empowerment.

The research informing this thesis sought to extend the overarching principles and methodologies of social sculpture into applied sculptural practices, borrowing practical

elements from previous research (L. Nabulime & McEwan, 2014; L. Nabulime & McEwan, 2011) into sculptural forms as a tool of communication in the lives of women living with HIV/AIDS in Uganda. It also sought to incorporate the doctrines of participatory action research as an empowering process enabling people to take command and do things themselves (Chambers, 1994a; Kapoor & Jordan, 2009). In this research, I contend that the participatory approach can provide an opportunity for young artisans who are usually excluded from most government development programmes to exercise their right to healthy lives, social awareness, and economic empowerment. Chambers (1994) has argued that its new popularity is part of changes in development rhetoric, thinking and practice which has been shifting from a standardised, top-down paradigm of things towards a diversified, bottom-up paradigm of people as it implies a transfer of power from "uppers" – people, institutions and disciplines which have been dominant, to "lowers" – people, institutions and disciplines which have been subordinate (Peter Oakley, 1991).

The next chapter explores the methodology, methods and mitigative strategies employed to interrogate the life experiences of young people infected with and affected by HIV/AIDS in the peri-urban geographies of Kampala.

## CHAPTER THREE

### METHODOLOGY

#### 3.0 INTRODUCTION

Art-based participatory research can be described as a process of collective engagements designed to address common community concerns such health disparities, social injustices and economic precarities and so on. It is a diverse field of study and often represented by many related terms, including community arts, arts in health, socially-engaged arts, applied arts and so on, whose variations in definition is often result of location and context (Walls et al 2016). More often than not, art-based approaches give rise to grounded, evidence-based findings and co-authored observations, arguments, thought and insights from local collaborations that seek answers to communal challenges such as health concerns and biased social stereotypes. In this research project, I sought to engage the use of applied sculpture as participatory art to build upon proven visual art-based approaches, and to extend previous research in innovative ways by creating a nexus between social sciences and applied sculpture in a developing country context.

This study contributes to the growing evidence that art-oriented social practices can help in achieving effective communication and engagement of the public (White, 2009, p. 85), in this case in building HIV/AIDS awareness and social-economic empowerment among young people in marginalised peri-urban settings. It argues that the integration of ethnographic methods with applied sculpture as a social practice opens potentially new ground for tackling societal challenges related to HIV awareness and prevention. Specifically, it proposes that these methods offer potential for tackling social and economic barriers linked to declining HIV/AIDS awareness and increasing prevalence of HIV/AIDS among vulnerable young people in marginalized informal communities, in this case the peri-urban industrial spaces of Kampala, Uganda.

The main fieldwork sites at Bwaise, Ndeeba and Katwe in Kampala City provided opportunities for dealing with the complex realities of HIV/AIDS which necessitate dialogue - “the art of thinking together and a living experience of inquiry within and between people” (Blaak & Van

Der Linden, 2016, pg. 6). As I explain in detail subsequently, the entry point to these informal, peri-urban industrial spaces was establishing primary contacts with known persons (carpenters, sanders, machinists, and welders) in the artisan community with whom I have worked previously in executing client-based projects in the selected artisan areas. This was mainly during the period between 2009 and 2017 when I involved particular groups of skilled artisans in collaborative projects, including the construction of museum casements and stalls for cultural exhibits in Igongo Cultural Museum in Biharwe, south-western Uganda (2009 - 2014) and television studio-set designing and construction at NTV Uganda, Serena Hotel, Kampala (2016), among others. This research was an opportunity to re-unite with some of these artisans to explore the possibilities of arts-based approaches in HIV/AIDS awareness and prevention among young people in Uganda. This prior contact enabled me to quickly build rapport and a network of 'research friends.' This was developed further through direct involvement in day to day working whilst expanding engagements with the snowballing effect. This eventually allowed open conversations and dialogue about personal life, society, health, HIV/AIDS and working experiences with young people in those informal peri-urban settings. It guided my research activities towards what has been described by several development practitioners as building towards 'local' participation and empowerment (Jupp, 2007; Mohan & Stokke, 2000; Banks et al, 2013) in grassroots communities. This was not without associated challenges, as discussed subsequently, including difficulties of interfacing with inadequately served populations (ISPs) in developing contexts.

### **3.0.1 Inclusion and exclusion criteria**

Young people and adolescents (ISPs) aged 15–24 years living and working in the artisan communities of marginalized industrial areas in the peri-urban precincts of Kampala were eligible for participation. Young people who were simply living in the townships without any connection of working within the industrial confines were excluded because most key questions focused on young people working in industrial space as artisans or those working in artisan-related auxiliary jobs within the industrial settings. I used a screening phrase on the consent form that indicated whether the potential respondents (ISPs) were living and/or working in the industrial setting or not.

Specifically, in this study, I define ISPs as young people and adolescents (15-24) living in potentially marginalised situations yet, broadly used to include (i) young people (mainly artisans) affected by and infected with HIV/AIDS – often challenged by inadequate information, related to sexual health, counselling support, treatment, etc. (ii) migrant workers (iii) uneducated and poorly-trained casual workers in industrial spaces. I use the term young people as a collective description of the above categories of ISPs. Surprisingly, findings from the social engagements and ethnographies with artisan communities in marginalized industrial spaces in this study, provide evidence that points toward shifts in demographic categorisation of young people beyond the statistical boundaries of 15-24 years to well above age of 35 in the informal contexts. Incidentally, the United Nation’s (UN) definition of youth states;

“There is no universally agreed international definition of the youth age group. For statistical purposes however, the UN- without prejudice to any other member states- defines ‘youth’ as those persons between the ages of 15-25 years” (<https://www.un.org/en/global-issues/youth>)

However, Uganda’s youth policy defines youth as 15-30 ([https://www.upfya.or.ug/wp-content/files/nationalyouth\\_policypopularversion.pdf](https://www.upfya.or.ug/wp-content/files/nationalyouth_policypopularversion.pdf)) and as such my definition in this participatory projects accords more with the Ugandan government’s definition than that of the UN. Many of the participants who consented to collaborate with me in all the study sites in Kampala insisted that they were still youths even beyond 30 years of age. They argued that in their workspaces young people between 20 and 36 years were all benefiting from government youth livelihood programmes, and this qualified them to be called young people. The self-categorisation of youths above 25 to 35 years as young people was fundamentally disorienting as the initial plan was to work with subjects between 15 and 24 years. Nonetheless, the process of identifying and recruiting participants was done with reflexive flexibility with several potential participants of 30+ years consenting to take part in the study. This somehow dictated initial interactions with their peers which necessitated efforts to reach a younger demographic level as the research progressed.

The overarching focus of using applied sculpture as an all-inclusive, participatory approach for HIV/AIDS prevention and empowerment among young people was twofold. First, I set out to empower young artisans/people to learn about HIV prevention and build their capacity to



contribute towards HIV prevention. Participating in art and creativity workshops was designed to help them build on their strengths, utilize local resources, and prioritize existing social networks/relationships to address issues concerning HIV/AIDS prevention in their community. This was a form of “community-based research” that sought to:

“identify and build on strengths, resources, and relationships that exist within communities of identity to address their communal health concerns”

(Israel et al. 1998, p. 179)

Secondly, I envisioned building and sustaining conversations and sharing stories mainly with young people (young artisans), as well as with community members and society at large, to demonstrate the impact of applied sculpture as an all-inclusive approach. This aimed to explore the potential for integrating cultural responsiveness in promoting HIV/AIDS prevention and awareness (through interventions/activities) whilst improving wellbeing and livelihoods (through economic empowerment). With the understanding of the challenges of working in informal spaces affected by HIV/AIDS and attendant problems among young artisans in marginalized communities (ISPs) that drive the need for this research, I attempt to highlight and address key barriers to HIV/AIDS prevention among young artisans in Uganda. Therefore, I framed this participatory project’s methodology and methods within the perspectives of public health, social justice, and economic empowerment, as I discuss subsequently.

Thus, this chapter outlines in more detail the ethnographic methods employed in the research and provides a detailed account of the fieldwork. It begins with an account of the semi-structured interviews that were carried out with different group of participants during interactive session and co-production process, the rationale behind this choice of method and its implementation in the informal spaces. The subsequent section explores the choice of participatory methods, first, by focusing on the gatekeeping and recruitment process for participants/action groups and second, by explaining the interactive processes and field note-taking experiences. Following this, the subsequent part of the chapter explores the co-production process that translated into the creation of applied objects for HIV/AIDS awareness and empowerment among young people. It elucidates the ethical concerns arising from the research methodology and how these were mitigated. Finally, the chapter considers the

challenges and limitations encountered, particularly at the time of Covid-19 outbreak during the research process.

### 3.1 FIELDWORK OVERVIEW

The participatory research was conducted mainly in three industrial locations in Kampala city, namely Bwaise, Katwe and Ndeeba, which are peri-urban townships located along the main highways leaving the city centre (See *Plate 10*). These industrial areas are characterised by congested workshop spaces and dilapidated shanty structures for local residents, artisans, and the larger business fraternity. Some of these informal structures also double as dwelling places at night and workshops or business points in the daylight. Today, the growing population<sup>13</sup> means that families in these zones have enlarged, ethnic and tribal differences are more glaring due to the diversity of immigrants, and consequently cultural/social conflicts and incompatibilities have become the norm (Wyrod, 2008). The situation is worsened by high and increasing prevalence rates of HIV/AIDS, with little or no deliberate state intervention and high levels of complacency putting the lives of many young artisans at high risk (Nakitende, 2015; Ortega, 2013).

In those industrial locations, I engaged with marginalised young artisans for more than 8 months of ethnographic study, built working relationship with them and eventually created opportunities that (a) helped develop and harness their creative talents through co-producing works which were informed and inspired by their personal and every day experiences, stories and social narratives, (b) enabled identification, articulation and sharing of knowledge about the economic and cultural barriers that fuel the spread of HIV/AIDS within their communities. This necessitated testing research tools and initiating contact for the main fieldwork through a pilot study in 2019. Thus, a two-month pilot (July – August 2019) was conducted in one of these sites (Bwaise industrial area) to familiarize myself with the geographical and social contexts of informal spaces for the benefit of research project. The main fieldwork was scheduled to take place between December 2019 and November 2020. However, due to the Covid-19 outbreak in March 2020, my research activities were severely interrupted for 4 months (between April

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<sup>13</sup> According to the chairman, Katwe industrial area, Buliggwanga LC1 (interview dated 15<sup>th</sup> August 2020), many people, young and old, travel or migrate from the neighbouring areas, townships and villages looking for casual jobs in the industrial spaces every day, which accounts for the high populations in these industrial areas

and August 2020). The state-led restrictions, which included a total ban on public and private transport and prohibition of all forms of gatherings beyond 10 people, left me confined at home in Lungujja, Kyobe Zone (a residential neighbourhood about 4km from Kampala city centre). The methodology was, therefore, adapted to make Lungujja the fourth study location for my research. The fieldwork took place in 3 phases (i) Pre-Covid phase (December 2019– March 2020) (ii) Lockdown phase with limited interactivity due to Covid restrictions (April – July 2020) (iii) Post-lockdown phase which marked the official resumption of research in the 3 industrial locations (August – December 2020). The three-phased participatory research thus, lasted one year from December 2010 to December 2020 as illustrated in Table 1.

Date	Location (site)	Activity
<b>Pre-lockdown Phase</b>  July – August 2019	Bwaise, Katwe & Ndeeba (Kampala)	<ul style="list-style-type: none"> <li>- Pilot study and contacting TASO ethic review body (TASOREC)</li> <li>- Meeting with NGEN+ officials, TASO and AIDS Information Centre.</li> </ul>
December 2019	Bwaise III, Katwe and Ndeeba industrial areas, Kampala	<ul style="list-style-type: none"> <li>- Meeting with Local council (LCs), Preparatory meeting with artisan leaders (SACCOs), individual artisans (primary contacts)</li> <li>- Participatory observation within artisan spaces</li> <li>- Face to face (unstructured) interviews with artisans</li> <li>- Recruitment of participants for action groups</li> </ul>
January – March 2020	Arua town and Bwaise industrial area	<ul style="list-style-type: none"> <li>- Interactive participation and participant observation in workshops</li> <li>- Interviews with IDI-Academy officials on the HIV/AIDS travelling exhibition team), artisans in workshops and non-artisans in both areas.</li> </ul>
<b>lock down Phase</b>		<ul style="list-style-type: none"> <li>- Meeting with LUCOHECO and other NGO officials, local councils (LCs),</li> </ul>

April – July 2020	Lungujja, Kitunzi, Kosovo, Kyobe and Wakaliga Zones, Kampala	<p>Village health Teams (VHTS), local carpenters and Local police (E.g., see <b>Table 5</b>)</p> <ul style="list-style-type: none"> <li>- Interviews with LUCOHECO executive, VHTs, division Mayor and some youth</li> <li>- Door to door health surveys (HIV/AIDS/Covid-19) with VHTS</li> <li>- Art and creativity workshops with young people (Infected with and affected by HIV)</li> </ul>
<b>Post-lockdown Phase</b> August – December 2020	Katwe industrial area and Ndeeba industrial area,	<ul style="list-style-type: none"> <li>- Interactive participation and participant observation.</li> <li>- Interviews with artisans and non-artisans</li> <li>- Co-production of applied objects</li> </ul>
November-December 2020	Makerere University, Kampala	<ul style="list-style-type: none"> <li>- Interviews with Mulago TASO top management and staff, AIDS activists, Academicians, HIV advocates, UNPYA and ICWEA field officials and Journalists</li> </ul>
January – March 2021	Makerere University, Mulago and Ndeeba, Kampala	<ul style="list-style-type: none"> <li>- Research dissemination events/ exhibitions of co-produced HIV/AIDS prevention artworks</li> <li>- Interviews with attendees, Community-based organisations (e.g., NGEN+, TASO, etc.), Journalists, HIV activists,</li> </ul>

Table 1: Fieldwork schedule

### 3.2 INTERVIEWS

“Talking to people is an excellent way of gathering information. Sometimes in our everyday lives.....”

(Longhurst, 2016, p. 143)

There are three types of interview in qualitative research: structured, semi-structured and unstructured. Whereas semi-structured interviews are a qualitative data collection strategy in which the researcher asks informants a series of predetermined but open-ended questions, structured ones also known as formal interviews, usually follow a pre-set list of questions which are often standardized across interviewees. In the case of informal settings where literacy rates are low and high levels of stigma around HIV/AIDS exist, unstructured discussions provided me and interviewees with the opportunity to take the discussion at full length and in whichever direction they chose, without strict conformity to the pre-set questions (Horton, Macve, & Struyven, 2004; Raworth, et al. 2012; Limb & Dwyer, 2001). While I had a list of pre-set question and an observation list during the interactive sessions and all participatory situations, I deemed it necessary to allow the interviewees to bring out their own ideas and thoughts, providing me with the opportunity:

“To understand the reasons why people, act in particular ways, by exploring participants’ perceptions, experiences and attitudes”

(Long, 2001, p. 219)

Similarly, as Valentine (2005, p. 111) argues:

“The advantage of this approach is that it is sensitive and people-centred, allowing the interviewees to construct their own accounts of their experiences, describing, and explaining their lives in their own words. This sort of conversation offers the chance for the researcher and the interviewee to have a far more wide-ranging discussion than a questionnaire would allow.”

In exploring the complex social-economic factors that have shaped the lives, attitudes, and behaviours of young people in informal spaces, semi-structured interviews provided an extensive baseline for data collection.

“As a “versatile means of collection data” it enables the development of a “deeper understanding of the research questions by exploring the contradictions within... participant’s accounts”

(Fylan, 2005, p. 67)

### 3.2.1 The pilot study conversations

The pilot study allowed me to familiarize myself with the peri-urban settings for the main research and identify potential participants and conducive spaces for participatory workshops. I spent over 3 weeks visiting and volunteering to work with groups of artisans in different points of each of the three industrial areas. During this time, I conducted several informal face-to-face interviews and participant observation with 10 young men between the age of 18 and 26 years but relying largely on casual conversations and interactive direct engagement in their artisanal activities to gather preliminary findings. I took photographs of spaces, and recorded the conversations with different artisan groups, especially carpenters and sanders. These artisans were casually employed, working as wood joiners, finishers, and sanders in compact workshop spaces and between corridors of dilapidated structures producing wooden furniture such as beds, chairs, and tables mainly in Bwaise industrial area. These processes helped me build the necessary rapport with groups of young artisans in anticipation of taking part in the participatory workshops during the main field work. They also helped identify shortcomings of some of the proposed methods. For example, formal consent forms were deemed inappropriate because most of the artisans I interacted with preferred verbal consent. I already had a bond of trust and free association was easy because I was known to them through previous work with them on commissioned projects at Makerere University. Formal consent forms risked fundamentally altering the nature of my relationship with participants by adding a layer of bureaucracy that was unfamiliar to them. Through verbal means I was better able to explain fully the nature of their participation, the ethical protocols of the project, issues of consent and anonymity, and their ability to withdraw at any time, and in ways that did not jeopardise the bonds of trust and familiarity we had already created.

The pilot also established that selected study sites held considerable potential for action research and positive artistic intervention that sought to facilitate genuine and open conversations whilst identifying and understanding conducive spaces for interviews, group discussions and co-production sessions with young artisans during fieldwork. This necessitated

the conduction of trial face to face interviews<sup>14</sup> in the form of semi-structured interviews with random actors in the artisan community, especially workshop owners, local leaders, and other potential contacts for interactive engagements in order to test the validity and reliability of the interview tools. As Barriball & While (1994, p. 328) cautions;

“In order to attain credibility, the research process must be both valid and reliable which....is a major challenge when a project is based on a semi-structured interview.”

Although this research did not rely solely on semi-structured interviews to interrogate the informal spaces, young people lives and HIV/AIDS, it was deemed crucial to ensure that they were tested for reliability and validity. This was meant to facilitate the correlation of interviews findings with those of other data collection methods employed during the interrogation process of the conditions and HIV risk factors that shaped the young people’s lives.

After the pilot research, I remained in contact with the TASO research and ethics co-ordinator, and NGEN+ (my official research partner with Durham University)<sup>15</sup> in Uganda. During the emails and phone call exchanges, I discussed my research progress with them, asked their opinions and incorporated various ideas in the thesis proposal. While the preliminary participatory engagements with the artisan community and local HIV support organisations during the pilot study shaped and augmented the methods to be used in the main fieldwork, the views from these individual contacts positively influenced my research questions and also the research design. Upon arrival in Uganda in December 2019, preparatory meetings were held with artisan leaders and research co-ordinators. As already mentioned, the same were conducted with the contacts I established during the pilot study in July 2019 and those I knew through my previous private projects in wood and metal fabrication at Makerere University in Uganda, where I was working as a course instructor in applied sculpture from 2006 to 2018.

I held review meetings with two NGEN+ co-ordinators to further explain the status of my research and confirm commencement of the fieldwork, and later held meetings with key

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<sup>14</sup> Trial interviews were conducted to test the validity and reliability of the instrument (nature, structure, and value of questions) in interrogating the local spaces and experiences of marginalized young in the context of HIV/AIDS people based on the set research objectives

<sup>15</sup> The AIDS Support Organisation (TASO) and the National guidance and Empowerment Network for People Living with HIV/AIDS in Uganda (NGEN+) were the main non-governmental (NGO) HIV support organisations that were involved in ethics protocol approvals and consultative work during the main field work in Kampala, with the latter responsible for granting the ethics review for human-related research in Uganda.

artisan leaders who put me in contact with local council (LC1) chiefs in the different research sites. Following on the previous meetings I held with them during the pilot, I explained my imminent fieldwork activities, sought their support and opinions, and discussed the research content, design, and its feasibility.

Entity	Divisions	Location/Area	No. of interviews	Total No.
Young People living with HIV/AIDS (PLHIV)	Rubaga Division	Lungujja, (Kitunzi/Kosovo)	30	35
		Ndeeba (Betania/Railway zone)	5	
Young people with unknown HIV status	Arua municipal Division	Green Valley industrial area (Olii Cell LC1)	8	83
	Makindye Division	Katwe industrial area (Buliggwanga LCI)	20	
	Kawempe Division	Bwaise Industrial area	30	
	Rubaga Division	Ndeeba (Betania/Railway zone)	25	
Artisan associations	Kawempe Division	Bwaise Furniture Makers' SACCO <sup>16</sup>	2	4
	Rubaga Division	Ndeeba 'Tukolelewamu' carpenter's group	2	
	Central Division	TASO, Uganda	4	
	Kawempe Division	ICWEA <sup>17</sup>	1	

<sup>16</sup>The Bwaise Furniture makers' (SACCO)-Savings and Credit Co-operatives is community membership-based financial institution that was established and owned by artisans working and living in Bwaise industrial area, Kawempe Division for the promotion of their social and economic interests.

<sup>17</sup> International Community of Women a Living with HIV/AIDS, East Africa (ICWEA) was represented by their field official who was working as an advocate for sexual reproductive health, HIV/AIDS and adolescents in Kampala and Wakiso districts in Uganda.



Non-governmental Organisations (NGO and CBOS)	Rubaga Division	AIDS Information Centre (AIC)	2	15
		LUCOHECO <sup>18</sup>	2	
		Village Health Teams (VHTs) <sup>19</sup>	4	
	NGEN+	2		
Authorities	All divisions	LC1 Village Chairpersons	4	4
<b>TOTAL NUMBER OF INTERVIEWS</b>			<b>141</b>	

Table 2: Interviews held in the different peri-urban locations of Kampala

Initially, I held interviews with some members of non-governmental organisations/community-based organisations (TASO, IDI, AIC, NGEN+ and ICWEA - See **Table 2**) aimed at exploring their interventions with PLHIV in Kampala. These interviews explored for whom these interventions are designed, the rationale behind them, the impact of these interventions from those HIV organisations' point of view, their opinions about the lived experiences of people living with HIV/AIDS in Kampala, and their understanding of the vulnerability of young people to HIV/AIDS in disadvantaged communities around Kampala. The interviews aimed at answering Research Questions 1<sup>20</sup> and 3<sup>21</sup> concerning mainly the roles of HIV Support organisations in HIV/AIDS intervention programming, support, and wellbeing of young people especially in marginalized grassroot communities. The extent to which young people have been involved in these HIV

<sup>18</sup> LUCOHECO- Lungujja Community-Based Health care Organisation is a Community-based organisation located in Lungujja Kitunzi whose primary mission is empowering communities to participate more effectively in HIV prevention and accessing treatment, care and support for People living with HIV/AIDS.

<sup>19</sup> Village health teams (VHTs) are also known as Community health workers (CHWs).

<sup>20</sup> Research Question 1: How can engaging with, sharing, and learning from every day young people/artisans' experiences and practices inform a better understanding of the everyday challenges facing young people in the context of the HIV/AIDS pandemic?

<sup>21</sup> Research Question 2: How might applied sculptural practices inform policy makers and providers of health information, and advance new approaches to improve HIV/AIDS intervention programming, awareness, prevention, and empowerment among young people/artisans in Uganda?

interventional initiatives, and livelihood projects in the informal sector were some of the keystones that shaped the nature and scope of interview questions conducted<sup>22</sup>.

On the 26<sup>th</sup> of February 2020 I had the opportunity to travel to Arua in Northern Uganda as a volunteer on the exhibition installation support team for the ‘traveling’ exhibition for HIV/AIDS (Basudde, 2018), organized by the Institute of Infectious Diseases (IDI), Academy for Health Innovations, Makerere University<sup>23</sup>. The purpose of volunteering on this HIV exhibition event was to participate in the installation process whilst interacting and conducting interviews with the organisers and attendees of the HIV exhibition in a rural context. I was also able to identify and collaborate with selected local artisans (carpenters and sanders)<sup>24</sup> from Oliy Cell LC 1 in Arua municipality’s industrial area during the installation of HIV exhibits at the Cafeteria Hall, Arua Catholic parish. The face-to-face interviews (unstructured) and conversations with the organisers and about 8 artisans selected from the Green valley industrial area<sup>25</sup> provided a comparative understanding of the factors responsible for increasing HIV transmissions and HIV risk among young folks around rural townships in urban contexts.

In Kampala, the interviews at grassroot level were conducted with help of Community Health Workers/ Village Health Teams (CHWs/VHTs) and local artisan leaders in Lungujja and the peri-urban industrial areas of Kampala respectively. Unfortunately, two artisan leaders in Ndeeba and Katwe industrial areas failed to respond to repeated contacts to participate in mobilizing

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<sup>22</sup> See Appendix D for sample interview templates/guides.

<sup>23</sup> The IDI Academy organised a one-month ‘Travelling’ HIV exhibition in Arua town. The overall objective was to continue with the documentation of the history of HIV in Uganda through archived materials. Following a successful inaugural HIV Exhibition at the Uganda Museum exhibition on 28th November 2018 by the Embassy of Ireland, the Academy for Health innovations under The Infectious Diseases Institute (IDI) won a grant from Wellcome Trust to take this exhibition to six different sites in Uganda, namely; Arua, Hoima, Rakai, Moroto, Wakiso and Kampala. The exhibition showcased Information, Education and Communication (IEC) materials from different organisations spanning from the last 30 years on the HIV/AIDS response in Uganda. These include photographs, videos, newspaper articles, and loaned artworks.

<sup>24</sup> Having realized that most people in the area were speaking Lugbara – the ethnic language of West Nile – particularly on streets dominated by informal activities such as hawking, street vending and Bodaboda riders, I resorted to using English. I later engaged a local bodaboda rider who offered to help me with translations (for a small token) during interactive engagements with artisans. My translator also took me to a nearby carpentry workshop where he had some friends doing woodwork at the green valley industrial zone.

<sup>25</sup> Green valley industrial zone is one of the biggest industrial zones in Arua town with over 18 workshop structures and several makeshift carpentry units. Here, I had an opportunity to interact with several young artisans for 3 days as I sought technical help while constructing pedestals for some of the loaned sculptures meant for the HIV exhibition (**Field diary, 27<sup>th</sup> February 2020**).

artisans to engage in the project activities. Most of the interviews were held in workshop spaces for the artisans and in homes for those artisans who lived in the neighbourhoods of selected study areas<sup>26</sup>. It is important to note, however, that most of the interviews with participants in the artisan community (industrial areas) were held after the lockdown period when the government had eased the restrictive stay-home measures in August 2020. These interviews, in particular, were aimed at exploring their everyday social and economic experiences and how these shaped their attitudes, perceptions and behaviours that have increased their risk to HIV in informal areas, thus addressing Research Objective 1.<sup>27</sup>

The interviews with individual persons living with HIV/AIDS (PLHIV)<sup>28</sup> explored different aspects of living positive and how they navigated challenges around social stigma and discrimination in their communities in the context of Covid-19. Most of the interviews were recorded with consent from the interviewees and in many cases, participants preferred to respond in the presence of their gatekeepers (VHTs), with whom they were routinely in contact as they collected Anti-Retroviral (ARVs) from hospitals on their behalf. Consequently, I had to allow the gatekeeper to participate in the interviewing process as most PLHIV chose to respond to questions in their presence and with strict anonymity. According to Kitchin and Tate (2013, p. 219):

“When interviewing people from marginalised sections of community, feminists would argue that traditional methods maintain and reinforce current social power relations: Feminists suggest that power relations within an interview must recognise that they cannot be neutral and objective. Genuine trust must therefore exist between the interviewer and interviewee, and the outcome of the research must also be genuinely empathetic and empowering.”

In their view, the interviewer must endeavour to develop a genuine rapport with interviewee based on shared concerns. Unfortunately, in the case of the Lungujja interviews, I could not

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<sup>26</sup> For the case of Lungujja area, in particular, the interviews with YPLHIV were conducted in their homes after the door-to-door HIV/AIDS health survey and Covid-19 relief-aid project with VHTs from LUCOHECO. This was enabled by seeking prior verbal consent and through phone call requests for interview appointments.

<sup>27</sup> How can engaging with, sharing, and learning from every day artisans’ experiences and practices inform a better understanding of the everyday challenges facing young people in the context of the HIV/AIDS pandemic?

<sup>28</sup> PLHIV often preferred to respond to interviews in the presence of VHTs as they confided in them as their caretakers which at times limited the scope and quality of the answer of the interviewee. However, during the art and creativity workshops they were able to develop self-confidence and freedom to express themselves.

easily build rapport because of the limited time for interviews, which were conducted during short-term home visits with VHTS in the lockdown period.

As discussed earlier, informal conversations were also a key source of information particularly in the industrial areas of Bwaise and Ndeeba. Because I was known to some of the participants especially during the interactive session in the industrial areas, where I had previously done projects with some artisans, this created opportunities for snowballing to other potential interviewees and spaces for interactive engagements. However, many participants preferred talking to me without using a recorder and were more comfortable sharing their lived experiences without being recorded. The issues around HIV/AIDS in their environment, a factor that shaped their risky behaviours, and how they built their social relations and sexual networks in the industrial settings, were very sensitive topics, and many would ask me to switch off my recorder before talking about specific details around the issues of sexuality and HIV/AIDS. Furthermore, there were situations when conversations during interactive sessions needed to be recorded but were either declined by the artisans who preferred not to be recorded, even after seeking their consent, or failed because of machine noise from the adjacent workshops. To compensate for these gaps, I endeavoured to take down notes from these interviews by retreating to a quiet place during breaks or at the end of the day. I was able to write down details from informal conversations and observed events that were critical for this research. This importantly helped me review some of the questions in the interviews as I realised that the level of sensitivity caused them discomfort while answering questions about masculinity, their sexual lives, and behaviours with young women in relation to HIV protection. Indeed, in some cases, I had to tactfully rephrase questions in Luganda using metaphors to navigate this challenge as some interviewees were shy or reluctant to share their personal (and sexual) experiences of life in informal spaces. The verbal constructs of metaphors in Luganda such as '*embwa*' to mean 'slim' (for HIV/AIDS) (Dugga, 2015, p. 65) and '*silya switti mukavela*' which meant 'I don't eat sweets with the wrapping on' (refusing condom use) - became lively phrases in giving a descriptive imagery that attempted to convey the extreme conditions of living with HIV and having unprotected sex respectively, whilst attracting and sustaining informal conversations around the challenges associated with HIV/AIDS among young people. In some cases, I also discarded questions which the interviewees were not understanding, were difficult to comprehend or explain, or were simply not relevant.

### 3.2.1.1 Taping and transcribing interviews and informal conversations

To complement written notes and field diaries, I used digital audio and video-recording equipment to capture interviews and informal conversations with prior consent from the interviewees or participants during interactive sessions. This recording equipment allowed me to concentrate on the interviews without the pressure of struggling to get the interviewee's words down on paper, whilst enabling the interviewee to engage in proper conversation. This helped me avoid unnecessary breaks and pauses to comprehend and ask for clarification. However, this at times was affected by external influences from people accessing the places of interview and noise pollution from nearby wood processing plants in the industrial areas, since participating artisans preferred being interviewed within or near their work premises in order to track of their unfolding projects.

The transcription of these interviews and all the recorded conversations was done during research breaks over the weekends and at the end of the co-production activities in December 2020. The recordings of interviews with stakeholders and other dissemination exhibition attendees were transcribed on my return to the UK in March 2021.

### 3.3 GATE KEEPING AND SELECTING PARTICIPANTS

“Accessing potential participants not only requires providing information about the research, but also that individuals are in position to exercise choice around whether or not to give their consent to participate. Yet much of qualitative research relies upon gate-keepers as a route of initial access to participants”

(Miller, 2012, p. 62)

As a research-tool testing phase, the pilot study provided the opportunity to touch base through gatekeepers and obtain enriching experiences through the 'site' familiarization process and sharing important information about the research to potential participants enroute to the main field work activities in December 2020. I also recognised the prospect to build a sense of identity with the artisans in spaces where I assumed an outsider role (Chambers, 1994d; Limb & Dwyer, 2001; Louis & Bartunek, 1992). This helped me develop a set of adaptive skills, a sense of community identity and ways of building on the existing social networks with key members of the artisan community. This was a critical experience as it turned out to be one of the key pillars in building rapport for collaborative partnerships

required for the co-production process, as discussed subsequently. Not only did this process allow for the testing of the ethical requirements in conducting interviews and HIV workshops, such as seeking consent to audio and video recording, take photographs and other essential participant protection protocols during interactive participation, it also enabled me to establish contact with key gatekeepers who included the following;

- (i) National Guidance and Empowerment for People Living with HIV/AIDS (NGEN+), which was the official partner with Durham University that oversaw the research Project in Uganda (**Figure 6**, Pg.345345)
- (ii) Artisan umbrella organisations in the respective industrial zones- Bwaise, Ndeeba and Katwe, e.g. The Bwaise Furniture makers' association and Ndeeba Furniture group (See **Figure 1** - Pg. 339, **Figure 2** – Pg.341, **Figure 3** – Pg.342, and **Figure 4** – Pg.343)
- (iii) Ethics review body- The AIDS Support Organisation's institutional Review Committee (TASOREC) – (See pg. 330)
- (iv) (vi) Local authorities (LCs) and Individual primary contacts known to me in the above-mentioned sites (see **Table 5**, Pg. 349)

As indicated previously, the research process was broken down into three phases - pre-lockdown, lockdown, and post-lockdown phases. In each of these phases, snowballing was used in choosing participants, albeit simultaneously altered with other recruitment modes based on place and time. Whereas random and purposive sampling were instrumental in providing contact with potential participants in every phase, snowball sampling remained the main approach to participant recruitment. This was a deliberate process to first establish initial contacts with gatekeepers, who provided direct contact with the young people (ISPs). They included, but were not limited to, people constituting what sociologists have described as 'hidden populations' -

“Those who are dispersed geographically, or at-risk sub-populations or hard-to-reach communities, or those who are quite invisible among the population. They can be described as ‘hidden’ because they are subject to stigma and “has networks that are difficult for outsiders to penetrate” (Heckathorn, 2011, p. 356)

Artisan organisations in the different peri-urban areas of Kampala and HIV-related organisations (TASO, NGEN+ and AIC) were first contacted during the pilot study in July 2019 (see Table II), including individual contacts with whom I had prior contact. The use of snowballing from these prior contacts enabled me to reach young people in marginalized peri-urban areas of Kampala. This specifically included contacting LUCOHECO in Lungujja, and artisan umbrella bodies, to identify potential participants in industrial locations in Bwaise, Ndeeba and Katwe townships (discussed more fully below).

The inability to swiftly identify and collect information about persons infected and living with HIV/AIDS in the diverse artisan communities led to the generalisation of the artisan community to be categorised as an ‘at-risk population’. This required exploring the everyday experiences of young people in informal industrial spaces whilst interrogating factors and conditions that have shaped the behaviours, attitudes and perceptions that perpetually generate risk of HIV infection, thus addressing Research Question 1. Navigating the complexities concerning young artisans infected with and affected by HIV/AIDS as a hidden population provided several challenges. With the exception of Rubaga Division<sup>29</sup>, Lungujja, where I was able to work directly with YPLHIV with the help of CHWs, the industrial locations in Kampala involved interactive participation with subjects whose HIV status was initially unknown, but later identified some HIV-positive participants through the snowballing exercise, also known as respondent-driven sampling method. I also used ‘respondent-driven sampling’, which is defined as:

a variation of chain-referral sampling methods that were first introduced by Coleman (1958) under the name snowball sampling. The basic idea behind these methods is that respondents are selected not from a sampling frame but from the friendship network of existing members of the sample”.

Salganik & Heckathorn (2004, p. 196)

In industrial areas, this sampling process began with selecting a group of artisans ‘as a small number of seeds’ (Heckathorn, 2011) who became the first people to participate in the study. These seeds then recruited others to participate in the study, as explained subsequently. This

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<sup>29</sup> Rubaga Division was the only Division in Kampala where gatekeepers were successfully engaged in identifying participants who were HIV positive. The role played by LUCOHECO in Lungujja was particularly helpful in mobilizing young PLHIV to actively participate in art and creativity workshops during the lockdown period.

process of existing participants recruiting future participants continued until the desired number of participants was achieved<sup>30</sup>. This kind of informal experience helped me connect with different research participants, not only in the industrial areas in the peri-urban townships of Kampala, but also in a residential neighbourhood of Kampala- Lungujja, where I was confined during the Covid-19 lockdown<sup>31</sup>.

### ***3.2.1 Recruitment of HIV positive participants in Lungujja***

On the evening of 30<sup>th</sup> March 2020, during a visit to a pharmacy, I had a chance encounter with a lady whom I discovered was a community health worker (VHT) in the area. I introduced myself to her and described my research to ascertain whether it could be of any benefit to them, and how it might relate with their work in grassroot communities in the greater Lungujja area. Fortunately, not only was she a VHT, but also a councillor for Local Council III (LC III) attached to Kampala City Authority Council (KCCA) for Lungujja-Kitunzi zone in Rubaga Division and a former nurse at a local organisation called Lungujja Community Health Care Organisation (LUCOHECO).

The next morning, as agreed, we met at the organisation's offices (also doubling as a clinic for reproductive health and HIV treatment services) in Kitunzi trading centre. Meanwhile she had already informed the CEO of the organisation, Mrs Takilambule Maxensia, about our meeting. It was probably the best time to identify with this organisation since it was organising a Covid outreach and relief programme for vulnerable people (disabled, cancer and diabetic patients, sickle cells patients and orphans) in the area for which I volunteered to participate. That exercise was also meant to support people living with HIV/AIDS - PLHIV who were on treatment and could no longer collect Antiretroviral drugs (ARVS) from hospitals because of the public

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<sup>30</sup> Interactive participation progressively allowed the snowballing effect to build a network of research friends from which action groups that participated in the co-production activities were selected.

<sup>31</sup>My research activities were severely interrupted by the Covid outbreak between 18th March and August 2020. With unprecedented state-led restrictions, which included a total ban on public and private transport and prohibition of all forms of gatherings beyond 10 people, I could not travel to any of my study sites. In the last week of March 2020, the government intensified its campaign to crack down on defiant communities, especially in some informal spaces such as Kikuubo (the busiest shopping hub in Kampala's CBD), Owino Market (one of the largest downtown markets for second-hand clothes) and many of the industrial zones in and around Kampala that had defied state-imposed restrictions to curb the spread of Coronavirus. This was followed by a drastic curfew to prevent people from leaving their homes after 6pm at the beginning of April 2020. Left with no option, I confined myself at home in Lungujja, Kyobe Zone, spending hours reading and transcribing the a few recordings and notes I gathered during the first week of engagement in Arua and Bwaise industrial areas.



transport ban in the country. This offered me with an opportunity to move with selected village health teams to conduct door-to-door Covid relief distribution. As part of a bigger programme, the distribution of relief items constituted the first phase of the COVID-19 aid project funded by the AIDS Health Care Foundation (AHF) based in the USA<sup>32</sup>. Through this project, I was able to identify young people with HIV/AIDS in April 2020.

With the help of two VHTs from LUCOHECO, 19 PLHIV were identified during a 2-week community Covid-19 relief project (18<sup>th</sup> April – 1<sup>st</sup> May 2020) conducted in three zones – Kitunzi, Wakaliga and Kosovo. When we visited homes of the PLHIVs, I was privileged to record and document the number of patients and vulnerable persons in different homes in these areas while giving out assorted relief items organised and packed by LUCOHECO. It was very difficult to distinguish me from the health team. Working with the community health workers helped position my role as an ‘insider’ within a larger team of village health volunteers (VHTs). In a way, this built a sense of confidence and trust among the potential participants (PLHIV) as we distributed the Covid relief items to their homes. Fortunately, the distribution processes enabled the successful identification of HIV positive participants, who later consented to take part in art and creativity workshops for HIV prevention in May 2020. Among them were prenatal cases (18-24 years) who were born with HIV and post-natal cases ranging from 19 to 36 years. My project was participatory in nature, designed as an all- inclusive programme using applied sculpture as a social practice, supporting interaction, participation and collaboration to generate narratives and dialogue around issues of HIV risk and barriers to HIV/AIDS prevention and empowerment among young people (in resonance to Research Question 2).<sup>33</sup> However, the Covid-relief recruitment drive was extended to involve youths in general without

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<sup>32</sup> On 25<sup>th</sup> May 2020, during the function to commemorate the 17<sup>th</sup> anniversary of the LUCOHECO, a community-based HIV organisation in Lungujja, Kampala, the organisation’s CEO launched the second covid-19 relief drive with support from the AIDS Health Care Foundation (AHF), a US-based organisation to support disadvantaged communities in the greater Rubaga Division. While Launching the drive, the Chief Executive Officer confirmed that the support was to be delivered in form of relief items to vulnerable families and individuals including, but not limited to, those who were living with HIV/AIDS (PLHIV) and cancer, who were severely affected by the Covid-19 pandemic. The first drive ran for two weeks (18<sup>th</sup> April -1<sup>st</sup> May) in the areas of Lungujja, Kitunzi, Kosovo and Wakaliga (Rubaga Division), in which I participated with a group of community health workers (CHWs) - **(Entry in Fieldwork diary, May- July 2020)**

<sup>33</sup> In what ways can collaborative partnerships between artists and artisans be created to enable the co-production of functional/usable forms that are communicative about tackling HIV/AIDS for social transformation and remain relevant to economic empowerment of young artisans?

necessarily raising concerns about their HIV status as criteria for involvement. This, therefore, led to the creation of two action groups<sup>34</sup> during the lockdown phase, namely: young people living with HIV (YPLHIV) as Group A, and Youth from slums and less privileged homes as Group B.

### **3.2.2 Group A: Young people living with HIV (YPLHIV)**

The first action group (Group A) was made up of young men and women who attested to their positive status (E.g., see *Table 4*, Pg. 350), confirmed by the community health workers with whom they were in direct contact for hospital visits and collection of anti-retroviral (ARVs) during and before the lockdown period. As explained subsequently, this group participated in the art and creativity workshops that explored how economic precarities, social injustices such as exclusion, and gender-based inequalities, other abuses, and stigma in particular, shaped their life and behaviours in the context of Covid-19. While working under strict observance of the Covid standard operating procedures (hand washing, wearing face masks and social distancing)<sup>35</sup>, participants were able to share their stories and life experiences at home and in workspaces where they were often challenged by social stigma and discrimination. It was particularly intriguing to experience the vitality of stories in communicating the trials and tribulations of living positively in the context of Covid-19.

### **3.2.3 Group B: Youth from slums and less privileged homes**

The second group (Group B) was made up young people from the disadvantaged families in the slums of Kosovo and Wakaliga, Kitunzi, 7 of whom where school-going students (17-20 years) and staying home due to lockdown, while the other 3 participants (18-22 years) were working in one of the informal spaces in Kampala-Owino Market as second-hand clothes vendors.

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<sup>34</sup> Action groups is the term used in this research to refer to a selected team of young people involved in the co-production process of art forms for HIV awareness and empowerment

<sup>35</sup> Participation in groups during this period (March – August 2020) was limited to only 10 individuals which was in accordance with the government-led ban limiting gatherings in a particular place to only 10 people in order to curb the spread of Covid-19.

During my stay in Lungujja<sup>36</sup>, trying to come to terms with the COVID-19 lockdown, I was able to travel through the small trading centre in Kitunzi on personal errands. Oftentimes I came across groups of adolescent youth loitering aimlessly in the area. These groups, especially adolescent men, would gather around pool tables and gambling spaces (Ludo and sports betting joints) in the trading centre. Having built rapport with the village health teams who were regularly on ground making health surveys in the area, we would occasionally meet at the nearby LUCOHECO office and talk about life issues.

Given the lockdown in the area, most of the youth were left idle and had resorted to all sorts of risky behaviours that potentially perpetuated the spread of HIV. Because I could no longer go to field sites in industrial areas, I decided to work with the CHWs and liaised with the local council chairpersons<sup>37</sup> of the neighbouring villages – Kosovo and Wakaliga – to engage some of the youth in my research. Most the youth were school-attendees who were supposed to stay at home since the schools were closed due to the Covid-19 lockdown. This engagement provided opportunities for grounded perspectives about HIV/AIDS in a time of the Covid-19 crisis among young people

### ***3.2.2 Recruitment of youth in industrial areas:***

#### **Bwaise Industrial area**

I spent close to 3 months (January – March 2020) doing interactive participation and ethnographic engagements with young artisans in the greater Bwaise industrial zone (Bwaise parish III). Initially, in the first 6 weeks, I worked as an apprentice moving from workshop to workshop spending at least 4 to 5 working days in each. The main aim was to establish contacts and research ‘friends’ whilst focusing on understanding everyday life experiences of young people in this highly dynamic and socially diverse setting while conducting random face-to-face interviews. I benefited from interacting with various groups of artisans whose social networks

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<sup>36</sup> According to the VHTS, Lungujja is traditionally deemed home to an affluent community but interspersed with informal settlements and for that reason, receives most government programmes. Accordingly, this was why VHTs prioritised those areas for HIV community support programmes initiated by the local organisation- LUCOHECO.

<sup>37</sup> The LC chairmen are the government representatives at village level who co-ordinate and oversee grassroots political activities and government programmes in Uganda. They are responsible for issuing permission for local community services, and introduction letters to new citizens and issuance of other relevant documents and performing other various duties as per the local government act of Uganda (1997).

(Friendship groups, connections based on geographic neighbourhood and relatives) enabled me build connection for further interaction and potential collaborations in form of action groups (Goodman, 1961; Heckathorn, 1997; Salganik & Heckathorn, 2004). As I continually interacted with the different individuals during in field study, I realised that many of them came from the same residential neighbourhoods, while others shared common up-country locations. This resonates with Israel et al. (1998, p. 178) who describe:

“Communities of identity being centred on a defined geographic neighbourhood or a geographically dispersed ethnic group with a sense of common identity and shared fate.”

I later connected with group of young artisans who were working in one open space, which I called the ‘furniture yard’ (comprising of a series aligned workshop units), managed under one umbrella organisation that provided social and financial support to artisan members in Bwaise called *‘The Bwaise Furniture Maker’s Co-operative Organisation.’* I subscribed to the cooperative through its Chairman in July 2019 to do an apprenticeship with expert artisans in its workshop units (as advised by my primary contact). The site accommodated over 20 artisans, mostly young men in their early 20s, working in various capacities (joiners, machinists, carvers, and sanders) while operating under different management units (workshops) within the same sheltered space (‘furniture yard’).

### **Katwe and Ndeeba Industrial areas**

Having spent over 3 months between April and July carrying out art and creativity workshops with young people in Lungujja, on the 3<sup>rd</sup> of August, I resumed my field research in industrial areas with my major focus on using interactive participation and ethnographic methods to capture more information in line with Research Question 1. The main focus for resumption was to continue with interactive engagements with young artisans, especially those engaged in metal fabrication, to observe, share and learn from their lived experiences (using participant observation, direct observation, photography, and audio/video digital recording with due consent from participants, mostly verbally and in some instances written). The idea was to explore ethnographically and understand every day artisanal activities, personal experiences, human interactions, workspaces, actions, and processes of metal working in the context of HIV risk. Crucially, Katwe was revered for its historical role in promoting indigenous technologies

such as tinkering, smelting iron ore, and coping factory and agricultural processing equipment imported from abroad to meet the growing local demand for such equipment. Over time this place became a hub for budding craftsmen from different backgrounds with hope of finding employment. According to a local authority on these areas:

“Today, it is a very diverse community with intersectionalities between cultures and tribes hence the naming the zone as ‘Buliggwanga’ which is loosely translated as (all-tribes) and railway zone in Ndeeba. Majority of young people are migrant workers from upcountry locations and the Democratic republic of Congo (DRC), school dropouts and uneducated youngsters, who throng to this industrial area in search for livelihood opportunities”

(Face-to-face interview, LC1 chairman, railway zone Ndeeba, 4<sup>th</sup> August 2020)

In order to capture the social dynamics and structural barriers concerning this hidden population in the context of HIV/AIDS, intensive engagement was required with young people through snowballing and ethnographic field work for close to two months<sup>38</sup>. However, given the limitation on time, I restricted my engagement to frequent informal conversations, limited unstructured interviews and participant observation to collect data in relation to lived experiences. This focused on exploring the structural, social, and economic aspects that shaped the behaviours, practices, and circumstances that have put the lives of young people at high HIV risk in a densely populated peri-urban enclave of Makindye Division in Kampala city. Snowballing again played a central role in shaping my connections in these industrial areas. For instance, on 3<sup>rd</sup> August 2020 I began by contacting a metal fabricator/machinist who used to help me in welding projects in Kampala called Mulangila (27 years).<sup>39</sup> He put me in contact with the LC1 Chairman for permission to conduct research in his area (*Figure 3*). He later put me in contact with his close friend near his workshop and a group of other metal fabricators in Katwe. For two months, Mulangila’s workshop served as my research base in Katwe industrial area

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<sup>38</sup> Due to interruption from the Covid outbreak, I was left with very limited time to extend the ethnographic activities beyond 2 months. I switched to Ndeeba industrial area for its diverse social and economic potential and commanding possibilities that pointed towards HIV complexities that engulfed a highly excluded artisan community, whilst offering a more conducive space in a favourable geographic location for participatory practical engagements and co-production processes.

<sup>39</sup> Mulangila was 27-year-old artisan, working as a machinists in Katwe and a long-time friend known to me since 2013 from previous projects in metal fabrication at Makerere University. I used to engage him in drilling and welding projects for clients in and around Kampala. He told me that he was introduced to the craft by his brother after dropping out of school in senior four in 2009.

from where I conducted interviews, wrote field notes, and initiated contact with other artisans in the area.

In Ndeeba, where many of the potential participants were migrants from Congo, Rwanda and up-country locations, engagement were initially slow, partly because of their fear of the being apprehended for working in the area illegally. In order to navigate this challenge, on September 10<sup>th</sup>, 2020, I met with a long-time friend, a carpenter, by phone, and he agreed to meet at his workshop the next day. I wanted him to connect me to one of the leaders of the artisans (carpenters and wood finishers). Identifying and choosing participants was a daunting experience, because the artisans here were from more diverse ethnic backgrounds. It was, therefore, necessary to get in contact with the leaders of this artisan community to build a sense of trust and social cohesion as an outsider doing research in a setting deemed to be potentially marginalised and sensitive to intruders.

After meeting the artisan chairman and briefing him about my participatory engagement with young people, he led me to the Local council office (LC1) for an introduction letter. The purpose of this introduction letter, as was the case in all the other settings, was to make my practical engagements with young people in this area socially legitimate. For 3 days in a row, I was able to traverse the industrial space in the company of one young person, Mumbere (one of the artisans from Bundibugyo district, western Uganda), who volunteered to help me conduct a familiarization tour of their workshop spaces. To negotiate my identity, I talked to all artisans we met in Luganda and also made sure I put on a tailor-made overcoat from one of the hardware shops because it looked exactly like the ones many of the artisans wore.

### **3.4 INTERACTIVE PARTICIPATION, ETHNOGRAPHIC NOTE-TAKING AND THE CO-PRODUCTION PROCESS**

Understanding the life of these young people working in peri-urban industrial areas required prolonged immersion and engagement and developing a sense of groundedness through intensive ethnographic work in the selected sites for one year (December 2019 to November 2020). Direct participation began at different times and took 2-3 months in each of these 3 artisan communities. The aim of this process was twofold; first, to gradually create a sense of

identity<sup>40</sup> with the young artisans, sharing knowledge and skills as they worked, studying their social contexts and identifying potential actors by building rapport and a network of research volunteer/friends who eventually formed the action groups for the art and creativity workshops for HIV awareness; secondly, to afford prospects of stimulating and sustaining conversations and stories about their everyday lives, identifying, articulating and sharing knowledge about the economic and cultural barriers that fuel the spread of HIV/AIDS within their communities. Much of the research work involved unstructured time in these communities, spending months, days and hours working and talking mostly with young artisans, not only inside carpentry workshops, but also outside in shaded areas, open metal workspaces, alongside machinery operators and so on. Nevertheless, I also interacted with workers in casualized forms of occupation such as sanding, varnishing and general wood finishing. I also spared time to visit, talk and held random in-depth interviews with one or two attendants, especially young women and adolescent girls working in bars, makeshift food joints and roadside businesses within the industrial zones.

To better understand the nature of work in which young artisans are involved, I spent two periods of over 20 - 30 days in each site to touch base, establish contacts, conduct random in-depth interviews (with artisan leaders, workshop owners and local leaders), complete a familiarization process whilst identifying conducive free zones for action group meetings and art workshops (E.g., *Plate 11*). It is unfeasible to generalise the ethnographic processes for these three industrial sites, because each one had its own peculiarities. Thus, interactive participation with young people differed based on the settings and physical circumstances at a given time. The interactions during the pre-lockdown period in the industrial spaces were long and incisive in exploring the everyday visible and invisible situations (artisan workshop operations/activities, behaviours of different actors and other variables<sup>41</sup> such as weather

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<sup>40</sup> Since one of the key principles of community-based research (Israel et al., 1998) recognizes the “community as a unit of identity: upholding the concept of community as an aspect of collective and individual identity is central to community-based research. Units of identity, for example, membership in a family, friendship network, or geographic neighbourhood, are all socially constructed dimensions of identity, created and recreated through social interactions”.

<sup>41</sup> In order to understand the conditions and factors that shaped young people’s behaviours and HIV risk, I occasionally stay until about 7 pm with at the local council offices in the industrial zones to observe what

vagaries such as rain, working at night, security concerns, etc.) that enabled collection of data in line with research question 1. On the other hand, during the lockdown period when I was restricted to working from home, the interaction with participants who were YPLHIV was strictly in closed spaces where external influences were limited, say from people coming from outside. My interaction with this group was often confined to about two contacts hours each day through story-telling, informal conversations and random unstructured interviews at different times and usually in a separate conducive environment within a closed area.

### 3.4.1 Ethnographic notetaking

“Ethnography is an intersubjective form of qualitative research through which relationships of researched, insider and outsider, self and other, body and environment, and field and home are negotiated”.

(Watson & Till, 2010, p. 121)

Throughout the field interactive sessions, I usually had a notebook as a field diary recording every time, I visited the study sites or informal spaces around Kampala. I moved with it at all times as it contained my contact details, appointments dates, notes about observations and fleeting incidents, notes about photographs and interactive activities and how they unfolded during active interfaces with different artisans in the industrial spaces. I recorded notes about everyday occurrences and observations during the interactive engagements with young people, especially in the industrial settings, at the end of each day. Anthropologist Sanjek, (1990, p. 7) speaks of field notes as:

“Representing the process of transformation of observed interaction to written, public communication: “raw” data, ideas that are marinating, and fairly done-to-a-turn diagrams and genealogical charts to be used in appendices to a thesis or book”.

He argues that whereas some researchers see their notes as scientific and rigorous because they are a record that prevents bias and provides data, others contrast field notes with data, speaking of field notes as a record of one’s reactions, a cryptic list of items to concentrate on, or a preliminary stab at analysis and so on. Oftentimes, I would (re)read the fieldnotes when

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happened in the evenings, especially when the majority of the workers are leaving, while residents of the area were returning home. Surprisingly, some of the industrial areas had structures which doubled as workshops during the day and dwelling places at night. So, staying behind provided rich opportunity to observe people movements and how young artisans were behaving as they left their working sites.



heading back home in a taxi or bus, or on non-research days. Reading through the different field diaries was very useful in reminding me of my appointments, transactions, and activity schedules, as well as triggering ideas on how to navigate the challenges and opportunities that I encountered during my field trips. I prepared different notebooks for each study site, and I would jot down important words, experiences and unique observations about young people's behaviours, social interactions, and informal conversations we had. This helped me shape and fill in detail in what I recorded in audio and video during the interactive work sessions at their workplaces. These fieldnotes were instrumental in helping me capture situations within the industrial spaces, people's moods, or movements or dressing especially when photography and video-recording were not possible. In this way, my writing and note-taking become open-ended, and filled any gaps that were left during the recorded situations.

Referring the fieldnotes provided memories to reflect upon and interpretations of my research experiences in informal spaces with young people involved, paying attention to social and working processes, their moods, embodied and emotional experiences, while providing a rich exploration and understanding of material visual culture in those informal environments (Watson & Till, 2010; Clemens, 2022). It also helped me scrutinize various aspects within a particular setting and spaces of engagement in the context of HIV risk and situations of marginalization among young people in their industrial confines. It not only addressed key concerns raised in Research Question 1,<sup>42</sup> but was also central in drawing intersectionalities between the different young people's settings and study sites. These facets provided enriching experiences that informed the theoretical and analytical discourses of this thesis.

#### **3.4.1.1 Sharing stories and every-day experiences for co-production**

“I walk 2 miles every day to come here, and I don't feel it because from the very first day, I feel like I found another place to act and see things differently”, one participant testified.

(Fieldwork Diary, 15<sup>th</sup> June 2020)

Undeniably, not all the participants were coming from the immediate neighbourhood of Lungujja where the workshops were held. I noted that they often reported on time despite

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<sup>42</sup> How can engaging with, sharing, and learning from every day artisans' experiences and practices inform a better understanding of the everyday challenges facing young people in the context of the HIV/AIDS pandemic?

their health challenges. Every morning, for the first two weeks, in a private space behind my home (away from public attention), we began the session with sharing personal daily experiences of life. They gave genuine accounts of living positively in communities where stigma and discrimination is common and how this impacted their wellbeing. In order to avoid stigmatising them further, I used the following approach: (i) I motivated participants to start sessions with the 'happy moments of life' in their own settings (ii) used storytelling sessions (stories that framed their lives)<sup>43</sup>, (iii) asked them to translate those experiences into sketches and later drawings (For example, see *Plate 12*). This allowed them to exercise their freedom of expression to break down any internal stigma,<sup>44</sup> alienation and self-pity arising from living positively with HIV in inadequately-served environments. This was often followed by open discussions regarding their stories and translated visual ideas. No matter how crude the sketches or drawings were, they still communicated their experiences in abundance while stimulating thought-provoking conversations around HIV issues. In turn, this created a mark of self-expression, visual ecstasy and creativity (Gray, et al, 2010; Linda, 2020; Okrii, 2020; Pink, 2005), which are also key attributes in applied sculptural practice. It helped participants develop self-confidence and self-esteem as they each realised that they were indeed sharing similar life experiences, only different in space and time. With due consent (usually verbal) from each of the participants, the discussions, I recorded drawing sessions and conversations as a participant-observer using photography and video/audio digital recorders.

Most importantly, the group meetings and action sessions lasted for 3-4 contact hours, often generating compelling scenarios where I had to contend with expressing empathy and psychosocial support whenever they broke down. In reality, I was neither a doctor, even when they presumed so, nor a counsellor. Working as an artist whose HIV status is negative was challenging and at times, I questioned my abilities to enable such people to realise their hopes by improving their wellbeing through collaborative participation. Nonetheless self-actualisation and intuition restored my positionality as a facilitator of action and change by helping others improve their livelihoods and wellbeing in the context of HIV/AIDS. Being in the

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<sup>43</sup> An anthology made up of the writings of 8 young people from informal setting shall be discussed in the subsequent chapters of this thesis.

<sup>44</sup> Felt stigma (internal stigma or self-stigmatization) refers to the shame and expectation of discrimination that prevents people from talking about their experiences and stops them seeking help...

same space every day with them as we worked, and sharing stories and testimonies from lived experiences, enhanced my presence and boosted my confidence as a legitimate peripheral participant (Bloch, 1994; Lawless, 2008). Drawing on this experience, the subsequent sessions were handled with resilience whilst augmenting participants' will to freely express themselves as they shared their lived experiences with minimum stimulus.

I still had to deal with the frequency of sudden lapses in health among the participants whose state of wellbeing was enduringly worrying. Much as all the participants informed me that were on treatment (ARVs), I noted that the onus of ensuring adherence and regular medical check-ups was more of a personal affair. During the workshops, perhaps due to myriad personal challenges, I observed that some of them were actually experiencing deteriorating health conditions (loss of weight, low appetite, and constant fevers), which pointed towards inconsistent uptake of ARVs or drug fatigue. Absenteeism, sudden fevers, and loss of energy often affected their performance during the workshops. However, this was addressed as we jointly drew up codes of behaviour for each of the participants in the following ways; (i) regular personal check on drug adherence, (ii) timely and healthful nutrition during the workshop sessions (iii) limiting contact and performance hours to a bare minimum (3-hour sessions per day), (iv) providing a motivational package (in the form of transport and lunch) and (v) working as teams during sessions (in groups of 4-5 participants). This was instrumental in motivating them to regularly attend with sufficient energy and revitalised enthusiasm to co-create ideas, forms, and strategies around HIV/AIDS issues in the context of COVID-19. Indeed, their presence contributed immensely to the findings of this research project at a time when everyone else was at home during lockdown in Uganda.

### **3.4.2 Co-production: Art and creativity workshops**

Creating partnerships and collaborations was at the heart of my participatory project with young artisans in marginalized industrial spaces in Kampala. I recognised the prospects and at the same time, acknowledged the challenges it presented during the course of engagement. In this section, therefore, I provide a summarised account of the co-production activities and events that possibly shaped the outcomes of this research project. In all, there were 3 action groups formed from the interactive engagements with young people in Kampala. As already mentioned, two were in Lungujja during the lockdown period and one in Ndeeba industrial

area. At the beginning of the action group sessions, I agreed with the participants to choose their own facilitator to craft a design agenda for the research workshops and jointly co-ordinate the creative process. As Mumford et al (2002, p. 709) argue,

“In creative work, the parties involved must define a problem, they must gather information and they must progressively refine and extend initial ideas to permit successful implementation; because these activities are all difficult to execute, creative work can be expected to be demanding and time-consuming activity”.

I requested that participants choose their own group facilitator who would jointly work with me as a participating observer in leading the creative process. This was intended to allow participants lead in practice and have full control of the process. Participatory work allows practice, to secure local action and resources; and empowering processes, to enable people to take command and do things themselves (Chambers, 1994).

In the 2<sup>nd</sup> week of action research, drawing on my skills in applied sculpture, we embarked on developing as sketches and Marquette (small models in soap and wood) which triggered and sustained the interest amongst participants as they translated their thoughts and stories into tangible forms. This allowed them to develop a set of skills in imaginative drawing, observational scaling, visual orientations in translating images into full-scale formations using permanent materials such as wood and metal. This was experiential learning for us, as the process involved a reciprocal transfer of skills amongst ourselves. However, we often encountered undue delays in starting workshops and finishing tasks on time. Indeed, most artisans could not regularly attend because of the nature of their casualized work in informal spaces. Many times, participants were torn between completing their own tasks and attending workshops<sup>45</sup>.

The methods of engagement with these young artisans provided a basis for building on strengths and resources within the artisan community while augmenting the existing relationships among them for improved capacity in terms of skills and knowledge in the context of addressing their communal health concerns (C. Wang & Burris, 1997). This addressed the

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<sup>45</sup> To reach this stage of engagement, there were many challenges especially in mobilizing member for group activities as many of them would take time negotiating unfinished business/tasks given to them by their ‘Bosses’, while others would occasionally go absent for personal reasons – hangovers due alcohol, ailments, etc.

second objective of this project. Yet, on the other hand, their perspectives as assenting participants illuminated powerful, hopeful, and discreet messages towards preventing HIV and economic empowerment among young artisans in informal peri-urban spaces.

I used interactive moments with groups to observe how they were socialising, behavioural patterns in groups, discussing their imminent social challenges as young people and how this practical interface could positively transform their perspective in the context of HIV/AIDS prevention. In industrial areas, participants jointly gathered wood off-cuts discarded from nearby carpentry workshops to be used in the construction of the artworks after the drawing sessions. Applied sculpture as a social practice provided the basis of engagement with these groups, allowing them to work with tangible material such as clay and soap to express their feelings and share lived experiences.

For all 3 action groups, the design processes during art and creativity workshops were standardised to allow 2 weeks of conversations, discussions, and 4 weeks of engagements in applied sculptural practice, producing sketches and soap/clay models, inspired, and informed by the everyday stories from participants. This inspired the production of artworks such as **Plate 33, Plate 40, Plate 41, and Plate 50**, which helped them build capacity and skills while at the same time demonstrating the potential to acquire new skills through collective participation and making contributions towards the HIV/AIDS/COVID prevention, awareness, and social-economic empowerment for grassroots communities. Having described the creative processes that were involved in the generating the applied objects for HIV/AIDS awareness, I now present a summarised systematic 4-way applied sculptural approach that was used to ensure that the co-produced art works are developed from collective, well-thought design conceptions, that contained substantive content and form in tangible materials that are durable, without compromising beauty and function to communicate and convey the intended HIV/AIDS messages, yet remain commercially viable to attract market value as initially conceived. The approach thus included; (i) Ideation level (ii) Concept/idea development (iii) Concept implementation (production of artworks) and lastly, (iv) Application process

- (i) Ideation level: This was the initial process of generating ideas or concept in form of inspiration generated from the interactions with the participants through conversations, stories, and every day lived experiences in informal spaces. The use

of ethnography in this research was primarily to provide a platform for interrogating young people's life experiences in the context of HIV/AIDS in peri-urban marginalised spaces that informed and enriched the creative sculptural process. So, this level of participatory design was centred on reviewing narratives from conversations about HIV/AIDS and contexts in which HIV/AIDS flourished to develop themes (such as stigma, lockdown, sexuality, etc.) for visual exploration with diverse group of young people. It also involved focused attention to physically observed experiences and working processes that enriched and facilitated the thought process for design. The process began with collective reflections and discussion of key aspects from their own stories and narratives that could be translated into 3-dimensional (3-D) applied forms communicative of HIV/AIDS awareness but with potential to attract a market value. The participant were guided on how to draw using ink, pencils and markers on bond and manila papers as they developed preliminary ideas (E.g., **Plate 18** and **Plate 20**). It was an entry point a rather complex exploration of ideas which required constant support to the participants, as many of them found it as a difficult experience given their poor educational history. Fortunately, in every workshop, they started slow and in intimidated ways but little by little they began to put incredibly communicating images which were later refined with my help. At the end two to three drawing exercises in each workshop, participant had picked interest and a series of sketches a preliminary work were realised. As they learnt how to engage with drawing tools, conversations around issues of HIV/AIDS kept the groups enthused and eager to sustain the creative journey. Photography, audio, and video recording continued as they process went on.

- (ii) Concept development; this was a systematic working towards making trials, refining, and exploring compositional aspects in term of amalgamating different visual images whilst negotiating on possible techniques and materials to be used. So, the drawings were adjusted to fit the technical and structural considerations for execution in 3-D. It also involved understanding the essential aesthetic and ergonomics of building form that would serve their intended functions. For instance, in the first workshop with HIV positive participants, benches were the

centre of interest as they suggested that such forms should be placed in open public areas like trading centres, which meant designing visual symbols and images as engravings that could be read as messages of HIV prevention before and after sitting on them. In this case participants oriented the drawings/images towards relief sculpture which required surface engraving and lines patterning using hand tools such chisels, gouges, and rasps (E.g., see surfaces on *Plate 40* and *Plate 41*). Ultimately, the process necessitated the use of an engraving machine which helped participants learn a range of studio methods for working on relief sculptures in ways that better the carving process done by artisans who craft beds and other furniture in the industrial spaces. In some cases, before transferring the design to the final surfaces, small models in soap and clay were built to enable participants grasp the technical and creative elements of designing process. Linking between ideas and later transferring to final material was intended to improve the workmanship of the participant which was in resonance with research question 2.

- (iii) Concept implementation; this level of designing process was essentially the actual building of the applied forms. It involved (a) choosing the final drawings as selected from different groups; (b) transfer of the drawings using pressing methods, stencils, and direct sketching, in some cases, selecting and organising material for the execution work; (c) choosing teams according to their personal skills and technical competences to handle different tasks; (d) mobilizing and scouting for external support from the existing experts (carpentry and moulding) in the greater industrial spaces. The entire process also involved checking on the quality of materials, identification of local available resources such as scrap wood, metal or board depending on the ideas developed. Local participation places weight of utilizing local resources and knowledge/skills that are possessed by the participants as this was a prime advantage of working with artisan groups in industrial spaces. All the above processes were recorded in pictures video and audio for purposes of analysis during the thesis writing phase.
- (iv) This was the last stage in the design process where all the artworks that were produced either in wood or metal were finished using varnish or painted over with

brushes by the participants to improve their visual appeal. Some of the works that needed accessories such as pedestals and support stands were selected and given the same surface and structural treatment for compatibility. They were then subject to the audiences where they were produced to obtain public responses towards their value as object for HIV awareness and empowerment. This includes interviews with the participants themselves, randomly selected artisan from the industrial community and the general public.

### 3.5 ETHICS REVIEW PROCESSES (TASO Uganda and Durham University)

As discussed, the pilot study in July 2019 provided me with an opportunity to initiate the process of seeking ethical approval, first from Durham University and second, from the local ethics review body in Uganda, The AIDS Support Organisation Review Ethics Committee (TASOREC)<sup>46</sup>. The over-arching purpose of these reviews was to ensure that potential ethical risks are managed appropriately, and to protect those involved (Khanlou & Peter, 2005; Ochieng, 2013; Vanclay, Baines, & Taylor, 2013). TASOREC's role was to ensure that, since it was health-related, this research project followed the protocols put in place, where compliance and due diligence had to be done by myself to realise positive study findings. This clearly resonates with Phillips et al.'s (2017, pg. 106) observation that;

“The role of the IRB<sup>47</sup> is to protect the rights and welfare of human subjects (participants) in research, and this obligation must take precedence over the interests of any researcher or organization. Documents submitted to the IRB should provide justification for the research and a plan for the conduct of research. The IRB provides oversight of research during the life of a protocol to confirm that the benefits continue to outweigh the risks, that the risks are minimized, and that the project should continue”.

To this end, assessment forms from both institutions detailing (a) data collection instruments to be used, (b) information sheet, privacy notice and informed consent forms (c) COVID-19 risk management plan (d) data management plan and (e) the study protocol (research proposal) were all submitted for review and subsequently approved. In the case of TASOREC in Uganda,

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<sup>46</sup> Despite undergoing a series of correctional amendments, including but not limited to translating the protocol documents into Luganda and the Covid-19 lockdown interruptions, the study protocol which was submitted in December 2019 and finally approved by “The AIDS Support Organization (TASO)” Research and Ethics Committee (TASO REC) on July 30<sup>th</sup> 2020 (TASOREC/008/2020-UG-REC-009)- while Durham University confirmed its approval by email on Friday, 12<sup>th</sup> June 2020 (See pg. 333 and 334) respectively for the approval details)

<sup>47</sup> IRB in full is Institutional Review Board



the information sheet, privacy notice and consent forms were written in English and translated into Luganda since the research was going to be conducted in informal spaces where literacy levels were deemed low and where Luganda is considered a culturally appropriate dialect. Additionally, a site risk assessment form was also submitted to the Geography Department of Durham University as a confirmation process for the commencement of the field work in December 2019. This contained information about (i) potential hazards such political demonstration in the place of the research (ii) description of activities in the field (iii) mitigation strategies in event of occurrence of any hazards, (iv) the parties/persons responsible for mitigation and so on. This was primarily intended to ensure my own safety and protection as a researcher during field work in informal industrial spaces of Kampala in Uganda.

### **3.5.1 Participant protection**

This section explains the key protocols that ensured the safety and protection of all the participants in during the interactive engagements and co-production process for one year of fieldwork. They included; (i) Informed consent (ii) Confidentiality, anonymity, and Privacy (iii) Protection from Harm.

#### **(i) Informed consent**

Central to this study was the need for informed consent from the participants as an ethical attribute which demands that research participants' rights had to be respected (Jacques M. Chevalier & Daniel V. Buckles, 2019; Khanlou & Peter, 2005; Minkler, 2004). I always took it upon myself to regularly present and read an information sheet, translated in the local language (Luganda) to all participants and in some cases, I endeavoured to provide copies to participants who could ably read. This allowed them to make informed decisions on whether to participate in the research activities. The information sheet<sup>48</sup> provided relevant details explaining why the research was being conducted in those selected study sites for the benefit of the participants to choose whether to participate in the process of ethnographic data collection. However, in most cases, I relied on verbal consent, not least because the literacy levels among the participants were low.

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<sup>48</sup> The Information sheet has been attached in appendix D

As stated earlier, all the participants were young artisans recruited into action groups of 10 – 15. All were given the opportunity to make choices about whether to participate in the research after sharing the information sheet. Participation was entirely voluntary, and the participants were allowed to withdraw at any time with no consequence. Many times, interactive participation happened on an everyday basis. Given the challenge of cultural diversity (with migrant workers) and educational disparities, most of the participants were often more comfortable with non-formal ways of interaction.

The action group in Ndeeba had over 19 participants with relatively low education levels: 2 senior four dropouts and the rest never studied beyond primary 7<sup>49</sup>. Whereas they could try to read some of the English words and sentences, they still could not comprehend the meanings contained in the information sheet and consent documents. Therefore, with a few exceptional cases, most of the research documents such as the information sheet, privacy notice and consent forms were written in English and then translated into Luganda. This resonated with ideas of embracing locally translatable concepts for grassroots communities where literacy levels are low (Minkler, 2004). The consent process was vital in the decision making process of conducting my field work activities as follows (i) choosing collaboration modes and technologies, (ii) mode of communication and operation, (iii) local materials to be used including the situated expertise and procedures during co-production (Banks et al., 2013). This subsequently helped me in generating coherent ethnographic data with the support of all parties involved- artisans, group leaders, political offices, etc. (Ochieng et al., 2013; Pohl et al., 2010; Polk, 2015). Engaging participants in their own workplaces (industrial locations) proved to be time consuming as it regularly required prior consent to avoid potentially raising questions of trespass, intrusion, and confidentiality, which could have jeopardized the credibility and success of the entire research project. Nonetheless I strived to allocate time and patience particularly during the recruitment of participants for action groups, allowing the process to be socially responsive, compassionate, and reflexive throughout the different stages of my field work activities.

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<sup>49</sup> A sample list of participants from the Ndeeba action group has been attached in Appendix D

## **(ii) Confidentiality, Anonymity and Privacy**

“Confidentiality is like an iceberg; only the tip is known, but what lurks unseen, below the surface is also a source of potential harm” (Tolich, 2004, p. 101).

If I had not given due attention to the three indispensable virtues of participatory engagements i.e., mutual respect, honesty and reciprocal trust, my research may have had adverse consequences for myself and the participants. However, in all my engagements from the pilot study (2019) into the main field work (2020), I ensured that the principle and value of confidentiality on the part of the participants was at the centre of my actions and decisions. This helped me to augment the quality of my findings and all the values associated with confidentiality such as autonomy, privacy and keeping a commitment (Petrova et al., 2016, p. 445; Vanclay et al., 2013). Throughout the field work, I endeavoured to maintain personal and professional attributes of honesty and respectfulness to the participants of this study. All the data was handled as confidentially as possible including concealing names (using pseudonyms) of participants. Furthermore, in cases where the results of this study were published in local media and dissemination events, for instance, at the launch of the Dissemination exhibitions at Makerere Art Gallery and TASO Mulago, in Uganda, individual names and other personally identifiable information were not included. Additionally, informed consent was obtained from all interviewees during interactive and co-production sessions (including all the audio and video recordings).

Most crucially, to further minimise the risk of confidentiality, I kept my research diaries and field notes in a locker rock at home (Lungujja) while I also protected transcribed field notes and other sensitive data in the form of video, audio, and photographic materials in securely encrypted files on computer cloud spaces (OneDrive-Durham University) using strong passwords. These sources could only be accessed by myself and supervisors on permission. The process of ensuring confidentiality was vital when dealing with the first group of participants who were young people living with HIV/AIDS; acting on their behalf and having autonomous respect for their vulnerability empowered them to freely express themselves during the discussion sessions and co-production activities. To protect the confidentiality of their data, new notebooks were used daily to reduce the possibility of unauthorized access. For participants who requested strict anonymity, no name or identifying information was

recorded on paper. Otherwise, all participants have been anonymised in this thesis and their privacy was duly respected through the use of robust and safe data storage.

### **(iii) Protection from risk of harm**

I undertook a research project which was participatory in nature using creative sculptural methods, which were introduced and shared by myself as an ‘outsider’ with the young artisans (Chambers, 1994d; Louis & Bartunek, 1992) in attempt to generate narratives and stories about every day experiences and HIV/AIDS. It also meant offering a means to ‘project young artisans’ own voices and positions’, which is described as empowering for participants who are often seen as marginalised or disempowered (Jupp, 2007).

Working as an outsider in my capacity as a privileged researcher, a Ugandan who is not HIV positive, but working with young men who are infected or affected by the epidemic, I took extra care to minimise the power gaps as much as possible. However, I also enjoyed a privileged presence, partially as an insider with considerable experience in artisanal work, which enabled me to engage in open conversations and meetings since I shared the same language with most participants. Generally speaking, Luganda is the most revered business language for its distinguished historical significance in building coherence among diverse ethnic groups working and living in Kampala’s informal enclaves. While the affluent communities and elite classes are accustomed to English as the official national language, informal spaces have embraced Luganda as a binding dialect for all shades of businesses, which aided my participatory work with diverse ethnic groups in industrial spaces throughout the entire research process.

This dual positionality created a semi-insider identity, which allowed me to build reciprocal and trustful working relationships young artisans and local Ugandan HIV support organisations and health practitioners<sup>50</sup> with considerable ‘insider knowledge’. At times, however, as Brooke (2016, p. 135) argues, initiating contact and interviews with some corporate executives in HIV

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<sup>50</sup> I worked with several local HIV support organisations (NGOs and CBOs) which include; The AIDS support organisation (TASO) and its Institutional Review Board (TASOREC), AIDS Information Centre (AIC), National Guidance and Empowerment Network for People Living with HIV/AIDS in Uganda (NGEN+), Lungujja Community Health Care Organisation (LUCOHECO), and the International Community of Women Living with HIV/AIDS, East Africa (ICWEA) with marginal contacts in Uganda National Young People Living with AIDS (UNYPA), as well as other local artisan bodies in the selected industrial areas in peri-urban Kampala.

organisations in Kampala required some degree of navigation around the gauntlet of personal secretaries and assistants, which led to undue delays during my fieldwork. Nonetheless, I built good working relationships with many of them, including artisan leaders which enabled me to collect insightful perspectives on everyday youth experiences in the context of HIV risk, prevention, and policy-related issues in light of the objectives of this research. Fluency in Luganda and English helped me circumvent some of the hidden and traumatising issues around persistent HIV related problems and also facilitated the use of culturally sensitive approaches (such as using idioms and metaphors in Luganda for sensitive issues like sex and sexuality) to social engagements with young people throughout the co-production process (Savage et al., 2006). Equally important is that working with young people who are potential agile, mobile, yet operating in very competitive settings was extremely challenging, as participants could not stay in the art workshops for planned periods of time because they had to work on their own projects. This therefore, required me to engage a rigorous approach to planning activities through which I explored their everyday lives (J. Campbell, 2002) in the context of HIV/AIDS.

During practical discourses in co-production workshops, several aspects of physical harm to their lives such as bodily injury from tool blades, accidents from lifting heavy materials, etc. were minimised through providing protective gear such as gloves, overalls and head visors, guidance and technical support from group leaders and myself. We occasionally experienced minor injuries and accidents during project errands, but they were immediately handled because I provided first aid boxes at the site of performance during the co-production of art forms.

#### **(i) Participants' welfare**

As an obligation to protect the rights and welfare of participants during the co-production sessions, I provided meals (sometimes snacks) and refreshments, particularly when we had lengthy sessions and occasionally when they had to wait at the study sites. A reasonable token of appreciation was often given out to them in compensation for time due to forgone opportunities and transport costs for study related activities. Most importantly, the tools and light equipment we used during the co-production of applied objects were also given to them at the end of the research activities as a form appreciation and support towards enhancing their livelihood opportunities.

Lastly, in order to avert conflicts of interest in terms of who takes credit for the findings, this research seeks to jointly produce knowledge and forms with young artisans through a co-production agenda, we mutually negotiated the design agendas and action processes with them resulting in co-ownership of data/findings. At the end, all the participants were recognised for their contribution towards the generation of the research findings at the launch of the first dissemination exhibition at Makerere University with ‘Certificates of participation’ which were presented to them by the guest of Honour, Retired Major Rubaramira Ruranga on 4<sup>th</sup> January 2021<sup>51</sup>.

### 3.6 DISSEMINATION OF FINDINGS

Every day experiences, group discussions (E.g., *Plate 12 and Plate 21*), thoughts, ideas and stories helped to inform, inspire, and facilitate the creation of art forms whilst demonstrating the efficacy of using applied sculpture as a tool of communication in addressing issues around HIV/AIDS prevention and awareness in the context of Covid-19 whilst contributing to the empowerment of these marginalised and socially excluded PLHIV in peri-urban spaces of Kampala. The output from the long and immense field engagements in those informal spaces gave rise to a range of findings as discussed in the subsequent chapters, and more profoundly tangible functional art forms (E.g., *Plate 22, Plate 32, Plate 40 and Plate 41*) through collaborative work with young artisans. These art forms were depicting lived experiences and narratives from stories shared during the group discussion in selected study sites. The creation of these artworks provided a platform for breaking the silence about stigma and social discrimination, privileging a straight talk forum with action groups whilst sharing practical skills for empowerment in the context of HIV/AIDS prevention among the participants. More so, co-production of those everyday objects was used to enhance social cohesion, reciprocal transfer of skills, knowledge and power as participants shared the control over the various stages of the research process to the end (Israel et al., 1998; Larkin L. Strong et al., 2009).

The outcomes of using applied sculpture as tool for HIV/AIDS prevention and empowerment of young people were shared in form of an audience reception exhibition of findings and

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<sup>51</sup> <https://sites.durham.ac.uk/GCRF-CDT/2021/01/28/major-rubaramira-ruranga-opens-research-dissemination-exhibition/>

HIV/AIDS artworks to public spaces/communities deemed impactful for its essence and relevance in contributing to the on-going national and global efforts to end HIV/AIDS as public health threat by 2030 fight HIV/AIDS in Uganda and elsewhere. The audience reception process also gave room for the much-needed feedback for improvement (with constructive criticism from attendees) and due affirmation of need to fathom applied sculpture as a potential tool for public health engagements in grassroots communities in developing contexts<sup>52</sup>. The communities for which the HIV/AIDS artworks exhibitions were held include academic institutions, health service providers and professionals, community-based organisations and non-governmental agencies, Ministries (Youth, Labour and social development and Health), individuals in HIV advocacy work and activism, participating communities, and the general public. However, due to limited time, only 3 dissemination events were held in strategic venues in Kampala as namely (i) Makerere University (University Art Gallery) (ii) TASO Centre, Mulago (iii) Ndeeba Industrial area Betania Zone).

#### **(i) Makerere University Art gallery.**

The reasons for holding the first dissemination event at Makerere University are threefold (a) its position as a partner institution with Durham University for this research project (a memorandum of understanding was signed in that respect) (b) it is representative of leading academic partners and institutions in HIV-related research work nationally and globally (c) it is one of the spaces where young people (students) are potentially considered one of the most-at-risk populations in the country. The function was attended by over 30 people including staff and management from Makerere University, students, representatives from CBOs such as LUCOHECO, ICWEA, UNYPA, BAYLOR Uganda and local media houses. It was officially launched by HIV activist Retired Major Rubaramira Ruranga and graced by the Vice Chancellor of Makerere University, Professor Josephine Nabukenya. In one of the key remarks of the launch, the Dean of School of Fine Art, Professor Kizito Maria, thanked me for inviting the communities that participated in the production of the artworks, as well as acting as a 'voice for the voiceless' young people in marginalised spaces in Kampala. After the exhibition, I conducted to

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<sup>52</sup> During the dissemination exhibition at Mulago TASO on 17<sup>th</sup> February 2021, the executive Director, TASO Uganda, Dr Bernard Michael Etukoit, who was also the guest speaker at the event asked me the following questions. "You clearly understand TASO very well, you also understand the history and the context of HIV epidemic in Uganda. Now, given that knowledge, what could you request TASO to do? What can we do in light of your work and how that can enhance the work that TASO is doing?"

face-to-face interviews with key attendees in order to gauge their responses towards the efficacy of applied sculpture in the fight against HIV/AIDS. Meanwhile, the journalists who attended produced articles about the exhibition in the local media.<sup>53</sup>

#### **(ii) Mulago Hospital, TASO Offices-**

This was the second venue for dissemination of the study finding on the 17<sup>th</sup> of March 2021 (See *Plate 13*). The event was organised in collaboration with office of the Manager TASO Mulago (Mr Nkabala Robert) and funded by GCRF-CDT, Durham University. The purpose of taking this exhibition to TASO was to enable providers of HIV treatment and testing services in Uganda and other professionals outside academia to make sense of the findings from grounded 'field' perspectives but also to evoke and sustain conversation around participatory art and HIV/AIDS – specifically applied sculpture as a social practice – that could potentially impact HIV intervention and programming for grassroots communities where modes of communication and information-sharing are predominately orate (L. Nabulime & McEwan, 2011). This occasion attracted over 60 attendees including management and staff from TASO, clinical officers from Mulago hospital, students, and HIV clients at TASO. This exhibition was officially opened by the Executive Director of TASO Uganda, Dr. Michael Bernard Etukoit.<sup>54</sup>

#### **(iii) Ndeeba open yard exhibition**

In Ndeeba, I organised a one-day exhibition on the 22<sup>nd</sup> of March 2020 which attracted a large crowd since the works were displayed in the open space in the middle of the industrial area near the railway in Betania zone (See *Plate 55*). Ndeeba being a highly informal setting, I chose to exhibit the applied art forms in the open unlike in the Makerere and TASO Mulago events where I exhibited indoors. This not only allowed for open interaction and face to face interviews with a diverse community, but also created a comparative platform to gauge the

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<sup>53</sup><https://cedat.mak.ac.ug/news/using-applied-sculpture-for-hiv-prevention-and-empowerment-of-young-people-in-uganda/>

<sup>54</sup> Dr. Michael Bernard Etukoit informed the audience how role of visual arts and how its evidence-based findings have demonstrated their potential in combating public health threat and in particular HIV/AIDS in sub-Saharan Africa through stimulating and sustaining dialogue and conversation about HIV and its attendant problems in marginalised urban settings as is the case with this research project today.



social and commercial viability of the applied objects that we co-produced with members of that community. Notably, I managed to conduct some informal face to face interviews with individuals from the crowd, although this was difficult given the crowded space and time available in order to invite attendees in conversation about the works and how they made sense of the messages that were contained in the work.

### **3.7 COVID-19 LOCKDOWN IN UGANDA AND UK**

Impact on planned research activities and results.

While severely affecting fieldwork, as discussed previously, the outbreak of coronavirus was also a blessing in disguise as it opened new opportunities of rethinking research action strategies as restrictive behaviours that were enforced by government to minimise the transmission of Covid-19 were in full enforcement. This helped me reframe ways of navigating social spaces as well as negotiating alternative avenues for exploring diverse contexts that shaped young people behaviours in the context of HIV/AIDS prevention.

Severe disruption to fieldwork lasted over 10 months. As discussed, lockdowns in Uganda (March-July 2020) prohibited research, which required an additional 3-months in Uganda to complete fieldwork/data collection. Consequently, this delayed my data analysis and writing up. Furthermore, the UK lockdown in January 2021 prohibited my travel back to Durham as planned, and added further complications to my abilities to work related to: (i) problems with technology and accessing Durham email due to inadequate mobile technology; (ii) lack of appropriate equipment in Uganda with which to analyse and write up data; (iii) maintaining regular online contact with supervisors, which was prohibitively expensive (iv) absence of a suitable place to work free from distraction and caring responsibilities, which have increased during the pandemic; (v) time lost to reviewing ethics protocols for approval, changing travel plans, rewriting risk assessments and travel insurance documents - at distance and with the same technological difficulties described above.

Lastly, whereas it might not have necessarily been related to structural limitations during my field work, the unrest and political violence associated with the 2021 general election campaigns in Uganda and severe disruption to internet access and social media also made it very difficult to work.

### 3.8 CONCLUSION

Conducting research with young people who are affected with and infected by HIV/AIDS is particularly sensitive and as such, it carries risks of increased vulnerability in the young people in informal spaces. The methodology of this study was designed with this in mind as it sought to ethically identify integrated and effective ways in which the young people would voluntarily participate within the research process, which included interactive session and co-production of applied objects. The participants were allowed to choose the mode and place of interview albeit the congestion in most of the industrial spaces where most participants lived and worked.

The interviews were largely unstructured and were conducted in a manner that minimised power imbalances, thus the young people felt relaxed and not threatened. To commence with field work required the engagement of research gate keepers who include community-based organisation and national HIV support organisations (See *Table 2*) to access the participants in the different study site and affording the ethics review process. During the co-production process, the action groups were allowed to use their indigenous knowledge and skills (integrated with sculptural techniques), and we mobilised materials from within the vicinity of the industrial zones which enabled them enjoy the processes and stimulated further dialogue about stigma and other HIV-related challenges in informal spaces. As a result, the data collected and applied objects that were co-produced were rich and reflected the participants' voices.

The data analysis provided insights into how the codes were derived before being integrated into the themes. It also demonstrated that the major themes to emerge from the data were mainly around (i) The inter-connected issues around marginalisation and economic precarities in the context of HIV/AIDS, (ii) The construction of young men's masculinities and gender inequalities in urban contexts and (iii) The role of applied sculpture as a social practice in understanding and interrogating young people's everyday lives to inform and inspire co-production of applied forms and knowledge for HIV/AIDS prevention and their empowerment.

The following three chapters present the key finding of the study in relation to these themes. To maintain anonymity, none of the young people's real names have been used; pseudonyms have been used instead. The next chapter explores what everyday life is like working and living

in the highly marginalized informal settings in industrial zones where relationships are forged in peri-urban spaces. It focuses on participants' narratives to reveal how marginalisation and economic precarities have shaped attitudes, behaviours, practices, and social identities among young people infected with and affected by HIV/AIDS.

## CHAPTER FOUR

### YOUNG PEOPLE AND MARGINALIZING EXPERIENCES

#### 4.0 INTRODUCTION

This chapter explores young people's accounts of their everyday social realities in informal spaces, recognising two significant forces that appear to be simultaneously shaping their thinking, interests, and behaviours with respect to the HIV/AIDS epidemic: (i) everyday life as a young person in marginalizing situations in the context of HIV/AIDS within informal spaces and, (ii) the nature and affordances of life in fluid and dynamic contexts of peri-urban development shaped by economic precarities. I focus on young people's ethnographic accounts of everyday life (relying on field notes recording conversations, interviews, participant observation, etc.) to inform and stimulate the creation of applied form intended to tackle HIV/AIDS among the youth working and living in the highly marginalized informal areas of Lungujja-Kosovo, Bwaise, Katwe and Ndeeba. Much of what participants told me was revealed in conversations during interactive sessions to generate ideas for participatory workshops; as discussed below, drawing, and sharing ideas in these sessions enabled conversations to emerge through which young people were able to articulate their everyday experiences. Specifically, I focus on how participants' narratives reveal how marginalisation and other interrelated socio-economic precarities (such as low educational and skills levels, rural urban migration, and labour exploitation) have shaped attitudes, behaviours and social identities among young people infected with and affected by HIV/AIDS. The purpose of this chapter is to set the scene for why it is important to use applied sculpture as a social practice for supporting young people in navigating challenges associated with HIV/AIDS. More specifically, the examination of marginalisation highlights the importance of applied sculptural practices that encourage health-enabling and/or health-enhancing behaviours, while also promoting socio-economic empowerment (see also chapters 6 and 7).

The chapter is organised into three major sections. In the first, attention is drawn briefly to the historical conditions that have led to youth marginalisation, and the interconnected issues related to their social exclusion in informal environments. Based on analysis of my

ethnographic and young people's accounts from field work, it focuses on three key aspects: exclusion in terms of local spatial geographies, HIV stigma and discrimination, and low educational/skill levels of young people in the informal spaces. The second section explores the economic precarities (poverty, labour exploitation, unemployment, and idleness) that shape the lives of young people and affect their behaviours, perceptions, and wellbeing in informal urban spaces. The third section links these accounts of exclusion and precarities with the socially engaged practice of applied sculpture, and its significance for understanding and tackling the socio-economic complexities that have allowed HIV/AIDS to flourish in informal spaces.

#### **4.1 EXISTENCE OF THE INFORMAL ECONOMY IN KAMPALA**

Socio-economic marginalization and economic precarities, which affect the lives and experiences of young people and increase their vulnerability to HIV/AIDS, are rooted in Uganda's post-colonial trajectory that has seen the growth of the urban informal sector. Political unrest in the late 1970s saw the economy go into 'free fall' (Kasfir, 1985, Wallmen, 1996). At this time, the economy was over-reliant on agriculture for development of infrastructure and foreign exchanges earnings. Further political unrest, corruption, and misappropriation of resources under President Obote in the 1980s led to the emergence of 'Magendo' (A Swahili word for black market) and the informal sector, commonly referred to as a second economy (Kasfir, 1983). Continued political instability halted migration into cities like Kampala, with reverse migration to the countryside becoming increasingly common. Living conditions for civil servants and others employed in the formal economy deteriorated and the Magendo economy, which combined black marketeering in foreign exchange and petty corruption flourished.

The growth of Kampala's informal sector has been subject to debate in urban geographies (Baker & Pedersen, 1995; Bibangambah, 1992). As Bibangambah (1992, p. 303) argues;

"The informal sector is not homogeneous; ...some aspects of it are counterproductive; ...the largest part of it is what has been called the 'Magendo' economy, implying that much of the activity is illegal, as the activities include petty crime, smuggling, black marketeering, prostitution and corruption; ...Shacks, squatter settlements and other unplanned or chaotic settlements labelled "town" but devoid of minimal public services such as water, drainage, transportation, educational and health services, rather than being a manifestation of development are instead symptoms of economic decay."

Similarly, the ruralization of urban areas through in-migration bringing subsistence agriculture and rural poverty – obliquely called urban agriculture – epitomizes that very decay, characterised by economic deprivation, absence of labour laws, zero health and safety rules, casualization of jobs, smuggling, waste collection, prostitution and drug peddling, which have been identified as some of the activities that are a source of livelihood in the informal sector (Bibangambah, 1992; Han, 2018; Young, 2019, 2021). With respect to Africa, and Uganda in particular, what has decayed or is decaying can be identified in three broad categories: institutional capabilities, infrastructures, and social values and standards (Baker & Pedersen, 1995). Nonetheless, the overall process of economic collapse in Uganda and wage earning in the formal economy has had serious consequences (Hansen and Twaddle 1991). As Kaguta (2020, p. 254) describes the periods between 1980 and 1986:

“There was a great shortage of consumer goods (sugar, salt, paraffin, soap and so on) and the whole economy had been informalized. There three most prominent words for informalisation were Magendo (smuggling), kibaanda (foreign exchange black market) and Kusamula (speculation): The informalisation of the economy had been preceded by the collapse of the formal sector.”

Towards the 1990s, there were unprecedented rates of rural-urban migration, which increased despite high levels of unemployment, low employment opportunities, and acute poverty in urban areas. Economic recovery in the country was very slow. HIV/AIDS infections rates also peaked (Gupta et al., 2008; Parkhurst, 2001; Murphy, et al., 2006), strangling all efforts of social and economic recovery. This was coupled with high levels of illiteracy and inadequate skills training in vocational crafts. Today, rural-urban migration persists, which has led to population explosions in informal settlements and in industrial spaces in particular, exerting pressure on limited resources, and causing a rise in social and public health problems (especially in relation to HIV/AIDS). The youth who have flocked to cities have resorted to casualized working, informal vending and squatting in cheap, squalid areas, particularly in and around industrial zones like the ones where I carried out my field work, in the hope of accessing job opportunities, social amenities, and health services, among other things. The process of restructuring and infrastructural development in the different urban settings led to growth and increase of small-scale technical cottage industries. These include wood processing and machinery plants using low technologies, wood, and metal workshops, and the Jua-kalis - the ‘street doctor’ entrepreneurs who fix things, recycle from scrap metals and discarded items,

and do a variety of 'odd-jobs'. The enduring crisis of the informal sector serves as a precursor to contemporary forms of marginalisation and economic precarity as they simultaneously overlap, alongside other HIV-related factors, to disempower and disadvantage young people living and working in peri-urban spaces in Kampala. While the local historical conversation about informality has provided important keystones to understanding the current state of informal lives in peri-urban spaces of Kampala, I argue here that similar conditions of informality continue to shape and complicate the everyday marginalising experiences of young people, as revealed through ethnographies of collaborative participation in the context of HIV/AIDS.

#### **4.2 MARGINALIZATION AS A FORM OF EXCLUSION AMONG YOUNG PEOPLE**

Understanding situations of marginalisation is paramount in providing a backdrop for why it is important to engage with applied sculpture as a social practice in countering such realities among young people in informal spaces. In most peri-urban settings, marginalizing experiences among young people not only go beyond highly visual forms of poverty, but also manifest in several specific ways. In this section these experiences are viewed and explored under different sub-themes including, spatial marginalization, rural-urban migrations, labour exploitation, unemployment, and idleness. There is a blurred boundary between poverty and exclusion where both may refer to marginalization as a concept (Bernt & Colini, 2013; Pierson, 2009; Popay, 2010). Although, poverty originally meant deficiency in the material means of subsistence, some academics go beyond this narrow definition. By adopting a broader perspective, they aim to respond to deep-seated socio-economic and political changes and increasing complexities. Indeed, Bernt & Colini, (2013) argue, in resonance with the findings of this study:

“The lines between poverty and exclusion are blurred and it is matter of controversy whether one term is more fitting than the other; that the term ‘exclusion’ can potentially provide a wider scope to the analysis of the dynamics producing a situation of disadvantage, that different forms of exclusion may or may not be related to actual lack of means (usually described as poverty), as people can be excluded on the basis of their race, age, or gender, etc..... In this context, social exclusion has been defined as “the lack or denial of resources, rights, goods and services and the inability to participate in the normal relationships and activities available to the majority of people in a society”

(Bernt et al., 2013, p. 5)

Similarly, according to Popay (2010, p. 296):

“The concept of marginalization, also referred to as social exclusion in some scholarly discourses, provides a framework for analysing the relationships between livelihood, well-being, and rights. Social exclusion or marginalisation, thus understood, is a fairly universal phenomenon seen at the global, national, and regional levels. The alternative approach to defining social exclusion is relational. This focuses attention onto exclusionary processes that are driven by unequal power relationships operating across four dimensions, economic, political, socio-cultural, and at different levels, individual, households, country, and global regions. These exclusionary processes create a continuum of inclusion/exclusion characterised by unjust distributions of resources, capabilities, and rights, i.e., socio-economic inequalities that in turn generate health inequalities.”

Popay further argues that this use of social exclusion is just another way of labelling disadvantaged groups and can be stigmatising. It presents the ‘problem’ as twofold: people are either included or excluded rendering unequal inclusion invisible. The participatory project through interactive engagement with young artisans was therefore a continuum of conscious and adoptive interrogation processes that brought issues of marginalisation to the fore in the context of HIV/AIDS. Having defined what is meant by marginalisation, I now provide an account of the different forms of marginalizing experiences, which are crucial in setting the scene for using applied sculpture as tool of social engagement for HIV/AIDS prevention-and-empowerment workshops among young people in peri-urban areas of Kampala (discussed further in chapters 6 and 7).

#### **4.2.1 Spatial marginalisation in peri-urban areas**

Informal settings such as Bwaise, Katwe and Ndeeba industrial areas, and Lungujja, provide opportunities to examine the spatial geographies (Whaley, 2018) that have shaped the thinking, attitudes, and behaviours of young people which, in turn, have created fertile ground for the HIV/AIDS epidemic to flourish in Uganda (Campbell, 2003). Today, these peri-urban informal spaces have become wealth accumulation areas, albeit at the expense of exploited young men and women who engage in casualized forms of employment in carpentry and machinery workshops as wood joiners, wood finishers, welders and timber and metal dealers. The majority are ill-educated migrant workers from rural locations, school dropouts and other disadvantaged youth from poverty-stricken families in the neighbourhoods of Kampala. Very few of these youth have the technical expertise and formal skills to work in these industrial



spaces. Congestion, noise, and air pollution characterise these settings, while the presence of unplanned dilapidated buildings, makeshift workshops (*'Ebibanda'*) and petty stalls add to the unpleasantness and danger of industrial spaces across Kampala. Most of these spaces have been characterised as chaotic violations of Kampala's aesthetics and sanitary standards, reflecting the colonial view of well-ordered urban space (Young, 2019). This has contributed to the extension of economic activity towards the margins of the city, complicating the meaning marginalisation in the local spatial geographies of Kampala. These peri-urban spaces of Kampala are continually transforming, as is evident in the expansion of formal commercial spaces (storeyed commercial buildings and other real estate properties such as petrol stations and supermarkets) which leave informal industrial settlements<sup>55</sup> overshadowed. This consequently provides cover for young people to freely engage in Magendo and Kusamula - speculation (e.g. Kaguta, 2020) - as well as the high-risk and often illegal activities, such as sex trade, gambling, petty crimes and alcoholism, arising from high levels of unemployment. The end result of these risky behaviours and practices has been perpetual risk of HIV/AIDS infection, yet it there is any hardly any adequate space/platform for these young people to freely talk about their experiences of marginalisation and how these impact their health and wellbeing.

From my field findings, young people living and working within the fringes of industrial spaces experience multiple forms of deprivation that inhibit social and economic transformation (see also Turshen & Wallman, 1998; Young, 2019, 2021). There is clear evidence of neglect by government leading to exclusion. For instance, there are no information signposts for Covid sanitisation in industrial areas, yet they exist in many other parts of the city. As examples of social or political exclusion, such experiences escalate complacency and lack of information among young people regarding issues relating to health risks such as HIV and Covid-19

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<sup>55</sup> Most informal industrial areas are located behind linear commercial buildings along the major highways from Kampala city. For example, Bwaise is on the Kampala-Gulu highway leading to the North, Ndeeba and Katwe industrial areas run along the Kampala-Masaka Highway to the West, and Nakawa is on the Kampala-Jinja Highway head East. Most are not officially gazetted by local government, which makes them highly informal industrial spaces that attract huge numbers of young people looking for casual jobs since there are no formal requirements of entry and engagement for work.

pandemics<sup>56</sup>, unsafe water, poor sanitation infrastructure, housing and inadequate provision of amenities and service on part of the local governments (Turshen & Wallman, 1998). As recounted in my field diary:

“On reaching the Bwaise industrial area at exactly 10:31am, I passed through a narrow road which was connecting from the main Kampala-Gulu Highway. As I moved all the way from the main road to the heart of the industrial area, I found a myriad of people doing different types of jobs ranging from roadside stalls for timber sales (Ebibanda), chapatis and sweets sellers to small carpentry and machinery workshops, mobile money booths, food kiosks, wood accessory retail shops and residential spaces in dilapidating shack buildings. Many of the roadside sellers and timber stalls operate almost towards the access road, prohibiting free movement of pedestrians and loading trucks into the industrial hinterland. The poorly-drained soggy road (almost impassable - *Plate 14*) stretching into the industrial artisan spaces provided a delicate panorama of an unsightly scenery similar to the informal experience in slum settlements of Katanga, Kivulu and Kosovo in Kampala”

(Field diary excerpt, 17<sup>th</sup> January 2020)

The physical settings, historical and social aspects of these spaces form the basis for understanding marginalization and exclusions that render the young people living and working here vulnerable and disadvantaged (e.g. Karolien et al., 2012; Lange, 2003; Turshen & Wallman, 1998; Young, 2021). This is explored further below through analysis of the different ways in which young people experience marginalisation and how this impacts on their vulnerability to HIV/AIDS. In what follows, first I explore the ways in which young people are locally experiencing the realities and impacts of HIV stigma, which remains high among the youth, then give accounts about the low educational and skills levels and show how they have affected their livelihood and wellbeing in peri-urban spaces of Kampala.

#### **4.2.2 Experiencing HIV stigma and social discrimination**

HIV/AIDS constitutes a very complex reality that affects almost every area of life (Kelly, 2010). As findings show, the emerging realities of HIV/AIDS in developing urban areas are rising prevalence because of negative attitudes towards testing and treatment, especially among heterosexual men who remain the primary propagators of HIV (Mills et al., 2012; Simpson,

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<sup>56</sup> The Covid-19 pandemic has become a new public health threat colliding with resurgent levels of HIV infection in Uganda and beyond. Drastic national lockdowns and curfews to prevent infection not only affected the economic and social wellbeing of informal communities most acutely, but also disrupted the daily routines of public life in Kampala.

2009; Siu, et al. 2014). This unfortunately has been exacerbated by the Covid-19 pandemic, which has hugely disrupted the public health landscape to create expanded contexts in which HIV/AIDS flourishes. This raises questions about possible ways of understanding and tackling emerging threats in relation to growing social stigma and the micro-level concerns of individual attitudes, interests, social identities, and behaviours in shared informal spaces. Whereas there have been strategic attempts in Uganda for the last two decades to tackle HIV among young people, social exclusion, and stigma (Subedar et al., 2018; Turshen & Wallman, 1998) remain problems that need to be further addressed. There are various circumstances under which young people experience stigma and social exclusion; my participation with young people exposes the realities of the HIV stigma, discrimination, and impoverishment they experience in Kampala's informal spaces.

Many of the HIV positive participants in this study reported a long history of challenges related to being isolated, neglected and socially disconnected from their communities and families, which affected their ability to improve their own livelihoods and wellbeing. These experiences denied them the potential to access to health support and care and at the same time escalated internal stigma<sup>57</sup>, which discouraged them from accessing testing and treatment. A 25-year male, participant G<sup>58</sup>, talked about feeling socially withdrawn and rejected by his relatives coupled with gossip by his neighbours, which affected his will and ability to seek medical help. In the long run his health started to deteriorate and instead of seeking treatment, he resorted to heavy drinking and isolation. During the first art and creativity workshop in Lungujja, Participant G recounts;

“I was living with my brother in Lungujja-Kitunzi and later in 2016 I got a wife and left his home to stay in a single roomed house in Kosovo<sup>59</sup>. After one year, my wife died, and my neighbours claimed that she was HIV positive. Instead of encouraging me to go for a check-up, they began to point fingers at me alleging that I will follow her soon

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<sup>57</sup> Enacted stigma also known as external stigma or discrimination refers to the experience of unfair treatment by others. It often leads to withdrawal and restriction of social support.

<sup>58</sup> Participant G (allegedly HIV positive) was one of the ill persons visited during the distribution of Covid relief items from Lungujja Community Health Care Organisation (LUCOHECO) to vulnerable families which had people living with HIV/AIDS (PLHIV) and other critically sick persons in Lungujja on 3<sup>rd</sup> May 2020. Ssentongo Robert has been used as a pseudonym in this research.

<sup>59</sup> Kosovo is another Kampala peri-urban neighbourhood with informal settlements that provides cheap accommodation for low-income earners.

(die). My brother and other relatives also started spreading rumours that I was HIV positive, yet at the time I did not have any signs of it. Eventually, when I started falling sick, I could not stand the continued humiliation from my own people as a young adult. I resorted to self-isolation, staying indoors almost every day, and also started heavy drinking (alcohol) to hide my problems. It was such a traumatizing experience for me because my relatives and the society had abandoned me. However, after getting bed ridden, I was taken by a Good Samaritan to Rubaga hospital<sup>60</sup> and I was diagnosed as HIV positive.” Whereas I am on treatment and getting better, I still feel abandoned and unwanted by own people”

(Field diary, Informal conversation, Lungujja, 3<sup>rd</sup> May 2020)

Accounts like this, and many others as explored subsequently, highlight Popay’s (2010) shopping list approach<sup>61</sup> that describes exclusion as a situation experienced by a particular individual or groups. Here specifically, Participant G’s feeling of being rejected as HIV positive was arguably a marginalizing experience. Sadly, in most communities in Uganda and elsewhere in sub-Saharan contexts, being HIV positive is still treated as a death sentence or lifelong curse. He said that at one time he received a call from community health workers (CHWs) in Lungujja who advised him to go to LUCOHECO<sup>62</sup> for testing and treatment, but he refused because of stigma caused by the rumours in the neighbourhood. Pita is not alone.

Another 23-year-old HIV-positive Participant H recounts how stigma made her feel marginalised in a domestic environment, which gradually jeopardised her wellbeing and freedom of expression. During an interview in one of the interactive art-and-creativity sessions in Lungujja, she responds as follows:

Interviewer: When and how did you know that you are HIV positive?

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<sup>60</sup> Rubaga hospital is one of oldest hospitals in Uganda that offers HIV treatment and counselling services to the people living in the neighbourhoods of peri-urban Kampala. Its Public Health Department has an HIV/AIDS care and treatment programme which is responsible for all HIV/AIDS care and ART services. HIV testing services (HTS) are offered to clients/patients for free. Patients/clients who test HIV+ are immediately started on ART.

<sup>61</sup> The shopping list approach is one of Jennie Popay (2010)’s notions of marginalisation in which particular groups, for example, indigenous peoples, the poor, the homeless, migrants, people with chronic/terminal illnesses such as cancer, HIV/AIDS, etc., and disabilities are excluded from a never-ending shopping list of things including: ‘a livelihood; secure, permanent employment; earnings; property, credit, or land; housing; education, skills, and cultural capital; citizenship and legal equality; democratic participation; public goods; family and sociability; humanity, respect, fulfilment and understanding among others.

<sup>62</sup> LUCOHECO in full is Lungujja Community Health Care Organisation, a Community-based organisation providing HIV/AIDS support, care, and counselling services to local residents in Lungujja, a residential peri-urban neighbourhood Kampala city.

Participant H: I started falling sick with constant headaches frequently, malaria and diarrhoea. Then I was advised to go for testing in 2008 but at the time my father was reluctant to take me for testing. For he never wanted me to know that I was HIV positive. And I found that I was positive

Interviewer: Ok, how and when did you get to know your status?

Participant H: After a long battle with malaria and constant cough, I decided to go to my Auntie in Lungujja-Kitunzi for medical treatment. My parents had abandoned me. But as I turned 15 years old, my mother died of HIV/AIDS. Then my father then came and told me that I was also infected at birth. I was left at the mercy of my auntie who took care of me as I grew up to the age of 18 years, albeit with a lot of resentment. Eventually, even my cousins started mistreating me and discriminated against me all the time. As I could no longer stand the harsh treatment and discrimination, a growing feeling of dejection and despair forced me leave their home to stay with a friend in Kosovo, a shanty neighbourhood in Lungujja, Kampala

(Interview excerpts, Lungujja, 10<sup>th</sup> June 2020)

The three key words in Participant H's account – abandonment, mistreatment, and discrimination – capture the effects of stigma (Muchena, 2021). Research has shown that many young people living with HIV today have prenatally acquired HIV or acquired it during or after birth when breast-feeding (Hazra, et al., 2010; Muchena, 2021). As my fieldwork indicates, many of these young people experience estrangement, exclusion, and stigma. They experience serious trauma with guardians and caretakers who not only inflict pain and instil fear, but also discriminate against them.

Both accounts (Participants G and H) are consistent with growing reports and social science literature that show how neglect and social isolation among young people living and affected by HIV/AIDS propagate social stigma and exclusion, which produces inhibitive behaviours that worsen their health conditions (Muchena, 2021; Parker & Aggleton, 2003). This points to the greater problem of marginalisation, which emanates from experiences of enacted stigma that lowers self-esteem and prevents young people from freely expressing themselves as they face deteriorating health conditions. These personal traumatic experiences of neglect experiences are real and truly marginalizing, often resulting in socially withdrawn identities.

During another interactive session in participatory workshops for HIV awareness in Ndeeba industrial area, more distressing experiences of marginalised living were brought to my attention. A 24-year Participant L approaches me.

“Please Musomesa<sup>63</sup> I have a brother (Artisan X, 22 years old) who was tested HIV positive. He lives here in the neighbourhood but of late, he has resorted to alcohol, started drinking heavily and refused to adhere to his drug regime. His health has gone from bad to worse. He has been isolating himself for months now and he doesn’t want to speak to anyone or even go for medical attention. What can I do?”

(Field notes; 20<sup>th</sup> October 2020, Betania zone, Ndeeba, 12:15 pm)

This narrative further demonstrates the effects of stigma and exclusion that shape young people’s behaviour, attitudes, and social identity within the industrial communities in which they live or work. When Artisan X reported to the workshop the next day, he admitted to being on Antiretroviral Therapy (ART) but said he was forced into social withdraw because of enacted stigma, gossip, and allegations of promiscuity as the cause for his HIV status within the community.

“I have failed to maintain my take my medicine because my neighbours keep gossiping about me. I would take to alcohol than to be humiliated every day. I keep drinking all the time to avoid public sentiments”

(Informal Interview, Artisan X, Ndeeba Industrial area, 21<sup>st</sup> October 2020)

His failure to conform to his prescribed drug regime and resorting to alcohol and drugs significantly affected his self-esteem and created a stigmatized identity of himself consequently affecting his health and wellbeing. As Neema et al., (2012, p. 232) argue, “HIV-related stigma discourages people from disclosing their status, entering care, and adhering to antiretroviral regimes, all of which represent missed opportunities for prevention”. However, when participant L’s brother accepted an invitation to participate in art and creativity workshops, he engaged with diverse group of young participants in co-producing applied arts forms for HIV/AIDS awareness, which helped him reframe his attitude, and reduced his fear and feelings of dejection. This is significant in the light of compelling field evidence in Uganda that suggests that a failure to address stigma and discrimination among young people results in limited uptake of HIV testing, treatment and support services (Mburu et al., 2014; L. Nabulime & McEwan, 2011; Neema et al., 2012; Uganda AIDS Commission, 2016).

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<sup>63</sup> ‘Musomesa’ means Trainer or teacher in Luganda

### (i) Complacency or Ignorance: The Lack of information

Talking to adolescent participants in informal spaces during interactive sessions to generate ideas for participatory workshops permitted deeper conversations around life histories and aspects of HIV-related stigma and exclusion, which also revealed the importance of interconnected factors such as lack of information about HIV (Bunnell et al., 2008; Opio et al., 2008; Riggs et al., 2018) and the availability of related health services. For example, A 34-year-old participant K, recounts how he contracted HIV in 2009 out of ignorance, but assumes he caught it from his girlfriend:

“I got my first girl friend called Sara in 2009 when I was in S.4 at 19 years. As you can see, I was young and inexperienced, yet Sara was older than me (28 years). She was working and renting a single room as a ‘nakyeombekedde’ (single woman who is either unmarried or widowed) in our neighbourhood. I used to go to her place every day to play a video game since her house was near our home. She would occasionally drink alcohol in my presence. One day she called me as I was going past her place. She was coming from the bathroom with a towel around her body. When I entered the house, she intentionally dropped the towel and seduced me to have sex with her. For sure, she had great body and looked healthy. It was hard for me to resist the temptation. Since I was inexperienced and still a virgin, she taught me how to have sex (without protection). After a while, I began to have fun and she started inviting me to her house regularly. However, one day, a friend, who was our neighbour too, told me that Sara was HIV positive because she had lost her husband to HIV. I did not take it seriously because she was physically strong, beautiful, and healthy. My doubts ended when I started falling sick (opportunistic illnesses – a heavy cough body sores – see **Plate 15**, and constant malaria), my friend came back and reminded me of how he had warned me before. Since that time, I lived in denial and started hiding from all my friends. My parents took me for testing, and I was found HIV positive. To make matters worse, they also began to openly discriminate me by separating utility dishes and household items. I became miserable, isolated, and disowned”

(Face to face interview, Participant K, Lunguja-Kosovo, 7<sup>th</sup> May 2020)

When I shared stories of similar experiences of stigma with participants (the majority of whom were young men) in other workshops in Bwaise and Ndeeba industrial areas, it was clear that many agreed that young people were experiencing the same trauma of neglect and self-imposed isolation that arose from wider societal discrimination. Several participants were able to open up about their own HIV/AIDS-related experiences and how they confronted them. However, at one point a participant asks:

“How would you say that someone is HIV positive when we cannot see any bodily signs like scars or red lips? We do not even see those taking ARVs daily, yet they are amongst us. Could being healthy looking mean being free from HIV/AIDS?”

(Participatory workshop, 20-year-old female participant, Ndeeba)

There are several possible answers to this participant’s concerns. First is it was deemed prudent to discuss how the possible ways in which HIV was transmitted. 10 out of the 13 participants had accurate knowledge of the different avenues of controlling its spread, except for a few disparities in knowledge about HIV prevention and control methods such as self-testing kits. They mentioned the traditional control methods such the ABC strategy (Abstinence, be faithful and use a Condom) and restraint from sharing surgical or piercing instruments. Only 8 were knowledgeable about the possibility of infection through blood transfusion. Interestingly, as the discussions unfolded, one participant who claimed to be a migrant from Congo claimed that: “Some of us are not aware of the new methods such as the self-testing kits that are advertised radios”. It was agreed therefore that it was extremely important to share relevant information about these challenges and knowledge about protection, and to seek testing and treatment services from nearby hospital within Kampala.

Despite existing gaps regarding information sharing and awareness about prevention, the HIV/AIDS landscape has changed significantly because of the success of biomedical interventions (e.g., Bekalu & Eggermont, 2012; Mafigiri et al., 2017; Murphy et al., 2006), the ABC strategy, ART (Antiretroviral Therapy), PMTCT (Prevention of Mother to Child Transmissions), VCCM (Voluntary Medical Male Circumcision). As discussed in Chapter 2, arts-based interventions (Berman, 2017; Brett-Maclean, 2009; Bunn et al., 2020; Clennon & Boehm, 2014; Nabulime & McEwan, 2011), such as music, dance and drama, body mapping and so on, have also been important in countering social stigma concerning HIV/AIDS. With these successes – particularly the use of Anti-Retroviral Therapy (ART) – HIV is no longer depicted as manifesting in bodily characteristics such as lesions, red lips, and TB-related constant coughing as it was in the 1990s. The greatest challenge, however, remains with seeking alternative modes of youth engagement, enhancing information-sharing channels and foster social-economic empowerment in ways that curtail the landscape in which HIV flourishes.



Otherwise, in various ways, ART means the disease is more hidden and young people's lack of knowledge and experience of how HIV ravaged communities and decimated human bodies in the 1990s is creating high levels of complacency (e.g. Popay, 2010; Subedar et al., 2018). Clearly, Participant K's case above shows that whereas marginalization is a direct consequence of stigma and discrimination, ignorance, and lack of sufficient information about HIV/AIDS prevention have increasingly made young people even more susceptible to contracting HIV. In January 2020, the same observation was made in a statement by the programme manager of the Infectious Disease Institute (IDI).

"Today complacency has become costly; the risk of complacency is greater now because people living with HIV have happy healthy lives as long as they adhere to the treatment, so the scary picture of patients is not there; the frail, Sickly and dying frame marked with multiple scars which was the representative image of whoever got infected with HIV is no longer there to scare people into keeping guard"

(Elvis Basudde, New Vision newspaper, 26<sup>th</sup> January 2020, Pg. 48): see also Kapp, 2008)

This statement resonates with the account of one of the participants during the co-production of applied objects and HIV/AIDS awareness discussion forum among a group of young participants in Ndeeba industrial area in August 2020. In a discussion session on the theme of '*okuvumula kusinga okwonga*', (Prevention is better than cure), Participant C, a 23-year-old female sander in Ndeeba, illustrates the problem of complacency among young people:

Participant B: Ok then, what are the key bodily signs that which show that someone is HIV positive or suffering from AIDS?

Interviewer: "Of course, I am not an expert on this. However, today the signs of HIV/AIDS are no longer the same as in the past. The best option is to rely on testing and seeking medical advice from health experts in our local hospitals. There is antiretroviral therapy (ART) for those who are infected which is available in all Health centre IVs in Kampala and in all other authorized HIV testing centres across the country. They are given out for free if you have been tested positive. Therefore, it is important for all of us to test and use condoms always. You need to know and access these services which are available, regardless of your age and social status. AIDS doesn't discriminate: You must always protect yourselves from contracting HIV.

Participant A: But now there are some adolescent girls/young women among us who are saying that they would rather become infected with HIV than getting pregnant.

Participant C: "Nange ye ngombo yange, 'OLUBUTO' lwensinga okutya". (Yes, that is my slogan too, I fear pregnancy [olubuto] much more than Embwa).

Interviewer: Did you just say? You don't fear AIDS?

Participant C: Yes, I don't fear HIV, I only fear pregnancy.

Participant B: Let her explain to us. Assuming she gets infected with HIV and not pregnancy, what would you do?

Participant C: Ok, once you get infected with HIV, you can still lead a normal life if you adhere to ARVs.

There are two interesting observations from the above excerpts. First, young people always found ways of avoiding referring directly to HIV/AIDS by using metaphors (Dugga, 2015). The word '*Embwa*' (Dog), is commonly used to refer to HIV/AIDS in informal workspaces and resonates with the belief and stigma in many communities that HIV is associated with promiscuity. Embwa relates the disease with stray dogs. The young people use the term to insinuate the element of promiscuity, which increases the impact of stigma on an individual. Second, Participant C's account is representative of the notions of complacency among many young women, especially adolescent girls, who dread pregnancy but still don't bother to protect themselves from acquiring HIV. Today, complacency has become heavily contested issue because of the growing biomedical and behavioural approaches to HIV/AIDS such as ART, ABC, PrEP and PMTCT, and other technological interventions provide renewed life opportunities to people living with HIV/AIDS (PLHIV) e.g. (Kapp, 2008; UAC, 2016, 2017, 2020; UNAIDS, 2017). This has significantly reduced the fear of HIV as a 'death-sentence' apparent in the previous decades (Parker & Aggleton, 2003; Wyrod, 2011). Many PLHIV have been put on treatment, while others are living positive with a suppressed viral load e.g. (Doshi et al., 2018; Elvis Basudde, 2020). Whereas this complacency may signal less stigma among some youth, findings still show that HIV largely remains a dreaded epidemic, with stigma associated with negative perceptions among local communities and other underlying factors that compromise health and wellbeing of those affected by and infected with it. There is mounting evidence that many young men avoid testing and seeking medical treatment, despite generally being more promiscuous (Mafigiri et al. 2017, p. 2). Thus, the case illustrated above not only demonstrates that identity and disclosure of HIV are very hard to negotiate among young people, but also that complacency results from both marginalisation – specifically lack of adequate information, knowledge, and access to testing facilities – and a lack of awareness among young people of how serious HIV is. Therefore, appropriate youth-centred interventions must be geared

towards educating young people about the importance of seeking HIV health support and social economic empowerment to induce positive action for change.

Having discussed experiences of stigma, discrimination and how the advent of biomedical interventions have increased levels of complacency among young people in the informal and HIV/AIDS prevention contexts, the following section explores and examines how low education and skill levels overlap as marginalizing experiences in shaping the landscape in which HIV flourishes in informal spaces in peri-urban Kampala.

#### **4.2.3 Low education and skills levels**

Today, despite gains made in the education sector, Uganda still suffers from high levels of ignorance and poverty (Evans, 2015). Over the last decade or so, the increased enrolment in both primary and secondary school through free education-for-all programme has significantly helped young boys and girls access education, particularly those who could not attend previously due to economic and cultural problems. However, questions remain over the quality of education, appropriateness of the curriculum, and high rates of school dropouts that mean that large numbers of young people (both uneducated and semi-educated) still end up in industrial areas looking for casual employment. Evidence from findings of this research show that most of the participants were school dropouts (between primary two and senior four). As discussed below, school drop-outs are associated with *'Abataasoma'* (uneducated people), *'Banekko'* (hawkers or sex workers), notions of idle youth, and rising level of HIV/AIDS infections, particularly in the greater Kampala city area e.g. (Choudhry et al., 2015; Simpson, 2009; Wyrod, 2016)

##### **(i) *'Abataasoma'*: The non-educated and social construction of identity**

The stark contrast in educational levels, particularly between those who are illiterate and semi-illiterate, makes marginalization a complex issue in informal spaces. Many youths who join these industrial spaces are inducted into the informal businesses and use Luganda as a business dialect and as a means of belonging, in spite of the existing ethnic diversities in these peri-urban locations. Industrial spaces are dominated by people who are least educated and a small group with limited education who, in the process of staying and working in these spaces, develop a common identity, describing themselves as *'Abatasoma'* – those who never went to

school. I noted that some participants were unreserved at calling themselves un-educated because they were doing jobs that did not require any specialized training. A 22-year-old wood finisher and senior four dropout recounts;

“I am Collecting scrap and loading metal bars into my boss’s hardware shop is all I can do without regret because I am not educated”, a 21-year artisan tells me about his contentment as a casual worker in Katwe industrial area. Nonetheless, it is an opportunity to learn on the job even when you are educated.

(Informal conversation, Participant N, Bwaise industrial area, 5<sup>th</sup> April 2020)

“After my S.4 studies at Fairway High School, Kampala in 2017, I stayed home for a long time. When my sister brought to work as a casual labourer, I felt indignant at getting involved at first. But my financial situation could not allow, I realised the need to adapt and adopt new ways of living. ‘Omanyi bwoba wasomako, olina eddala mwewetwalila’ (You know, when you are educated, you assume a certain social status). Those who are not ready to learn new ways of living will always remain poor. It hurts to be in a place like this one when you have had some education, but the economic dictates of life pushed me here. So, I keep going, learn new methods and progress”

(interactive session, Bwaise industrial area, 5<sup>th</sup> April 2020)

Most young artisans who participated in the art and creativity workshops recount how their failure to complete school confined them to finding casual jobs in informal industrial spaces because such spaces are potentially accommodating to the uneducated and less or least-educated populations.

Ironically, many of the migrant workers join these informal spaces without basic industrial skills, such as wood joinery and metal fabrication that are the main activities in these locations. They thus have no choice but to take precarious odd jobs and casual tasks, such as sanding, loading, scrap collection and so on, which are poorly paid and unreliable. Being confined to such tasks due to lack of specialized skills and expertise in industrial operations is one of the most frustrating experiences among urban youth who come with the anticipation of securing better livelihood opportunities and work options (Moses, 2016; Rotheram-Borus et al., 2012; Tukundane et al., 2015). This form of marginalisation is compounded by lack of opportunities for apprenticeships through which to acquire industrial skills, which adds to their frustration and disillusionment, and leads some to turn to unscrupulous or illegal activities. This situation is corroborated with findings from Green valley workshop in Arua industrial area, West Nile,

Uganda<sup>64</sup>. On the 29<sup>th</sup> of February 2020, I interacted with two male carpenters A and B (18 and 20 years respectively), who participated in building the pedestals for the HIV/AIDS sculpture exhibits for the IDI (Institute of Infectious Diseases) travelling exhibition at the Catholic parish Hall in Arua town. As we crafted the bases, I saw another group of about 6 young men converging around small makeshift structure, a couple of metres away, so I asked them:

Interviewer: what are those men doing over there? Are they craftsman or idlers?

Carpenter A: They are part of us. They are wood sanders and timber loaders, but because of inadequate technical skills, they rely on casual forms of work such as sanding, grinding, and loading. They find themselves idle because they have to wait for assignments from carpenters or timber dealers. In the process of waiting, they begin to gossip and some resort to smoking a local herb called Mira, playing cards, and drinking alcohol.

Interviewer: What is Mira?

Carpenter B: Mira is local herb which grows as weed in gardens but harvested for consumption as a potent herb. We used it to get more stamina to work for long hours without resting. Some people claim that it boosts one's sexual appetite/libido. In other cultures, like the Ganda culture, it is called Enjaga (opium). It is also as a lucky charm for getting customers. Those men over there keep eating the weed (which they mix with chewing gum to disguise its smell) especially when they fail to get work. They eventually become high and for some reason get rowdy, doing all sorts of weird things including hauling insults to passers-by.

Interviewer: Are there any other side problems associated with this practice (Mira smoking)?

Carpenter A: Yes of course, it affects us in many other ways. For instance, those who are addicted to it hardly concentrate on their jobs, while others are forced to behave in ways that are sexually offensive especially to young women who work in this industrial area.

Such accounts confirm that young people engage in risky activities and behaviours resulting from lack of adequate skill to keep them busy at work, consequently finding themselves involved in risky behaviours that expose them to HIV infection. Similar findings from Bwaise and Ndeeba industrial areas in Kampala show that young men often get high with drugs and disappear into nearby makeshift bars to enjoy the company of young girls and women who work as bartenders. The inability to retain jobs or seek better paying jobs and opportunities

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<sup>64</sup> On the 26<sup>th</sup> of February 2020 I had the opportunity to travel to Arua in West Nile region of Uganda to volunteer with the installation support team for the traveling exhibition for HIV/AIDS organized by the Institute of Infectious Diseases (IDI), Academy for health innovations, Makerere University.

due to inadequate skills leads to such HIV-risk behaviours and disillusionment among young people. In the same vein, during my introduction session as a fieldworker in one of the interactive working meetings with a group of young welders in Katwe industrial area, an artisan asks me in Luganda:

“Lwaki ffe Abataasoma otutawanya? Ot wagazaki nga tetusobola nakusoma luzungu lwamwe?” Tuleke, gwe tolaba betufanana? - “Why are you disturbing us, yet we never went to school? We are not educated, and we don’t understand English, leave us alone. Don’t you see how we look like?”

(Field diary, Katwe industrial area, 3<sup>rd</sup> August 2020)

My identity was now at the centre of interrogation. Unlike the others, I was dressed in a relatively new overall. Fortunately, my fluency in Luganda and a primary contact with a member from within the group meant the meeting could proceed. In responding to their concerns, I knew it required more tact to avoid losing the much-needed rapport that I was trying to build at the time. My role as semi-insider (who could speak Luganda fluently and with grounded expertise in applied sculptural practice) played a crucial role in navigating situations of social exclusion experienced in several spaces of participatory interaction with non-educated artisans amongst school dropouts<sup>65</sup> who acknowledged enduring difficulties in reading and translating their stories into pictures during the participatory workshops.

Similarly, a 24-year university graduate who joined the artisan community as a professional engraver from Makerere University<sup>66</sup> recounts his exclusionary experience of working with artisans in Bwaise;

“In 2018, my first experience as a privileged graduate (sculptor) joining a highly uneducated artisan community was rather frustrating especially when they realised that I was a graduate from Makerere University. At one point an artisan boldly told me that I was in wrong place, insisting that I belonged to the elite class that is supposed to be working in Kampala’s central business District (CBD) and as such they could not bring

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<sup>65</sup> Out of the over 30 artisans who participated in the art and creativity workshops in the different peri-urban locations, only two were University graduates. The rest were school dropouts and uneducated youth. The majority were primary school dropouts. Many of the uneducated ones did not show any interest in participating in the research project.

<sup>66</sup> Interview with a graduate of Bachelor of industrial and Fine Art from Makerere University, who joined the artisan community in 2017 as a wood engraver.

me jobs; partly because I was dressed differently and accustomed to mixing the local language with English”

(Field diary, Informal conversation, Bwaise, 8<sup>th</sup> April 2020)

To this graduate, being educated was essential in establishing himself as an accomplished craftsman. In trying to fit in to the new community at the time, he identified with the local artisans by donning similar overall and using the Luganda as a business language. However, he admits:

“It is not easy to work with young people who are largely untrained and are learning on the job. When I first opened my workshop, many young men did not want to associate with me particularly when they saw me dressed in heavy cotton overall and using good equipment. They tend to believe that whoever joins their spaces ought to speak, appear or behave like them. So, I had to quickly adjust by acquiring outfits like those they wear. If you do not change, then they begin negative propaganda about your business”

These mentalities around informal living and working tend to strangle the potential of improving working methods and transformations geared towards skills development, consequently affecting their livelihoods. Such experiences raise a number of questions (i) who feels marginalized or disempowered and how? (ii) Why/how would one feel so disadvantaged because of educational differences? (iii) Was it a form of identity crisis or social conflict? The answers lie primarily in addressing issues around marginalisation, perhaps, in ways that bring actors in the same space with similar or related practical involvement through inclusive participation, to tackle exclusionary tendencies, raise awareness about HIV/AIDS prevention, stimulate active involvement and free expression whilst integrating socially engaged practices that abhor divisive and discriminatory engagements- as explored in detail in the subsequent chapters.

### **(ii) Leaving school: encountering the unknown**

Many young people leave school with hope to find lucrative business opportunities and workspace. Unfortunately, they end up in informal spaces where work is predominantly casual and poorly paid. In a casual conversation with 23-year Carpenter Y, in the greater Bwaise industrial area, he observes:

“Many young people, especially adolescent girls, drop out of school for financial reasons, while other leave because of early pregnancies, try to look for work in less restrictive spaces such industrial areas where casual jobs are common and require little

or no skills. As life gets harder, some choose or get initiated into alternative income sources as they try to get by. “Olusi bakola lwagulo emilimu egyo nga bwogimanyi” (Sometimes they go out and about for those weird evening jobs)”

(Field diary, Informal conversation, 20<sup>th</sup> February 2020)

When I asked what he meant by “*Olusi akola lwagulo emilimu egyo nga bwogimanyi*” (Sometimes they go out and about for those weird evening jobs), he replied: “selling her body for money in one of the neighbouring sex work hotspots in Bwaise-Kimombasa”<sup>67</sup>. This area has a poor reputation regarding precarity and HIV risks. For example, in 2013, Monitor Newspaper (Ortega, 2013a, p. 24) lamented about life in Bwaise:

“Kimombasa—where sex is sold 24-7, “there are several sections of emaciated sex workers. They use all the vulgar words at their disposal and not even the presence of their children deters them. These emaciated ones, I understand, make up the faction of HIV positive sex workers. Devoid of hope, they offer sex at any amount, at any hour with or without protection. Some of their teenage children have already been initiated into the practice”

The population of Bwaise is highly vulnerable, with extreme levels of poverty, many school dropouts, prostitution, single mothers, and domestic violence, with attendant social stigma and other intractable social problems (ibid. p. 24). This narrative about this sex business resonates with scenarios that young people told me about during my fieldwork in Bwaise and Katwe industrial areas. Having explored the main exclusionary experiences of young people and the interconnectedness of the responsible factors in the context of HIV/AIDS, I contend that without creatively addressing such conditions among disadvantaged communities, young people continue to remain susceptible to HIV infections in those less-served informal spaces. The next section addresses the interrelated issues of economic deprivation, rural urban migration and labour exploitation as overlapping conditions that have left young people at the margins of impoverishment and prone to perpetual HIV risk.

#### **4.3 ECONOMIC PRECARITIES AS MARGINALIZING EXPERIENCES.**

Cultural anthropologists define precarity as an emerging abandonment that pushes away from a liveable life (Han, 2018; Stewart, 2012). In a growing body of scholarship centred on social marginalization, the concept of precarity has come to be described as a situation in which

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<sup>67</sup> Kimombasa is one of the centres of commercial sex in Bwaise town (within the precincts of one of the study sites - Bwaise industrial area), Kawempe Division, Kampala.



certain populations suffer from failing social-economic networks and are thereby exposed to injury, violence or even death. Moreover, the impoverished (migrants, temporary workers, elderly, the homeless and racial minorities) are often blamed for their own poverty (Barchiesi, 2003; Young, 2019), with precarity seen as a result of moral failure of individuals. This masks the power relations and structural violence embedded in the global political economy (Stewart, 2012). As my fieldwork reveals, economic precarities in their different contexts increasingly shape the HIV/AIDS landscape in ways that are detrimental to the well-being and livelihoods of young people in informal spaces. Understanding life as precarious suggests that social existence itself depends on interdependence at both micro and macro-levels through care for others (Han, 2018; Stewart, 2012).

Ironically, while the government is neglecting these areas, they constitute important spaces for young, practicing artisans and industrialists who are using minimal resources to contribute to economic development, not only at micro level for household incomes, but also in terms of macro-development through paying taxes. The absurd taxes policy on property and real estate reflects a conflict between the state and productive citizens where many of them in the informal spaces are presumably earning less than one dollar a day because of ‘casualized’ forms of employment<sup>68</sup>. The local government levies through the Kampala city council authority (KCCA)<sup>69</sup> on businesses and property are entangled with unofficial practices such as corruption. The bad tax regimes and negligence on the part of government, in many ways, through underhand methods, major actors who are either the landlords, elders and/or owners of workshops avoid paying taxes by sub-letting premises and pass on the burden by exploiting their young workers who sub-rent industrial spaces, thereby pushing them to margins of survival. In a conversation with one the workshop owners under the Bwaise furniture makers SACCO<sup>70</sup>, when asked why most artisan are evading taxes, he replies;

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<sup>68</sup> Casual employment refers to the type of occupation where wages are paid only for the actual worked time, meaning they do not get paid for holidays or leaves of any kind.

<sup>69</sup> KCCA is the body mandated with issuing trading licences for micro-level business and collecting property rent from small scale businesses in Kampala district

<sup>70</sup> Savings and Credit Co-operatives (SACCOs) are community membership-based financial institutions that are formed and owned by their members in promotion of their economic interests. In Uganda, savings and credit

“The government and KCCA in particular, subject us to high rent levies from our workshops and spaces we occupy yet they don’t improve the infrastructure in our industrial area. Do you see the state of the road that leads to this place? (See *Plate 14* and *Plate 16*). It gets extremely impassable during the rainy season, and we lose business. Otherwise, we find ways of evading taxes by conniving with revenue officers. Others simply pass on the tax burden to those young people who are sub-renting workshops thus affecting their incomes, yet they get meagre pay”

(Interview, Muso Faisal, 19<sup>th</sup> August 2020)

Social exclusion comes in form of a downward ripple effect of the tax burden to those at that the lower scales who, in most cases, the young people are operating as carpenters, sanders and carvers or welders in workshops. This arguably causes collective harm and consequently stifles collective development affecting employment, the livelihoods and wellbeing of those young people. It is important to note that such exclusionary tendencies have had detrimental effects on the young actors who toil through hard work every day to pay ground charges for the spaces they occupy (see, for example, *Plate 16*), leaving them needing to find alternative means of income to sustain themselves and their families. As participant F, a 27-year machinist<sup>71</sup> in Katwe reveals;

“You will find that most of the young men we employ in our welding section prefer to operate late in the night to avoid the daily levies by council collectors. This also forces the food vendors to work late into the night as they wait to be paid for the food they served during the day. This has always put the lives of young women in danger because they get assaulted by drug addicts and criminals who waylay them as they pass through dark corridors between workshops and residential alleys to go home”

(Interview conversation, Katwe industrial area, 3<sup>rd</sup> August 2020)

As these experiences become routine, such accounts reveal the underlying impacts of social exclusion that degenerate into social problems such as drug abuse, sexual assault, alcoholism, commercial sex and so on, which in turn create a fertile ground in which HIV/AIDS thrives. However, not all is lost. Some young people struggle to find positive ways of negotiating

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cooperatives act as financial intermediaries, channelling savings into loans, provide saving opportunities for the people in both the rural areas and urban areas.

<sup>71</sup> Participant F was my primary contact who worked with me before the Covid lockdown in February. He is one of those artisans (machinist) who has been working in Katwe industrial area for over 10 years and has lots of experience in artisanry production with young people.

economic dilemmas to sustain their livelihoods and wellbeing such as joining micro finance institutions or artisan associations in their respective areas. For instance, a group of young artisans from Bwaise industrial area were involved in a savings scheme intended not only to raise money for ground rent, but also for future investments in other private businesses (Figure 17). As recounted in an excerpt from my field diary, this also caters for contingencies and family obligations:

“At 12:38, as we were busy sanding with a group of young women (in their mid-20s) outside a makeshift carpentry workshop, I saw a woman dressed in a UGA-SAVE Micro Fund overall talking to Participant N (Wood finisher/sander) and after a brief chat, they entered the workshop store and on coming back, I saw her jotting down some notes in a small pink book (*Plate 17*). After which, she told me that UGA-SAVE Micro Fund is a local micro-finance institution which helps to save money for artisans who are employed in this industrial area; That since we are very busy every day, the organisation always sends its agents to collect our contributions from our workplaces daily. Each member is expected to deposit between 1000 and 3000 shillings per day since most of us are engaged in casualized working (earning less than 10,000 shillings- Approx. \$3) a day. However, some artisans are unable to join the fund because they earn very little money. Otherwise, having the UGA-SAVE offices conveniently located in the heart of Bwaise town enables us to withdraw our money since it is partly saved to pay for the ground rent and other contingencies of life”

(Field diary, 6<sup>th</sup> August 2020, Bwaise Industrial area)

In referring to ‘some artisans being unable to join the saving group’, Participant N’s observation not only points to greater challenges of meagre pay by employers (mainly furniture workshop owners), but also to high levels of unemployment and limited job opportunities, implying that some of the artisans or young people tend to become socially excluded due to a lack of means/income. This increases the likelihood of resorting to illegal activities in the fringes of the industrial spaces such as sex work, gambling, alcoholism and Magendo to boost their livelihoods. This exposes them to increased risks of HIV/AIDS, as it is usually a last strategy in trying to overcome economic exclusion (Muriisa, 2008). Having discussed how economic exclusion in form of taxing young people in ways that affect their livelihood, I now turn to discussing how poverty, rural urban migration and labour exploitation interlace into a complex web of precarity for young migrants joining the industrial spaces of Kampala

### **Poverty, rural urban migration, and labour exploitation**

Simultaneous trends towards the urbanisation of poverty, with the poor moving into towns and cities faster than the rest of the population have been scrutinised in scholarly discourse

(Bibangambah, 1992; Hunter, 2010; Martins, 2014; Pedersen, 1992). The high levels of poor young people moving from rural locations to escape unproductive agricultural practices into urban areas in search for job opportunities has had tremendous effects on demographic composition. Negative consequences on health and social life in peri-urban areas are visible in the impacts of HIV/AIDS on the everyday experiences of unemployed youths (Byamugisha, Shamchiyeva, & Kizu, 2014). My study with young people infected and affected with HIV/AIDS in Kampala revealed that while the majority young people are forced to leave their homes/villages due to poverty, domestic violence and gendered abuse, others were trafficked by relatives and casual labour dealers into work as casual day labourers in informal industrial spaces of Kampala. Oftentimes, after realising that they have been duped, they start seeking alternative ways of survival to meet their everyday life obligations and wellbeing, and to support their families.

My research reveals that when they migrate from villages into industrial spaces to escape rural poverty, many young people land low paying casual jobs such as food vending, wood finishing (sanding and vanishing), loading timber and goods on trucks, hardware shop attending, bartending and so on, while others, especially young women, simply fail to get better paying opportunities and end up engaging in auxiliary businesses such as roadside stalls for light goods, scrap metal and wood off-cut and saw-dust packing and sales etc. While many relocate from the countryside in the hope of getting better work opportunities, findings show that many end up in squalid industrial spaces doing casual jobs. As a 23-year old sander-cum-carpenter (Participant V) testifies;

“After losing my father to HIV/AIDS in 2016, we had no means of livelihood. So, I travelled from Gulu<sup>72</sup> to Kampala upon a charcoal truck and started looking for casual jobs in Ndeeba industrial area to support my mother and siblings back in the village. I did not have any skills so had to settle for sanding as an apprentice. At one point I had to collect and sell scrap metal from Katwe for survival”

(informal conversation, Ndeeba, 23<sup>rd</sup> August 2020)

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<sup>72</sup> Gulu is a district in Norther Uganda. It is approximately 300kms from Kampala city.

Similarly, in an interview with Participant W, a 20-year-old artisan on 5<sup>th</sup> October 2020, evidence of frustrations of migration and economic misfortunes due to lack of skills are revealed.

Interviewer: What are doing here and how did you find work in this industrial area in this area

Participant W: I am wood finisher. Most people call us sanders. I joined this industrial area in 2017 after my senior four exams when I dropped out of school in Bundibugyo because of financial difficulties and came to Kampala to meet my brother who was working as a carpenter on Ggaba road in Kampala. So, when I met him, he instead referred me to a friend who had a bigger workshop in Ndeeba. I did not have any field experience nor skills to work in any technical spaces.

Interviewer: How did you manage to get started in this new area, yet you did not have any skills?

Participant W: It was one of the most frustrating experience of my life. Having been connected by my brother to a carpenter in Ndeeba industrial area, I walked 7 miles from Ggaba to meet him. It was getting dark, and I had first to find where to sleep. With nowhere to sleep, no blanket nor mattress, Zaidi advised me to make use of his makeshift workshop as an option and later made me work as an askari (security man) to safeguard his workshop at night. He made me work for long hours every day with very little and sometimes no pay at all. With no immediate alternatives, I had to use this opportunity to acquire wood working skills. I depended on casual jobs like cleaning other carpentry workshops and loading timber to get some little subsistence as a beginner.

Participant W's accounts of life as a migrant in the fringes of Kampala city is representative of many young people who find themselves living at the margins of life such spaces. Lack of practical skills confines many to labour exploitation in casualized jobs which cannot even adequately sustain their welfare as growing individuals. Participant W is caught in a trap of dilemmas. (Working as a night askari and toiling every day with little or no pay). With little or no technical skills, he must work at night, which also prevents him from realising his potential by pursuing a decent job. Findings show that as more youth, especially young men, migrate to these industrial spaces, that those who fail to get any work resort to petty crime (pickpocketing, gambling, and sex trade), while the young women often in such circumstances find themselves engaged casual sexual relationships as a way of surviving in these male dominated spaces. At times some of these youths are recruited and transported trafficked by

unscrupulous middlemen from villages to towns. These experiences are further corroborated in accounts by Participant X, a 30-year Kafunda<sup>73</sup> owner in Katwe industrial area who attests:

“I employ five girls in my food joint, two of them are single mothers who migrated from upcountry (Kasese) while the others are school dropouts who were recruited and trafficked from eastern region. These women are between 16 and 26 and were desperate and ready to work here. The one from Kasese are brought to me by our agents for a commission. I pay them more or less 5000 shillings per day because that is what the business can afford, even when I clearly know they have to meet several needs – transport, pay rent, lunch, and personal effects such as make-up etc. The problem with us here, unlike the formal jobs, our work is basic and highly casual.”

(Informal conversation, Katwe, and 21st Feb 2020)

*As a 23-year food vendor (Participant Z) from Bwaise industrial area;*

“I am a food vendor with Sikyomu restaurant here in Bwaise industrial zone. I come from western Uganda. My job is to look for potential customers among artisans in workshops and in the industrial neighbourhood. My boss pays me between 4000 and 6000 shillings basing on the proceeds of the day. It means working very hard to be paid better. Sometimes I have to feed on leftovers, which often pushes me to ‘kweyiya’ (seek alternatives)”.

When I ask her what ‘Okweyiya’ means, she replies;

“It means going for transactional relationships (getting different boyfriends to buy me lunch and other necessities in exchange for sex)”

(Informal chat, participant Z, Bwaise, 6<sup>th</sup> March 2020)

Not only are these accounts crucial, but also important in helping us understand the social and economic texture of the environment and circumstances in which these experiences occurred. Working in the industrial spaces is daunting and risky. As narrated by Participant X and Z, many young women working as food vendors are exploited in ways that tempt them into risky behaviours that expose them to HIV infections. Meanwhile, most of the young women and adolescent girls work in auxiliary spaces and are largely involved in jobs like roadside petty businesses such as selling sweets and biscuits, timber kiosks (*‘Ebibanda’*), vending second-hand clothes and mobile money booths, where owners exploit them through making them work long hours for meagre pay. Food vendors are the worst hit group, as they spend the greater

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<sup>73</sup> ‘Kafunda’ is a common Luganda word used in most informal spaces to mean a small makeshift kiosk for food or bar or barber shop.

part of everyday combing industrial spaces for potential customers (carpenters, sanders, timber dealers, loaders, wheelbarrow pushers, boda-bodas, etc.). Selling food yet getting through the day on an empty stomach is particularly cruel. It is no surprise, then, that many get in touch with different men who offer to supplement their daily earnings in exchange for transactional affairs. This increases their susceptibility to sex work and HIV risk as they get by.

Through these testimonies, the interlinked phenomena around economic deprivation and HIV/AIDS can be understood (Bruce & Hallman, 2008; Gupta et al., 2008; Seeley & Pringle, 2001). Several studies suggest that poverty drives many girls to accept relationships with older men who are prepared to give money, goods, or favours in return for sex (transactional/cross-generational relationships). The unequal power relations reflected in such relationships affect adolescent girls' ability to refuse unsafe sex, and expose them to sexually transmitted infections, including HIV/AIDS e.g. (Bruce & Hallman, 2008; Smith, 2002; Subedar et al., 2018). Evidence from participatory field engagements in informal spaces like Katwe, Ndeeba or Bwaise confirms the long-held view that HIV/AIDS disproportionately affects young women (Kim & Watts, 2005; Nicholas, 2010) because they experience more marginalizing and dehumanising situations than men as they navigate spaces of economic deprivation. On the other hand, however, one wonders what happens to those young people who are trafficked or migrated when they get infected with HIV/AIDS and choose to return to their rural homes? Unfortunately, as migrants return or leave their work in urban spaces with HIV (knowingly or unknowingly), there are very high chances of infecting their regular partners or other sexual partners (e.g. Gould, 2004). Although migration-led HIV transmission is not the primary concern of this research, the discussions around rural-urban experiences are a strong reflection of dire consequences of increased labour mobility in the context of HIV/AIDS in the greater Kampala city and beyond.

Having discussed the different experiences of marginalisation among young people in peri-urban Kampala and how they have shaped the landscape in which HIV thrives, the final section of this chapter draws attention to why it is important to use applied sculpture as a social platform towards local participation for HIV prevention, awareness and supporting youth towards socio-economic empowerment through skills development and capacity building.

#### 4.4 WHY APPLIED SCULPTURE MATTERS IN THE CONTEXT OF MARGINALISATION

Marginalization remains a complex condition of disadvantage which youth and grassroots communities experience as result of those vulnerabilities and interrelated factors explored above (e.g., Bernt & Colini, 2013; Mehretu et al., 2000). Indeed, young people's exclusionary experiences in informal spaces such as HIV stigma, labour exploitation, low education, and skills levels and so on, all of which increased their vulnerability to HIV, can potentially be addressed through using applied sculpture (participatory art) as a socially engaged practice. Accordingly, using participatory art workshops to explore such challenges was a deliberate attempt towards building HIV/AIDS awareness first, by dealing with how to enable disadvantaged youth to talk about their everyday marginalizing experiences in ways that expose the socio-economic barriers to HIV/AIDS prevention among young people. The worryingly high number of young men competing for few women in industrial workspaces is a matter of critical concern; with stigma, discrimination, trafficking of young women, casualized working are among other key factors identified as affecting livelihoods and the social wellbeing of young people in informal spaces. Inevitably, however, increased fluidity in mobility of young workers especially young women criss-crossing peri-urban spaces, calls for strategic engagement to control the likely transmissions that happen with mobile populations. The question of defining the possible communication and sharing platform with young uneducated people about HIV/AIDS and its attendant problems remains contentious if not addressed in ways that help them navigate it.

Notably, the different forms of exploitation and labour mobility in peri-urban spaces is arguably a result of inadequate skills for job retention, a need for improved livelihood opportunities, and complacency that arises from marginalisation and discrimination (Riggs et al., 2018; Uganda Aids Commission, 2016). Additionally, there are still several gaps in recognising HIV/AIDS as a development problem whilst confining the responses to the epidemic to biomedical and behavioural approaches e.g. (Kelly, 2010) without addressing empowerment concerns to stem underlying social-economic factors that have allowed HIV/AIDS to flourish in many informal spaces in Uganda and beyond.

These observations, field experiences and narratives thus form the foundation for understanding the informal spaces in which the young people negotiate their lives, setting the stage for using applied sculpture as an interventional social platform. As a potential solution,



applied sculpture (as a social practice) can allow young people living in such marginalizing circumstances, particularly those infected with and affected by HIV/AIDS, to freely express themselves whilst developing their knowledge, skills and talents in ways that build capacity for better livelihood and wellbeing. The harsh realities of stigma and discrimination associated with HIV/AIDS are at times very hard to talk about in ordinary situations of life, especially among the youth in communities where forms of communication and information-sharing are predominately orated e.g. (L. M. Nabulime & McEwan, 2014; L. Nabulime & McEwan, 2011). In a way, as the subsequent chapters demonstrate, applied sculpture potentially permits the use of tangible materials such as metal, wood, and clay to express oneself in ways that may have a long term visual and practical impact through acquired technical skills in fabrication, drawing and social engagement (see also chapters 6 and 7).

#### **4.5 CONCLUSION**

This chapter began by describing the continued existence of informal spaces and lives in Kampala and arguing that historical conditions of informal sector development in the city are central in the understanding of the current marginalising experiences among young people in relation to HIV epidemic. It suggests that every-day experiences of marginalisation in the form of social exclusion, HIV stigma, discrimination, and economic decay, provide important contexts for initiating participatory interactions and workshops that could allow young people to engage in conversations. Thus, the chapter captures something of the everyday lives of young people in informal areas of the city and suggests that practical applied working, such as participatory workshops, can provide an enabling environment in which young people feel able to share experiences of their marginalisation (Berman, 2017; Walls, Deane, & O'Connor, 2016). Clearly, evidence from the interactive sessions during fieldwork – ethnographic fieldnotes, interviews, audio transcriptions and participant observation – suggest that young women and adolescent girls, in particular, remain highly vulnerable to HIV risk in informal spaces. The economic precariousities (poverty, labour exploitation, idleness and limited job opportunities), low education and skills levels are a part of the interconnected social predicaments that provide a compelling standpoint for understanding the increased vulnerability of young men and women, especially adolescent girls, in negotiating sex, identities and wellbeing in the context of HIV/AIDS (Bell & Aggleton, 2013; Choudhry et al., 2015; Jewkes & Morrell, 2010): And

indeed, recent findings also suggest that as long as socio-economic challenges are not addressed, HIV/AIDS infections will continue to grow: the intersectionality between poverty, sexual rights and AIDS remains as one of the biggest challenges in the struggle against AIDS in Africa (Wyrod, 2016).

This chapter sets the scene for making sense of the role and importance of applied sculpture in exploring lives of young people in the context of HIV/AIDS and economic empowerment. It provides the context for the participatory art workshops (and the socially engaged practice of applied sculpture), which explore deep-seated issues around sensitive aspects such as sex and sexuality, gender inequalities, masculinities, and other social barriers to open communication about HIV/AIDS among young people in informal spaces. As demonstrated in subsequent chapters, applied sculpture creates possibilities for expressing feelings and experiences that cannot be put into words, provoking thought, and discussion, likely to influence health-enabling behaviours, and probably provide some basis for economic transformation through improved individual livelihoods. Although its potential for livelihood enhancement, impacts and behaviour change call for subsequent follow-up research to ascertain the extent of such benefits among the youth. In the chapter that follows, I focus on how the process of co-production (visual explorations of everyday experiences) helped to build trust and enabled young people to talk about sensitive subjects like sex, gender, and HIV/AIDS, whilst linking the social practice of applied sculpture with sharing knowledge about work, HIV risk, its prevention and potential for youth empowerment.

## CHAPTER FIVE

### APPLIED SCULPTURAL PRACTICE, URBAN MASCULINITIES AND GENDER INEQUALITIES

#### 5.0 INTRODUCTION

This chapter brings together a set of ethnographically detailed accounts related to using applied artistic practices (applied social sculpture) in exploring deep-seated issues related to sex and sexuality, masculinity, and other gender inequalities in the context of HIV/AIDS among young people in informal spaces. This chapter, thus, enables expression of visual ideas and experiences that provoke thought and discussion with the intention of influencing health-enhancing behaviours and practices, and to improve HIV/AIDS awareness, prevention, and youth empowerment. It primarily draws on the participatory involvement of young people in action groups through sharing their lived experiences (stories and life histories) as sources of inspiration to inform and facilitate visual representations that confront barriers to HIV/AIDS prevention and youth empowerment. The purpose of this chapter, therefore, is to demonstrate how the process of co-production of knowledge, skills, and forms helps to build trust and enables young people to openly talk about taboo subjects like sex, death, gender injustices and HIV/AIDS, while linking the social practice of applied sculpture with the sharing of knowledge about HIV/AIDS risk, its prevention and youth empowerment. It also helps to show how the process of collaborative engagement through participatory art workshops enables participants to enhance self-esteem, improve their work skills and most crucially, sustain conversations and dialogue about HIV/AIDS causes and the need for behavioural change. It emerges that young men's participation in the construction of masculinities is a key factor in the rising levels of HIV infection manifested in their high level of alcohol consumption, compounded by the misogynistic tendencies of blaming women for men's proneness to risky sex when drinking. This, as further revealed through participatory dialogue, shows traits of sexual objectification of women and the far-reaching consequences of sexism perpetrated by young men. These understandings provide the basis for the creation of tangible objects (three-dimensional – 3D - artworks in permanent materials such as wood and metal act as tools of communication) to confronting these challenges in the context of HIV/AIDS prevention and

awareness among young people (discussed further in Chapter 6). They provide the essence of why it is important to use applied sculpture in encouraging young people to unlock their inherent talents but even more crucially, enable them talk openly about their vulnerabilities in the context of HIV/AIDS in peri-urban spaces.

The chapter is organised into two sections. The first focuses on how group conversations and discussions based on every day experiences and regarding critical social issues like gender, sexuality and HIV-related death emerge. It opens discussions underpinning the ordeals of young women working in male-dominated industrial spaces/artisan communities in Kampala, using visual explorations that allow free expression with anticipation to stimulate behavioural change and HIV prevention. The second section explores and discusses ways in which young men participate in the construction of urban masculinities in informal spaces that eventually increase their vulnerability to HIV infections. It elucidates the interconnectedness between work, HIV/AIDS and sexuality and how applied art helps reveal elements of misogyny<sup>74</sup> and other hegemonic urban masculinities (see, for example, Connell & Messerschmidt, 2005; Wyrod, 2008, 2016) related to the rising levels of HIV/AIDS infections among young people. As indicated above, discussions in both sections are centred on demonstrating the importance of applied sculpture (reference is given to generated artworks) as a stimulant for group dialogues and capacity development to enable them to reframe mentalities, interests, attitudes, practices, and behaviours in ways that are expressive and health-enhancing to counter the spread of HIV/AIDS in informal spaces.

Having mentioned that combining stories, every-day experiences and drawing are central to enriching applied sculpture as a social practice, I now explore the ways in which this collaborative approach facilitates the understanding of critical social realities such as sex, gender, and death in relation to HIV/AIDS among young people. I also attempt to show, in some cases, how the emerging visual ideas from stories and every day experiences were developed and translated into tactile three-dimensional concepts (applied objects), while linking the social practice of applied sculpture with the sharing of knowledge about HIV/AIDS and its prevention

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<sup>74</sup> Misogyny is a form of displeasure, contempt for, or ingrained prejudice against women.

in less-served communities where opportunities for formal education are limited or non-existent.

## **5.1 CRAFTING STORIES FROM THEIR OWN EXPERIENCES**

Stories are a vital form of communication through which people, communities and society at large relay messages, entertainment, experiences, and knowledge to others. They bring meaning to our lives and experiences and enable us to connect with our inner selves, with others and with society. Similarly, the underlying premise of narrative inquiry is the belief that individuals make sense of their world most effectively by telling stories (Hill et al., 2002). It is also believed that:

“Stories contextualise and humanise knowledge and they deal almost exclusively with the know-how of applied art, so essential to skilled practice. Stories require the narrator to recognise and reflect upon his/her life positions, roles, and motivations, and in so doing create an opportunity for the narrator and the audience alike to develop new perspectives.”

(Bowles, 1995, p. 365)

Stories appeal on a number of levels, firstly, they entertain, and are capable of evoking an emotional response, which may be pleasurable, but which also may be therapeutic at a deeper level for the person. They are capable of evoking fellow feeling and promoting greater understanding, and are vehicles by which individual concerns may be validated and legitimised in the words of others (Attig, 1992), fostering hope and enabling a more positive orientation towards specific situations. Therefore, working with young people (both infected with and affected by HIV/AIDS) provides an opportunity to jointly reflect on real-life experiences, particularly those that are hard to openly narrate in everyday life. Each of the stories that were shared reveal the complex situations in which young people continue to knowingly engage in risky sexual relationships and how applied sculpture enables and sustains open conversations, imagination, creative thinking, and practice towards HIV/AIDS awareness, enabling prevention, and engendering empowerment.

### **5.1.0 Stories and visual imagery about sex and death in the HIV/AIDS context**

The process of applied artistic practice (social sculpture) typically begins from visual exploration of situations or scenes (using ink, pencil, or colour on paper) of ideas developed from narratives and stories or issues from our immediate social environment. It is these ideas

that are translated into tangible forms (in metal, wood, and clay), making them both utilitarian and aesthetically appealing. I argue that it allows young people to use visual imagery to communicate their awareness of critical social issues through stories, and most crucially, in ways that help in breaking the silence about their everyday situations of living with and/or confronting HIV/AIDS and its attendant problems (see also Berckmans et al., 2016). At the beginning of each participatory workshop, all the artisans who consent to take part are registered and assembled in a space safe from undue intrusion since the industrial area is a very busy hub (See *Plate 18*). Accounts of their precarious existence from the participants are openly shared during the participatory workshops, duly recognizing of their power as holders of local knowledge and mutuality (e.g., Chambers, 1994; Cornwall & Jewkes, 1995; Jupp, 2007). This enables conversations and dialogues to progress in line with the objectives of each workshop. Bringing together participants from diverse ethnic/social backgrounds under one design roof (brainstorming and drawing sessions) is, a key catalyst for a gradual but steady transition towards addressing social and structural barriers through open communication. The process not only builds rapport, but also enables the participants to appreciate the essence of collective engagement (Jennings et al., 2012; Wilson et al., 2007) in relation to sharing and understanding their everyday social experiences in the context of HIV/AIDS in the peri-urban geographies. Effectively, this was done through storytelling, collaborative writing, and illustrative drawing as icebreakers for co-creating applied artworks (*Plate 18*). Notably, group performances in workshops provided the participants with opportunities to present their stories and the visual exploration of their lived experiences on paper (2D). Sometimes, the beginnings tend to be murky as participants would feel uncertain about circumstances surrounding their engagement (Scope of work and contingencies such as intrusion by non-participants), albeit the reassurance of favourable creative protocols, practical benefits, constant reinforcement, and encouragement. For instance, during one of the participatory workshops in Ndeeba industrial area, I recollect that:

“As I looked around, I noticed a relatively unique situation. A sizeable crowd occupying a fairly small interior which is devoid of the common working apparatuses used by craftsmen apart from art pencils, improvised drawing boards and papers. Over 14 participants (3 female and 11 male) converging around me (some seated on benches and others standing) inside a little makeshift structure covered with sisal sacks fastened on several interlacing wood pillars acting as walls and roofed with patches of rusty iron sheets. The entrance is appearing blocked because of the limited space inside.

All the participants are dressed in rather dirty outfits and new face masks (which I gave them as a primary Covid-19 safety measure). Twenty minutes into my introduction. I notice a young man (about 20 years old) squeezing through the participants to reach me. No sooner had he gotten closer than one participant hurriedly pulled him by the hand and said “*Yanga, wano tuli mumusomo. Oyagala ki?* (Young man, our workshop is already in progress, what do you want?). Conspicuously, two things crossed my mind. First, I observe the astuteness of this particular participant who I admittedly identified as a potential group mobilizer before the start of the workshop. Secondly, the intrusion is a sign that even other members of the immediate artisan community seem particularly keen to follow what is happening inside. Meanwhile, the intruder quickly asks with humility, “Please *musomesa* (teacher), allow me to join the group”. So, I immediately break my communication and called everyone to attention. ‘Look here’, I said, ‘let’s give this young man a chance to participate’. Maybe he has something special to share with us in this workshop. Suddenly, a voice from one participants at the back comes roaring through. “*Oyo namuyise ngatutandika nagana, Kati atwagaza ki?*” (I called him at the beginning of this session, and he refused. Now what does he want now?). In his defence, the intruder confesses, “yes it true you called me, but I did not understand the essence of this workshop until I heard the open talk about HIV/AIDS prevention and developing our crafting skills and talent”. Soon after, I verbally ask him whether he would consent to become a regular participant in the subsequent workshops to which he accepts without hesitation. Murmurs of contentment filled the air, and the session continued”

(Field dairy, participatory workshop, Ndeeba industrial area, 21<sup>st</sup> October 2020)

After the next creativity workshop, I wrote:

“Many of you encounter diverse life experiences that you hardly share with friends or narrate them openly in your workspaces’, I remarked and then, began a short conversation about my personal love-life, sex, and HIV/AIDS. Thereafter, I decide to ask them questions about their sex life/stories and love relationships. For it seems as though sex issues are perceived as taboo when they all momentarily keep silent. Suddenly, one 23-year-old male participant remarks “*Mubuwangwa bwawano mubuganda tekikirizibwa kwogela mubya mukisenge mulukale* (It is culturally abominable to talk about sex issues publicly here in Buganda). I then tactfully decide to encourage each of them to write down stories or draw their experiences on paper which eventually blossomed into thornier issues related to sex and sexuality, multiple relationships, sex work, poverty, and AIDS-related death. Initially, four male participants boldly volunteer to begin. After listening to their stories, I quickly challenge one of the girls to contribute afterwards. She hesitantly looks around as if to see what her friend’s reaction is. Unexpectedly, the third female participant who is seating next to her insinuates; “*Oyo yatusinga obumanyi mubya lavu*” (She know love issues better than all of us). Since she is the eldest of the three girls in a male dominated group, she reservedly accepts”

(Field dairy, Participatory workshop, Ndeeba industrial area, 24<sup>th</sup> October 2020)

Meanwhile, a female participant M begins to share her story about a colleague (fellow artisan) who had sex with a woman into the carpentry workshop (See **Plate 19**). Other participants were shocked by the account. “*Okwo kweyiiya*” (*That’s hustling*), a male voice is heard from the back. As I shall explain later, this turns out to be the title for this story. Interestingly, it also encouraged the rest of the participants to feel encouraged to talk freely about their everyday precarious experiences. Meanwhile, I engaged the participants into writing down their stories in groups of three in order to support each other (with my guidance), and later chose the most captivating stories drawn on paper (2D) with a powerful visual appeal.

Following this, the group completed the exercise of collaborative writing and drawing, not only in recognition of the possible similarities in social and personal experiences, but also to allow each member to offer support and contribute to the collective effort of story documentation as seen in **Plate 18**. It was a way of guiding and encouraging collective performance, while dealing with potential fears associated with taboo topics, literacy deficits and expressive communication related to group sharing. As a common co-operation strategy within groups (e.g. Kim et al., 2001), deliberations were based on one presentation at a time to give chance to each and every participant to make their contributions. In the long run, the process was helpful in setting the stage for collective selection of the most provocative stories and narratives that were finally transformed into co-produced applied artworks for HIV/AIDS prevention and empowerment (see Chapter 6). Taken together, the most touching and relevant stories and narratives generated interesting debates about emerging ideas, a process that allowed participants to develop their creative thinking and expressive skills. The discussions were centred on the emergent themes related to sex work, unequal gender relations, death, masculinity, and so on, which formed the basis for conceptualising these issues into visual representations in 2D (paper, plywood, etc.). The biggest hurdle, however, was how to begin translating the imaginative ideas, stories and lived experiences into concrete visual images. In order to build extra confidence, the participants were first given quick drawing drills<sup>75</sup> for two days, on how to draw fleeting ideas in line work using pens and pencils (E.g., **Plate 19, Plate 22, Plate 23**, etc.).

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<sup>75</sup> Quick-minute drawing refers to the short span session designed to guide learners in line drawing to develop observation and transfer skills when deriving inspiration from the immediate environment, social phenomena, or a written brief/narrative.



### 5.1.1 Emerging Concepts

From over five participatory workshop sessions, three unique stories emerged. These were (i) *Okweyiiya* ('Sex in the workshop' presented as Artwork A - **Plate 19**) (ii) *Malaaya vva kumutembeyi* - ('Hawker leave the vendor alone' presented as Artwork B - **Plate 22**) (iii) *Embwa ya' nawookeera*<sup>76</sup> ('Sexual relationships, HIV/AIDS and death' presented as Artwork C - **Plate 27**). These three artworks form basis of the deliberations about the critical social issues in this first section. Remarkably, the interest among the participants in developing drawing skills, including the subject matter (themes) of their illustrations, was, in a way, a catalyst for empowering them to discuss critical social issues such as sex, intimate relationships, HIV/AIDS, and how some of their young peers were involved in risky sexual relationships for monetary gain. In what follows, I present and explore those themes, here-in labelled as artworks A, B and C, and the centrality of applied social sculpture in understanding these social realities among young people in the context of HIV/AIDS

#### 5.1.1.0 Artwork A: *Okweyiiya* ('the urban hustle') as young women work in male-dominated settings

Artwork A – '*Okweyiiya*' (The urban hustle) – was selected and codenamed by the participants during the concept development stage of the co-production process. I use the term urban hustle in exploring the everyday dealings associated with uncertainty and accepted informalities that pervade realms of everyday life among youth in precarious urban geographies (e.g., Thieme, 2017). This resonates conspicuously with the exploration of everyday experiences of negotiating life and HIV risks in marginal urban areas among young people through conversations and storytelling. '*Okweyiiya*' is based on a story about an artisan *who had sex on the bench in his workshop in the Ndeeba industrial area* (See **Plate 19**), as narrated by a female participant M, and later, as I shall subsequently explore, by Participant Q (Artwork D - See **Plate 32**). Both stories are related to situations of having unprotected sex, narrated, written, and visually translated, which further stimulated and sustained the subsequent group discussions on unsafe sex practices among the youth and other related themes. '*Sex on the bench (Okweyiiya)*' by participant M is a visually explicit rendering of a

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<sup>76</sup> *Embwa Ya' Nawookeera* is a Luganda expression used to refer to the deadly epidemic of HIV/AIDS in central Uganda. It was first described as Nawookeera by habitants of Rakai district which was the epicentre of the epidemic in the early 1980s when the worst cases of the disease were reported by the Ministry of Health (MOH) and local witchcraft doctors (Kyotalengerire Agnes, 2019).

reconstructed scene that tells us about a love making session that happened inside the workshop at dusk. Participant 'M' (female artisan) speaks of a real-life experience she witnessed while she was at her workstation near a colleague's carpentry workshop in the Ndeeba industrial area. The illustration depicts two people having sex on a workbench while the woman's baby sleeps underneath. This is M's story:

"Sometime in September 2018, there was a young woman who came with her baby on her back along the old railway line which runs through to the next trading centre from Ndeeba. Then we heard a male voice calling out. It seems the man who called the woman was one of the carpenters here. At first, I thought he knew the woman, so I did not bother. I continued with my work (sanding) outside our kibaanda (makeshift workshop). To my surprise, the carpenter had called the woman and agreed to make love inside the workshop. Meanwhile, the baby she was carrying was placed under the carpenter's table as they began their love making. When they finished, they seemed to have a disagreement on the payments. It started as murmurs before it escalated into loud voices inside the kibaanda, and I was forced to reach out to see what had gone wrong. No-sooner had I arrived than I heard the woman stammering that she had sacrificed her body to get money for her baby's food. When the two saw me, they pretended nothing happened and the woman hurriedly picked up the baby and left. By the look on her face, I could tell that she was sulking and utterly disappointed. Shortly after the carpenter also shamefacedly moved out and disappeared. I was left in disbelief about why our colleague had indulged in a sexual act with a 'stranger, moreover, a woman with a baby. I also suspected that they did not even use any protection as there was no sign of any used condoms inside the kibaanda. It also seemed to me that the woman was a sex worker who was trying to get a means to support her child because, frankly speaking, without being judgemental, how do you accept to give in to a stranger in complete disregard of protection from HIV, other STDs, or pregnancy?"

(Participatory workshop, Ndeeba Industrial area, 22<sup>th</sup>October 2020)

After narrating her story, participant M who is also a single mother, immediately remarks,

"Many young women are desperately risking their lives to survive; selling my body cannot put food on my plate because I work to support myself and my family. Besides it would put my life at risk of getting infected with sexually transmitted diseases (STDs) especially the HIV virus."

(Participatory workshop, 24-year-old female sander, Ndeeba)

These reactions strongly point towards the participants' awareness of the presence of social decay and deprivation that lead to such risky behaviours and the threat it poses to young women's lives in informal spaces. Most of the participants concede that many of the artisans

in the industrial space are fond of ensnaring desperate young women who are aware of the epidemic and the causes of its spread but are reluctant to take precautions. As the discussion unfolds further, I begin to contemplate why young people knowingly engage in perilous sexual behaviours that would lead to poor health and possibly eventual premature death (As explored in *Plate 27*). As we take a break from a drawing session, I ask participants why some are not bothered about protection. The responses of most of the male participants resonate with participant M's narrative in chapter 4 (vide infra, pg. 21) where she admits to being involved in transactional relationships (*Kweyiyi*) which entail acquiring different boyfriends to buy her lunch and other necessities in exchange for sex - a reflection of the economic necessity of sex work (e.g., Coombes, 2019). In the same breath, a male participant also concedes:

“In the event of getting a girl who agrees to exchange sex for some transport to go home, very late in the evening, where do you get the time and space to buy a condom? We simply go to a nearby lodge for a short encounter. ‘*Olina kweyiyi*’ (you just take the risk)”

(26-year-old Wood workshop owner, Ndeeba)

### **Confirming having sex without protection**

With the term *okweyiyi* increasingly becoming synonymous with sexual risk and urban hustle, the narrative above appears to confirm the existence of risky sexual practices among young people in informal spaces. The workshop owner's reaction, thus, invokes several questions. Are condoms conveniently available at places of work and leisure spots such as bars, hotels and lodges as purportedly advocated by the Ministry of Health (MOH)? Are the young people aware of the potential risks of un-protected sex and whether self-testing options exist? How can young people with such a mind-set be expected to change their behaviour by just talking about these experiences? What stands out, though, in the discussions with most of the participants is the way they view themselves as victims of circumstances. Most participants seem reserved on whether they had the courage to openly reach out for a condom from designated places of supply such as drug shops or pharmacies. It is sometimes intimidating to openly ask for a condom from a pharmacist in the presence of other customers. As one participant points out:

“When you go to buy a condom people will look at you as if it is crime. It is a very intimidating atmosphere especially when you go to a pharmacy or drug shop just to buy condoms. Besides, where do you get the time if your sex partner is in hurry?”

(Informal interview, 18-year-old Male sander, Ndeeba)

Another participant quickly adds:

“If I want to make love with my girlfriend, using a condom ceases to be an issue. Even if she visits me occasionally for casual sex, I don’t mind because I know she has come to make me happy. After all she is mine.”

(Informal interview, 20-year-old Carpenter)

These responses were not contested within the group. Most of the male participants attest to having gone through the same experience at some point in their lives for fear of missing the sexual opportunity or being perceived as promiscuous by observers/public. Significantly, the participants’ responses suggest that their ability to make rational and wise decisions is compromised by their desire for sexual gratification. Meanwhile, participants also affirm that condoms are no longer supplied to the different places of leisure (bars, inns, lodges, etc.) in the informal spaces. As several participants attest:

“We no longer find condoms in these lodges nowadays. They used to bring them here in bars and toilets within the industrial area back then in 2015 by The AIDS Support Organisation (TASO) and AIDS Information Centre (AIC), but I think they gave up. So, it is up us to find where to buy them when you have something.”

(Participatory workshop, 220year-old artisan, Ndeeba, 25<sup>th</sup> October 2020)

Talking about the issue of absence of condoms in leisure spots sparks yet another related discussion about alternative ways in which the participants could protect themselves. It emerges that most of the participants are not aware of the existence of self-testing kits that are already on the market to help them keep the spread of HIV under check. Despite their awareness of conventional methods of controlling the spread of HIV/AIDS – abstinence, faithfulness, and condom use – participants report that little has been done towards promoting the self-testing kits in informal spaces, despite the regular messages on radios and other social media platforms. Unfortunately, the idea of taking HIV prevention messages to grass-root communities, such as the artisan populations in industrial spaces, remains contested proposition. As participant Q observes:

“Most of us do not have time to listen to radios or watch TVs during the day because we are very busy and when we retire in the evening, we go home exhausted. Government should revive the programme for mass HIV/AIDS sensitisation that used to be done in grassroot communities in Kampala.”

(20-year-old Carpenter, Ndeeba industrial area)

In addition, both male and female participants also expressed fear about what they perceive as malicious behaviour among some people living with AIDS who do not want to die alone. They argue that since some of the women they date are sex workers (Bamalaaya) and HIV positive, they deliberately prick the condoms during the sexual act. The practice tends to reach the confines of domestic spaces as couples in relationships are confronted by similar experiences. As a female participant C recalls;

“Sometime in 2017, I went to visit my boyfriend who was very sick in Makindye, Kampala. Because he had been sick for quite some time, I found when he was a bit frail. As I vividly remember, on the morning of 4<sup>th</sup> February 2017, he opted to go for testing and discovered that he was HIV positive. In the afternoon, he came back home with a very gloomy face. No sooner had he entered our muzigo (rented room) than he pounced on me, slapped me twice while shouting on top of his voice, *Gwe wabuleta* (It's you who brought it, referring to HIV). I felt deeply humiliated and intimidated at the same time as I could not say a word. Moments later I fled for my life because he became more infuriated. Yet, I painstakingly know that my boyfriend was living recklessly with had other girlfriends but couldn't admit it. I left crestfallen and worried. A week later I also picked the courage to go for testing and fortunately I was negative”

(Participatory workshop, 25-year-old female participant, Ndeeba)

This account clearly highlights a common problem of men blaming women for the spread of HIV with mounting evidence pointing towards issues of gender-based violence and misogyny (e.g., Ging & Siapera, 2018; Graham, 2020). It is now commonplace for most young men to blame women for promiscuity and the possibility of transmitting HIV/AIDS in Uganda. In my view, this possibly translates as a gender - and culturally-affirming practice (Barker & Ricardo, 2005; Price, 2020; Wyrod, 2016) that centres on the sexist ideology of male superiority as young men continually fail to acknowledge their fault and quickly propagate misogynist claims against women and the environments that allows that habit to flourish. As they begin to draw their experiences, several participants sympathise with participant C. One 32-year-old male participant eulogises the courage of his sister who stood firm to deny accusations by her husband who alleged that she had infected him with HIV/AIDS.

Although this situation is not explored in depth, the entire discussion triggered several other exploratory drawings of everyday precarious experiences (e.g., *Plate 18*, *Plate 19*, etc) which reveals something of the intrinsic value of applied social sculptural practices in preventive engagement against HIV/AIDS. The interlace of drawing, 3-D crafting and discussions demonstrate the ways in which the approach is able to engage youth in collective performances (e.g., *Artivists 4 life*, 2013; Jennings et al., 2012) that potentially stimulate and sustain conversations about their plight, particularly of young women working and living in male dominated spheres in informal settings. It elevates the importance of applied social sculpture in enabling young people talk about extreme misogynistic practices thus creating awareness about these experiences to inform and allow alternative spaces of engagement through research to stem this problem among the youth (see also Schulkind et al., 2016).

Interestingly, it also emerges that as the participants translate their drawings into 3D soap concepts in physical space (See *Vide infra*, *Plate 20*) some young women, especially Banekko (sex workers), attest to the habit of using soap foam to bath after sex claiming that it protects against contracting the HIV virus. As the sculpting process begins, one female participant volunteers to cook (on a paraffin stove) the small bars of soap pieces which later solidify on cooling, which we cut into bigger solid blocks to distribute among participants to the 3D begin sculpting process (See *Plate 20*). I then challenged every member to share a personal story about value of soap in their sexual life. Meanwhile I notice that the one woman is particularly talkative and seemed to be more enthusiastic with the project. She then fleetingly remembers:

“One day I had a one-night stand with a man from was working upcountry. We did not have an HIV test because it was late date (midnight). After sex, I saw him rush to bath with soap. I became so inquisitive and asked him why he had done so. He said that it was a way of stopping any possible HIV transmission to him in case I had it. This was quite unbelievable to me, but I tried to do the same.”

(24-year-old Female participant, participatory workshop, Ndeeba)

This precarious situation slips through the conversations about the multiple uses of soap as a household essential. I swiftly challenged the group to respond to her experience about using soap in relation to HIV/AIDS. They all murmured and a spiral of several voices of uncertainty about the truth in using soap against the Virus. Suddenly, I heard one of the participants admit;

“I was also told that using soap can save you from contracting HIV after a sexual encounter and I tried it sometime, although I am not sure if it really worked”.

(Workshop participant, Ndeeba industrial area, 20<sup>th</sup> October 2020)

I then quickly advised that;

“There is no medical evidence that soap can protect you from catching \HIV/AIDS during or after un safe sex. I advise you to first go for an HIV test with your partner or to use condoms always”

(Field notes, Participatory workshop, Ndeeba industrial area, 20<sup>th</sup> October 2020).

Indeed, her narrative is triggered by as reflexive thoughts about the wider possibilities of utilizing soap as a sculptural material, encapsulated in the conversations geared towards understanding their own lived experiences in the context of HIV/AIDS. The opportunity to engage in working with soap as a medium of creative engagement espouses the value of sculptural social practice as a platform that evokes self-confessions, candid talk and social cohesion that allows people to express themselves about the condition of precarious living in relationships, while also revealing the lack of knowledge and awareness about HIV among young people. It also created a space in which misconceptions could be begun to be challenged. The time I gave them to create designs in soap enabled the participants to share important aspects of their precarious experiences in informal spaces. This enables them to share thoughts, hands-on skills, and creative ideas, hence understanding the ways in which they can be supported and enlightened about the consequences of reckless decisions in the context of HIV/AIDS.

#### **5.1.1.1 Artwork B: ‘Malaaya vva kumutembeyi’ (Hawker, leave the vendor alone)**

As highlighted in Chapter 4, transactional sex is one of the leading social problems that have catalysed the spread of HIV/AIDS in informal spaces in Kampala. Many women and adolescent girls - school dropouts and single mothers - many of whom are migrants from neighbouring villages and upcountry locations, fail to find decent jobs in the informal sector. They resort to quick-money schemes such as gambling, ‘magendo’ (black-marketeering) and sex work, which have become commonplace in and around the fringes of the city. The evidence depicted through drawings and narratives from the participatory workshop shows that young people have now become victims of the flourishing sex trade in the areas in the peri-urban spaces of Kampala. The visual impression in *Plate 22* is captured from the story narrated by participant

Q based on his early days as an apprentice in carpentry. His story describes one of the ways in which women (oftentimes referred to as Baneko<sup>77</sup>) cannot afford to buy goods and services, so, they offer to trade for sex. It is also clearly documented that many young women in are often confronted by temptations of making economic gains from immoral situations in informal environments (e.g., Choudhry et al., 2015).

***'Malaaya vva kumutembeyi' is born.***

In this Luganda expression, *Malaaya* means prostitute/hawker, *vva* means 'leave' and *kumutembeyi translates as 'the vendor'*. So, the narrative, 'Hawker leave the vendor alone' was coined during a pictorial critique at a participatory workshop in Ndeeba by participant Q. After presenting the visual contents of his story, he narrates his story:

Participant Q's story:

"In February 2017 I began to work as a sander in one of the carpentry workshops in Ndeeba. I did not have any experience in wood working so it took me a couple of months of hands-on-practice to master the art of sanding and basic wood joinery. After a while I began to produce light wood furniture such as shoe racks, wooden hangers, coffee tables and small stools using canes. Meanwhile my friend who had taught the craft had started earning some good money out of vending his furniture products in the neighbouring areas. So, in the process I joined him to sell my products beyond the confine of the industrial areas. Little did I know that it was such a hustle to carry merchandise around to find potential buyers! So, one day I decided to go out and sell some of my products. As I strolled towards Nsambya, a residential neighbourhood, about 2 miles from Ndeeba industrial area, I met a group of young women seated on veranda on one of the flats. Then one of them called out to see what I was selling. She took an interest and decided that she wanted to pay for a shoe rack. I had priced it at 10,000 shillings. She then told me to follow her through the alleys to a closed quadrangle behind a storeyed building. She walked into the house and came back with 5000 shillings. She insisted on paying half the price and topping up with a 'short' (meaning quick sex). I got confused as she continued to pester me for sex in exchange for the rack. Because I was desperate for money, I almost gave in. However, on second thoughts I decided to leave. Meanwhile, another woman came by and whispered to me, 'Bwomala jangu tulabe' (when you are done with her, come we see). No sooner I had I moved a few metres away than the other woman also comes calling that she wanted me for a 'sweet deal'. She grabbed the shoe rack items, and she dragged me back towards her muzigo (rented room). It was now getting dark. Time check, 7pm. Terrified and exhausted, I had to flee for my dear life."

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<sup>77</sup> Baneko is an acronym for '*banekolera gyange*' translated as 'women doing their own businesses. It is a term which is conventionally preferred by women who deal in sex work for a livelihood in informal contexts. Local communities refer to them as 'Bamalaaya' (prostitutes).



(Edited story, participant Q, Ndeeba participatory workshop, 24<sup>th</sup> October 2020)

This narrative reflects several similar stories I heard of the hustle involved in living in informal spaces. It was a funny yet concerning account of an uncomfortable and unfortunate experience. It is typical of the situations of desperation and risk of encountering the unfamiliar spaces in the context of HIV/AIDS. All participants wondered whether the narrator was truthful about forfeiting the money without succumbing to the sexual propositions. Such experiences seem to be commonplace for young people as they try to get by in informal spaces. The excitement about the story ignited the imagination and interest of several participants and they agreed to collectively create a storyboard using local materials from their work environment. Participant Q's story, supported by another resultant artwork (*Plate 23*) shows sex work hotspots which artisans navigate as they hawk their merchandise, and plainly demonstrates the persistent relationship between HIV/AIDS and poverty (e.g. Grant, 2010; Joseph & Joseph, 2010; Mushengyezi, 2003). As portrayed in the drawing above, the hawker and prostitute appear to be caught in transactional dilemma. In most informal contexts, young artisans are often forced to engage in light furniture vending within the fringes of urban Kampala to survive. Yet still because of poverty, they tend to engage in sex work in their neighborhoods. Worse still, they cannot afford to get married so have no stability in their relationships. They end up in a one-night stands or short-term relationships which breed into the bigger networks of sex trade and increased HIV transmissions.

To further expound on participant P's experience, participants talk about how commercial and transactional sex is becoming very common across all trading centres between Kampala and Ndeeba within a radius of 4km of the city's central business district (CBD).

While transactional sex is defined as the exchange of favours, gifts, or money for sexual activity, commercial sex can mean any form of commercial sexual activity such as sexually explicit performances, prostitution, and participation in the production of pornography (Choudhry et al., 2015; Gysels et al., 2001). Inside informal spaces, both transactional and commercial types exist as the participants indicated. Routine occurrences of both were reported in all the informal spaces during fieldwork, as young people become ensnared in the complex web of commercial and transactional relationships for survival. In *Plate 23*, participants draw an annotated map showing the different hotspots (trading centres) where most of the

prostitutes/sex workers hang out to survive. This relays visual evidence of the existence of prostitution within their spaces of work. Ordinarily, one would describe it as a map without a scale, yet in applied terms, it is a visual representation of the spatial geographies that accommodate a spiralling sex business linked to rising rates of HIV/AIDS among young people in Uganda today (e.g. Gysels et al., 2001; Kyendikuwa et al., 2017; Ntozi et al., 2004). In the workshop, female participants espoused the view that sex, since it is desirable as a source of pleasure and as a means for economic gain, leads many young women to traverse several townships to ply their trade. Nonetheless, Choudhry et al. (2015, p. 383) clarifies:

“In public health, transactional sex is often differentiated from commercial sex work since participants do not identify themselves as ‘prostitutes’ and ‘clients. Exchanging gifts for sex is often a part of a broader set of obligations that might not involve a predetermined payment”.

To most of the participants, the distinction between the two terms does not matter. They contend thus:

“We don’t need to distinguish between the two. Whoever engages in sex with different people for money, pleasure, or material things here is called a ‘malaaya’ (prostitute). This is what we are seeing and experiencing. In our contexts, there are no such exceptions as long as someone engages in sex work”

(Group discussion, participatory workshop, Ndeeba, 28<sup>th</sup> October 2020)

As tacitly revealed in **Plate 23**, most of the participants agree with the view that, indeed, sex work was part of their everyday experience as many witness friends and colleagues getting involved in the business as an alternative way of making ends meet. Notably, the discussions about sex work and HIV risk were directly provoked by the story and design process initiated by participant P. This enabled the participants to stay creatively curious and focused on sustaining discussions and working as a unit – an instance of collaborative performance<sup>78</sup> (e.g. Prosser & Loxley, 2007; Sánchez-Camus, 2011). As **Plate 24** shows, it not only allowed the participants to continue with selected themes but also enabled them to enjoy light moments filled with jokes and chitchat about the different social issues unfolding in my presence as a

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<sup>78</sup> Collaborative performance is one of the key components of applied sculptural practice which allows performers (artists or experts) to integrate ideas and simultaneously share key design solutions in order to achieve the desired 3D artwork.

facilitator. It encapsulates moments of bonding, reflection, creative thinking, and practice in the context of HIV/AIDS prevention and social transformation among the participants.

Meanwhile, I instruct all the participants to select the different shapes of wood cut from plywood by participant P for sand papering. In the process, we all gather around one bench and begin to talk about the various skills and challenges encountered during the drawing sessions. In many ways this enabled them to ask questions while deliberating on possible methods of joining the sanded pieces on to the panel prepared for the intended relief work (*Plate 24*). These pieces were cut out to create female shapes to be assembled figuratively to represent sex workers at the different hotspots in the peri-urban spaces as illustrated in *Plate 26*. As the discussions about the sanded pieces unfold further, most male participants seem to hold the view that the growing number of sex workers who frequent workspaces, social centres/joints like bars, restaurants, disco theatres, and on streets, is a result of limited employment opportunities in the informal spaces. As they complete the sand papering process of the small shapes representing sex workers, several participant remark:

“I see them every time I go out to sell my furniture products in the neighbouring trading centre like Nateete and Kabuusu in Lubaga division, including our own industrial spaces. These spots are busy with school-going youth, traders, revellers, and truck drivers who are their potential customer base”

(24-year-old male participant, Participatory workshop, Ndeeba)

“Sometimes you cannot easily distinguish them from other revellers especially in the evening. It is only when one whispers words such as *‘mukwano, bebi, oba daddi, gangu wano* (Hey dear, babe, or daddy please come here), that you realise that they are hookers at work.”

(20-year-old participant, Participatory workshop, Ndeeba)

These narratives confirm knowledge of the existing sex work activities in their neighbourhood as young artisan get by during day. They are reflected in the resultant co-produced artwork developed by participant P that shows the hotspots of sex workers which is, in a way, a form of social awareness that sex trade exists. The youths are clearly aware that such spaces are associated with precarious behaviours such as drugs use, alcoholism, and reckless sexual engagements.

This final artwork - **Plate 26** depicts how sex workers and their pimps formed clusters of syndicates and gangs stationed at different areas in the peri-urban locations around Kampala. Participant Q creatively uses symbols of houses, road networks and bands of women (**Plate 25**), interspersed with men to show that sex work thrives in the urban fringes where commuter taxis, lodges and other leisure amenities exist to facilitate the business. Perhaps, what remains remarkable about the process of executing this artwork is the latitude it allows the participants to explore and debate the realities of the attaining pleasure by engaging in sex trade despite its consequences for the lives of those involved. While it is very hard to openly disclose those who buy sex, the voices of those affected are heard through a variety of ways as some male participants admit to having occasionally been engaged in sex work. This also points towards the growing temptations young men face on a daily basis, and their tendency to blame the women, despite having some understanding of their extreme poverty. They also attribute these experiences to peer influences, drug and/or alcohol consumption (see also Kalichman et al., 2007; Schulkind et al., 2016; Wandera et al., 2021). This is further explored in the next section, which elucidates the hegemonic notions of masculinity based on young people's accounts of their social realities and related HIV risk in informal contexts.

#### **5.1.1.2 Artwork C: 'Embwa Ya' Nawookeera' (Entanglement with sex, HIV/AIDS, and death)**

Several young people gave accounts of being obsessed with memories and unforgettable experiences of the multiplicity of AIDS-related fatalities that have framed their social world (e.g. Silin, 1995). The participants give accounts of their struggle to overcome the AIDS-related loss of their loved ones such as parents, siblings, and friends as they attempt to orient themselves to the desolate realities of working in informal spaces. In particular, reference is made to corroborating accounts of personal experiences of a migrant worker in Ndeeba who witnessed his sister succumb to HIV/AIDS in 2018. The grim experience is captured in his symbolic 2-D (HIV patients on drip) and 3-D demonstration of the agony of confronting the premature death of his sister (**Plate 27** and **Plate 28**).

The 20-year migrant worker (participant Q) narrates how he encountered HIV/AIDS in Kampala after leaving Bundibugyo (western Uganda). His drawing (**Plate 28**) and the eventual 3-D artwork (**Plate 31**) communicate messages about HIV treatment and death. He uses the power of visual imagery to emphasise the interface of a reckless sexual life and inadequacies of

medical care and support in hospitals, which aggravates the experience of terminally ill HIV/AIDS patients.

“I recall the three months I spent sleeping on the floor as I took care of my guardian sister in a hospital with little or no attention from the medical staff there. She was my only guardian after losing both my parents to HIV in 2013. It all began when we decided to relocate with her from Bundibugyo to Kampala (Katwe) to start a new life after the loss. Since it was hard to find decent employment, she ended up in sex work to support me and herself. She got involved in multiple sexual relationships to raise money for my school fees. Unfortunately, she tested positive for HIV in 2017, became critically ill and was hospitalised. I dropped out of school to tend to her in hospital. I was still young (14 years), and I had to take care of her for three months. Because we didn't have enough money to cover the bills, the doctors would take hours and sometimes the whole day before they came to check on her and other frail patients. She grew thinner and weaker by the day until she passed away four months later. It was such a traumatising experience for me - my second time to encounter with HIV/AIDS. To make matters worse, I witnessed 3 other patients' breath their last simply because of inadequate care and support facilities there.”

(Participatory workshop, Ndeeba industrial area, 19<sup>th</sup> October 2020)

In depicting an HIV patient on a drip, participant Q visually explores one of those clinical stages that are central to averting the possible fatality of HIV. Indeed, he attempts to bring to the fore the unseen painstaking situations compounded by lack of resources to support his sister's life. The traumatizing experience he encountered witnessing several people die every hour of the day exposes the dire conditions of hospitals and the challenges for the medical personnel while dealing with the critically ill. During the workshop, his narrative evoked similar accounts and discussions from other participants about sex and death as a taboo subjects within communities. Admittedly, the silence that surrounds bereavement is likened to times when people are overwhelmed by fear and stigma and the eventual isolation associated with HIV infection. Two participants point out:

“When people get to know about your HIV status, they immediately pass judgement on you as being adulterous and shameless. Sometimes people may refer to you as ‘Omulambo ogutambula’- A walking corpse”

(Female participant, Ndeeba participatory workshop)

“AIDS is like a death sentence. Some people will leave you to rot away at your home or in a hospital. Even relatives discriminate against you”

(HIV positive Carpenter, Ndeeba participatory workshop)

Both narratives seem to affirm the view that being HIV positive and encountering HIV-related death usually represent a gruesome reality with rather complex manifestations which not only leave the infected and affected loved ones in pain and agony, but also heavily stigmatised. These experiences always leave a lasting mark of sorrow and depression that affects those who are left behind. HIV treatment and caretaking can be a daunting experience particularly for those who are close to the patient. Participant Q's artwork gives an emotionally laden message about the impact of HIV/AIDS on people's lives. The trauma people experience equally points to the importance of knowing one's HIV status to avoid the stress or fear of the unknown. Nonetheless, fear, stigma and death related to HIV/AIDS, have been well documented (see Bruce & Hallman, 2008; IRIN, 2014; Kelly, 2010; Muchena, 2021). The artwork (*Plate 29* and *Plate 31*) further exposes the social challenges encountered while in hospital such as inadequacies in care and support, lack of medicine and poor sanitation in many health facilities across the country that lead to many deaths. While there is greater concern about the ways in which HIV is transmitted today, sex among young people still accounts for millions of infections around the world (Piot, 2000; UNAIDS, 2014, 2020). In what follows, I attempt to demonstrate how participant Q is collectively helped to build the HIV ward (Artwork C - *Plate 31*) using selected junk wood from nearby carpentry workshop.

### **Building the HIV ward/hospital concept (as interpreted from the sketch**

As shown in *Plate 28*, *Plate 29*, and *Plate 31*, transforming participant Q's concept into 3-dimension artwork is a rather long process that required deep immersion into creative thoughts, time, and commitment to hands-on working with all the participants. In this way, we were able to generate the desired 3D form (applied artwork):

“As I make an impromptu visit to Ndeeba industrial artisan area on Saturday, 1st November 2020 at about 2pm, to check on the progress of the wood forms being built by the participants (because I failed to show up on Friday due to heavy down pour that lasted several hours), I then find when they have just finished assembling the beds and a shell of the structure representing a typical hospital ward. Shortly after a brief chat, I join them to try out a mock-up of the constituent parts that make up the hospital concept as conceived by a participant in *Plate 27*. i.e., the hospital shell and the bed with patients on drips. In the process of building the idea, the participants propose and agree that the bodies of the patients be created from wood spindles, and later reshaped to include some human detail. These spindled body-like shapes are then placed on the beds to represent critically sick patients lying alongside dead bodies in the same ward. As he shares his ordeal in the beginning, participant Q insists on

depicting himself (symbolically) lying down on a bare mattress next to corpses as he took care of his sick sister in hospital”

(Field diary, participatory workshop with artisans in Ndeeba industrial area, November 2021)

However, before placing the spindled forms to represent the dead bodies (*Plate 29*) in the hospital ward, we request that one of the team members – a carpenter – improve the shapes by suggesting the legs and a rib cage impression to symbolise a sense of pain, agony and wasting away caused by AIDS. Meanwhile, one of participants further suggests that:

“It would also be wise to leave some bodies in the original shape as it would show death amidst medical efforts to sustain life in our local hospitals. But also expose the challenges associated with inadequate facilities like limited storage space for the dead (morgues) which increases patient trauma, stigma, and hopelessness”

(Carpenter, co-production session, Ndeeba industrial area, 2<sup>nd</sup> November 2020).

These narratives demonstrate that the process of collaborative working enables participants to simultaneously develop a set of skills, such as creative application of design details like form and texture, design thinking and oral expression, which are at the heart of this participatory project. Beyond its ability to expose the inadequacies in our health system within the context of AIDS treatment, the artwork implores for a collective responsibility to deal with the stigma attached to the treatment of the disease. The effort undertaken by Participant Q to disclose what he has experienced as inhumane treatment, that it is intended to encourage more compassion towards people with HIV/AIDS. This also enables the participants to express their emotional experiences which may have been more difficult to access through interviews alone. Indeed, his creative portrayal of corpses on beds with the carer sleeping on the on the floor, in a way, illustrates the value of applied sculpture as a socially and organically acceptable avenue for peers, activists, artists, and other public educators for tackling HIV/AIDS in communities where formal education may be non-existent or limited.

In this section, I have attempted to discuss how stories, drawings and 3-D forms helped facilitate dialogue and the understanding of the critical social issues like urban hustles, sex, and death in the context of HIV/AIDS among young people, showing, in some cases, how the emerging ideas are developed and translated into visual and tactile three-dimensional applied objects. The process of creating these objects enables dialogue, knowledge exchange, and

increased awareness of an otherwise taboo subject among young people and situations of blaming women for the spread of HIV in informal contexts. In the section that follows, I explore and discuss ways in which young men participate in the construction of urban masculinities which eventually increase their risk of HIV infections. I argue that young men in the peri-urban areas of Kampala tend to participate in the construction of their masculine identities in ways that affect their health-seeking behaviours and also increase their HIV risk. Yet again, as indicated previously, applied social sculpture is fundamental as an enabling platform upon which such critical gender issues (sex, HIV/AIDS, and hegemonic masculinities) can be openly explored and understood in the context of HIV/AIDS.

## **5.2 WORK, HEGEMONIC MASCULINITIES AND HIV/AIDS**

Masculinity surfaces as a central theme shaping young people's accounts of HIV-related experiences and behaviours in informal spaces. Various defined as an identity, a social role and form of power, masculinity is not exclusively associated with men (Connell & Messerschmidt, 2005). A vivid pictorial exploration and co-production process of applied sculpture with young participants in the fringes of urban Kampala provides glimpse into the some of the social experience of young people in the context of HIV/AIDS. Masculine identities have been shaped and crafted by young males as a way of negotiating their daily fears and struggles to remain socially cognisant of themselves as possessive and dominant - resilient, highly sexual and economically productive beings (e.g. Campbell, 2003; Skovdal et al., 2011). Nonetheless, as previously stated, this section attempts to explore the role of applied social sculpture in understanding the notions of hegemonic masculinity among young men in informal industrial spaces in Kampala. Four artworks (themes) that were created by participants are used as a basis for exploring and discussing the various ways in which young men participate in the construction of dominant masculinities in informal spaces. These artworks are labelled as Artwork D (the beer party), Artwork E (HIV bench – depicting genital sores), Artwork F (My lover-boy) and Artwork G ('*Namboole*')

### **5.2.1 Artwork D: Entanglement with alcohol and sex**

The first major theme that emerged from the participatory engagement with young people in informal spaces of Kampala was the growing tendency of young and old men to enjoy heavy drinking in local bars within the industrial areas. Whereas it was pointed out that idleness was



one of the main reasons for men to spend time in bars, most of the participants considered drinking as an activity involving the search for sexual liaisons and the bars as places for finding sexual partners cheaply.

According to the findings from participatory workshops, 13 out of 19 participants indicated that young men often targeted and took advantage of young women and adolescent girls' vulnerability at drinking *bufunda* (pubs). In an artwork created and crafted from a story about a drinking spree (dubbed 'The beer party'- **Plate 32**), participant A uses the power of visual images to emphasise the devastating effects of high alcohol consumption related to irresponsible sexual behaviours such as unprotected sex and sexual abuse. As I shall explore shortly, his artwork evoked and sustained further group discussions about men's inclination towards short-term relationships and the multi-layered consequences of cross-generational sexual behaviours among young women and older men. In **Plate 32** (The 'beer Party'), participant 'A' attempts to depict a time when he went to one of the bars in the industrial neighbourhood.

"One evening I invited one of the girls (artisan) to a nearby makeshift bar for a drink. After several rounds, I decided to go with her to my home. I told the girl to come along with me and she accepted but on condition that she leaves very early before dawn. As we strolled back home, we carried our bottles of booze. The girl held bottles in both hands as we continued drinking all the way home. As we were about to reach my house, I turned off into the nearby bush to pee. Unfortunately, I lost consciousness and fell down. Whatever happened there after, I couldn't tell. In the morning she told me that we had sex at night, and she was demanding money before she could leave."

(Storytelling session. Ndeeba industrial area, 20<sup>th</sup> October 2020)

"As he displays his illustration, all the participants went into laughter. Sharing such an incident, even though it is a common occurrence in the informal areas, was rather embarrassing. For a few minutes, he feels nervous, but a while later, several other male participants quickly identify with him as they attest to similar behaviours"

(Field diary, Ndeeba, 24<sup>th</sup> October 2020)

Evidently, from this story it is conceivable that the impact of alcohol on one's sense of judgement, reasoning and responsibility is compromised and sometimes completely subdued, as alcohol consumption remains strongly associated with risky sexual behaviour and HIV infection (e.g. Kalichman et al., 2007; Schulkind et al., 2016; Wandera et al., 2021). While discussing participant P's drawing, the female participants confirm witnessing fellow young

women, and mainly adolescent girls frequenting bars and other drinking *bufunda* (pubs) during working hours, wearing see-through dresses, miniskirts, and other provocative attires to allure men. As the female participants attest:

“I usually see young girls hanging out in pubs in this neighbourhood dressed in very short skirts and heavy makeup in order to seduce men. Many put on see-through dresses to easily draw them for transactional affairs” What do you expect men who are already high on drugs and alcohol to do in such circumstances?

25-year-old female wood sander, Ndeeba)

“I used to go out with my fellow friends every evening to bufunda in the outskirts of this industrial area to engage in commercial sex to supplement our incomes. Unfortunately, oftentimes some men used to think that we are infected because of the way we dress to attract their attention in these leisure spaces, yet we mainly do it for survival”

(22-year female scrap wood dealer, Bwaise industrial area)

Whereas most men claim to be acting under the influence of alcohol to engage in transactional affairs, the above narrative seem to confirm the role played by women in influencing the sexist attitudes among men: As one male artisan points out:

“Most of the women come as sex workers in our *bufunda* (pubs), and indeed behave in very provocative ways.... Siting on high stools and in awkward positions to entice us... But I enjoy seeing them that way. Oh yes, I like it. Even if you don't have money to negotiate for sex, at least you feed optically”

(Interview, 31-year-old male participant, Ndeeba industrial area, 10<sup>th</sup> October 2020)

Sometimes, because of such behaviours, young men are inclined to claiming that women provoke them into risky sexual attractions and sexual encounters especially when they get drunk. This also manifests as misogynism and blaming women for the spread of HIV/AIDS, yet men are deemed primary actors in its transmission. Conspicuously, situations of sexism and misogyny are further supported by previous research (Ging & Siapera, 2018; Graham, 2020; Walloch, 2009). Meanwhile, it also emerges that the practice of taking women to bars or social places (*E.g.*, **Plate 32**) is a source of pride and an opportunity to show-off among young people in formal spaces as it is a sign of a financial prowess among peers. To others, it is a way of expressing ownership (objectification) of a particular woman among their peers. As one male participant affirms:

“Taking out a girl to a bar or restaurant is one way of showing others that she is mine. It makes me feel visible and powerful. My peers will respect me especially if the girls are liked by many.”

(19-year-old Male sander, Ndeeba)

Related to this young man’s statement is the notion of male pride and possession of the woman being a symbol of superiority. As demonstrated above, the participatory workshops provided spaces during breaks from practical undertakings to further discuss such critical issues in respect to these expressions and performances of masculinity. This was a recognition of the value of collective youth engagement, giving voice and telling stories (C. Mitchell, 2006), which I contend is part of the affordances of applied sculpture as a social practice. Similarly, participant P’s artwork triggers more visual explorations and debates around three critical themes about hegemonic perceptions and practices among young men. They include: (i) exploiting women’s vulnerabilities; (ii) irresponsible sexual conduct and unprotected sex; and (iii) materialism and cross-generational sexual relationships. Each of these themes are explored in Artwork E, Artwork F and Artwork G respectively.

#### **5.2.1.1 Artwork E: Irresponsible sexual conduct and unprotected sex**

*Again, Plate 32* represents a picturesque rendering of a typical youth routines (going to bars). Such experiences are part of the numerous stories related to youth involvement in reckless social conduct and sexual behaviours as shared during the participatory sessions. During the workshops, each participant is encouraged to write or narrate his or her story and then translate it into a set of images or drawings. For example, participant A’s illustration reveals what many young men do as they leave in the evenings, especially after a busy day. With great enthusiasm, participants begin to discuss issues of alcohol, a risky sex life, and HIV during the drawing and discussion sessions as they confirm having witnessed artisan friends persuading young women and adolescent girls to drink alcohol and visit bars even during work hours. They would get the women drunk and hurriedly take them to nearby lodges for quick sexual escapades (usually without protection). Several participants admit to taking girls out to *bufunda*, getting over drunk and having unprotected sex;

“I enjoy taking alcohol every evening because it helps me reduce stress. So, whenever I get paid, I find time to enjoy life with my girlfriends in the beer pubs (*Bufunda*) around here. Sometimes it’s hard to think about protection when you get drunk.”

(26-year-old male sander)

“I usually go out with different girls on appointment. When I get drunk, I go with one of them home. Because I enjoy hanging out until late, sometimes I forget to buy condoms from the pharmacy.”

(20-year-old carpenter)

“One day I went to a nearby Kafunda during day to have a beer, I met three young women who accepted to give me company. We drank all day and later after the spree I chose one for a one night-stand, only to realise in the morning that I had sex with her without protection.”

(27-year-old wood engraver)

Although most of the male participants did not consider use of condom as paramount for their own safety during such escapades, they appeared equally unbothered by arguing that they banked on sheer luck, and if not luck then the availability of drug shops and HIV testing services (HTS) in nearby health clinics. It reminded me of a popular catchphrase of the 1990s “Balinsalamu embawo?” (“Do they want to cut me up for timber?”).

“...An attitude that contained criticism of the past as well as the present. They felt that they were unlikely to live long enough to be cut up for timber like big trees. They would rather be around only for a while and would not allow the government or the medical professionals to prevent them enjoying their lives. Even though magendo and AIDS with all the witchcraft suspicions, mistrust, suffering and death that they implied had shaken the social and moral foundations of the communities and made life miserable for many, the young people preferred their acquired lifestyle and the risks it involved over the prospective return to the rural reality of the pre-magendo and pre-AIDS days”

(Kuhanen, 2010, p. 32)

The slogan “Balinsalamu embawo?”, henceforth, emerged among the youth and young adults in Rakai District, Western Uganda when they expressed criticism of the HIV/AIDS control strategies that were meant to help them govern the lives and intimate behaviour of individuals. Interestingly, many of the young people involved in sex work in the industrial spaces seem to harbour similar fatalistic attitudes, well aware of the risks of their precarious engagements and seeming content to continue in their trade rather than wallowing in poverty in their informal neighbourhoods. However, some of the participants reported regular use of condoms with their casual partners in a bid to avoid contracting HIV and other STDs. For instance, one carpenter says:

“I cannot afford to waste my life over these girls. None of the girls am dating are my intimate to me, so, risking with unprotected sex could be suicidal. If I decide to go with one of them, I make sure I have condoms at home.”

(Interview, 20-year Carpenter, Bwaise industrial area)

Corroborating accounts from both the Bwaise and Katwe industrial areas indicate that many young businessmen open several ‘*bubaala*’ (mini-bars) amidst the congested furniture workshops in order to target idle artisans who are potentially susceptible to raucous behaviour, bar-hopping, drug abuse and hanging out with women. Some participants describe the consequences of heavy drinking during a sculpting session:

“Several businessmen are opening up Bufunda (small bars) to tap into the ever-growing young population in this area. It is mainly the young artisans who are fond of buying and drinking alcohol (local gins such as Kitoko, vodka, Kalaso, etc.) from these bufunda while they work or as they wait for potential customers. This practice has not only lowered our productivity at work but also exposes us to the risk of getting HIV/AIDS and other sexually transmitted diseases (STDs). For example, one day, I move from one bar to another, and I eventually got so drunk that when I picked one of the waitresses from the last bar, I could not even think about getting condoms from the shop. In the morning I realised that I was already in a mess. I could not even report for work because of a strong hangover.”

(23-year-old Male Wood carver, participatory workshop, Katwe Industrial area)

“Sometimes I spend time in the nearby kafunda enjoying my Sachets of vodka as I wait for clients to bring me work to do. It is one way of meeting up with friends and having fun. As a man it’s paramount to meet fellow men in such social places to chat, share ideas and/while getting high or cooling off.”

(Participant B, Scrap collector, Participatory workshop, Ndeeba)

These two narratives resonate with analyses in other situations of the risks of reckless social life and complacency (e.g. Schulkind et al., 2016; Wandera et al., 2021) among young people in peri-urban areas. Their failure to desist from such behaviours increase susceptibility to engaging in unplanned sexual relationships. Going to makeshift bars during working hours out of idleness, getting high on drugs and/or consuming alcohol is potentially one of the surest and fastest ways of entangling oneself in sex work in these informal spaces.

On the other hand, during the mini display and critique of their illustrations in the participatory workshop in Ndeeba, several participants admit to having had sex without using condoms even when they were clearly aware of the danger of contracting the HIV virus. Echoing participant

M's narrative, workshop members also mention that using condoms robbed them of the opportunity to enjoy sex (e.g. Campbell, 2003; Mitchell, 2006), completely disregarding the alleged high levels of HIV/AIDS infections among their colleagues in the industrial area. In another artwork produced in an art and creativity workshop in Lungujja (*Plate 33*) participant Y drew and engraved images of a penis in a symbolic fashion to depict the consequences of unprotected sex. In his testimony to accompany the artwork he writes:

“One day I had unprotected sex with my girl’s friend and after two days I notice painful blister around my genital organs. I feared for the worst when my house mate insisted that sores were associated with HIV infections. Grippled by fear and uncertainty, I could not go to the hospital. I instead took local medicine and the blisters disappeared.”

(Participatory workshop discussion, 17-year Male participant, Lungujja)

As the young man narrated his experience, it sounded baffling as all the participants looked perplexed by this medical condition. They begin to murmur and giggle about the incident. A 19-year-old female participant then asks,

“Why do such conditions happen when you are HIV positive? Is it Nkumunye<sup>79</sup>?”

As the drawing session ensues, everyone seems to remain visibly bothered by the ordeal. Instinctively, another participant aptly responds:

“HIV experts say that it occurs when your body is overpowered by the HIV virus. Apparently, my doctor told me that when the immune system weakens, opportunistic illness such as Tuberculosis (TB) and body sore or herpes/blisters are bound to affect different parts of the body including the private organs.”

(28-year-old HIV positive male participant, participatory workshop, Lungujja, May 2020)

His testimony triggers further debate about the physical signs caused by HIV as participants concluded that the best option is always reaching out for medical help and testing to avoid wrong diagnosis and self-treatment which often escalates the situation. Similarly, several participants also attest experiencing HIV-related itchy conditions prior to testing:

“For several months before being diagnosed with HIV, I constantly developed itchy sores around on my genitals. After the testing positive, the doctors confirmed that

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<sup>79</sup> *Nkumunye* is a local term used to describe a condition where the male genital organ begins to disintegrate little by little until it breaks off.

those were genital herpes which usually result from a failing immune system. I was then subjected to taking sceptrin and later ARVs to avert their resurgence.”

(Informal conversation, participatory workshop, 24-year HIV positive male participant, Lungujja, May 2020)

“When small sore-like blisters attacked my private parts, I was forced to go for medical check-up as I considered it to be a simple UTI (Urinary tract infection). Unfortunately, I tested positive to HIV, and they put me on ARVS which I am taking up to now.”

(Informal conversation, participatory workshop, 21-year Male participant, Lungujja)

Not only do these narratives echo contestations between ignorance and awareness among young people, they also generated discussions about the importance of seeking medical help in situations of uncertainty. These narratives clearly signify that improving the level of awareness among participants is of great importance in terms of seeking timely treatment and the discouragement of anti-hospital attitudes held by many youths in informal spaces. Crucially, the engraved imagery (See *Plate 33*), appears to explicitly depict a generic appearance of blisters (herpes) in a visually provocative manner that triggered further conversations about the consequences of unprotected sex. Additionally, this relief-like representation of the infected genital organs laced with the words ‘STOP THE SPREAD OF HIV INFECTIONS’ in *Plate 33* is centred on understanding the subject of sexuality, often forbidden in cultural contexts in Uganda. Talking about sex or showing sexual organs explicitly in public is taboo in Ganda culture and for that reason young people find it culturally offensive to openly speak about issues to do with them (also see Nabulime & McEwan, 2011). However, the abstracted expression of infection in a way that shields it from obvious cultural bias to the benefit of the participants and many young people who may avoid open verbal discussions of sex. Additionally, Participant Y’s narrative also echoes the negative attitudes among young men who do not want to go for testing and medical help. It reveals the difficulties posed by young men’s attitudes towards seeking medical support in case of HIV-related illness. Such stereotypes among young men in grassroots communities are well documented (e.g. Mafigiri et al., 2017; Moletsane et al., 2007; Muchena, 2021; Parker & Aggleton, 2003). It is imperative to note that the 2D and 3D visual explorations of social realities of living in informal spaces encouraged group participation and confidence-building among participants to freely express themselves, as demonstrated in *Plate 19*, *Plate 22*, *Plate 25*, and *Plate 30*. As part of the

aesthetics of applied artistic practice, the process of drawing, for instance, allowed participant P to share his personal experiences with alcohol and how it influenced his behaviours in ways that influenced his friends to pick up girls from *Bufunda* and take them home. The drawing particularly enabled him to own up and to share his experiences with other participants during the workshop. The male participants also revealed how several artisans fondly kept sachets of alcohol in their pockets and consumed it as they got on with their daily work.

### 5.2.1.2 Artwork F: Materialism and the cross-generational relationships

Oftentimes, young women are lured into sexual relationships because of money. They choose to pay for what they cannot afford with their bodies because to them it is the only way to make a living. The need to acquire what one does not have at whatever cost is a major catalyst to the spread of Aids in the informal communities (Avila et al., 2021; Jewkes & Morrell, 2010; Wellings et al., 2006). We also discussed why young women were voluntarily accepting sexual advances from different men (old and young) that manifest as transactional and/or cross-generational relationships. For example, I engaged in a conversation with 21-year female participant (Wood finisher), who remarks that:

“Most of the young women (adolescents, single mothers, school drop-outs, widows, etc.) who migrate from upcountry locations and others from neighbouring villages, attempt to find their own way to the informal spaces in search for casual employment and end up in these restaurants, bars, and food joints as the only alternative. These young women come to these spaces to find ways of earning to support their families but unfortunately, they are low paying job which cannot sustain their lives well. Adolescent girls, in particular, have a different set of wants, for instance they need to buy good clothes, make-up, and other personal effects to look attractive yet what they earn is insufficient to cater for that. They end up succumbing to pressure from wealthy workshop owners and artisans who take advantage of their vulnerability. At times our employers here make us to wait until dark (past 7:00 pm) to receive daily pay. This makes some of the unsuspecting adolescent girls to fall prey to unscrupulous ‘bosses’ who use such delaying tactics to sexually assault them as the night falls. Many times, they use money to lure them into risky sex encounters because they have options for survival”

(Field diary, informal conversation, Bwaise industrial area, 20<sup>th</sup> May 2020)

This narrative is interconnected to female participant S ‘s illustration (*Plate 34*) generated during a discussion and visual explorations in a participatory workshop about the social realities of survivalism among young women from Ndeeba industrial area. In this illustration, participant ‘S’ chooses to portray herself as the girl who is taken out by her lover to a nearby guest house



and later emerges out alone. In her illustration, she seems to expose how young women behave in ways that exonerate them from tainted sexual behaviours in informal spaces (to avoid potential conflict with other boyfriends). In her script excerpt, she writes:

“In order to avoid any suspicions, I make sure I leave my boyfriend’s home alone. I don’t allow him to escort me..... Besides, I make sure I keep part of the money I earn, and then let men who come to me in the name of love to cover for my expenses, say one man pays for transport, another one rent or food and the other medical bills, and so on. And to avoid being caught, I try to allocate different appointment dates for each. Because most of them work with me here I also endeavour to monitor their movements and plan accordingly.”

(21-year-old Female sander, participatory workshop, 26<sup>th</sup> October 2020, Ndeeba)

Clearly then, these young women intentionally sustain multiple affairs within complex networks of sexual liaisons. One participant in the workshop asserts:

“*Babawuuba*’ (frequent sexual engagement), in a way, implies that they are voluntarily involved in continuous sexual escapades in order for favours, work opportunities, money, gifts and so on for survival”.

(24-year machinist and welder, Katwe industrial area)

Specifically, the word ‘*Babawuuba*’ comes from a Luganda verb ‘*okuwuuba*’ which means ‘to swing’. Therefore, ‘to swing’ in this context, means ‘perpetual sex’. Invariably, such expressions also bring to the fore issues of sexual abuse, coercion, and violence (Oriel, 2005; Wandera et al., 2021). While some young women tend to hold the view that they are engaged in sexual encounters for material gains. In the same breadth, a female participant contends:

“A woman who accepts me for material things is a *malaaya* (sex worker). However, it is also true that many women tend to participate in acts of infidelity, promiscuity, or sex work for material benefit mainly due to poverty. Indeed, several of them in these industrial spaces vulnerably engage in sex with married bosses/artisans who pay them handsomely to keep their sexual affairs a secret. This, in the process, allows men to create and enjoy wider sexual networks as they also take advantage of new recruits (adolescent girls and young women) who join the industrial areas as casual workers”.

(23-year-old female food vendor, Ndeeba industrial area).

This arguably propels sex work as a broad concept with boundaries that are difficult to define (Schulkind et al., 2016). In geographical contexts, Mark Hunter in ‘Love in the Time of AIDS’ narrates accounts similar to participant S’ story;

“In South Africa central to women’s claim to the right to plural lovers is the tremendous sense of conflict that dominates relations between men and women. “I have heard young women say I have more than one boyfriend because I was annoyed when I caught him (being unfaithful for the first time, so I thought let me find myself another” Majority (of women) do it because they say, you cannot stand on one foot.... In a climate of acute gender tensions, few men will not have heard women calling multiple boyfriends, their ministers of finance, transport, and entertainment”

(Hunter, 2010, p. 147)

Understandably, the consequences of such behaviours are far-reaching as they lead to social conflicts and the likelihood of increased HIV transmission among young people. Disproportionately, high HIV infection rates among young women aged 15–24 years have been attributed to their greater involvement in relationships with older-aged partners. Whereas early studies emphasized economic concerns in the context of poverty as driving girls to accept or seek the attentions of older employed men, close-grained studies reveal a complex interplay of meanings and motives that prompt both men and women across socio-economic strata to engage in intergenerational and/or cross-generational sex (e.g. Leclerc-Madlala, 2008). This is also echoed in an interview with Ntege Angella, a 28-year-old HIV-positive participant and an adolescent and sexual reproductive health expert working with ICWEA (International Community for Women Living with HIV/AIDS, Eastern Africa). When asked what she believes are the major factors that make young people vulnerable to AIDS, she replies:

“...Because young people don’t have money while the older people have it, which leads to cross-generational relationships. Now it so happens that maybe my boyfriend has no money, but I passionately love him. Unfortunately, because he has no money, I get different boyfriends or a sugar daddy who can afford to get me an iPhone and other expensive things... If someone overpowers you with money and you cannot bargain for protection - you are clearly vulnerable.

(Interview excerpt, Lungujja-Kosovo, 30<sup>th</sup> June 2020)

While Ntege’s account provides insights into the growing desire for materialistic life among young girls and women in marginalised informal spaces (see also Luke, 2015), it raises the important issue of lack of the necessary skills to seek better employment and the lack of information that compromises their decision-making and ability to say no to unprotected sex, which becomes transactional. Ntege’s explanation of the unequal power relations in transactional sex reflects how economic inequality exacerbates HIV risk among impoverished young women and adolescent girls (Hunter, 2010; Mubiru, 2019; Sanderson & Kindon, 2004).

Thus, so far, this chapter has attempted to demonstrate the centrality of applied social sculpture in exploring the magnitude to which alcoholism has shaped young men's mentalities in relation to women's vulnerability while asserting their sexuality and manhood traits in informal spaces. The final sub-section explores the ways in which young men engage in multiple sexual relationships in the interest of self-gratification and performances which negatively affect women's participation and mobility in peri-urban areas.

### 5.2.1.3 Artwork G: Hegemonic allegories of sexuality

My fieldwork suggests that there is evidence of a growing tendency among young men to exercise traits of dominance as they exploit the powerlessness of young women and adolescent girls in informal spaces in Kampala (e.g. Choudhry et al., 2015; Nicholas, 2010). Participants talk about their uncouth sexual attitudes of young men towards women, often taking advantage of their vulnerability, sometimes in violent ways (e.g. Dunkle & Decker, 2013; Schulkind et al., 2016; Wandera et al., 2021). Their use of metaphoric and derogative language while engaging sexually with several girlfriends demonstrates a form hegemonic masculinity as a sign of power in informal contexts. In my research, young men give visual and narrative accounts about their participation in creating spiral sexual networks and use rather patronizing words such as '*nakalya*' (I ate her/slept with her) or '*okwetaasa*' (*satisfying one's sexual urge*) in reference to using and dumping unsuspecting young women and girls, literally serving as sources of self-gratification while giving space to other sexual contacts.

In *Plate 35– Artwork G above*, participant R depicts different couples switching simultaneously in a brothel in one the informal areas in Kampala. Many young women and adolescent girls are victims of gang sex which manifests as a concealed form of masculinity among young men. Participant R, a young woman, symbolically depicts a headboard to represent '*Namboole*' as a sexual pitch or playground. Incidentally, Uganda's main national football stadium is found in a place called Namboole a metaphorical reference to sex as a form of football - a male sport in which balls (presumably women) are passed around. Young people now use the name metaphorically to refer to the conventional 'bed' (where sex is performed). During a brief conversation about her artwork, participant R notes that:

"Some men have made it a habit to lure our female friends into love affairs, taking them to '*namboole*' as a form of pride and to show off among their peers. Sadly, these girls

become openly humiliated when these male partners take to gossiping about their short escapades (telling their male friends that she is a recent sexual contact- Nakalya), which forces them to migrate to other informal locations (townships) to avoid further embarrassment”

(Participatory workshop, Ndeeba, 25<sup>th</sup> October 2020)

In the process of relocating to new spaces, the likelihood of transmitting HIV and other STDs increases as these young women/adolescent girls take their labour services to other informal spaces. Participant R’s illustration (*Plate 35*) depicts coupling with different girls within the industrial setting, translates into a complex web of sexual networks. His work also echoes the symbolic portrayal of a young woman in the middle of several men confirming the existence of broad sexual connections in the fringes of industrial spaces (*‘Tetukuta’*- [sexually insatiable] – see *Plate 36*) as illustrated by an 18-year male (participant B).

Both artworks (*Plate 35* and *Plate 36*) appear to portray young men involved in sexual competition, exploitation, and sexual gratification. This finding is consistent with those of feminist activists who have portrayed these practices as a form of sexual objectification of women manifesting through male sexual dominance, which consequently affects women’s health as men continually sustain unprotected sex relationships with them (e.g. Oriel, 2005; Simpson, 2009). Participants talked about how young men developed domineering traits of toughness, lack of emotion, physical strength, and competition amongst themselves. Several participants confessed to knowledge about using bold language as figure of speech:

“If I want to engage with a girl sexually, I simply tell her ‘tugende e’namboole leero’ (Lets go to ‘Namboole’ today). That signals my interest in having sex with her and she accepts, albeit with some conditions.”

(21-year-old Male artisan, workshop participant, Ndeeba)

“Sometimes when I talk to my friend about a new catch (girlfriend), it makes me feel like I am exercising my sexual prowess. I would also tell him that ‘Kano ka kwetaasa’ meaning that she is for sexual satisfaction only – like a one-night stand”

(23-year-old male sander, Workshop participant, Katwe)

“Several men decide to ring-fence the young women, and especially adolescent girls for long-term relationships. They prefer to call their sexual contacts as ‘Ako Kantu kange’ (She is mine). On the other hand, the men who are married or not ready to settle down fondly use phrases like ‘I want to kwetaasa’ (to imply dating a young woman for sexual pleasure only).”

(19-year-old Male carpenter, Ndeeba Industrial area)

All these narratives subtly represent traits of social vulnerability and naivety among young women and adolescent girls as factors shaping the bold masculinities that prompt young men to justify their performance and demonstration of manhood and sexuality in marginalized urban settings.

Similarly, these socially constructed ideals of masculinity are further explored in another artwork by a female Participant T (*Plate 37*), who talks about how young people often find a challenge of controlling their sexual behavior because of their own pressure to be recognized as men by their friends and sometimes in accordance with wider social and cultural norms (e.g. Jewkes & Morrell, 2010; O'Brien & Broom, 2013; Simpson, 2009; Wyrod, 2011). As a result of such influences many young men deem it culturally appropriate exercise their maleness by having another sex partner (which they refer to as a 'side dish'). Participant T entitles her artwork as '*Omutima gw'omulenzi gubeera eno eneeri*' (*A heart of a young man is always back and forth*) to figuratively represent the notion that:

"Young men's hearts are like Bluetooth. They are quite insatiable and therefore difficult for them to settle for one girl. Every young man in my workplace wants to have two or more girlfriends as way of showing that that they are men enough, but it always leads to social conflicts."

(Informal conversation, participatory workshop, Ndeeba, 25<sup>th</sup> October 2020)

This participant uses her artwork to represent the bitter consequences of having several sex partners while also supposedly being in a steady relationship. She chooses to use familiar symbols like the shape of the heart to allude to love and commitment, yet inside the heart, is a pigeon representing the act of sharing between the couple. Ironically, inside the pigeon is a silver fish (Mukene) a common symbol used to refer to patriarchal construction of polygamy common among men in local communities - also manifesting as a cultural barrier to stemming HIV/AIDS (e.g. Jewkes & Morrell, 2010). With the help of other participants, her artwork is further rendered with multi-faceted textural inscriptions that valorize the power of faithfulness as an important keystone towards HIV/AIDS prevention and awareness. As this artwork suggests, young people in serious relationships are pressured into acquiring 'side dishes' either for personal pleasure or in response to cultural norms. The consequences of such behaviors

are far-ranging as they not only lead to aggravated infidelity, but also various forms of gender-based violence among partners. This finding broadly supports the work of other studies linking infidelity and gender-based violence as stimulant for increased HIV risk in grassroots populations (e.g. Kaye, 2004; Laing et al., 2013). Indeed, many of the participants during co-production workshops in Ndeeba and Katwe also confirmed that most of their sexual relationships expand over time until they turn into a complex network of risk involving multiple relationships and high levels of promiscuity in the industrial ghettos<sup>80</sup>, consequently contributing to the high HIV infection levels in industrial spaces.

### 5.3 CONCLUSION

This chapter began by describing how the simultaneous process of engaging participants in storytelling and illustrative drawing (visual explorations – (E.g., *Plate 15, Plate 19, Plate 22, Plate 23, Plate 28, Plate 32, Plate 34* and *Plate 37*) enabled open conversations about sensitive taboo subjects like sex, gender, and HIV/AIDS among young people. It has attempted to demonstrate the importance of applied sculpture, as a social practice, in stimulating young people's ability to better express themselves as a vital aspect of confronting HIV/AIDS in their lives. It shows how the multi-dimensionality of applied social sculpture (stories, drawings, and the use of local resources) was able to (i) recognise the value of local knowledge, and the everyday social experiences through visualised exploration of metaphoric expressions (E.g., *Plate 29, Plate 31, Plate 33*, and *Plate 36*) (ii) raise consciousness and awareness of critical social realities with respect to HIV/AIDS (E.g., *Plate 15* and *Plate 33*), hence fostering youth participation towards personal involvement in HIV/AIDS preventive activities such as advocacy, activism and agency for the benefit of the wider informal community (E.g., *Plate 11, Plate 12, Plate 20, Plate 21, Plate 24, Plate 30, Plate 38* and *Plate 42* and (iii) tap into and boost young people's expressive and creative capacities (E.g., *Plate 22, Plate 27, Plate 32, Plate 33*, and *Plate 41*, to confront those long standing gender-related barriers to HIV/AIDS through applied works (Staten, 2014; Wells, 2012, 2016). Certainly, these barriers have been understood as a deterrent to health-enhancing behaviours and empowering youth lives in the context of

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<sup>80</sup> 'Industrial ghettos' is a term used in this research to refer to the informal settlements that serve as dwelling places for both industrial casual workers and residents from other work areas in the fringes of the industrial spaces. Many of these unplanned housing units are known spaces for sex work while some of them double as wood workshops during the day and dwelling places at night.

HIV/AIDS in informal spaces. The design and co-production of artworks as a lengthy creative process could not adequately challenge some of the problematic claims that participants made, especially the blaming of women for the spread of HIV, but it does expose the often-sexist attitudes of young men (and even some women, it seems) that perpetuate the myth that women are to blame for spreading HIV. As revealed in the different sections of this chapter, the value of applied social sculptures potentially lies in the ways it implicitly suggests a need for follow up work, especially with young men, to challenge these assumptions, along with its potential to boost livelihoods and influence behaviours among the youth. Additionally, with respect to the first research question<sup>81</sup>, it has been shown from this analysis that, despite the shortcomings, applied sculpture is a valuable social practice for HIV/AIDS awareness and prevention, especially through youth engagement in marginal urban areas. It has drawn particular attention to the fundamentals of applied artistic practice and literacy in which issues of self-expression e.g. (C. Mitchell, 2006), skills acquisition, and knowledge-sharing towards HIV awareness and prevention e.g. (Schmahmann, 2013; Wells, 2012) have proved instrumental in the understanding the social realities, especially gender injustices and taboos that continually allow the epidemic to flourish among young people in the fringes of Kampala city and beyond. Most crucially, this chapter has demonstrated why applied social sculpture is important in facilitating open communication, information-sharing and social awareness among young people in the context of HIV/AIDS prevention in communities where opportunities for formal education are limited. It can also be used to encourage many to rethink alternative ways of confronting their miserable situations to recreate themselves as producers of knowledge, social advocates, and empowered actors in transforming their livelihoods and wellbeing in informal contexts.

The next chapter focuses on the efficacy of applied sculpture in contributing to HIV/AIDS prevention and youth economic empowerment through creative thinking, hands-on skills development, and co-production for capacity building among young men and women in informal contexts.

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<sup>81</sup> Can applied social sculpture be used to facilitate open communication, self-expression and increase HIV/AIDS awareness, prevention, and encourage behavioural change among young people in marginalized spaces of Kampala?

## CHAPTER SIX

### APPLIED SOCIAL SCULPTURE, HIV PREVENTION AND YOUTH EMPOWERMENT

#### 6.0 INTRODUCTION

This chapter focuses on demonstrating the efficacy of applied social sculpture in contributing towards HIV prevention and youth economic empowerment through creative thinking, hands-on skills development, and co-production for capacity building among young men and women in informal contexts. It seeks to show how the socially engaged practice of applied sculpture attempts to tackle socio-economic precarities such as unemployment, poverty, misinformation, lack of self-esteem, lack of skills and so on, intended to engender preventative and livelihood benefits, while fore-fronting collective youth participation (e.g. Bell & Aggleton, 2013; Bruce & Hallman, 2008; Checkoway & Gutierrez, 2006; Tukundane & Zeelen, 2015) in peri-urban urban settings of Kampala.

The purpose of this chapter, therefore, is to demonstrate the ways in which the creative practice of applied sculpture helps in contributing towards raising more awareness about HIV/AIDS and its prevention among the youth, and later to the wider community. Additionally, it also affirms the ways in which the creative approach contributes to the open expression, enhancement of knowledge, skills, and enriching talents of young people towards co-creating 2D and 3D artworks with inscribed messages anticipated to launch preventative and economic benefits in their social world. Conspicuously, this process also enables us to learn how art can bring young people together, boost their confidence to talk about HIV/AIDS, with implications for sharing with other members of the community in which they live. I attempt to show these potential benefits basing on four specific examples of co-produced artworks: (i) HIV benches (ii) HIV bed (iii) Covid house and (iv) Covid-19 bikes. These four examples ostensibly provide the basis for the discussion of how the creative practice of applied sculpture enables youth participation in critical consciousness-raising about two colliding epidemics and their empowerment, with preventative and economic benefits with anticipation of boosting their livelihood opportunities, health, and wellbeing. The discussions have been structured towards



describing and explaining how conversations, stories and visual experiences inspired the creation of 3-dimensional artworks with the intention of using them as tools for raising awareness of HIV/AIDS, its prevention and youth empowerment. This was done in two ways. First, by providing participants with instructions/guidelines on translating their stories about every day experiences/social realities in informal settings into surface drawings meant to evoke explicit visual imagery for HIV/AIDS prevention, and; second, through collaborations to transform the visual ideas into three dimensional concepts, while recognising the need to improve the talents/crafting skills of young people intended to better their health, wellbeing, and livelihood opportunities.

The chapter is organised into three sections. The first focuses on two selected examples of artworks showing how the process of applied social sculpture enabled conversations and stories of everyday experiences of young people, then facilitated the creation of artworks/objects as tools intended for raising HIV/AIDS awareness along with preventative benefits. The second section provides an interface with the Covid pandemic and how it furthered opportunities for the youth to talk about their entanglement with the emerging health and livelihood threats, which in the process, enabled them to acquire more skills through creative working. The third section, then, explains how the participants benefited from participation through skills and capacity building as they generated the artworks for HIV/and AIDS/Covid awareness. It, thus, expounds on the potential of applied sculpture in responding to the specific skills needs of young people while sharing knowledge and stories about the different issues regarding HIV transmission, prevention, tapping into the use of local resources through collective youth participation in peri-urban communities around Kampala.

In what follows, I explore the potential of applied sculpture in enabling collective action (open group conversations, dialogue, and creative working) to generate artworks for raising awareness about HIV/AIDS with reference to two selected creative outputs I co-produced with the participants: HIV benches and the HIV bed (*Namboole*)

### **6.1 HIV BENCHES AND BED FOR PREVENTATIVE AND ECONOMIC BENEFITS**

Young people, especially those who are HIV positive, face several obstacles to social participation, including fear of public disclosure and negative stereotyping by workmates and relatives. Notably, successful arts-related interventions to tackle the HIV/AIDS epidemic

require that messages be created, designed, and implemented by the people most affected by the epidemic (Boneh & Jaganath, 2011). Applied artistic practice (AAP) provided an opportunity for participants to give accounts of their precarious experiences through participatory workshops, which were designed to respond to the need to induce critical consciousness about HIV awareness and preventive knowledge-sharing among participants. As explored in Chapter Five, sharing every-day experiences, storytelling, and drawing, combined with ethnographic methods, were core aspects in facilitating and informing participatory workshops designed to encouraging direct interaction. They also encouraged dialogue towards developing collaborative sculptural and writing options that illuminated participants' lived realities in the context of HIV/AIDS.

At the start of the workshops, based on my guidance and instructions, the participants explored the use of the various ways of telling their experiences. These included drawing images and writing short notes on pieces of paper given to them in the workshop.

“... Let’s begin with reflecting, sharing, and writing down on our personal everyday experience of living with HIV/AIDS. Noticeably, some participant seemed to have difficulty in expressing themselves using their personal experience. How about writing down something about yourself. How you encounter your health challenges or someone close in your life. “Talk about your Life changing moments, the good and the bad ones”, I suggested. Starting with conversation related to peripheral experiences and people tangential to their lives, somehow, helped many to open up: Talking about experiences of loved ones create opportunities of mentioning aspects directly connected to their individual lives. Stories about helping friends and relatives through testing in hospitals, encouraging them to take their ARVs and abstaining from sex gradually emerged. Some participants chose to tell their stories by drawing images about themselves while other began by using soap and clay to express themselves and this eventually enabled them to become confident to chat about their most difficult experience of living with HIV.”

(Field diary, Participatory workshop Lungujja, 10<sup>th</sup> May 2020)

Engaging in conversations about general experiences related to health, people, and their workspaces/society (also see Chapter 5) allowed them to build the initial confidence to further express themselves supported through drawing, storytelling/writing, and modelling, thus stimulating free discussion about experiences and benefits of the collective engagement. We reflected on what they know (every-day experiences) and then chose the best methods for translating their ideas into artworks – helping them develop their drawings with visual appeal

without losing the essence of HIV/AIDS awareness/prevention messaging. For instance, in the participatory workshop captured in *Plate 38*, I instructed the participants to visually share their daily ordeal of experiencing and dealing with the signs of HIV and how it affected their social behaviour and resilience. As one female participant testified, as a consequence of the growing stigma and public negative perception arising from being viewed as HIV positive, manifesting in significant health deficiencies such as weight-loss and developing skin rashes, she became socially withdrawn from her local community.

“When my health started deteriorating due to HIV-related illnesses, I began to feel unwanted and neglected. Most of my friends started gossiping about my sudden and continued drop in size and body rash. Everyone started isolating me and I could not cope with staying put with them. I found solace in my single room in Lungujja, become depressed and socially withdrawn. But now, this participatory process is helping me realise that world still cares about my plight. The group discussions and drawing process are helping me regain my esteem I now feel encouraged to talk about my personal experiences with others. I think that by sharing what I have gone through may even help another person to refrain from reckless sexual behaviours that may put his/her life at risk of HIV infection.”

(Participatory drawing/modelling session, HIV positive female participant H, Lungujja, 25<sup>th</sup> May 2020)

To help her relate her story/experience visually, I requested participant H to work with another participant (acting as a model) to describe and capture one of the moments that tormented her through illness using coloured pencils (*Plate 39*). Depicting herself in a squatting posture showing one of the symptoms of HIV infection (bodily sores and vomiting due to fever) was captivating to other participants who admitted going through similar situation of helplessness. She explicitly attempted to reveal how HIV/AIDS may affect one’s body based on her own lived experience. During the same session I encouraged participants to make short notes against their illustrations as a way of documenting the untold details of their experiences for the benefit of viewers, and also to enrich the final concepts for modelling in the final artworks. As Participant H presented her finished drawing for discussion, one of the participants remarked.

“Oftentimes, it is important to seek medical advice on time when you fall sick. When I started developing constant fevers last year (2019) I quickly sought medical help. I tested HIV positive, but I have not experienced bodily sores ever since I was diagnosed because I have been consistently adhering to my drug regime. Doctors say that adherence is very helpful in supporting the immune system against opportunistic illnesses like cough/Tuberculosis, skin rash diarrhoea, etc.”

(Participatory drawing session/critique, male participant V, 25<sup>th</sup> May 2020)

The drawing sessions evoked further conversations on how HIV decimates the immune system of the victim. While creating maquettes from the drawn illustrations, several participants admitted to encountering the several challenges related to deteriorating health, but also acknowledged how hard it was to share these experiences with those who were not infected because of the risks involved. As participant K noted:

“We face a lot of discrimination because of some the physical signs of HIV such thinning, pale eyes and/or body rash. Once people suspect you are HIV positive, they tend to isolate you, even when you try to mingle with them at work or in social events for instance when in bars or video halls watching soccer - *Mubibanda* - Pubs

(Participatory discussion, HIV positive male participant, Lungujja, 25<sup>th</sup> May 2020)

These and other similar stories shared during the participatory sessions provided a rich repertoire of ideas to draw from in developing HIV awareness messages during the creativity workshops. After the preliminary guidance on how to translate stories and every-day experiences into drawings (Seen in *Plate 12*, *Plate 18* and *Plate 43*), I engaged participants in the practical construction/design sessions, exploring their potential as contributors to knowledge (see Stuart, 2010). This helped them build thoughts, ideas, and actions related to their everyday experiences which led to the creation of applied artworks. This was also in the hope that their participation may have a positive impact on influencing better sexual behaviours and perceptions using applied artistic methods. I now turn to the first two artworks selected as examples to demonstrate how sculpture helped participants to build confidence and creative skills with potential livelihood and preventative health benefits - Artworks A (HIV benches) and Artwork B (HIV bed - *Namboole*) - *Plate 40* and *Plate 41* respectively.

The first artwork (A) is a series of benches (HIV Benches - *Plate 40: Also, section 6.1.2*), each carrying messages intended for HIV/AIDS prevention targeting other youth in the community. The second artwork (B) is the ‘HIV bed’ (*Plate 41: Also, see section 6.1.3*) derived from the storyboard espoused by participant T in which she captures one of the masculine ideals of young men engaging in multiple relationships for self-gratification and the objectification of women. Both artworks form the basis for the discussions about using applied sculpture for HIV prevention.

### 6.1.2 ARTWORK A: Wooden benches (*Bufoomu*) for HIV prevention

The ideas generated from shared experiences were transformed into pictures, illustrations and inscriptions as participants were supported and grew in confidence to talk about their lived experiences and health. Interestingly, the bench concept was conceived through a conversation with an HIV participant who shared a personal experience of sharing a bench with his friends in a sports pub during one of the first participatory workshop:

“One day when I went to watch a match in a video hall, I found my friend who accept to sit with me on the same bench. However, after a while, another friend joined us and somehow the bench was not enough for all of us. So, he decided to push me off while shouting on top of his voice: “*Oyo mulwadde was siliimu aveeko*, tamutusiiga. That guy is HIV positive; he can infect us too. With all the humiliation, I couldn’t confront him. Instead, I immediately left the hall.” (Participatory workshop, 24-year-old HIV positive participant H, Lungujja)

His narrative echoes one of those untold stories of discrimination and trauma experienced by people living with HIV as they engaged within their communities. It also highlights the problem of lack of knowledge about how HIV is transmitted among the youth. In a response to his experience, another participant observes:

“Such things happen to us all the time. It’s rather hard to openly tell people to desist from discriminating. The lack of compassion and the harsh treatment meted on us by friends in public makes it hard for us to openly disclose our status for fear of such consequences”.

(Group discussion/ storytelling session, 25-year-old HIV positive female participant, Lungujja)

Expressions of fear about disclosure clearly echoes the presence of strong traits of social withdrawal and silence among young people living with HIV about their plight in public spaces. I asked the participants.

“How about devising a way of expressing your concerns for the protection of rights, safety and advising the youth on how to deal with the epidemic? Supposing we write messages on bench forms in ways that are explicit about raising awareness and prevention intended for places where most youth can read them”?

The participant agreed. I stressed that the benches could be turned into objects with words to communicate vital prevention messages to other youth. After brief group discussion about the possibilities and usefulness of crafting messages about HIV prevention, participants agreed to participate in the construction of the benches for their functional and durable potential in communicating explicit messages intended to raise awareness about the epidemic among the urban youth.

#### **6.1.2.1 Making the wooden benches:**

As *Plate 42* shows, the participants were helped to build the benches from scrap wood panels that were discarded outside a local carpentry workshop space in Lungujja. Having realised the difficulty of obtaining cheap wood from the timber stocks in industrial spaces, we opted to work with a local carpenter whose workshop is located along the main road in Lungujja during the lockdown. Working with him helped the participants acquire hands-on skills in cutting and joining wood, while also allowing them to continue sharing life experiences in homes and at work. It created a sense of cohesion among the participants as they began to learn the benefits of teamwork, while at the same time building their skills. It also permitted them to gain confidence as they constantly joked about their performance and social engagement while appreciating the value of using found materials (junk wood) to construct the benches.

“I mobilized a few participants who were familiar with the Lungujja neighbourhood to identify carpentry workspaces where we could freely interact, and collectively develop works using wood and metal. Because of the lockdown at the time very few businesses were open so, finding carpentry workshop in the neighbourhood was quite difficult. Fortunately, we identified a small roadside carpentry workshop in makeshift structure whose owner accepted to provide working space and technical help to the participants in building the wooden forms (*Bufoomu*). The next day I sent two of the participants to a hardware shop to buy nails and sandpaper to start the crafting/design process.”

(Field diary, Participatory workshop, Lungujja, 20<sup>th</sup> May 2020)

Notably, the concept of the wooden benches is based on the lived experiences of young people infected with and affected by HIV/AIDS, specifically, from the informal settings of Lungujja - Kitunzi, a peri-urban neighbourhood of Kampala. After identifying the carpentry site, design of the benches started with regulated intervals and breaks to prepare materials and take refreshments, which also allowed the participants to relax and freely interact. As we worked through the preparation of the found wood and offcuts - sanding and creating cutting lists (see

**Plate 42** - with the help of the carpenter, participants kept on sharing their everyday experiences such as domestic work issues. We also chatted about the absurdities of working in open environments and how the public perceived people living with HIV in their informal local spaces. Several participants talked about the growing situations of discrimination and social stigma in homes and at work, promiscuity and hegemonic masculinities that have forced many young people, especially young men, to practice unsafe sex and avoid HIV testing (see also Chapter 5). The simultaneous integration of dialogue and sculptural practice (wood fabrication) was central in facilitating the creation of HIV benches.

#### 6.1.2.2 The crafting the prevention messages for the benches

Navigating the interactive sculptural processes provides creative avenues of experiential learning in which the participants spontaneously espouse diverse concepts related to everyday situations of their informal life. To develop appropriate prevention messages, I encouraged each participant to write down and then talk about their personal experiences of dealing with the disease and share ways in which they have able to handle it resiliently for the benefit of others in the groups. After the discussion, several ideas and stories were translated into visual forms using pens and pencils. Many of the participants were able to visually translate their personal experiences (E.g., **Plate 38**) of encountering HIV and other conditions of precarious existence. Meanwhile, I would constantly encourage and guide them to translate those experiences and thoughts through free-writing and sketching out messages on paper. Together with the participants, we were able to identify appropriate HIV prevention catch-phrases from their stories (e.g., be faithful, use condoms, take your ARVs on time, *Genda wekebeze, Mila edagala*, etc). The images/sketches from their shared stories seemed powerful as expressions of concern and caution about behaviours in the context of HIV/AIDS.

As **Plate 43** shows, two of the participants are concentrating on transferring messages and developing concepts for encouraging sexually responsible choices to stop the spread of HIV. Interestingly, this manifests one of the ways in which participants given an opportunity to voice their concerns about HIV. The use of visual expressions and stories about the health and social repercussions of young men and women/adolescent girls who have made it commonplace to indulge in sex trade or multiple and cross/intergenerational sexual relationships for material and monetary gains (see Chapter 5) is quite clear in the messages they conveyed. The

peculiarities of young people refusing to use protection in sex because of certain masculine ideals are some of the other factors can be challenged by creatively confronting these in 3D artworks. As seen in *Plate 43*, participants chose to design communicative wooden benches based on the reality that these were common objects in the places of leisure they visited in Kampala. Several HIV positive participants brainstormed the key aspects that helped shape their resilience through illnesses related to HIV infection. The words such as “use condoms”, “ARVs are good for life”, be faithful and HIV disrupts your future, etc, were also selected from the everyday experiences/stories. Personal experiences informed the choice of message that was used on the benches.

“Before I started ARVS, my body was very thin. I got stigmatised- fear everyone around me. It was through my friend who took me to hospital, got tested and put on TB treatment for 6 months. This was before getting ARVs. When I started taking ARVs, my health got better, I gained weight and healthier and was quite happy. Only that now Covid-19 has affected my dieting of late the doctors told me that my adherence was good and subjected to 6 months prescriptions, so I get my medication and only go back for check-ups after few months.

(Participatory workshop, drawing session, Lungujja, Participant H on 9<sup>th</sup> July 2020)

On 9<sup>th</sup> July 2020, two of the participants reported earlier than usual (about 8:30 am) in dirty and shabby clothes. They were visibly sad and drained.

“We have been critically sick and living on hand-outs for close to two months. We have not been working for two month and as such we could raise money to pay for our accommodation”. My workshop assistant quickly arranged for some food and tea for them. As they took their tea, they told me of how they were chased out of the house for failing to pay for their rent for three months. “We had to sleep in a nearby church because it is a communal place and they could find where to bath”, one of them said. “I could not take my medicine (ARVs)”, the other mumbled. I am afraid that missing one day would affect their health in the short run. At 12am, they both took a nap as they claimed to have hardly slept at night.

(Field dairy, participatory workshop HIV-positive couple, Participants H and K), Lungujja, 10 July 2020)

This account echoes the excruciating experiences that often prevent people living with HIV from realising their full potential of enjoying life and being able to participate in their day-to-day activities. It added to the other participant accounts of how important it is to maintain their drug regime to ensure a longer and health life, despite other difficulties of living in



informal spaces. For most of the participants, using visual imagery seemed to help minimise anxiety and stress related to HIV stigma and discrimination at work in informal spaces. Some participants pointed out that:

“Art can create a quick escape from the excruciating realities of confrontation from other people such as, enacted stigma from gossip, taking ARVs daily, etc., and still be able to responsively talk about safety to others. It is a relaxing and refreshing experience from ordinary work.”

(Interview, 24-year-old HIV-prenatal participant, Lungujja, 25<sup>th</sup> June 2020)

“Drawing images/messages on paper and wood surface is very helpful in expressing ourselves regarding sensitive subjects like sex and HIV/AIDS while communicating to other people about protection and other health enabling practices.”

(Informal conversation, 26-year-old female participant, Ndeeba 25<sup>th</sup> June 2020)

Shared applied practice helped the young people to share personal HIV experiences in a way that shields them from wider societal stigma, providing the basis for helping those whose status is compromised by infection to overcome the causes and consequences of the social issues they face (Moxley (2013).

While executing this project, each of the benches is given specific dimensions (See **Plate 43**) in a way that gives room for mass production so that they can be taken to different locations. The possibility of reproducing the benches means that stencils for the design are cut and kept, while the frameworks in wood are given standardized ergonomic measurements that make these benches usable and comfortable for public use in social spaces. In particular, participants suggested that these benches should be mass-produced in a variety of local languages to encompass inclusivity and diversity into the wider process of national HIV awareness/prevention (i.e., Luo for Northern regions, Lunyoro/Rutoro for Western, and Lusoga for Eastern and Luganda for central and southern regions of Uganda). Area and business centre deemed to have high youth populations ought to be earmarked for place of such benches to increase on the awareness of the disease. For instance, **Plate 44** shows a busy scene captured

during the Covid-19 lockdown period from a local trading centre near Kampala - Lungujja-Kitunzi<sup>82</sup> which is potentially ideal for such benches. As one participant points out;

“It is one of the typical social joints where property brokers converge during day as they wait for opportunities or customers. They are usually joined by young boys from the neighbourhood who are idle and jobless spending time playing cards and Ludo while sitting on benches - locally called Bufoomu”

(Field diary, Participant identification survey, Lungujja, 17<sup>th</sup> July 2020)

Participants argued that such places (see the iron-roofed shade in the middle ground of *Plate 44*) could be ideal for the placement of the HIV awareness forms/benches as they would easily attract attention because of their visual appeal while communicating the intended messages to the users. In the same vein, participant K reiterates:

“Sitting on benches (*Bufoomu*) in busy social spaces in trading centres (for example, in spot betting joints, pubs, Ludo and pool table spaces) facilitates social interaction with the masses, which in a way, serves a duo-purpose of HIV information-sharing and utilitarian support”

(Informal conversation, participatory workshop, 35-year-old HIV participant, Lungujja, 10<sup>th</sup> June 2020)

Clearly then, participants seem to recognize the transformative power and the extrinsic purpose of placing the benches in open social spaces as a way that enhances social cohesion and message conveyance as different people may visually and cognitively appreciate the intended information about HIV/AIDS. However, another participant cautions:

“If the intended user happens to be in a state of stress or distraction, the benches may be less likely to serve their intended function. Otherwise, the messages have been designed in a non-confrontational manner because they are intended to serve as both educational and utilitarian tools for ‘breaking the silence’ and raising awareness about the intractable barriers to HIV/AIDS prevention in our social or workspaces”

(Group discussion, 24-year-old student-participant, Lungujja).

Indeed, as *Plate 40* portrays, these wooden benches are decorated with critical consciousness-raising messages about the need to protect oneself from getting infected but also maintaining health-enhancing behaviours for a healthy life among the youth. Some of these stories

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<sup>82</sup> A busy Scene from a local trading centre (Near Lungujja-Kitunzi market) in Kampala captured on 17<sup>th</sup> Jul 2020 during a participant identification survey. Its typically one of those ideal sites where HIV awareness forms/benches can be placed for their visual and functional impact in relation to HIV/AIDS awareness and prevention

provided the much-desired ideas presented in form of phrases meant to encourage the youth avoid situations that put their lives at risk.

In what follows, I select two examples from the HIV-bench series to further demonstrate the ways in which some concepts were creatively manipulated by participants with intention of sharing HIV prevention messages to other youth audiences (i) the padlock concept, (ii) the mini-bench concept (*Genda wekebeze and mira edagala*)

(i) Padlock concept - Saying no to unprotected sex

The participants engrave a padlock to one of the supports on the bench with the phrase, “say no to unprotected sex” in contrasting dark in-lays of stained shellac used for wood finishing to clearly espouse the need for keeping guard from unsafe sex (See Bench A - *Plate 45*). Several other catchphrases are inscribed on the top of bench A; ‘get circumcised’, ‘use condoms to avoid AIDS’ and a landscape with a house to figuratively proclaim that HIV is doesn’t end with spaces of precarious existence, but rather goes beyond into homes of the well-to-do communities. The messages seem to echo the rhetoric of HIV prevention as championed by Uganda’s Ministry of Health (MOH) or other public health consortiums in the fight against HIV/AIDS. It’s quite clear that the inclusion of these explicitly short but creatively rendered messages is intended to provide lasting visual and provocative impact to the observer’s mind once placed in appropriate public spaces in which youths congregate. Participants argue that using artworks/objects as vessels for appropriate HIV prevention messages is aesthetically powerful and advantageously durable, unlike the fleeting messages contained in print media and radios which the youth hardly pay attention to while at work (especially in busy, noisy spaces like industrial zones) or leisure spaces.

Interestingly, the padlock concept (above) was conceived by a couple<sup>83</sup> at the workshop who confess to living a life of difficulty with dire financial challenges: staying and working in highly marginalized setting in Kosovo subjects them to high levels of economic exploitation, social discrimination, and social stigma. To avoid situations like this, they suggest that the youth must guard themselves at all times, lest they fall victim. Young people symbolically engraved a

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<sup>83</sup> This couple are long-term sexual partners in which one is HIV-infected, and the other is not.

padlock with the words 'No to sex' to emphasise the need for young people to abstain and/or go for testing before sex. Nonetheless, they also testify that:

"We were counselled on how live positively and have HIV-free children. However, because of misinformation or ignorance, the public and my relatives were completely opposed to the idea of staying with a woman (my wife) because they all knew she was diagnosed with HIV. But because we both went for testing and got counselled (with contrasting results, I emerged negative, and my wife confirmed positive). She was then put on ARVs and now has a suppressed viral load (The doctor advised that her adherence to HIV treatment would significantly reduce the chances of infecting me to about 99%). We have been able to wither the enacted stigma/pressure from our families and friends who were against our union and now, we have two healthy children. I, therefore, encourage young people to know that being informed about their HIV status is particularly vital in making important life decisions, including how to avoid or live with HIV."

(Informal conversation, Participant K, Lungujja, 8<sup>th</sup> May 2020)

Although, this participant seems to be concerned about the negative perceptions about the likelihood of infection, biomedical intervention through antiretroviral therapy (ART) and psychosocial support (counselling) from the hospitals has been a key pillar in helping him navigate this fear (see Doshi et al., 2018), alongside Uganda's 90-90-90 targets<sup>84</sup> set by Ministry of Health (MOH). This kind of breakthrough means people living with HIV (PLHIV) can live better live and have children if young people are encouraged to seek medical guidance through regular testing before sexual engagements and treatment with adherence for those who are infected to suppress their viral load. Nonetheless, young people must constantly be reminded to distance themselves from other social evils like sex work, multiple relationships and most importantly, having sex without testing or using condoms. These were the primary motivations for creating the padlock decorated wooden benches with messages for HIV prevention.

(ii) Mini-bench concept:

All the benches were decorated with critical preventive messages such as 'Be faithful, 'AIDS disrupts your future' and 'Be aware' encircled by the AIDS ribbon at one end, meant to raise HIV/AIDS awareness and prevention among the youth in urban centres. However, of interest are the two miniature benches (Bench B and C - *Plate 46*) which have inscriptions in Luganda,

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<sup>84</sup> The 90–90–90 targets envision that, by 2020, 90% of people living with HIV will know their HIV status, 90% of people who know their HIV-positive status will be accessing treatment and 90% of people on treatment will have suppressed viral loads

i.e., *Genda wekebeze* (go for testing) and *Mira edagala* (take your medicine - in reference to ARVs) respectively. The participants believed that most youth avoided HIV testing and often refused to adhere to their ARV prescriptions (by either hiding them to avoid open disclosure or merely forgetting to take them due to tight working schedules). They also expressed deep concern that most of the infected youth were aware of the repercussions of acting against medical precautions. They, thus, proposed and engraved those two explicitly powerful messages in Luganda on each of the small single sitter benches so that messages could remain particularly obvious. Participants H and K contend that:

“The messages in Luganda can easily spark conversations on the disease among the local folks using them in social spaces as particular individuals often grapple with stigma and fail to express themselves openly to discourage others from reckless behaviours. These benches therefore become an avenue to communicate preventive engagement for the un-infected youth”

(Participatory exhibition, HIV positive couple, Lungujja, 20<sup>th</sup> July 2020)

Indeed, participants concurred that through such visual statements barriers to HIV prevention can be shattered and HIV-related deaths reduced. It is also observed that those simplistic expressions communicating the need for protective behaviours are legible for both poorly educated and educated youth are critical in most peri-urban communities where stigma and discrimination still exists. With participants attesting to the precarity of their lives that leads to encounters with alcoholism and sex work, young people viewed themselves as big risk takers as they transitioned into adulthood. They, therefore, realised the need for regular testing to develop an HIV-aware culture, hence advancing the concept of '*genda wekebeze*' (*Go for testing*). We also shared knowledge about the availability of testing options such self-testing oral kits and clinic-based support, which offers a broader safe platform for helping the youth avoid HIV/AIDS. For those who were HIV positive, the concept of '*Mira edagala*' (*take your ARVs*) was meant to encourage them to constantly adhere to the medical prescriptions to maintain and sustain the suppression of their viral load. Whereas it was particularly helpful for the participants to learn how to build the benches using carpentry skills, it is equally important to recognise that the vitality of the construction process allowed and encouraged them to engage in conversations about their social life, relationships and HIV/AIDS before embarking on the creative exercise.

Having created the benches, we then discussed where they could be best placed or utilized so as to have the biggest impact. Participants proposed that such forms would best be placed and used in leisure or public spaces where youth usually converge to socialise (sports pubs, Bufunda/bars, restaurants, or even in hospitals, drug collection points, marketplaces in trading centres, etc.). With expert guidance, they strived to build them without compromising the ergonomic and functional qualities to suit their intended purpose as discussed in the section that follows. Primarily, these benches are conceived as pedagogic tools (e.g., Coombes, 2019) that can be used cheaply, mass-produced, and widely distributed to disseminate HIV prevention messages and encourage the youth to practice safe sex, change their attitudes towards health enhancing behaviours such as HIV testing and treatment, or perhaps, relay more information regarding adherence and compliance with complex drug regimes

### **6.1.2.3 Engendering creativity through crafting the wooden benches**

Dealing and working with groups of young people whose creative capacity is hardly known is a daunting experience. During the participatory workshops with young people living with HIV it was noted every individual possessed a different set of skills (wood joinery, painting, or finishing), although some seemed to have little or none at all. Regardless, the process of collective performance/co-production enabled each participant to share some creative skills (use of line, form colour texture, etc.) and knowledge (stories and other information) they each had, which culminated in a number of interesting visual concepts and artforms addressing the different issues affecting the youth in the context of HIV/AIDs in peri-urban geographies. The ability to reveal one's status was highlighted as one of the key aspects in dealing with internal stigma associated with living with AIDS.

“Most participants affirmed that disclosure is vital in tackling HIV/AIDS among youth. Many of my friends who chose to live a life of denial and isolation experience despicable situations punctuated by fear, social withdrawal, health deterioration and eventual death” (Participatory workshop, HIV positive resident, Lungujja, 20<sup>th</sup> May 2020).

Another participant says:

“The day I disclosed my status to my friends at work I felt relieved. They sympathized with me and vowed to support me through the challenge. I now feel encouraged to work with everyone else”

(Participatory workshop, Participant K, Lungujja, 20<sup>th</sup> May 2020)

These testimonies about their HIV status were psychologically important, allowing participants to find alternative routes of expressing the agony and trauma of living with HIV/AIDS during the workshops. These experiences instilled more confidence in other participants to open up about their lives and in turn boosted their creative ability. With continued support, several participants were able to develop a variety of creatively built concepts related to HIV prevention and, in particular, the disclosure dilemma among the youth. *Plate 47* shows the abridgement of the words ‘HIV-positive’ into ‘HIV PZTV’ by participant K, emerging as a subtle indicator of the participants’ level of creativity encapsulated in the process of building the messages for prevention. The participant’s intention is to encourage young people to openly disclose their HIV status for the wellbeing and safety of others. The ability to think and act creatively, in this regard, makes his motif a potentially powerful statement in spaces where talking about AIDS is taboo. Thus, developing a mind that can imaginatively navigate negative perceptions among the youth is particularly empowering and enables individuals with such skills to negotiate related challenges in their lives or at work. This is one example where identification and enrichment of the participant’s talents is the prime essence of applied social sculpture in bettering their livelihood opportunities through capacity development, stimulating hidden and untapped instincts for creative manipulation of materials and visual concepts. After encouraging them to draw the images and words on paper, I demonstrated how to carve their designs drawn on wood to complete the HIV benches.

Importantly, collective engagement with participants enabled them to explore the varieties of methods, consciously simulating their ideas with my help to execute the concepts. It is anticipated that this process may have lasting impact on their skills development and also reshape their attitudes/perceptions towards health-enabling practices and behaviours which could possibly translate into better livelihood and wellbeing opportunities (e.g., Kesby, 2005; Kindon et al., 2007; Nabulime & McEwan, 2011). Importantly, the crafting of the HIV benches facilitated positive thinking and creative practice towards skill development meant to raise

more awareness of the epidemic, its prevention and potentially expand that into the wider society in which they live and beyond. It is hoped that such benches, if mass produced and distributed to as many youth centres as possible, can be very helpful in heightening their awareness about HIV prevention, stimulating the ability to change their attitudes and learning new visual approaches and self-expression (e.g., De Lange, 2008; Marschall, 2004; Nick Malherbe & and Mohamed Seedat, 2016)

Having explored how the HIV benches were designed, I now turn my focus to Artwork B - HIV bed, explaining how it was developed as an alternative for tackling HIV/AIDS.

### **6.1.3 ARTWORK B: The HIV bed (5ft x 6ft) – See *Plate 41***

During another participatory encounter with young people in Ndeeba industrial area, participant T reflects on her prior relationship that turned sour because of infidelity (by her boyfriend) to create a positive message intended to help other young people to navigate such situations. Collectively with other participants, she developed the idea (through drawing and carving) to reveal (*Plate 41*) her experience of disloyalty by the boyfriend who decided to bring his other girlfriend to their home, a concept that was later transformed into a headboard of a bed.

Young people often find controlling their sexual behaviour challenging because of peer pressure, social norms, and cultural beliefs. As a result, many young men find it necessary to explore and exercises. The drawing I discussed in Chapter 5, pg. 197 (Also see *Plate 41* *Error! Reference source not found.*) showing the heart, pigeon and fish symbolising multiple sex partners became the design for the bed. This highlights young men's masculinity of having several sexual partners. The multi- faceted motif rests on the headboard (face) of the bed alongside other bold inscriptions that convey the message of AIDS prevention and awareness. This design could be described as a classic tool meant to create awareness of and commentary on the disease. As a one of the dissemination event participants at Mulago TASO exhibition observes:

“This bed is so symbolic. Usually, people get infected while having sex on the bed, sometimes because they have forgotten about protection. When they have a bed like this with messages about safe sex practices they will reflect more on protection”



(Formal Interview, Dissemination exhibition, TASO Mulago, 17<sup>th</sup> February 2021)

Similarly, one of the participants in Ndeeba remarks:

“This has been a very unusual experience for us. It’s an unconventional way of raising HIV awareness. Surely, there is no way a couple can sleep on it without thinking about unprotected sex. The phrases about behavioural measures inscribed on the poles and the beautiful design on the headboard are very explicit”

(Informal chat, Wood finisher, Ndeeba industrial area, 3<sup>rd</sup> November 2020)

Both accounts are compelling. Figuratively, the concept of the HIV bed- ‘Namboole’ - demonstrates the power of visual expression derived from eliciting genuine self-reflective responses and collective participation based on young people’s every-day experiences in informal settings. It is also seen in the way participants tried to navigate the technical challenges of carving the design and enriching the entire concept with HIV messages, thus, making it a highly imaginative artwork of a bed, rather distinct from the highly conventionalised modes of IEC<sup>85</sup> materials for HIV awareness (e.g., print/ electronic media messages, radio adverts etc.). Additionally, this form of experience invokes a kind of agency for and among young people reminiscent to the advocacy work of Kate Wells (Wells, 2016) and Kim Berman (Berman, 2018) in South Africa.

To complete their bed design, participants proposed the multiplication of the fish shapes along the supports (poles) of the headboard (*Plate 48*). According to participant T, the fish symbolically represents the link between the culture of dating multiple partners among men and rising levels of HIV transmission in Kampala. Participants also suggested that the inclusion of words of encouragement/advice on the artworks could be thought-provoking for the end-user or observers towards influencing their behaviours and practices. After Participant T narrated her story, issues of infidelity and unfaithfulness were brought to the fore. One male participant, a senior four dropout, who seemed confident and was a regular contributor throughout the workshops, asked the group:

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<sup>85</sup> IEC means Information, educational and communication materials. These may include; Infographics, Flyers, leaflets, brochures, social media posts and television adverts, audio spots for radio, billboards, murals, and posters.

“How many women have you slept with without using protection. They all look at each other and smiled. One participant rose up and spoke:

“That is the hardest question my friend. Who among us is going to tell you the truth? I have had very many girlfriends, but I remember the number of times I have had unprotected sex”

(Engraving session, participatory workshop, 26-year-old participant, Ndeeba, 18<sup>th</sup> October 2020).

Most male participants appeared challenged and kept quiet for a while as they looked at each other. Indeed, the message seemed to provoke participants into rethinking their actions and, perhaps, to take responsibility of the consequences of their action and their personal role in spread of the epidemic. They unanimously agreed to put the words on one of the poles (*Plate 48* – pole A). After engraving the words on to the pole (A), a participant remarks:

"I don't think anyone would ignore self-protection after reading such a message. You can't fail find a way out or else you pay the price later. If engraved somewhere on the bed, this message may not only help the users to rethink their sexual behaviours to avoid HIV/AIDS, but also inspire them to encourages other to desist from unprotected sex and promoting important health issues"

(Interview, participatory mini critique, wood finisher, Ndeeba, 10<sup>th</sup> November 2020)

This echoes several other responses that demonstrated the impact of the creative practice in engaging young people in a practice-based collaborations tailored towards HIV awareness. While the aim of stimulating expressive messages on the bed poles was to evoke the critical consciousness about the ills of reckless sexual behaviours, in general, the poles completed the HIV bed concept, making it stand out as a visual milestone in both generating open expression on critical HIV issues and skills development. Thus, participants pointed out that:

“This bed may be constant reminder to the user for staying cautious. The idea has helped me appreciate the need to be faithful, tested and self-protect from contracting HIV/AIDS and other STDs. It is unwise to sexually engage with someone without testing for HIV or if you have to date, give it some time before you decide to give in for sex as measure for trustworthiness and loyalty in growing a relationship.

(24-year-old female participant M)

“I am particularly inspired by participant T's concept of the heart and the pigeon in which she implicitly explores the challenges of promiscuity and disloyalty in the context of HIV/AIDs among young people. To many of us, it is a lesson to reckon within the context of leading a responsible sexual life, sticking to one partner to avoid the repercussions of catching HIV and other STDs

(Formal interview, participatory workshop, 27-year-old Participant A, Congolese migrant/artisan, Ndeeba)

Their recognition and anticipated assimilation to the importance of HIV testing was the most captivating experience that reshaped the conversations and working processes with young people during the participatory workshops. Many seemed to acknowledge the inevitability of some social problems that appeared to flourish beyond social exclusion such as alcoholism, objectification of women, multiple sexual relationships, infidelity, poverty, and cultural influences, which are unlikely to disentangle from the informalities that define their lives (see also chapter 5). Thus, the rationale to prioritise and embrace HIV-testing as prevention was conceivably one of the best options among the participants towards tackling the epidemic in peri-urban areas.

Having revealed that many young people ignored protection, the participants suggested using the bed as a vehicle for conveying protection messages to their loved ones. Participant T, asked:

“How about engraving a strong statement on the bed supports that would deter young people from engaging in unsafe sex? Let put words that will prompt the users in to rethinking their actions” about the need to indulge in safe sex”.

As for the second pole (B) - *Error! Reference source not found.*, I proposed to them stringing together words in acknowledgement of the existing traditional behavioural and biomedical approaches known to them combined with socio-economic empowerment as an essential component for HIV prevention. Indeed, several conversations with the participants showed that they had some knowledge about the existing interventions methods with include the ABC and HIV testing and counselling policy by the Ministry of Health, but also acknowledged the presence of several discrepancies (such as inappropriate modes of disseminating vital HIV prevention information to informal spaces) meant to stem the tide of AIDS among the youth. Having mentioned that poverty, lack of vital information and high employment levels were some of the key drivers of HIV transmission among the youth (see Chapter Five), they argued that improving skills with creative approaches may potentially help them improve their livelihood opportunities. Thus, they added “Abstain, faithfulness, condom use + test and treat + Empowerment = Ending AIDS” on the second pole (B). In view of the above aspects, applied social sculpture clearly has value in HIV/AIDS awareness and prevention, creating artworks as

communication tools and generating collective participation of young people infected with and affected by the epidemic.

The next section discusses two co-produced Covid-19 artworks (ARTWORKS C and D) which show how applied sculpture attempted to build skills and capacity while giving voice to young people who are marginal within the economy and were among the most affected during the Covid-19 lockdown in Uganda. Indeed, it provides a plausible case study that clearly illustrates my argument about the importance of enabling open talk, breaking the silence related to stigma, discrimination, and taboos, and building confidence and resilience among young people, as well as bringing them together to enrich their skills. The Covid artworks are a brilliant example of what applied sculpture can do in engendering preventative practices with livelihood benefits among the youth in peri-urban spaces.

## **6.2 COVID-19 OVERSHADOWS EFFORTS TO FIGHT AGAINST HIV/AIDS**

Following the Covid-19 outbreak<sup>86</sup> in March 2020 (Owiny, 2020), there was a sharp drop in the mobility of people within Uganda. The government imposed drastic interventions focusing on (i) geographical containment and creation and management of testing centres with the quarantining of Covid suspects (ii) home confinement and curfews mandated through the enforcement of the presidential directives barring passenger movement across the country, (iii) the prohibition of gatherings and the closure of establishments and/or premises, as preventive measures to control the spread of the pandemic (Ahabwe, 2020). With no active civil aviation and complete ban on passengers commuting in and around the country, many people particularly those infected with HIV (PLHIV) in the remote countryside and informal urban spaces were left stranded. This affected every single sector of the economy.

In response, the research project was adapted to explore how applied social sculpture might enable young people to respond to emerging challenges of the Covid pandemic in parallel with efforts to combat HIV/AIDS. These colliding pandemics created a state of panic for many people, especially during government-imposed lockdowns to curb the spread of coronavirus in

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<sup>86</sup> On Tuesday, March 24, just three days after Uganda had registered its first COVID-19 victim, the President of Uganda banned taxis, boda bodas and buses from operating. In over a week, the Ministry of Health had recorded five more cases of coronavirus, bringing the total number to nine. On the third day, 27<sup>th</sup> March, the number those who have tested positive has risen to over twenty two (Tugume, 2020).

public spaces. This meant that people were no longer leaving homes, giving perpetrators of domestic violence and gender-based violence (GBV) opportunities to oppress their victims and heightening the HIV risk (Achan, 2020; Senyonyi, 2020; UNAIDS, 2020c). There is growing evidence confirming that the impacts of the COVID-19 pandemic are not gender-neutral. Winnie Byanyima, UNAIDS Executive Director argues:

“The impacts of lockdowns and travel restrictions imposed in many countries to curb the spread of the COVID-19 pandemic, the failure to designate sexual and reproductive health services and services for survivors of violence as essential services, and the undermining of women’s economic security have compounded the barriers for women and girls experiencing abuse, especially those who are trapped at home with their abusers.”

(UNAIDS, 2020a)

Under these circumstances, engaging young people was, in way, a temporary emergency intervention to enable them to navigate the social realities of living under mandatory confinements (lockdown and curfews)<sup>87</sup> with restricted movement which further curtailed the lives of people living with HIV/AIDS. The latter were mandated to seek permission from local authorities (Local council chairmen) to use private vehicles as a means of transport to reach their medical centres to collect their ARVs. Many of them, in the process, were denied the chance to sustain their medical regime, since it was very expensive and against their rights to privacy and confidentiality (Venkatesh, 2020). Consequently, this led to increased stigma and the escalation of AIDS-related illnesses and death across the country during the lockdown period.

Adolescent girls and young women are also increasingly being subjected to early marriage, unwanted pregnancies and trafficking, missing out on education because of school closures and lacking access to comprehensive sexual education and reproductive health services, including contraception and abortion, as a result of the COVID-19 pandemic (Musasizi, 2020). Notably, it also led to increasing violence against women and amplifying existing gender

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<sup>87</sup> Uganda was subjected to three types of lock down i.e., geographical containment, home confinement and prohibition of gatherings and the closure of establishments and premises. These were state-led strategies instituted between March and August 2020 designed to prevent epidemic hotspots from contaminating other parts of a country or region. Exemptions were usually be made to ensure the flow of food and other essential services and commodities in different locations, and there were clear restrictions for people travelling form their home areas and public gathering areas in order to curb the rapid spread of the coronavirus in the country. Also see (Haider et al., 2020)

inequalities, further exacerbating HIV risks and vulnerabilities for women (Achan, 2020; Masinde, 2020). Yet, at the same time access to gender-based violence services, as well as HIV and other sexual and reproductive health services were being reduced or are unavailable during the pandemic. Violence against women is a major factor driving risks for HIV—in areas with a high HIV burden, such as sub-Saharan Africa (e.g. Doshi et al., 2018; Hladik et al., 2017; Mafigiri et al., 2017; Uganda Aids Commission, 2020). Research shows that women subjected to intimate partner violence are 50% more likely to be living with HIV and men who are perpetrators of violence tend to be at higher risk of HIV themselves and to use condoms less frequently, thus increasing the risk of HIV transmission (Riggs et al., 2018; UNAIDS, 2020c).

The potential for violence arising from the lockdown discouraged many women and adolescent girls living with HIV from disclosing their HIV status to their partners, families, and health-care providers, and has made it more difficult for women and girls to stay on HIV treatment (Cassolato, 2020; Senyonyi, 2020). Some participants talked about gender-based violence:

“This lock down has forced my sister to stay with our mukko (Son-in-law) who very abusive and inconsiderate. Their economic situation has even aggravated the matter. He flogs her almost every day”.

(Discussion session, art and creativity workshop, female participant, senior three, Lungujja, 6<sup>th</sup> May 2020).

“My niece was raped by a family friend who had come to visit them before the lockdown. On the day the President announced the national lockdown, the visitor did not have any option but to stay because their home very far. On day three, he took advantage of the isolated guests’ wing to lure her, only to report later the next day that she was raped, and the guy had vanished”

(Discussion session, Art and creativity workshop, male participant, Lungujja, 6<sup>th</sup> May 2020)

These experiences were discussed by workshop participants and culminated in a co-created artwork in form of a wooden house with a rustic finish/burnt effect to figuratively represent pain, agony, the denial of rights for young people living with AIDS and the indefinite confinement of women with the perpetrators of violence in homes (See *Plate 49*).

### 6.2.1 ARTWORK C: The Covid house (Figurative depiction of the padlock as a coronavirus)

While transforming the clay piece (Image I) to a figurative structure, dubbed the 'Covid house' – Image II (*Plate 49*) – using discarded wood and scrap metal bits obtained from a nearby carpentry workshop in Lungujja, the participants further discussed the consequences of the restrictions on the lives of marginalized communities in informal areas. Participants pointed out that most of the young people especially adolescent and young women have been locked up with their abusers in homes due to the state-led restrictions meant to curb the spread of Covid-19 (Delaleu, 2020; Shivakumar, 2020; Youtube, 2020). In response, participants simulated a housing structure, first as a simplistic clay model and later reproduced the concept in found wood (with rustic effects) and scrap metal. They attached a Covid-like metallic padlock to symbolise the confinement and violence some young people are experiencing due to the stay-home regulations. Furthermore, participants observed that many of the victims of domestic and gender-based violence have ended up as single-mothers and breadwinners in their families with many of them getting trapped in casualized employment in the industrial spaces as food vendors, sanders, roadside traders, and some in sex work (also see Chapter 5). During the art and creativity workshops in Lungujja, one of the participants, a rights activist and adolescent reproductive health advocate with ICWEA<sup>88</sup> re-counts:

“Battering wives and other forms of gender-based violence restrict young women and adolescent girls’ decision-making and erodes their sexual and reproductive health and rights, including deciding if, how, when and with whom they have sex, their ability to protect their health and their ability to access HIV prevention services and stay on treatment”

(Formal interview, HIV positive female participant, 'Art and creativity' workshop, Lungujja, 10 May 2020).

Her account is mirrored in several scholarly archives (Jewkes & Morrell, 2010; Macpherson et al., 2020; OHCHR, 2020). The COVID-19 pandemic has reflected the importance of ending violence against women to achieve gender equality, economic empowerment and ending AIDS; it has also shone a light on the importance of preventing factors that entrench it among young

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<sup>88</sup> ICWEA - International Community of Women Living with HIV Eastern Africa is a regional advocacy network and membership-based organisation based in Wakiso district, Uganda. ICW Eastern Africa believes that gender inequalities and the lack of sexual & reproductive health & rights for women are at the heart of the HIV epidemic (<https://www.icwea.org/about-icw/>).

people by prioritising youth engagement and utilization of local resources (UNAIDS, 2020a). Interactive engagements with young people during the lockdown were inspired by this need and gave rise to a series of Covid-related visual representations in wood and metal to act as tools of communication about personal and community resilience against both HIV/AIDS and Covid-19.

In what follows, I provide a brief exploration of the processes of applied artistic practice in enabling young people develop Covid-19 bicycles in recognition of their ability to cope with unprecedented circumstances caused by the Covid pandemic while evoking efforts to confront the setbacks encountered in the fight against HIV/AIDS in their lives and the community.

### **Developing the Covid bike concept**

With the COVID-19 pandemic affecting all sectors of the economy in Uganda, reduction of health services to people living with HIV/AIDS and other key populations emerged as one of most adverse challenges during the Covid-19 pandemic. For this research project, it turned out to be an opportunity to draw lessons from HIV participatory interventions and engage unemployed young people in Lungujja<sup>89</sup> exploring the entangled experiences of the two colliding pandemics whose stigmatising traits are similar. The Covid-19 lockdown meant young people spent less time in institutions such as schools and skills centres while others in the informal settings struggled with very limited work opportunities. Other youth who were reported by community health workers (CHWs) as HIV positive were also severely affected by interruptions of their medical routine, leading to deterioration of their health, increased gender-based violence (Delaleu, 2020; Senyonyi, 2020), stigma, social isolation and deaths in homes. With life constrained under highly restrictive state-led measures, young people especially those who use drugs, gays, sex workers, alcoholics, and the chronically ill people with diabetes, sickle cell anaemia and cancer, many of whom live in areas poorly served by transport infrastructure, were unable to access treatment, such as HIV services. The only means legally permitted were bicycles, which became critical to ensuring access to HIV prevention, testing and treatment services during COVID-19. To capture these challenging social experiences,

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<sup>89</sup> Lungujja was one the study site which emerged as a result of interrupted field work in industrial areas of Kampala because of the national lockdown imposed by the government to curb the spread of Coronavirus (20<sup>th</sup> March – 30<sup>th</sup> August 2020)



participants developed the concept of the Covid bicycle,<sup>90</sup> with the imitation of the coronavirus as wheels (See *Plate 50*) to metaphorically depict the painstaking local experience of navigating the informal spaces without public transport such as commuter taxis and buses.

### 6.2.2 ARTWORK D: The Covid bikes

Before executing the covid bike concept, participants began by exploring ideas about their knowledge about the pandemic (See *Plate 51* and *Plate 52*)

“To further familiarize participants with the likeness of the coronavirus, on the morning of 10<sup>th</sup> June 2020, I sent four participants for a quick errand to buy some workshop materials and also search for newspapers which had illustrations of the corona virus. Fortunately, they bought several copies of the New Vision newspaper – a local Ugandan news daily - which had sensitisation posters about covid-19. The purpose of sending them out was to help them learn one of the ways of sourcing for visual inspiration, while, at the same time, enable them to appreciate the visual appearance of the virus that was causing havoc across the world. During the workshop session, they all shared the newspaper images and captured the likeness of the virus in their drawings which, later, inspired them replicate the nob-like projections of the virus on the bicycle wheels. They began with simulating the concept in soap by creatively improvising with cotton swabs to represent the projecting features on the coronavirus” - as seen in *Error! Reference source not found.* above

(Excerpt, Field diary, Lungujja, 11<sup>th</sup> June 2020)

The concept of the bicycle idea emerged and developed from a story of one of the HIV positive participants who confessed to having borrowed a sports bike to fetch his ARVs from a hospital, 15 miles away from his residence in Lungujja. During a participatory workshop in Lungujja, he translated his experience by drawing himself riding the bike in an attempt to express the painstaking experience of collecting his ARVs from a distant health facility outside Kampala city, made worse by his poor health. To capture the pain and stress of pushing a bike with punctured tyres uphill, fellow participants advised that presenting the wheels of the bicycle should ideally have spikes similar to the Covid virus to represent the hardships he faced. On executing the idea, participants used the spikes on the wheels of the bike to contextually expose the excruciating distress encountered by PLHIV to collect ARVs from distant locations in Kampala and beyond. Despite the hardships, the use of bicycles not only facilitated the saving of lives, but also helped minimise the risks of exposure, stigma and discrimination by avoiding the need

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<sup>90</sup> For bicycles are a common means of transport both in urban and rural settings in Uganda. They are relied on as a cheap form of transport to markets, hospitals, and other workplaces

to seek permission from local council chairmen to access private vehicles or motorcycles whenever collecting ARVs from hospitals (Joseph Kizza, 2020; Kasujja, 2020).

During the participatory workshops, participants corroborated that the only regulatory and legally acceptable means of transport was using bicycles which also belonged to a few households who had acquired them before the lockdown. Participants gave account of their ordeals of using bicycles during the lockdown:

“Because I had run short of my ARVs I had to request my neighbour to borrow his bicycle so that I could collect my medicine (ARVs) from TASO Mulago which is about 6kms from Kosovo where I stay”

(Art and creativity workshop, Lungujja, participant Y, 3<sup>rd</sup> June 2020)

“I registered with Kisenyi health centre IV in Kampala for my ARVs. Right now, I am unable to walk the distance (about 4kms) because I don’t feel well. I have depleted all my medicine and I must collect another dose in time before the last one runs out. I have to borrow a bicycle so that I go very early tomorrow before dusk. It is best to go before sunrise to avoid the scorching sun”

(Informal conversation, HIV positive participant, Lungujja, 3<sup>rd</sup> June 2020)

“Last week I had to ride over 9kms to pick my wife’s medicine from Mildmay Uganda<sup>91</sup> on Entebbe Road. It is very painstaking journey because of the winding hills and stretching inclines. Being sickly and riding a bike cuts down on your health. When I came back in the evening, I developed ulcers and a severe headache”

(Art and creativity workshop, Male HIV participant, Lungujja)

These accounts capture some of the difficulties faced by PLHIV during the Covid pandemic. Whereas some have been helped by the local community-based organisations like LUCOHECO, many other HIV patients and those who were infected during the lockdown have been incredibly unfortunate. The government failed to provide alternative means of helping them to continue accessing hospitals and also quick, convenient avenues for testing and treatment services across all the informal centres in the country. Similar critical public health challenges associated with the Covid-19 pandemic are well documented (AFP, 2020; Cassolato, 2020;

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<sup>91</sup> Mild May is a specialist HIV hospital in Uganda which has been at the forefront of HIV & AIDS care, treatment, and rehabilitation since 1988, continually adapting and responding to meet new, often complex, and rapidly changing needs. It is at Lweza on Entebbe Rd, Kampala

Jewell et al., 2020; Lancet, 2020; Osman et al., 2020; UNAIDS, 2020b). The creative workshops were designed to give the marginalized youth a social platform to voice their experiences, and while being supported<sup>92</sup> they collectively acquired new skills through which to develop their own consciousness towards building resilience and health-seeking behaviours. The workshops also enabled continued support from local community-based organizations such as LUCOHEO93 and TASO<sup>94</sup>.

### 6.3 SKILLS DEVELOPMENT AND CAPACITY BUILDING AMONG THE YOUTH

Working with young people through applied sculpture is one participatory approach with the potential to be empowering and socially rewarding. Young people were able to develop their hidden or inherent creativity to tackle their own social and economic challenges by involving in processes of ideation, stories related to their everyday experiences and physical observation of their own environment.

Facilitating the skills development processes and creative abilities of the participants, in the long run, enabled them to ignite the sense of awareness about the eminent precarious situations that engulf their lives to the detriment to their wellbeing and livelihoods. The reciprocal nature of socially engaged practices like applied sculpture (see also Garrido Castellano, 2018; Sánchez-Camus, 2011) enabled me as a moderator of the participatory activities to enrich my crafting skills whilst also sharing expertise on applied elements and principles of design<sup>95</sup> that enabled participants to enhance their technical competencies (See *Plate 52* and *Plate 53*). A participant testifies during one of the participatory group critiques.

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<sup>92</sup> During the participatory workshops, members were often facilitated with transport, food and other reasonable field obligations related to the research. In a way, this encouraged participant to remain focused and regularly attended.

<sup>94</sup> TASO is The Uganda AIDS Support organisation played a key role of providing HIV services in liaison with LUCOHECO, especially by sending ARVs for participants who were unable to commute to the Mulago hospital to collect their medicine during the lockdown. Through their VHTs, the affected participants were able to receive their drugs while in workshops

<sup>95</sup> The elements and principles of design are the interlocking components of a motif that give its appearance and function an interesting visual appeal. The elements include line, form texture, colour, shape, and light, whereas the principles are; balance, depth, harmony, contrast, perspective, and economy to mention but a few

“I have learnt how to design, weld, and engrave words onto wood using both manual (chisels, gouges and so on) and mechanised means (using a router) on found material such as wood offcuts. Hopefully this will help me better my crafts and improve my earnings”

(Participatory critique, 27-year-old male artisan, Lungujja, 15th June 2020)

The applied artistic practices could have been new to most of the participants, but the most important aspect about the collective exercises is the likelihood of benefiting from the learnt skills acquired and new knowledge about their own health for future livelihood opportunities and application towards their wellbeing and livelihoods. It was conceivable that the end result of the collective youth engagement efforts is to prepare a potentially fertile ground for future application of learnt skills, influence their decisions towards behavioural change and shared wellbeing. The applied artistic approaches gave room for harnessing local knowledge and inventiveness in ways that could enable participants to adopt and adapt to experiencing themselves less as a ‘subject of an experiment’ and more as agents of change in their own lives (Berman, 2018). Participants were also empowered by stimulating their inherent creative capacity and artisanal competencies, with ample expert guidance and reasonable facilitation with the intention to improve their capacity and livelihood opportunities in the context of HIV awareness and prevention.

The primary objective of encouraging groupwork and building partnerships was to emphasise the vitality of numbers in tackling precarious social issues transcend the individual to the large youth population in informal contexts.

“At the start of the workshop in May 2020, consenting participants would gather in numbers (over 12 participants) every morning to begin the workshop session. At the end of day, we could share new knowledge and skills about their crafting work and health related issues. This prompted most of the participants to spread the message about the essence of the workshop by word of mouth to other members of the community. So, every other morning new interested parties would come to register for participation. When the design processes began, I identified and guided participants based on their technical ability to start the practical processes of co-producing artworks (Dividing and allocating tasks based on the skills). This allowed them to connect with other artisans in their community to execute some design details (e.g., stripping wood pieces and mechanised sanding, process the wood in the mills) and also initiating new contact for technical support”

(Field diary, participatory workshop Ndeeba, 10<sup>th</sup> June 2020)

Using applied social sculpture has thus enabled collective engagement towards prevention activities as participants shared their lived experiences particularly those that affect health and livelihoods. In the *Plate 54*, groups of participants are captured while trying to help each other to execute the different artworks developed during the participatory workshops. Following the clockwise direction, the first image shows researcher helping participants fix the roof of one of the HIV models developed by participant Q (See chapter 5). The next image captures participants sharing their visual design under a makeshift structure in Ndeeba industrial area and so on. As explored previously, several factors such lack of skills, unemployment, masculinity, and other cultural barriers, were responsible for shaping the landscape in which HIV flourishes. The images in *Plate 54* clearly show some of the group performances and interactive discussions during the participatory workshops in which the youth collectively talked about issues affecting youth lives in informal space. This potentially projects applied social sculpture as a potential platform for inclusive participation and open communication in which youth of diverse backgrounds converged to share their everyday experiences in the context of HIV/AIDS. It enabled participants openly talk about their experiences, some of which were addressed through the co-production of artworks inside and outside the carpentry and welding workshops of the artisans. The ability to interact willingly and participate in art workshops was one of the significant affordances of applied artistic engagement in informal spaces and was a form of social empowerment that enabled participating young people to confront their own problems related to the HIV epidemic and better livelihood opportunities. Indeed, applied social sculptural practice helped young people engage in practical ways of visualising their world to raise awareness about HIV/AIDS. It also encouraged them to at least think and talk about finding ways of reducing risk and curbing the spread of HIV. The participants were supported to improve their creative abilities through skills acquisition intended to help better their livelihoods and wellbeing.

#### **6.4 CONCLUSION**

This chapter began with demonstrating how the wooden benches and the HIV bed were developed by through participatory engagement with the youth as tools for raising awareness about the HIV/AIDS. It then showed how the participatory workshops allowed the youth to collectively open up about their precarious lives to share stories of encountering HIV/AIDS,

specifically through the use of visually creative and expressive methods. The chapter also shows how young people were able to explore and develop their crafting skills while simultaneously confronting the Covid-19 pandemic as a traumatising experience. They were able to share experiences about home confinements, travel bans and closure of businesses, which affected their livelihoods and the health of those living with HIV. These challenges were recognized by participants, visually interpreted as stigmatising and inhumane in both the HIV/AIDS and Covid -19 related artworks – the HIV benches (*Plate 40*), HIV bed (*Plate 41*) Covid house (*Plate 49*) and the Covid bikes (*Plate 50*). These art works illuminate the potential of applied social sculpture in evoking candid conversations with young people about critical social issues related to the two colliding pandemics (HIV/AIDS and Covid-19) and inducing (i) Behavioural change (e.g., using condoms, HIV testing, treatment: Covid -19 social distancing, regular sanitization and face-masking) and (ii) adaptive strategies (personal and community resilience) of confronting situations of fear, discrimination, social isolation, and stigma related to the diseases. The chapter also demonstrates how the creation of applied objects (especially the HIV benches and beds) engendered team work and boosted the crafting skills of the participants. Collaborative practice imbued synergies among the participants to realise social emancipation for bolstering confidence, social insight, and self-actualising experiences as an empowering process towards improving their livelihood opportunities. There is significant evidence that sharing skills and knowledge in the design and making of artworks enabled communication about how to practice better behaviours and improve livelihoods among the participants.

Applied sculpture, in a way, enabled young participants to openly express themselves about their everyday social experiences, through sharing and developing new knowledge and skills, and translating them into 2D and 3D form (applied objects in some instances) purposed for HIV/AIDS awareness and prevention. Indeed, better ability to freely talk about social realities and HIV/AIDS in formal contexts is a way of preventing the spread of an epidemic like HIV. The participants were able to speak openly, and their ideas were collectively transformed into visual expressions. For instance, during the brainstorming sessions and discussion session for the modelling process using soap and clay that designed the Covid bikes, a participant boldly confessed that:

“.....at first, she tormented me as she started touching and caressing my private parts. She actually taught me how to have sex because I was still a virgin. Soon after the sex she advised we both use soap to cleanse our private parts. When I asked why she was insisting on using soap. Because I was not informed well, I believed her. Building artworks with soap in this workshop has reminded me of this experience and i think it is important for other young people to know the dangers of having unprotected sex and how misinformation may escalate the risk of getting STDs and HIV infections”

(Informal conversation, Participant K, Lungujja, 31<sup>st</sup> June 2020)

Participant K’s remarks echoed the growing experience of many youth who seem to lack the right information about protection and, indeed, participants revealed how it was hard to engage with other youth on personal level. The participants then realised the vitality of collective engagement and how everyday materials could invoked critical discussion around taboo topics like sex.

“When you speak to friend /peers about the risks involved in having unsafe sex, they instead label you as a womaniser” Most youth need to be informed about protection e.g., Why, and where to get the kits, how to use them, when to use them and detecting whether they are expired or not.

(19-year-old male participant)

“Our peers tend to think that it only doctors who have the right information about their health and, in particular, HIV-related issues. They never heed to our advice”

(24-year-old female HIV positive participant)

These responses are a clear indication of how participants were inspired towards expressing personal difficulty of sharing critical experiences of living with HIV, but most importantly triggered open conversations about it. The conversations that developed through collaborative performances gave the young people a voice through which to articulate their experiences and provided a sense of self-empowerment that could inspire other young people to overcome HIV/AIDS related challenges in informal environments. Three narratives clearly summarise participants felt as self-empowering about working as a group in workshops for HIV awareness:

“Working with other participants in building artworks for HIV awareness/prevention has enabled me realise the value of raising awareness and the essence of living a meaning sexual life. Understanding the realities of recklessness resulting from marginalising experiences shared other participants through participatory art is motivating and encouraging for better actions for a safer a healthier sexual life

(Participatory critique, 24-year-old female participant, Ndeeba)

“The skills of collaborative working acquired through sharing stories, writing, and executing artforms from our own experiences with an expert has helped us understand our crafting and creative abilities, strengths and weaknesses which is motivating for future applications and work opportunities

(Participatory critique, 29-year-old male participant, Ndeeba).

Producing artworks through creative thinking and practice helped young people spend some time reflecting on the potential risks of reckless sexual behaviours. The opportunity to collaboratively engage enabled participants to gain experience organizing with other people, identifying local resources, and developing artworks as tools for communicating HIV awareness and prevention, which could also be described as a form of psychological empowerment (potentially working towards understanding these issues as a starting point for change among the youth). As demonstrated in the informal conversations and open dialogues about HIV/AIDS during the participatory workshops, participants were able to engage in collective activities aimed at inducing behavioural change, skills acquisition (E.g., *Plate 20, Plate 30, Plate 42, Plate 43* and *Plate 53*), and building partnerships through mobilization, thus increasing personal and collective responsibility which signifies enhancing social empowerment. Demonstrably, young HIV participants, too, were helped to feel more competent and less alienated (Levens, 1968; Zurcher & Snow, 2017). This enabled them to sustain interest and increase responsibility and perceived control of the creative activities, which later translated into regular attendance and freedom to interact with each other and their community. The impromptu gathering of several non-participants around our gazetted workspace as we discussed health issues in groups and performed creative tasks was indicative of wider interest in the community.

The next chapter summarises the key findings of the participatory research with young people, focusing on the ways interactive engagement for improving HIV/AIDS prevention enabled them to enhance their self-esteem through reception events and HIV/AIDS artworks exhibitions of the co-produced applied objects to the wider public. It also provides a discussion on the impact of these findings and their implications for advancing applied social sculpture as a potentially new pathway for addressing youth empowerment and, in particular, the knowledge-practice gap regarding HIV/AIDS and its prevention among health practitioners and towards reshaping public health policy decision-making in Uganda and beyond.



## CHAPTER SEVEN

### APPLIED SOCIAL SCULPTURE: AUDIENCE RECEPTION, MAKING SENSE OF FINDINGS AND IMPLICATIONS

“Creativity workshops are very helpful in inculcating social discipline, artistic skills, and sharing information about important health issues such as HIV/AIDS and its prevention”

(24-year-old female participant M, Participatory workshop, 29<sup>th</sup> October 2020)

#### 7.0 INTRODUCTION

The engagement of young people in crafting HIV/AIDS artworks through participatory workshops (using applied social sculpture) was not only intended to increase awareness of HIV/AIDS and its attendant problems among young people, but also to create preventative and livelihood benefits among the participants. The opportunity to share life experiences in their informal communities inspired and facilitated the creation of a range of artworks, skills, new knowledge, and information that would benefit the participants and their communities in the context of HIV/AIDS prevention. Previous chapters have demonstrated how everyday stories of precarious existence can be successfully transformed by co-production into powerful HIV-message laden artworks. This chapter captures an exploration of audiences' sense-making of the findings and artworks produced during the coproduction processes with participants in the context of HIV/AIDS prevention. It offers an extensive discussion of how the participants and audiences make sense of the results of participatory engagement with young people and how their involvement might have potentially impacted their lives and the communities in which they stay. This chapter explores the processes and impacts of sharing the findings with the research participants, and the taking the artworks generated from the participatory workshops taken back to the wider communities and relevant stakeholders in the study (in response to research question III). Ultimately, the sharing of the research findings serves as a public outreach strategy intended to demonstrate the importance and potential of applied social sculpture with regards to information-sharing in raising awareness, building new knowledge, engendering healthy attitudes among young people to make better informed and more positive choices about their health and wellbeing.

The primary aim of this chapter is to demonstrate how the findings of the study were received by the wider public, which includes the general artisan community, academics, public health professionals, practitioners, and other stakeholders in the fight against HIV and AIDs in Uganda. The essence of public outreach is to demonstrate the potential of participatory, applied sculpture in contributing to preventive engagements and the likely economic value with and among young people infected with and affected by HIV/AIDS, involving creative experts and stakeholders while harnessing the possibility of rethinking HIV/AIDS awareness and prevention and youth empowerment in development contexts.

Conversations and interviews with attendees and the research participants themselves were conducted during the reception events and provided a rich repertoire of thoughts, ideas, insights, comments, and suggestions that inform the core purpose of this research among young people. In order to effectively communicate the findings of this study, I opted for a formal two-pronged approach to engaging with the general public and stakeholders such as NGOs and health professionals: (i) Sharing the project results through a public lecture and presenting summary findings in a written report) and (ii) an open formal display of the co-produced artworks in an exhibition. However, for the wider artisan community, the approach was less formal given the nature of the industrial settings in which they operate where spaces are congested with furniture displays and unplanned makeshift workshop units. This did not permit a formal gathering/open public lecture. Instead, the sharing of findings and exhibition event in these spaces was staged within the industrial spaces to enable free interactivity among the researcher, workshop participants, and the artisan community with the aim of sharing and learn from the exhibits.

The chapter is organised into three key sections. The first section discusses the process of sharing of the findings and feedback from the research participants and the artisan community in Ndeeba industrial area. It outlines and analyses the feedback in terms of what the research participants and members of the artisan community learnt from the artworks and the potential changes they might consider regarding their attitude and behaviours. The importance of being able to speak openly about HIV/AIDS, sex, and so forth, and the livelihood opportunities and other benefits that might be derived from the exhibition of artworks are also discussed here. The second section provides a detailed account of the actual reception events, highlighting

where, why, and how they were organised in the different public areas (e.g., at Makerere University art gallery) to include NGOs, health practitioners and policy makers involved in the fight against HIV and AIDs. It expounds on the different activities performed during the dissemination event, the event participants/attendees and the overall reception and the feedback on the artworks and the project as a whole. The last section deliberates on the outcomes of the presentation of the findings to the stake holders who included, among others, the general public (media coverage and reports in the newspapers), as well as addressing the audience's reception of the events. This section ends with responses of the research participants about their art works featured in the open public spaces and insights from other stakeholders (e.g., NGOs such as TASO, NGEN+, LUCOHECO) about the potential impacts and benefits of this research and possibilities for future collaborations.

Before proceeding to exploring how the reception events were conducted, I provide a detailed account of how the findings were disseminated to the research participants and members of the artisan communities, exploring the contexts in which the dissemination works were done as well as analysing the feedback from the various actors involved.

## **7.2 RECEPTION OF FINDINGS BY THE RESEARCH PARTICIPANTS AND THE ARTISAN COMMUNITY**

During the twelve months of interactive engagements and participatory workshops in the greater peri-urban fringes of Kampala city, meaningful relationships were established among the different youth from different cultural, gender and social backgrounds. This inspired comprehensive and genuine conversations about the disease, within the context of young people's lives. Applied social sculpture permitted the collective production of functional artworks or familiar objects from ordinary materials like soap, wood and metal accessed from the local community, which created opportunities for diverse conversations about HIV/AIDS. Typical of these artworks are benches, beds, and bicycles constructed with spikes to evoke the Covid- 19 pandemic that convey messages aimed at raising awareness about HIV/AIDS prevention and infection among young people. The technique of working collaboratively to produce the everyday applied objects/artworks is essential in constructively engaging youth, and therefore, improving their skills and confidence in the long run.

On the 1<sup>st</sup> and 2<sup>nd</sup> of November 2020, the first exhibition event was organised in Ndeeba industrial area as a part of sharing of findings from fieldwork and collaborative working with

young people in raising awareness about HIV/AIDS. The purpose of this event was to share findings with the general artisan community in which the research was conducted and create an opportunity for the audience to interact and give their feedback on the artworks produced during the participatory workshops. There was no formal setup such as a marquee or exhibition hall as the congestion and compactness of the makeshift structures in the industrial setting prohibited this. The exhibition was, therefore, staged within the open spaces provided by the local craftsmen (surrounded by their furniture displays). This allowed the general artisan community which did not directly participate in the creative workshops, to interact with the exhibits freely and conveniently.

A few formal interviews were also conducted in the nearby makeshift workshops with permission from the owners. All those who consented to take part in the interviews were asked basic questions regarding how they perceived the artworks, whether they understood the messages contained conveyed in the artworks, their value in relation to HIV prevention and awareness, and personal questions as to age, health status, etc.

### **7.2.1 Ndeeba Industrial area**

While the research was conducted in four different informal spaces of Kampala (Bwaise, Ndeeba, Katwe, and Lungujja), Ndeeba industrial area was purposively chosen as the main dissemination point for the research findings to the artisan community and general public for two main reasons (i) it is highly representative of the target audience for which the research was intended with more or less similar peri-urban situations and challenges affecting young people (ii) the research participants in Ndeeba proved to be more diverse, and were interested in and committed to the project through the workshop phases. In comparison to other study sites, more time (3 months) was spent engaging with these artisans and their community, which paved way to the creation of one of the most potentially compelling HIV artworks of the project – the HIV bed.

When we concluded the participatory workshops in Ndeeba industrial area, we agreed with the workshop participants to run an open exhibition of the works to share our findings and experiences with the rest of the artisan community in line with the objectives of the research. This marked the beginning of the reception process, where an open exhibition of these works in one of the free spaces within the industrial area that was identified by one of the workshop

participants who sought permission on our behalf from the owners (timber dealers and carpentry workshop owners). With the help of the area local council chairman several youths were contacted and encourage to visit the exhibition. The older male participants who were the more active during the co-production sessions, spearheaded the setup of the exhibition in the open yard. The artworks were placed randomly in the spaces left between the furniture works produced by the local craftsmen. The biggest artwork – the HIV bed – was placed in front of the makeshift structure where we conducted the creative workshops as the owner agreed to remove all his furniture to create space for it. Interestingly, this kind of arrangement gave us two major advantages: (i) the artworks, especially the HIV benches and bed, were able to stand out with marked unique features such as engraved imagery and words, which were in sharp contrast with the ordinary furniture forms of the other artisans, (ii) this gave us an opportunity to easily draw the attention of several artisans and other people plying their trade within the precincts of the industrial zone. Since Ndeeba industrial area is a very busy space and a space of transit and work, it was not feasible to create a formal exhibition space for the exhibition away from industrial zone. Research participants suggested setting up the exhibition within the free space in order to easily attract the busy community with convenience. Although the people who visited the exhibits was quite diverse, the event was mainly dominated by artisans who live and work in Ndeeba industrial area. In general, the attendees/participants in the exhibition included carpenters, casual workers (sanders, food venders, roadside vendors, hawkers, etc), unemployed youth, mobile traders, passers-by, and other businesspeople who had flexible tasks and work schedules within the artisan community.

The following field diary excerpt describes the process of setting up the exhibition

“On the morning of 1<sup>st</sup> November 2020, a team of seven male workshop participants reported as early as 7:00 am to begin the display of the works. First, I guided them one how to use discarded wood blocks collected from the nearby carpentry points by arranging, trimming, and painting them to appropriate sizes for use as pedestal for the bigger artworks such as the bed. These blocks were meant to avoid the artworks from getting into contact with the dusty ground. While our display layout was dictated by the compact spaces left by crammed finished furniture of the artisans, it turns out to offer a good comparative advantage due to the creative render of the message laden HIV artworks. Despite getting permission from the exhibition space owners, it seemed agreeable with my team that sticking to the existing displays would endear other artisans and the general public to freely interact with our exhibits without affecting their day-to-day sales work (Taking their customers around). Meanwhile, six other male

research participants together with three female volunteers joined an hour later to complete the display process as they interacted with other exhibition participants from the neighbouring wood workshops. Indeed, because of limited space for display the HIV benches, in particular, were randomly placed between the furniture works of the other artisans but still stood out since they were uniquely crafted with emblazoned messages about HIV prevention. The display took us over four hours of teamwork to complete, thus, allowing the artisan community and a mammoth of passers-by, mobile traders, and some of the idle youth in the vicinity of this industrial area the rest of the day to enjoy and interact with the artworks. We chatted and talked about the emerging ideas and diverse observations about the artworks. I also conducted informal interviews with five random exhibition participants by 6pm”

(Field diary, day one, exhibition event, Ndeeba industrial area, 2<sup>nd</sup> November 2020)

As previously mentioned, the open display of the artworks attracted the attention of passers-by, such as young people working and living in the Ndeeba industrial vicinity, who interacted with me and the research participants who were acting as exhibition attendants (See *Plate 55*). Since the artworks were placed alongside the furniture works by other artisans, it was deemed necessary to have two of the workshop participants acting as stand-by volunteer guides for those walking by to see the exhibited artworks. It was notable how these artworks drew the attention from the general industrial community who included roadside vendors, charcoal dealers, second-hand cloth sellers, restaurant workers, timber merchants and boda-boda cyclists working in and around the industrial zone. The interactions of these people with artworks, especially the HIV benches and bed, inspired open and spontaneous conversations among the attendees about HIV/AIDS and the challenges encountered by young people, especially adolescent girls and young women who work in male dominated spaces in peri-urban geographies of Kampala. For example:

“Crowds of youth gathered around the artworks and interacted with the participants while I engaged them into casual conversations about their own experience as related to HIV/AIDS and how they interpreted the messages contained in the pieces on display. As I began to conduct my first informal interview of the day with one participant (A machine operator from the near timber processing workshop), I noticed groups of young people murmuring about the fascinating imagery particularly on the HIV benches as they seemed engulf in conversation about the messages being conveyed. Importantly, engaging the viewers in one-on-one conversations and random group exchanges was very helpful in understanding how they perceived the displayed artworks and what this meant for their possible change in attitude towards their health, behaviours, and social practices. Meanwhile, it was an incredible experience to see

loads of youth cramming around the benches and HIV bed to see, read the inscription loudly, touch and sit on these artworks”

(Field diary, Day two, exhibition event, Ndeeba, 2<sup>nd</sup> November 2020)

Since it was a two-day informal exhibition (without cataloguing the artworks and no curatorial assistance) with surging numbers of people gathering around the exhibits, I used the opportunity to share the research findings, deliberating on how young people were grossly affected by economic precarity and HIV/AIDS, with displayed artworks attracting more and more crowds to the venue. At the end of the two days, I managed to engage several exhibition participants in one-on-one conversations and also conducted ten interviews with the research participants (4) and other artisans (4) and general public (2) as several other attendees were keenly looking and interacting with the artworks on display. During the interviews, I mainly focused on seeking their opinions about five important aspects: (i) what they learnt from the artworks and how they might have affected their attitudes and behaviours (ii) the importance of open communication about HIV/AIDS and how the artworks contribute to this (iii) how the people living and working in the informal areas benefited from viewing the exhibition in relation to education, information and breaking the silence about HIV/AIDS and inspiring other to learn and improve livelihoods (iv) Benefits to the youth and other people in the informal spaces of viewing the artworks (v) The skills and capacity building prospects as well as economic benefits of engaging in creative projects among the young people. These are discussed more fully below.

#### **7.2.1.1 Learning from the artworks - possible change of attitudes and behaviours**

There are several benefits that were potentially realised from engaging young people in the creative workshops for HIV/AIDS prevention, particularly in Ndeeba. First, however, I would like to reiterate that according to the HIV positive participants from Lungujja, the purpose of creating the HIV benches (*Plate 40*) was twofold; (i) to act as seating facilities in open social spaces and (ii) to serve as tools for communicating messages of HIV prevention among young people. Thus, the visual imagery/messages about HIV/AIDS on these everyday objects, as I noticed during this exhibition, were instrumental in stimulating candid conversations, which enabled me to garner more responses regarding the implications of the artworks for potentially changing behaviours and unsafe practices that have allowed HIV to thrive in their

social spaces. To most attendees and research participants at the dissemination event, these artworks were uniquely expressive and thought-provoking regarding self-protection and restrictive behaviours for better health. A few selected responses support this observation:

“The benches, in particular, contain provocative imagery that prompts one to reflect and openly deliberate on critical health issues that relate to HIV/AIDS. Actually, one of them which shows the disintegrating bits and sores on the male genitals is rather scary. It motivates me strongly focus on safe sex practices to avoid getting HIV virus. For instance, using a condom, seeking medical help, or even taking an HIV test with my partner”

(Informal interview, exhibition participant, Day one, Ndeeba industrial area. 1<sup>st</sup> November 2020)

“It has been quite hard for me to abstain. These artworks, especially the benches, have reminded me of how it is important for me to behave wisely to avoid getting HIV. So, when I get a new girlfriend, I will first take time to study her then go with her for testing before having sex”

(Informal conversation, Participant W, Ndeeba art exhibition, 2<sup>nd</sup> November 2020).

“I learnt several things from the participatory workshop and exhibition. First, to ensuring being HIV-free by avoiding multiple sexual partners: That my safety against AIDS starts with me. Secondly, I should stay occupied with activities that may keep me creatively busy and productive which minimises the time that would be wasted in reckless encounters”

(Formal interview, 25-year-old research participant, exhibition event, Ndeeba, 2<sup>nd</sup> November 2020)

These accounts clearly echo the potential impacts of these artwork in facilitating conversation about taboo subjects and improving the knowledge of the participants and other youth as they appeared to evoke better perception and attitudes towards HIV/AIDS prevention. Acknowledging the need to ‘first have an HIV test on getting a new girlfriend’ by a 25-year-old exhibition participant W suggests a consciousness-raising aspect that stands out as one of the valuable learning attributes beyond visual aesthetics that makes these HIV artworks meaningful to the young people and their communities.

#### **7.2.1.2 The importance of open communication about HIV/AIDS**

Evidence from the field work showed that ignorance and stigma attached to the disease are still major obstacles to the wellbeing and health of young people living and working in marginalized industrial zones of Kampala. This partly explains why numbers of HIV/AIDS



infections are again on increase (UAC, 2020). The likelihood of stigma associated with HIV/AIDS makes it difficult for young people who are infected to disclose their status or even openly talk about their social and health challenges. As previously mentioned, encouraging open expression and dialogue about the epidemic among the youth using creative approaches linked to applied social sculpture was at the heart of the research. While questioning the potential of this approach to tackling HIV/AIDS among the youth, the project invested time in engaging with young industrial artisans (infected with and affected by the disease) to openly talk about their everyday experiences, which eventually boosted their confidence. Consequently, they were able to share important information with significant preventative and the likely economic benefits. This approach also opened up crucial practical avenues for candid expressions in the form of artworks, addressing issues related with raising awareness and creative strategies for bettering young people's health and livelihoods in marginalised space in Kampala (see also see chapter five and six).

Most importantly, during the reception event at the open exhibition of the artworks in Ndeeba, it was clearly noticeable that those artworks which had scripted messages engraved on to their surfaces drew most attention as several event participants were seen and heard reading the messages loudly to the rest. This triggered various debates among the viewers who occasionally engaged the participants in conversations about the circumstances that surrounded their livelihoods, living with HIV/AIDS, and wellbeing as invoked in some of the artworks. The artwork of 'Malaayas in Ndeeba' (*Plate 23*) and the HIV bed (*Plate 41*), in particular, drew the most reactions as attendees openly espoused witnessing similar circumstances depicted in the artworks. One participant stated:

"The silhouettes of young men and women, I see in this relief work (Malaayas in Ndeeba) are clustered in way that seems to reveal areas of sex work here in this industrial neighbourhood. This business has trapped many of my friends into the web of reckless activities such as using drugs, smoking and alcoholism which has put their lives at the risk of getting infected. Some are actually infected. We can no longer hide the fact that sex trade is part of our lives as many of the idle youth have resorted to drug addiction, alcoholism, and multiple dating as a way of life. This artwork has tickled me to talk about these social ills affecting us here. I hope this could be a starting point towards sharing these tough experiences among the youth and help them change"

(Informal conversation, exhibition event, 30-year-old carpentry workshop owner/artisan, Ndeeba, 2<sup>nd</sup> November 2020)

Another said:

“Most people get HIV/AIDS on bed when having sex. It is interesting to see such a beautiful artwork which is in form of ordinary furniture talking about the consequences of infidelity or having multiple partners. I cannot hide the pain I experienced when I caught my boyfriend cheating on our bed. I feared for my life, and I decided to have an HIV test. Unfortunately, it turned out positive. I have been quiet about status for long but when I saw this bed, it rekindled the memories of my sexual life with him but at the same time re-ignited hatred I developed after knowing his secret affair. Sharing this experience makes me feel better. I think it may be the same for others.”

(Formal interview, participant, Exhibition event, Ndeeba, 1<sup>st</sup> November 2020).

As seen in (*Plate 55* and *Plate 56*), the large crowds at the dissemination event seemed to suggest that the displayed artworks were engaging mainly because they were every day ordinary objects- beds, benches, etc, with eye-catching messages about HIV/AIDS. As some participants observed:

“I was curious to come closer to see how the designs engraved on to the furniture forms were done. It surprises me to see that they are actually talking about HIV/AIDS and how we should guard against it”, a 20-year-old artisan said

(Informal conversation, Exhibition event, mobile trader, Ndeeba, 2<sup>nd</sup> November 2020).

“I have always feared to speak about the disease because of the negative perceptions from the public. I think it is the stigma attached to AIDS denies us the freedom to openly talk about it. The words of encouragement on those benches such as go for testing, ARVs are good for life and so on are quite motivating. Seeing more of this is re-assuring especially for those who are infected”

(Interview, exhibition event, roadside vendor, Ndeeba, 2<sup>nd</sup> November 2020)

These narratives provide evidence of the potential of the artworks to evoke and foster free expression about participants’ experiences of the HIV pandemic. They clearly add to those voices upholding the importance artworks in getting young people to talk openly about the disease. The level of interaction and conversations at the dissemination event seemed to suggest an elevation in the sense of confidence among participants to express themselves about the disease as the artworks may have stimulated their consciousness about the consequences of being infected and living with HIV/AIDS. All through creative workshops and

the dissemination event, open conversations and stories about personal experiences proved very helpful in invoking others to talk and confront their own challenges related to health and their livelihoods. Indeed, listening to several event participants opening up about their life experiences related to the disease by interacting with the artworks was remarkable, since this rarely happens in public spaces due to stigma surrounding the disease.

### 7.2.1.3 Education and informational benefits to participants and community

While the HIV benches and bed captured most attention, all the artworks were educative and informative to the intended audiences. The unique details appearing on their surfaces in the form of engraved images and words made them distinct and visually eye-catching to the spectators during the exhibition event. The HIV message laden benches (including messages such as '*Mila edagala*' – Take your medicine', '*Genda wekebeze*' – Go for testing) - **Plate 46** to the HIV bed - **Plate 58** and other relief works the artwork were unique and appealing to the audience at the event. They stood out among the ordinary furniture forms belonging to the local artisans, and many participants concurred with the HIV/AIDS messages and the imagery, in particular, which seemed to be clearly understood.

'*Mila edagala*', according to the workshop participants, was a clear and open message to encourage those who are infected to adhere to their drug regimes in order to maintain a healthy life. During the dissemination event the following was noted:

"After reading the words that say '*Mila edagala*' and 'ARVs are good for your life' on one of the benches on display, a participant talked about colleagues who take their ARVs in secret. "They don't want others to know they are infected with the virus. Young people tend to hide and stay away from their work especially when they become sickly"

(Field diary, dissemination/exhibition event, Ndeeba, 2<sup>nd</sup> November 2020)

An older participant confirms this view:

"Many of our young workers here don't want to take their ARVs especially when they are at work. They tend to hide away while some deliberately leave their medicine at home which has affected their health in the process. The message on this bench (**Plate 46**) is quite spot-on. It is my belief that when one see this message it will be strong reminder to regularly take their medicine. The youth need to be constantly encouraged to maintain their drug regime and this is what this message could be about"

(Informal interview, exhibition event, 34-year-old timber dealer, Ndeeba Timber dealer).

These accounts reflect the potential of the artworks in getting the messages across to the intended audience. They are educative and informative especially to young people who often seem uncertain and unaware of the lifesaving medicine for HIV/AIDS. This kind of messaging coheres with the national targets pursued and spearheaded by the Ministry of Health to ensure that those persons who have tested positive are put on treatment (ARVs) to suppress their viral load as part of the ambitious 90-90-90 targets (see Elvis Basudde, 2020). In addition, '*Genda wekebeze*' was tagged to one of the benches - **Plate 46** to remind all the youth and the rest of the community to always seek medical help, and also test for HIV/AIDS in order to protect their loved ones.

The artisan community and event participants, in particular, were also captivated by the way ordinary everyday objects such as bed, bikes, benches, and so on were used as tools of communicating messages about the epidemic. Many of those who interacted with the artworks seemed drawn by the creative inscriptions of HIV message as these everyday objects uniquely stood out in conveying health-enhancing information. One observed:

“The use of familiar objects (house, beds, benches, etc) with messages about the HIV epidemic uniquely distinct and presented in a simplistic fashion, even though some have abstracted details. The bed and benches, in particular, are used in our everyday life and we can easily identify with them as utilitarian. The messages conveyed are quite clear and informative. For example, the words such as use condoms, get circumcised and say no to unprotected sex on the benches are very helpful in encouraging us away from getting infected with HIV or other STDs.”

(28-year-old artisan/attendee, Ndeeba)

However, as some participants observed that the messages inscribed on the artworks should be in a simple local language (say Luganda for youth in Kampala) as they can easily relate with them. This might be helpful for them to read and comprehend the HIV messages better. Nonetheless, during the interviews at the venue of the exhibition, four out of five participants were able to read and understand the inscribed messages on the benches. “ARVS are good for your life”, a participant read out the emblazoned words loudly when I asked him to share with me what was informative about one of the benches he sat on during the interview. He added,

“The message is very clear. Taking ARVS can help you live longer if you adhere to the prescription given by the doctors”

(Formal interview, exhibition event, 28-year-old participant, senior two drop-out, Ndeeba).

This affirms that the messages on the artworks were simple to read and concise and educative as well (E.g., *Plate 40*, *Plate 41*, etc.). By provoking discussion, reflection and acknowledgement, the artworks have potential to influence the attitude and behaviours of the intended audience and the youth in the context of HIV/AIDS prevention.

#### **7.2.1.4 Engaging with youth and other people through social sculpture in informal spaces**

At the beginning of the participatory workshops, it was quite hard to predict the impact and outcomes of the creative engagement with the artisans, despite having clear intentions and objectives. After weeks of collaboration and performance, the outcomes were very clear and visible in terms of the physical outputs not only to the research participants but also to the general artisan community. Indeed, the products from the creative workshops provide reference points for the benefits to the participating youth the wider community in and outside the informal spaces. One of the local leaders who was occasionally in touch with me during the creative workshops with the research participants visited the artworks and remarked:

“It is very interesting to see how this program has engaged our young artisans with diverse backgrounds such as the idle youth, migrants from the countryside, casual workers from the neighbouring villages, and so on. The creativity shown in the artworks and the purpose for which they crafted is very clear and helpful to them especially in terms of influencing better behaviours and livelihood prospects. With the rising level of HIV/AIDS infection among our youth, I would strongly call for more workshops of this nature in the neighbouring area beyond the industrial zone”

(Dissemination event, LCI chairman, Betania zone Ndeeba).

In the same vein, other participants also stated:

“The involvement of young people in this participatory project potentially demonstrates how the open interactive and creative efforts may possibly contribute towards the growing preventive knowledge for improved livelihoods and health of young people. Sharing information, say, about self-testing kits, pre/post-prophylaxis medicine used before or after rape or unplanned sex encounter to prevent HIV, talks about safe sex practices such as condom use, testing, and other critical health issues in our community were helpful deliberations in view of supporting young people towards navigate social challenges related with HIV/AIDS during the workshops”

(Formal interview, 36 – year - old event participant, Ndeeba, 30<sup>th</sup> October 2020)

“It is extremely important to take such creative workshops to other informal communities to help them learn, build resilience, and confront critical social and health challenges related to HIV/AIDS. As a community in which this program has been conducted, the benefits if we have been able to benefit, I am certain that even other youth groups/communities will be inspired to learn and change their behaviours through such participatory engagements”

(Informal conversation, workshop participant W, Ndeeba art exhibition, 1<sup>st</sup> November 2020)

Clearly this demonstrates the potential of applied artistic practices and workshopping to engage local communities (young people) in discussions about disease, sex, HIV prevention etc. The importance of extending similar workshops would enable other communities to appreciate the health knowledge and practical skills that might be acquired from their participation.

Furthermore, during the exhibition participants proposed to anchor wooden signage (*Plate 57*) with the words HIV/AIDS (our responsibility and a global solidarity) arguing that it resonates with the messages in the artworks intended to help other people in the industrial fringes to develop the confidence to talk about the disease and change their behaviours. The exhibition of the artworks and the dissemination process was intended to inspire other artisans in the informal economic spaces. As one participant noted:

"At least our friends will pick up the messages silently and change their behaviour. Most of them tend to lead reckless lives, so, they need such messages placed within our workplaces. We can be advocates in our own space and that's why we have put up this sign at the entrance of our workshop and will also request to stay with some of the benches so that we look at them every day. We are not shy to talk about HIV that we were part of this process. You have empowered us and to share what we learnt with other”

(Informal conversation, exhibition, research participant, Ndeeba, 2<sup>nd</sup> November 2020)

The message in the narrative appears to be very clear. By displaying the signage, they created out of a discarded wood panel, the participants voiced the need to mobilize their community towards appreciating efforts designed to stem the tide of the disease. Getting the message across with posters and wording in their community could be a way of raising more awareness and building confidence among the community members to confront the epidemic in their neighbourhoods.

### 7.2.1.5 Livelihood benefits of engaging in creative projects

The participatory workshops, in particular, were instrumental in providing the young participants with opportunities of learning new ways of developing and expanding their craft using creative methods in applied sculpture. Based on the feedback they gave, participants affirmed acquiring skills in drawing, modelling, enjoyment of visual translation, open discussion, and interpretation of their story, intended to provide a foundation for improved future prospects in their crafting business. As mentioned in previous chapters, the project was intended to boost the skills of youngsters in informal industrial spaces to advance their creative abilities that would improve their livelihoods and health. Berman (2018) uses her own fieldwork as a case study to show how hands-on work in the arts with learners of all ages and backgrounds can contribute to economic stability by developing new skills, as well as enhancing public health and gender justice within communities. Similarly, my field evidence and feedback show how hands-on work using applied sculpture with young people of diverse backgrounds in informal spaces can contribute to economic wellbeing by developing and sharing creative skills, as well as enhancing public health and social justice.

The collective engagement of disadvantaged youth attempted to equip them with skills to enhance their life experiences in areas where opportunities for formal education are very limited. Findings from interviews conducted with research participants and other youth provide an interesting lens into their observations about the vocational and occupational benefits of the project engagements:

“It has been a very helpful process because these workshops encouraged open discussions, enabled learning, and sharing of knowledge about important health issues such HIV/AIDS and its prevention. This in turn helped in building resilience and most crucially the creative skills that can be used to better our economic opportunities. For instance, the process of transforming scrap wood or found materials into utilitarian objects provided insights on how to enhance commercial value on our products while tackling the challenges related to idleness and limited employment opportunities”

(Formal Interview, open exhibition, 24-year-old female participant M, Ndeeba)

This response points to the potential benefit of participatory projects in yielding economic benefits through the conversion of less costly, often recycled or waste materials to create works for sale. The participant highlights the importance of finding meaning in utilizing

discarded materials for better economic gain which some of the participants had not considered previously. During a separate interview with a male participant who attested to having had difficulties in securing a decent livelihood, he described the benefits of the creative workshops:

“I have always settled for low paying casual tasks because I didn’t have specific skills that are relevant for profitable crafting jobs. But now I am so grateful for having participated in these creativity workshops because they have enriched my crafting skills - sanding, building pedestals, engraving, etc. Previously, I didn’t know the importance of drawing in developing new designs for functional works.

(Formal Interview, research participant, dissemination event, Ndeeba, 2nd November 2020)

Another 26-year-old craftsman and research participants at the exhibition mentioned how engaging with project activities had enhanced his creative potential, acknowledging how the challenges they encountered while executing the artworks became a skills-gaining process:

Interviewer: We talked about HIV/AIDS and ways in which it spreads during our creative workshops. Through your story about sex work near your workplace (*Plate 23*), you were able to develop a visual concept to raise awareness of such challenges. Do you think that the kind of artistic input involved is helpful towards building your creative abilities as a craftsman?

Research Participant: Yes of course. The whole process of developing my concept has helped me and the group. At some point we seemed to be stuck on how to develop the designs through conversation, drawing and group work. But with guidance and team support, the creative process become elaborate and steadily progressive until we co-produced the final works. Sketching images, documenting, and crafting our ideas with local materials broadened our creative insights and the power of teamwork which may possibly translate into better crafts after this project. Besides, many of the participants have been able to pick ideas that are relevant to the different fields of work we do here in Ndeeba. For instance, as a bed maker I have been able to appreciate the alternative ways of creating new headboard designs through drawing with inspiration from my social experiences”

Clearly, these experiences echo the numerous ways in which the participants recognised the value of applied social sculpture in helping them navigate the HIV/AIDS landscape in their areas of occupation. However, I am particularly intrigued by testimonies from two immigrants who were fully engaged in the workshops from the beginning:



“Some of us are Congolese migrants from upcountry locations. We are ill-trained, homeless, and struggling to find decent work here. Adapting to the harsh living and working conditions with little or no skills to get employed in the furniture workshops confines to casual jobs like collecting chippings, offcuts, and loading. Fortunately, I have learnt how to burnish and improve the designs for their light furniture works such as shoe racks, wooden hangers for vending in the neighbouring villages. Hopefully, this will improve my earnings”

(Formal interview, 27-year-old Participant A, Congolese migrant /artisan, Ndeeba)

“Learning new applied skills literally means improving the quality of our furniture product. I was particularly inspired by participant T’s concept of the heart and the pigeon in which she implicitly explored the challenges of promiscuity and disloyalty in the context of HIV/AIDs among young people. I actively witnessed the entire design process that climax into a beautifully rendered storyboard (See *Plate 58*) as we collectively transformed it into a well-crafted headboard with creative exaggerations of relief carvings, forms, patterns, and a figurative imagery that made the final bed aesthetically powerful, and marketable.

(Formal interview, 22-year-old artisan, Congolese migrant /artisan, Ndeeba)

“Every person who viewed the bed enquired about its price. We usually sell beds of that size (6ft x 5ft) between shs. 450,000 (£100) and 600,000 (£130) Uganda shillings depending on the design and type of wood. However, with this particular bed, most exhibition attendees were impressed by the sense of design and the subtle integration of the HIV messages, and some offered to purchase it at one million shillings (about £220). That alone was remarkable and empowering economically. It provides evidence that applied art has a real potential of boosting creative capacity to generate functional products that can attract a better market value hence increasing the commercial viability of crafts, thus, bettering livelihoods. Improved livelihoods also mean better ability to sustain a good health (treatment, medical check-up, testing, etc.), meet family obligations for those with families, as well as limiting the risks associated with risky behaviour related with alcoholism commercial sex, gambling, and illicit businesses for survival in these marginalized urban neighbourhoods”

(Field diary, Informal conversation, open exhibition, Participant P, Senior two dropout, Ndeeba industrial area).

All these accounts point to significant benefits derived from the participatory workshops: (i) enriching their creative ability, (ii) producing artworks that have clear economic value that could, in future, help build more secure livelihoods, (iii) inducement of health-enabling practices (e.g., regular use of condoms, regular HIV testing, using of self-testing kits, open conversations about sensitive subjects like sex and HIV/AIDS, etc.), which were at the core of our discussions about epidemics such as HIV/AIDS and Covid-19 throughout the workshops.

Participants also recognised that the creative processes are very helpful in developing simplistic designs that are unique for furniture products, which can generate extra income without necessarily increasing the cost of production, for example, enhancing surface decoration and building artworks using found materials/scrap wood with simple carving tools such as rasps, saws, chisels, and gouges. Indeed, in helping participant Q construct his idea of the hospital ward (*Plate 59*) and other figurines, participants demonstrated the power of the artistic processes in enabling them utilize local material such as scrap wood, metal and plyboards to create functional everyday objects like beds, benches, chairs and so on.

At the end of the two-day event, participants requested that two benches be left in the workspace because of their power in conveying the message about HIV which they said was easier to share than verbal communication.

### **7.3. SHARING OF FINDINGS TO WIDER PUBLIC AUDIENCES**

The research findings were shared through a presentation and written report, and through an open exhibition of selected co-produced artworks to the stakeholders, policy makers, and the general public. Again, this was deemed important for generating valuable feedback about the benefit of this research while potentially contributing to the on-going local, national, and global efforts to end HIV/AIDS as public health threat by 2030 in Uganda and elsewhere.

As previously mentioned, all the reception events gave room for the much-needed feedback for improvement (with constructive criticism from attendees) and affirmation of the potential of applied sculpture as a tool for public health engagements in grassroot communities in informal economic contexts. The intended stakeholders for which the HIV/AIDS exhibitions were held included: academics, health service providers and professionals, community-based and non-governmental organisations, government ministries (Youth, Labour, and Social Development and Health), individuals in HIV advocacy work and activism, participating communities, and the general public. Due to limited time as a consequence of the Covid-19 restrictions, only 2 audience reception events were possible in formal environments/venues in Kampala. They included (i) Makerere University Art Gallery and (ii) The AIDS Support Organisation (TASO) centre/head offices in Mulago, Kampala. At both events, I presented the project findings as a report (highlighting key findings from the entire research project), followed by an open exhibition of the artworks created during the participatory workshops.

### 7.3.1 Makerere University Art gallery.

The purpose running a reception event at Makerere University was to draw the attention of key stakeholders in the fight against HIV and AIDS towards recognizing applied sculpture as a potential method for initiating, mobilizing, and encouraging open dialogue and creative engagement among the youth in informal economic settings. Moreover, it was envisaged that this could contribute to wider efforts aimed at improving health and wellbeing in the context of HIV/AIDS prevention. Additionally, the event was also meant to provide the much-needed feedback on the project findings and the co-produced artworks related to tackling the challenges associated with HIV/AIDS among young people in peri-urban Kampala. Other reasons for holding the first dissemination event at Makerere University are threefold: (a) its position as a partner institution with Durham University for this research project (a memorandum of understanding was signed in that respect); (b) its ability to bring together representatives of leading academic partners and institutions in HIV-related research work nationally and globally; (c) its status as a venue in which academic research is regularly disseminated to policy-makers and other key target stakeholders.

The reception event at Makerere University was staged as a formal function inside the art gallery where the report of the findings was presented as a 45-minute public talk in the first room of the gallery, with some artworks displayed in the background and the majority displayed the other two gallery spaces.

“On the eve of the exhibition at the Makerere art gallery – 3<sup>rd</sup> January 2021, I went with four volunteers who were part of the research participant in Ndeeba to help with the loading and offloading of the artworks on a hired truck from Ndeeba to the venue. We reached the gallery at 10:00am, offloaded the artworks and began to draw out a layout of artworks in physical space inside the gallery with the help of gallery technician based on the catalogue we had prepare with him the days before. Later, at about 1:00pm we started installing the artworks in the two of inner sections of the gallery. The first section of the gallery was spared to host the dissemination launching function (Presentation of the project findings, speeches, and official opening of the exhibition the guest of honour) first phase of the event. Using stings, hooks, and nails we were able to complete the display of all the artworks along with their posters by 7:00pm

(Field diary, exhibition event preparations, 3<sup>rd</sup> January 2021)

While the middle section of the gallery (*Plate 61*) displayed works about HIV/AIDS prevention which included the HIV bed, HIV benches, HIV ward and the Malaayas in Ndeeba), the second section contained the Covid-19 artworks. They included the Covid bikes which were anchored on to the gallery walls (See *Plate 60*) for clear visibility. A full colour catalogue for the exhibited artworks was generated to enable the event participants/viewers to appreciate the purpose of the exhibition in the context of the research project. Each artwork was presented with a brief description of its conception, a caption and a poster explaining the process of co-production and its intended purpose. It is imperative to note that since all the artworks were collectively produced during participatory workshops, a list all the workshop participants was generated, and certificates prepared for their recognition as contributors to new knowledge in the context of HIV prevention. The certificates of participation were awarded to each participant at the first exhibition launch at Makerere University. Overall, the exhibition setup was staged in such a way to suggest the emerging overlap of the HIV/AIDS with the Covid-19 outbreak and how these were incorporated into the prevention and awareness efforts initiated through this participatory project for the youth.

Since the reception event was planned as a formal function, I sent out special invitations in form of invitation cards to several notable dignitaries in academia, HIVAIDS support networks, and key stakeholders such as local youth NGOs and others engaged in the fight against the disease. Posters about the event were designed and displayed at strategic points, for instance at university faculty notice boards and NGO offices around Kampala. A large banner was placed at the main gate of the University and nearby community social centres to publicise the event among the students and the general public from the areas in and around Makerere. Out of necessity, several posters were placed at strategic point outside Makerere University (Katanga, Bwaise and Kikoni) which are highly informal neighbourhoods and known locations for concentrations of student hostels. We hoped to draw the attention of some marginalized youth and students residing in hostels in these spaces.

Furthermore, the gallery attendant, whom I co-opted onto the exhibition organising team, also made attempts to publicize the event on social media using WhatsApp and Short Messaging texting to members of the art community, HIV/AIDS support individuals, organisations, and the general public. He also ensured that all the official invitation cards that we issued were

delivered to the intended recipients. Notably, the event was organised with support from the Makerere Institute of Heritage, Conservation and Restoration (MIHCR), which is mandated to manage the University Art gallery at Makerere. While Makerere University is key stakeholder as a research partner in the participatory project and supported the dissemination/exhibition event through one of its administrative organs Makerere University Institute of Heritage Conservation and restoration (MIHCR), the overall event was fully funded and supported by Durham University through the Global Challenges Research Fund Centre for Doctoral Training (GCRF - CDT).

Over 70 individuals visited the exhibition after the launch<sup>96</sup>. The event itself was attended by over 30 people (See *Plate 63*), including staff, management, students, and alumni from Makerere University, research participants from Lungujja and Ndeeba, health experts, well-wishers, friends, and representatives from Community-based organisations (CBOs) such as Uganda Community Art skill Development and Recycling (UCASDR), National Guidance and Empowerment Network of People Living with HIV/AIDS (NGEN+), Lungujja Community-based Health Care Organisation (LUCOHECO), International Community for Women Living with HIV-Eastern Africa (ICWEA), Uganda Network of Young People Living with HIV/AIDS (UNYPA), and BAYLOR Uganda<sup>97</sup>. On arrival, each participant was handed a copy of the event programme and a catalogue of the exhibition. Furthermore, the exhibition was planned to last for one month (4<sup>th</sup> – 30<sup>th</sup> January 2021) to allow more people to visit and share their thoughts and opinions about the project. Indeed, this prompted me to spend several hours for four days each week at the gallery to take the opportunity of interacting with the visitors who came after the Exhibition launch. Each time a new guest visited, I could seek a one-on-one conversation to gather more feedback about the project and how best it could be furthered to benefit the youth beyond the project scope. Several media outlets, including the *Daily Monitor* publication,

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<sup>96</sup> According to records captured in the visitor's book at the gallery as at 30<sup>th</sup> of January 2021 when the exhibition was pulled down, over 70 individuals had visited the exhibition. Most of them registered their names and wrote constructive and positive comments and observations about the project and the artworks.

<sup>97</sup> Baylor-Uganda, also known as Baylor College of Medicine Children's Foundation-Uganda, is a nationally recognized non-governmental organization since 2006. Baylor-Uganda was founded as an affiliated not-for profit entity with the Baylor International Paediatric AIDS Initiative (BIPAI), a network of Paediatric HIV care and treatment Children's Clinical Centres of Excellence (COE) and international program with the goal: To reduce morbidity and mortality due to HIV & AIDS, non-communicable diseases, pregnancy, and related maternal and childhood conditions in Uganda.

the *New Vision* newspaper, Capital radio, and *Red Pepper Publications* from Kampala sent their representatives to cover the HIV/AIDS artworks exhibition. The media department of Makerere University was also represented by its Public Relations Officer Mrs. Betty Kyakuwa. Further details about media coverage are discussed subsequently. Extracts from my field diary give a flavour of the reception:

“At about 4pm after delivering a report about the key findings of the project and responding to observations, comments, and questions from seemingly enthralled audience, I requested the Dean of school of Fine Art to make a few remarks about the event and to invite the guest of honour - HIV activist and CEO of NGEN+, Retired Major Rubaramira Ruranga to officially declare the exhibition open. “After delivering his speech at about 6pm, the guest of honour handed certificate to the respective research participants. He thanked the participants for having accepted to take part in the project whose agenda is youth-centred and demonstrated it by potentially in helping them become their own agents through confidence building, open dialoguing, and shared creativity to generate objects that could positively impact them and their communities towards tackling HIV/AIDS and its attendant problems. He opened the exhibition to the public at exactly 5pm and all the attendees were ushered into the gallery space where they signed into the visitor’s book and were guided through the exhibit by myself with the help of the gallery assistant.” The reception event was also graced by the Vice Chancellor, Makerere University, Professor Josephine Nabukenya and other notable individuals from various health and academic organisations. Since the exhibition space was in the same area within the gallery, the attendee easily walked through to see the exhibits as I accompanied the guest of honour and a few other guests while explain details about different artworks. After about 30 minutes, I conducted some formal interviews with some guests and the day’s function ended at about 8 pm”

(Field diary, exhibition event, Makerere art gallery, 4<sup>th</sup> January 2021).

Diverse members of the audience seemed to recognise the level of success of the dissemination event as a well-attended function, demonstrating the value of the project to the community and engendering practical collaborations with young people towards dealing with their own health and the economic precarities they face in peri-urban spaces.

According to the Director of Makerere University Institute for Heritage, Conservation and Restoration (MIHCR):

“The exhibited artworks are an unequivocal statement about the place and power of the youth in determining their own destiny and the survival of the marginalized informal communities in the context of epidemics like HIV/AIDS”

(Formal interview, audience reception event/exhibition, Professor George Kyeyune, Director, MIHCR, Makerere University, 4<sup>th</sup> January 2021)

Similarly, the Dean of the Margaret Trowell School of Industrial and Fine arts (MTSIFA), Dr. Kizito Maria Kasule in his speech at the opening function remarks:

“I particularly thank the researcher for inviting the communities that participated in the production of the artworks and acting as a ‘voice for the voiceless’ for the young people in marginalised spaces in Kampala”

(Official launch of the audience reception event /exhibition, Dean’s Opening speech, Makerere University, 4<sup>th</sup> January 2021).

Both remarks clearly echo the importance of using visual approaches in towards youth engagement and inspiring them into dealing with their own marginalising experiences and collectively working to better the health and livelihood opportunities.

The guest of Honour, CEO of NGEN+, Retired Major Rubaramira Ruranga, commended young participants, some of whom were present, for their involvement in knowledge production against HIV/AIDS for the general good of other young people. Adding to the participant and researcher’s voices and visual expressions at the exhibition, he stressed that:

"There was no reason as to why people should contract HIV even if raped. The existence of post-exposure prophylaxis (PEP), an emergency treatment to prevent HIV after exposure, has given us a second chance to live. This treatment is given before 72 hours after exposure or rape. In the urban centres, HIV increase has been attributed to a number of factors, including, poverty, illiteracy, ignorance, a thriving commercial sex industry and lack of knowledge of matters relating to the spread of HIV. I condemned people who hide the fact that they have HIV and end up infecting their partners. I have never infected my wife despite having 6 children with her after I was diagnosed with HIV. I attribute this to having knowledge and information about the disease. Please make sure the HIV awareness workshops reach the rural communities”

(Official Speech, audience reception event / exhibition, Retired major general Rubaramira Ruranga, 4<sup>th</sup> January 2021)

His remark connects well with the testimonies about the worrying levels of HIV infections among the youth and the need to provide more knowledge and information, and positive messages about the disease as shared by the participants during the creativity workshops.

During a formal interview with the Major General, he referred to one of the HIV benches which depicted an image of the diseased genitalia. He observed that:

“The image of the male genital parts with sores I have seen on that bench prominently portrays a metaphoric concept, as the participants appeared to portray a twofold prototype of good versus bad conscience about HIV/AIDS epidemic. The bad conscious represented the HIV virus as deadly represented by the Imagery of herpes, Whilst the good conscious represented the aesthetics of resilience and visual humour and functional enrichment -utility of benches as sitting objects”.

(Interview, audience reception event/ exhibition, Retired major general Rubaramira Ruranga, 4<sup>th</sup> January 2021)

While concluding his presentation, the chief guest stressed the need to take the project to the rural areas as HIV/AIDs is reported to be talking its toll on the youth in these areas:

“I hereby call on researchers to expand this project to the countryside to help the rural youth who are facing the unprecedented level of HIV infection as reported in the media today”

(Closing remarks, reception event/exhibition, Retired Major general Rubaramira Ruranga, 4<sup>th</sup> January 2021)

His remarks echo similar comments by several other event participants who visited the exhibition and after the launch. For example:

“This projects seem to have focused more on engagement the youth in meaningful creative workshops against HIV in Kampala, yet many are rotting in the upcountry rural locations are face with similar marginalizing experiences related to joblessness, limited learning opportunities, lack of health-enabling information and other factors that allow HIV/AIDS to flourish in their spaces”

(Interview, Research and Administration Assistant, BAYLOR Uganda, 5<sup>th</sup> January 2021).

“The research shows great potential in educating young people about the scourge among the young people but one wonder why many of the creative and health project are concentrated urban Kampala when youth on rural areas are grossly suffering from the growing risks associated with the HIV infections – stigma, lack of vital reproductive health information and lack of skills which affects their livelihood potential, so on”

(Comments, visitor’s book, Exhibition event, male visitor from MTSIFA, Makerere University, 12<sup>th</sup> January 2021)

This clearly suggests there is a need for further inquiry into the possibilities of extending participatory engagements to the young people in the countryside beyond the urban settings (see Chapter 8). As already noted, many youth have left villages to look for livelihood



opportunities in Kampala, often having lost loved ones to the epidemic in their villages. Having explored the experiences and feedback from engagement with the public in the first formal event at Makerere university, I now turn to the second formal audience reception event that was staged in TASO Mulago, Kampala.

### **7.3.2 Mulago Hospital, TASO Uganda Offices**

“When I look at the artworks you realise how amazing it can be to move away from paperwork routines to using objects that communicate volumes of messages about HIV prevention”

(Opening speech, Reception exhibition, TASO manager, Mulago, 17<sup>th</sup> February 2021)

The second formal event for reception of the study findings was held on the 17<sup>th</sup> of March 2021 and organised in collaboration with TASO at their offices in Mulago, Kampala. The was attended by among others, the Executive Director of TASO Uganda, the Centre manager of TASO Mulago, Mr. Nkabala Robert, HIV/AIDS peer-group leaders, management, and staff from TASO, clinical officers from Mulago hospital, interns, well-wishes, members of the medical fraternity in Mulago hospital, students, and other support staff at Mulago. The purpose of taking this exhibition to TASO, Mulago was to enable them as providers of HIV treatment and testing services in Uganda and other health professional outside academia and those attached to local communities to make sense of the findings in their own context, but also to evoke and sustain conversations around participatory art and applied sculpture as a social practice that could potentially enhance HIV intervention programming.

As at Makerere University, this reception event was organised as a two-phase process. First, it involved presenting the project findings via PowerPoint, followed by a fifteen-minute breakfast interlude to allow the event participants to ask questions and give their feedback about the report and project in general. Second, the presentation was supported by an open exhibition of all the artworks arranged in three moderately sized tents (approximately 14sq.feet) provided by TASO. The first two tents accommodated HIV/AIDS awareness and prevention artworks while the third housed the Covid-19 pieces. All the artworks were accompanied with written caption and posters showing the processes of production with the project participants and messages contained in the respective artworks. The display of artworks and ushering of visitors at the event was done with help of two community health workers (CHWs) from

Lungujja (LUCOHECO) together with the five volunteers who were part of the research participants from Bwaise study area. Mulago being proximal to Bwaise, it was easier for these participants to travel to the venue on time. Meanwhile, at the TASO offices where the event was organised, a big banner was placed at their main entrance a week before the event to publicise the dissemination exhibition as a potentially important function to the TASO community, Mulago hospital, local workers, clients of TASO Uganda and the general public in and around Mulago area. The occasion was graced by over 50 attendees who signed the visitors book that was provided by TASO. These included the top administrative staff of TASO, student interns, medical personnel from Mulago hospital, support staff, security officers from Mulago, friends, research participants, clients from the TASO HIV clinic, community health workers from LUCOHECO (Lungujja) and media representatives.

While presenting the findings report, I occasionally referred to the displayed artworks which were very close by in the open tents at the TASO centre:

“Soon after presenting the finding at approx. 11am, 17<sup>th</sup> February 2020, I requested the centre manager TASO who coordinated the event to make a few remarks and later officially invited the chief guest - The Director General of TASO Uganda, Dr Ekomoloit Micheal, to address the event participants. Given that the reporting session was scheduled to last only 30 minutes, the attendees were allowed about ten minutes to ask questions. Thereafter, the centre manager aptly called the chief guest who, after a few positive remarks, declared the exhibition open to the public. While guiding them through the exhibition tents, it took me over 30 minutes to explain all the exhibits (e.g., See *Plate 66*). Soon after, I conducted the first interview with the chief guest before he could leave, and later with the four staff from TASO, 3 HIV clients from the TASO clinic and a few notable individuals who walked by to visit the exhibition during the day walking

(Field diary, Exhibition Day, 17<sup>th</sup> February 2020)

#### **7.3.2.1. Feedback from the Mulago reception event**

Messages about HIV/AIDS prevention and treatment inscribed on objects used in everyday life were the centre of attraction for the attendees at the exhibition event at TASO Mulago. They identified with the concerns raised in the artworks as they closely echoed the those they pass

to their clients on treatment and outreach places across the country. According to the Chief executive Director of TASO Uganda:

“This exhibition showcases a variety of artworks, but in particular the HIV benches which clearly demonstrate their effectiveness in relaying awareness and prevention messages for local communities especially in busy trading centres where young people usually gather.” They supposedly stimulate the youth on their sex life. Phrases such as ‘Be Faithful’ and ‘AIDS Disrupts Your Future’ are powerful messages that invoke the critical consciousness about protecting our lives from HIV”

(Opening remarks, audience reception event/exhibition, TASO head offices, Mulago, Kampala, 17<sup>th</sup> February 2021)

Interestingly, several staff from TASO and the medical fraternity in Mulago hospital proposed that these benches could potentially have a significant impact if placed at distribution centres of ARVS and local health centres where many youths converge to collect their ARVs, for testing and other medical reasons. A member of staff proposed that:

“These HIV benches are very explicit about conveying preventative messages to the youth. They could be idea to mass produce them for use at our drug distribution centres in the different regions in Uganda” Since these centre re convergency point many young people it would be very helpful to engage them to raise more awareness about the disease”

(Interview, audience reception event, Drug distribution coordinator, TASO, 18<sup>th</sup> February 2021)

In reference to the exhibition, the centre manager TASO, Mr Nkabala Robert informed the audience how visual arts, and the evidence-based findings of the research, have demonstrated their potential in combating the public health threat of HIV/AIDS in Sub-Saharan Africa through stimulating and sustaining dialogue and conversation about HIV and its attendant problems in Kampala’s marginalised urban settings such as Bwaise, Katwe, and Ndeeba. Similarly, many attendees voiced their support for using creative approaches in tackling the ever-changing situations surrounding the AIDS epidemic in grassroots contexts. They pointed out the importance and impact of visual modes such as those exhibited to the public in invoking conversations about culturally sensitive issues such as sex, HIV/AIDS, and other gender-based injustices arising from culturally affirmed practices among male dominated communities, including industrial artisan communities.

## 7.4 OUTCOMES OF THE RECEPTION EVENTS

“We have been used to IEC materials and fliers with public literacy challenges; We also realised that most young people in the peri-urban artisanal spaces have not been fully reached and actually there are confessions that many of them are not well learned and therefore take time to contextualize and understand issues to do with HIV prevention”

(Formal Interview, TASO manager, Mulago, 17<sup>th</sup> February 2021)

There were several significant outcomes in form of observations and feedback from the audience reception events:

- (i) The interviews suggest that in all the three-audience reception of findings events – Ndeeba, Makerere University and Mulago, attendees/event participants were impressed with the novelty and possibilities of the project, particularly in terms of education, raising awareness and facilitating open discussions among young people. Attendees observed that such exhibition events would be meaningful if taken back to all communities where the artworks were produced and other parts of the rural countryside to further raise awareness and support young people out of precarious situations.
- (ii) All the research participants from the different study sites were given certificates of recognition during the launch of the HIV/AIDS artworks exhibition at Makerere University in recognition of their role as knowledge contributors to the participatory project. As already mentioned, the certificates were awarded by the guest of honour in the presence of the Vice Chancellor of Makerere University at the inaugural exhibition at Makerere university art gallery. These certificates were meant to help the research participants appreciate their contribution and engender further social engagement with their communities by boosting their confidence as knowledge producers about HIV awareness and informal livelihoods in urban areas. Certificates are intended to empower them to acknowledge their potential in helping others and their society to tackle challenges associate with their wellbeing and livelihoods. As one of the recipients confessed:

“This certificate makes me feel recognised and encouraged to do more about helping other young people in our community to learn about the importance of HIV prevention as well as participating in health-enhancing activities and creative practice to better their health and wellbeing”

(Formal interview, research participant, reception event, Makerere art gallery, 4<sup>th</sup> January 2020)

Exhibition feedback also suggests that policy-makers and practitioners were keen to see the project expanded and developed as part of a “sustainable creative solution to HIV/AIDS among the youth”. Indeed, some stakeholders pointed out that:

“I see that marginalised youth benefiting more from this project in terms of skills development especially in improving their crafting business which implies bettering their livelihoods and in turn be able to avoid situations of financial difficulty that might lead to behaviours that put their lives at risk of getting infected.

(Interview, TASO official, 17<sup>th</sup> March 2021)

“This project tends to provide the much-desired platform for open dialogue which is stimulated and facilitated by the artworks created through collaborative engagement of young people. The messages contained in these artworks can inspire straight-talk conversations about the disease which I believe advances the agenda of free expression that could help tackle stigma and discrimination associated with it”

(Interview, audience reception event, medical doctor, Mulago hospital 18<sup>th</sup> February 2021)

“You obviously understand TASO very well and you know the history and the context of HIV epidemic in this country. Given that knowledge, what can TASO do in light of your work with young people and how can that enhance the work that TASO is doing?”

(Interview, audience reception event, TASO executive Director, Mulago, 17<sup>th</sup> February 2021)

This clearly indicates the potential interest that the project generated among the key stakeholders such as NGEN+, and TASO noted that this project is particularly relevant in helping to diversify strategies for fighting HIV by incorporating applied artistic methods/approaches with the existing approaches or to create policy alternatives to encourage youth engagement, develop preventive knowledge, dissemination, and dialogue in the context of HIV/AIDS and informality. In responding to the question raised by the executive director of TASO, I proposed that the works created with the young people could be taken around the country (as a

travelling exhibition) as exhibits for raising more awareness in upcountry locations where TASO could co-ordinate the process furthering awareness activities in rural communities. Several other suggestions were forthcoming:

“Most of these artworks, especially the benches and bikes, can be reproduced in multiple numbers at a cheap cost with support from local NGOs for distribution in centres where many people converge such as markets, schools, hospital, and so on, to further engender HIV/AIDS awareness and health-enhancing information (sex education) and with other preventative benefits to the diverse audiences”

(Interview, audience reception event, HIV/AIDS counsellor, TASO, Mulago Kampala, 18<sup>th</sup> February 2021).

The HIV benches, in particular, are a more compelling display than other artworks and they seem to easily relay HIV prevention strategies to grassroots communities - market places, social centres, where locals gather for leisure in trading centres since it assimilated favourably (in form of everyday objects). I strongly suggest taking the HIV benches to other workplaces such as garages, markets, schools and so on, as a way of communicating about HIV prevention to the youth and the general public.

(Informal conversation, exhibition event, Centre manager, TASO, Mulago)

(iii) Media attention and open publicity (see, for example *Plate 72*): The presence of the news media representatives and freelance journalists gave publicity to the important contributions that young people can make as knowledge producers regarding HIV/AIDS awareness, prevention, and empowerment. Press coverage and reporting of the exhibition provides evidence of how well it was received and what the audience took from it. Examples include articles published about the events through:

(i) Daily Monitor Newspaper/publications by Denis Nsubuga, (<http://www.monitor.co.ug/uganda/magazines/life/artistic-twist-to-hiv-awareness-3300138>),

(ii) The Makerere Public Relations Office by Betty Kyakuwa (<https://cedat.mak.ac.ug/wp-content/uploads/2021/09/Jan-Mar-2021-3.pdf>), and

(iii) The Independent publications by Dominic Muwanguzi (<https://www.independent.co.ug/adoption-of-visual-arts-in-the-fight-against-hiv-and-aids/>)

The presence of the media suggests that the publication of more information about the potential of participatory engagements through applied sculpture might help young people navigate HIV/AIDS in peri-urban informal spaces by provoking the much-desired candid conversations about the disease. I observed several journalists interviewing some of the event participants. In an interview with one journalist, a participant hinted at critical importance of this research in provoking dialogue about HIV/AIDS among young people and raising awareness among a diverse audience:

“This research has added to the demonstrated that art can be effective in breaking down the silence, taboos, enabling dialogue about sexuality and challenging HIV/AIDS stigma, with potential to change sexual behaviour among communities

(Informal conversation, Dominique Muwanguzi, The Independent, 2<sup>nd</sup> February 2021)

Similarly, the testimony given made by the CEO of NGEN+ given to one of the journalists who attended the TASO Mulago reception event has potential to have had a wider impact on encouraging people those who read the resulting article to open up about the disease:

“Talking about HIV in secrecy does not help. There is no reason why anyone should die of AIDS today. People should not hide the disease.... The Retired Major Rubaramira said, he had never infected his wife despite having 6 children with her after he was diagnosed with HIV. This he attributed to having knowledge and information about the disease.... The artworks in the exhibition such as the HIV benches have shown silence about AIDS can be broken”

(CEDAT Newsletter, Betty Kyakuwa, Makerere University press, March 2021)

These narratives also bring to the fore the role of art and, in particular, the importance of applied social sculpture in enabling open dialogue and sharing of vital information on HIV/AIDS and other health-related matters among marginalized young people in Uganda.

## 7.5 CONCLUSION

This chapter has accounted for how the findings of the study were shared with wider audiences beyond the artisan community where the artworks were produced. It has demonstrated that the feedback from the sharing process augmented the project as an important keystone in re-emphasising the growing role of art (applied social sculpture) in addressing HIV/AIDS-related concerns of vulnerable young people in informal contexts. Indeed, the reception process provided a helpful lens for advancing art as applied social practice as a potentially new pathway in confronting social economic situations that have allowed HIV/AIDS to entangle with young people's health and wellbeing. It thus plays a potentially important part in fore-grounding and sharing every-day experiences of young people and empowering them as co-producers of knowledge and participants in engendering preventive actions against pandemics (specifically HIV/AIDS and Covid-19). The scale of ambition of the participatory engagement with young people may not entirely transform behaviours and livelihoods or curb the rising rates of HIV infections among the youth, although follow up work may be needed to assess the longer-term impacts on participants and their communities. However, the events provided opportunities for feedback, inspiration, and reflections on the effectiveness of applied sculpture in supporting the young people at risk of HIV/AIDS and what they reveal in unguarded moments of personal interactions of the social realities of life and work in marginal areas of Kampala.

The audience reception event provided a useful platform for exploring and understanding responses from audiences concerning the use of applied sculpture, and also potential insights into the potential of applied sculpture for generating health-enabling and HIV/AIDS preventative benefits among young people in informal economies. Based on the various responses from the diverse dissemination participants, applied social sculpture has demonstrated its potential as an inclusive, educative, and empowering practice intended to awaken the inherent potential of young people in tackling their own social-economic challenges. It has also illustrated its capacity to help young people acquire skills that may boost their economic opportunities thereby reversing some of the social consequences resulting from health-related deficiencies (such as stigma, discrimination, etc.) and other particularities which are insufficiently addressed by other medical and social-political interventions. The artworks, mostly functional objects (or symbolic of functional objects) such as benches, bed,



and bikes, were familiar enough to enable open conversations about AIDS, thus signalling their potential in helping to breaking down social stereotypes and stigma around HIV/AIDS. The artworks showed the effectiveness of visual metaphors in sending emphatic, highly figurative but explicit, messages while evoking the much-needed conversations and feedback from diverse audiences (stakeholders, policy makers and general public) through the dissemination exhibitions. The audience reception events also gave voice to the personal experiences of the research participants and revealed something of their everyday lives to the public. Accordingly, feedback from the research and event participants, it was clear that their experiences facilitated authentic and relevant visual expressions and narratives. Applied social sculpture thus has a role both in revealing the realities of precarious and risky lives in peri-urban areas and the potential of art in finding solutions to social problems in the context of HIV/AIDS prevention.

The events also suggest that this research has contributed, albeit in a small way, to wider social, economic, biomedical, and academic scholarship intended to inculcate and encourage preventative practices and eliminate the social-economic impact of HIV/AIDS on the youth populations in marginalised urban settings. It also demonstrates that applied sculpture deserves attention as an effective approach to dealing with rising HIV/AIDS infection in social research, nationally and beyond. It provides a model for how practitioners, policymakers and related stakeholders can integrate applied art as a vehicle in the fight against the now surging number of infections among youth in the informal areas.

The next chapter provides the summary of the whole thesis and develops recommendations for future research into art for health and participatory engagement in Uganda.

## CHAPTER EIGHT

### HIV/AIDS AND YOUNG PEOPLE IN INFORMAL URBAN SPACES: SUGGESTIONS FOR WAYS FORWARD

“When serious and sustained efforts are made to ensure young people live in a supportive environment, and have the knowledge, skills and services to protect themselves, HIV rates decline”

(UNICEF, 2002, p. 23)

#### 8.0 INTRODUCTION

This thesis set out to explore the use of applied sculpture as a social practice among young people infected with/affected by HIV/AIDS in the peri-urban spaces of Kampala Uganda. Specifically, it aimed to stimulate and facilitate open communication among young people about precarious every-day experiences, harness their potential, build their confidence for self-expression, and increase their awareness of disease risk and prevention. To meet these aims, the research sought to understand the everyday experiences of these young people; to identify, articulate, and share knowledge about their everyday experiences; to engage them in participatory workshops intended to harness talents towards creating applied forms as tools of communication about HIV/AIDS awareness and its prevention whilst building capacity for social-economic empowerment; and to demonstrate, as well as advance, applied social sculpture as a potential approach for HIV/AIDS awareness and prevention among public health policy decision makers and providers of health services in Uganda. This chapter reviews the research findings and their implications for applied social sculpture in promoting HIV/AIDS awareness as well as youth empowerment. It also explores the potential of participatory research, inspired by notions of art having the capacity to move beyond the spaces of galleries into an expanded field beyond the visual and into the social (Nabulime & McEwan, 2014; L. Nabulime & McEwan, 2011), for challenging the long-standing precarious experiences among young people in the context of HIV/AIDS.

The chapter is organised into four sections. The first section summarises the research findings with regards to the research aims and questions outlined in the introductory chapter. The second section then reviews the implications of the findings in relation to the importance of

applied social sculpture as a potential platform for HIV/AIDS, awareness, prevention, and empowerment among young people in marginalized peri-urban spaces. It also briefly discusses the shortcomings of the approach in dealing with young people in the context of fighting HIV/AIDS in informal spaces. In the third section, the implications of the research findings are reviewed with a view to making some initial recommendations in relation to practice and policy programming connected to the fight against HIV/AIDS in Uganda, and beyond into wider Global South contexts in which tackling the disease remains a major development concern. Finally, the last section proposes suggestions for future research in the field of applied social sculpture, HIV/AIDS awareness, prevention, and empowerment and explains why this matters.

## **8.1 SUMMARY OF RESEARCH FINDINGS**

Addressing research question I:

The first research question concerns how young people living and working in the marginalized peri-urban spaces of Kampala encounter precarious situations in their spaces of work in the context of HIV/AIDS. In response, the research sought to examine the everyday life experiences of young people and the ways in which these interface with social economic conditions that shape the landscape in which HIV/AIDS flourishes. The findings of the participatory research project are explored at length in Chapters 4, 5 and 6 and are summarised here under five headings; (i) Exclusionary experiences emanating from the existence of the informal economy, (ii) Experiences of stigma and discrimination, (iii) Gender inequality, (iv) Urban masculinities, and (v) Challenges emerging from the collision of two pandemics: HIV/AIDS and COVID-19.

### **8.1.1 Exclusionary experiences**

The study areas involved in this participatory project were purposively selected from the peri-urban, informal economic precincts of Kampala, including, Bwaise, Ndeeba and Katwe industrial areas.<sup>98</sup> Out of necessity, the Lungujja residential neighbourhood was added to the geographical scope due the emergency of the Covid-19 (see chapter 3). These spaces provided opportunities to examine the socio-spatial geographies that have shaped the thinking, attitudes, and behaviours of young people that, in turn, create a fertile ground for the HIV/AIDS

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<sup>98</sup> Considered to be Industrial locations with diverse populations and a huge concentration of youth (young men, women, and adolescent girls) engaged in casualized forms of employment, along with a high turn-over of those looking for job opportunities on a daily basis as migrants from neighbouring areas and upcountry locations.

to flourish in Uganda. Defined by the existence of *magendo* (black markets) and *Kusamula* (speculation), the informal industrial spaces in which most young people find their means of a livelihood were reported by participants to be havens for desperate school dropouts, *abataasoma* (the non-educated). They are also spaces in which structural poverty, inadequate amenities, limited job prospects, sex work, and so on, are inextricably entangled with exclusionary experiences emanating from the existence of the informal economy. Research findings show that most of these areas are occupied by ethnically diverse groups of young people (as most participants claimed to be migrant workers from industrial neighbourhoods and upcountry locations of Uganda, such as Bundibugyo, Kasese, and Luweero) with low literacy levels, which is exacerbated by limited formal training/learning opportunities. Related to this, there is a great deal of complacency and ignorance concerning the spread of HIV/AIDS and its attendant problems. Testimonies reveal much about the conditions that favour the spread of HIV/AIDS such as *magendo*, prostitution, labour exploitation and trafficking of young women and adolescent girls for casualized employment in male dominated settings. These are some of the primary factors that are shaping the landscape in which HIV/AIDS thrives. Field evidence shows that these factors clearly entangle with the social-economic realities of the lives of young people, particularly young women and adolescent girls living, working, or searching for work opportunities, thus raising the risks of HIV infections.

### **8.1.2 Stigma, discrimination, and complacency**

Stigma and social discrimination seemed to dominate the social realities of young people in most peri-urban spaces where the research was conducted. Many of the HIV positive participants reported a long history of challenges related to being isolated, neglected and socially disconnected from their communities and families, which affected their ability to improve their own livelihoods and wellbeing. Accordingly, these experiences denied them the potential to access to health support and care and at the same time as it escalated internal stigma, directly affected wellbeing, and impeded young people's ability to practice health enhancing behaviour and control the effect of the epidemic on their lives and community. Abandonment, mistreatment, and discrimination are terms used by participants that clearly captured the effects of stigma. Findings clearly show that neglect and social isolation among young people living with and affected by HIV/AIDS propagates social stigma and exclusion,

which produces disinhibited behaviours that worsen their health conditions. Participants lacked access to full and accurate information about HIV/AIDS, its manifestations and prevention strategies, particularly, the modern self-testing oral kits and information on how to use them

Some HIV-positive participants attested that the epidemic is, in many ways, becoming more hidden with many young people lacking the knowledge and experience of how HIV ravaged communities in the 1990s, thus creating high levels of complacency. Moreover, ART means that HIV is no longer manifesting as commonly in visible bodily characteristics such as lesions, red lips, and TB-related constant coughing as it was in the past. The participatory findings also show that HIV stigma has prevented some young people, especially men, from seeking health care, fulfilling their personal/family economic obligations, and disclosing their HIV status.

### **8.1.3 Gender inequalities and economic precarity**

Notably, through conversations in the participatory workshops, it emerged that most young people, particularly young women and adolescent girls, were engulfed in a complex web of social injustices related to gender inequality. These emanate from socially constructed circumstances related to the domineering male presence in the crowded industrial spaces around Kampala. These open discussions revealed something of the ordeals of young women working in these male-dominated workspaces and provide an insight into three factors that increase the vulnerability of the women to HIV infection. First, extreme poverty forces many young women (many of whom are either semi-illiterate, school dropouts or escaping domestic violence) to find low-paying casual jobs in industrial spaces as food vendors, *bufunda* waitresses and wood sanders. Second, this economic precarity exposes them to potential sexual exploitation and abuse by young men and older counterparts who act as middlemen and bosses in these spaces. Inevitably, because many of the young women, adolescent girls are poor, desperate and lack specific employable skills, they end up in the margins of industrial occupations including, petty businesses (e.g., roadside vending, hawking merchandise, etc), gambling and sex work, which also exposes them to drugs and alcoholism, hence making them more vulnerable to the risk of HIV/AIDS infection. Third, as discussed in Chapters 4 and 5, it also emerged that many young women and adolescent girls were trafficked from upcountry

locations into industrial spaces with promises of well-paying jobs, only to end up in the hands of unscrupulous businesspeople and those associated with the sex trade.

Additionally, the stereotypes attached to sex as taboo and other critical gender issues were raised by participants as they admitted struggling to confront cultural biases which are fuelling the epidemic in their community.

#### **8.1.4 Hegemonic masculinities:**

The participatory workshops reveal evidence of young men expressing hegemonic forms of masculinity that significantly shaped the landscape in which HIV/AIDS flourishes. This form of male identity stood out as influencing dominant and dangerous social practices including promiscuity (Barker & Ricardo, 2005; Wyrod, 2011, 2016b). High levels of alcoholism were reported among several young artisans, who participants described as regular bar hoppers and socially delinquent. They habitually perform their daily tasks while consuming alcohol kept in their pockets, which compromises their ability to make rational decisions leading to engaging with sex workers and/or casual sexual encounters with several young women without protection or prior testing for HIV. The sexual exploitation of women by young men is fuelled by masculine ideals of objectifying women and self-gratifying attitudes, which manifest as culturally affirmative practices, and the presence of high numbers of vulnerable young women and adolescent girls who fall victim as a result of unfavourable social-cultural realities of living and working in informal economic spaces. Participants also admitted to engaging in reckless sexual encounters as a source of sexual gratification while harbouring misogynist perceptions of women as sexual objects. In particular, most participants talked about how they and other young men showed intimidating traits of toughness, lack of emotions, physical strength, and competition amongst themselves and confessed to using misogynistic language to refer to young women in their workspaces. The ultimate consequence of their actions is their involvement in reckless social and sexual behaviour leading to rising rates of HIV infections, while at the same time blaming women and adolescent girls for spreading HIV virus among young men.

Findings also indicate that most adolescent and young men are inclined to the belief that they are old enough to make informed decisions about sex and their health. Incidentally, on the 26<sup>th</sup> of February 2020, I had the opportunity to travel to Arua in west Nile region of Uganda to

volunteer with the installation support team for the travelling exhibition for HIV/AIDS organised by the Institute of Infectious Diseases (IDI), Academy for Health Innovations, Makerere University. One of the reasons was to generate information from respondents who would view the exhibited materials

In Arua, adolescent boys described themselves as grown-ups - *Ambabo*- a Lugbara word meaning “I am mature, and I can do anything”. They argued that HIV is a *Malarya*, another Lugbara word meaning “it no longer kills”, less fatal because of new biomedical interventions, particularly ARVs, which are available in most health centres across the country. Knowledge of the fact that young people who test positive to HIV are put on treatment, which prolongs their life expectancy if ARVs are adhered to well, ironically seems to be fuelling complacency among young people.

### **8.1.5 The significance of two colliding pandemics**

Much as the conditions for the spread of HIV have been worsened by the Covid-19 pandemic, there are similarities in the utility of social sculpture in raising awareness and tackling the spread of both diseases. During the lockdown in Kampala, participants attested to having been very badly affected by the enforcement of preventive measures which included; (i) geographical containment and creation and management of testing centres with the quarantining of those suspected of having Covid; (ii) home confinement and curfews mandated through the enforcement of the presidential directives barring passenger movement across the country; (iii) the prohibition of gatherings and the closure of establishments and/or premises (Ahabwe, 2020). Young people, particularly those infected with HIV in the informal urban spaces could no longer reach out to their workplaces nor leave their home, hence they were left stranded. This unfortunate reality affected every single sector of the economy and also placed constraints on this research project with young people. People living with HIV/AIDS confirmed experiencing immense stress from stigmatising regulations, such as being required to seek permission to secure vehicles to collect ARVs from their respective HIV treatment centre. It also emerged that even at community level, HIV treatment activities were suspended in order to shield patients from Covid-19 infections. For instance, on the 2<sup>nd</sup> of May 2020 – an article by Dr. Joshua Musinguzi, the head of the HIV/AIDS programme at the Ministry of Health, in the *New Vision* newspaper confirmed the suspension of some HIV services like testing

activities countrywide and circumcision. This clearly meant that new HIV infections were likely to rise and those in need for free testing services were left on their own since most of the medical supply points such as pharmacies were limited and out of supplies to sustain the demand for self-testing kits.

At this time, there were growing reports of rises in cases of gender-based violence (Achan, 2020; Delaleu, 2020; Masinde, 2020), with participants affirming that the Covid-19 restrictions (travel bans and stay-home directives) continued to confine the victims (young women and adolescent girls) in closed spaces with the perpetrators of violence, exposing them to higher incidents of rape, physical abuse, sexual assault, incest and so on. This has raised concerns of a rise in HIV infections during the lockdown periods in Uganda, although evidence has yet to be gathered to substantiate these claims.

## **8.2 VALUE OF APPLIED SOCIAL SCULPTURE**

### **8.2.1 “Stimulating discussion, tackling stigma, and raising awareness”**

Addressing Research Question II:

Findings from field engagements with young people in Kampala have attempted to demonstrate that participatory art (applied social sculpture) is a potent tool in stimulating and facilitating candid conversations about HIV/AIDS and creating awareness of critical social issues in the peri-urban/informal communities where opportunities for formal education are severely limited. The co-produced artworks, inspired and informed by stories and every day experiences of young people in marginalized informal spaces for the dissemination exhibition on HIV/AIDS, echo this reality, augmenting the idea of collective youth engagement within the context of HIV/AIDS awareness and prevention and empowerment in Uganda. In this collaborative enterprise, the participatory design and making of objects such as HIV benches and Covid bikes sought to raise questions and provide answers about key issues that surround the disease, such as discrimination and stigma, taboos about sex, masculine ideals of sexism, misogyny, and social-cultural stereotypes. Clearly, the empirical field evidence shows that the integrated application of ethnographic methods (participant observation, photography field notetaking, etc.) and applied artistic processes (modelling, carving, engraving, burnishing, wood joinery, etc.) ignited and sustained an open conversation about the pandemics (HIV/AIDS and Covid-



19). This resulted into the co-creation of familiar everyday objects – benches, bicycles, houses, etc. – that can be potentially effective in reducing the impacts of disease among young populations in marginalized peri-urban geographies and beyond. The participatory workshops were concerned with art, creativity, HIV/AIDS awareness, and prevention, and suggest that participants were strongly motivated to further protect themselves and their partners from against infection and encouraged those who are already infected to maintain their drug adherence and health enabling practices and take measures to protect their partners.

Applied social sculpture has shown its vitality in evoking personal narratives and inspiring the design of artworks intended to reshape young people's perceptions about the HIV/AIDS epidemic and how it can be prevented. This has been achieved through a number of ways, including building confidence, encouraging self-expression, capacity building through creative activity and co-production, skills acquisition/development, collective knowledge production, integrated with the ethnographic documentation of narratives, stories and other every-day social experiences related to HIV/AIDS in informal contexts (see chapters 4, 5, and 6). All the artworks that were produced for the public exhibition and engagement echoed the need to engage young people and their communities in the fight against the disease, which resonates with the second and third research questions. Evidently, the participatory process and applied sculptures explored a critical aspect in the fight against the disease, which is fostering a collaborative approach to inform and engender better policies and programming for the youth by government and other providers of health and HIV information services in the country. The co-produced artworks stimulated further discussions and invaluable feedback about their potential role in breaking down the social stereotypes and stigma surrounding the disease at the dissemination events. Shortcomings notwithstanding, applied social sculpture has tried to provide empirically grounded responses from the young participants about tackling HIV/AIDS, backed by results from the dissemination exhibition process as explored in the previous chapter.

### **8.2.2 Limitations**

Despite the successes in encouraging dialogue about sex, disease, and behaviours, as well as building skills and confidence as evident from the participatory engagement with the young people, several limitations were recognized and warrant some attention.

(i) Cognitive challenges: The first noticeable concern about working and sharing with young people in the informal spaces was the fact that many of them were school dropouts and poorly educated. Research participants sometimes struggled with the difficulty of writing down their personal experiences and stories during the creativity workshops. Not only did this affect their ability to fully share their experiences/ideas, but also significantly retarded the process of illustrating the concepts for execution in final materials as artworks. To navigate this challenge, participants were grouped in accordance with artistic ability and literacy levels to support each other in sharing stories, ideas, and skills, thus, learning in the process.

(ii) Another contextual factor that affected the efficacy of applied artistic approach was occasional low participant motivation because the compensation I was able to offer them was not commensurate to the opportunity cost incurred through leaving their daily artisanal work to attend. Attempts to provide working kits during the workshop and giving them simple hand tools (such as saws, cutters, planers) and PPE equipment (such as masks, overalls, gloves) after the workshops seemed insufficient to encourage total commitment to the creative workshops. Several participants were regularly engaged in private wood finishing tasks, which led to inconsistencies in attendance and completion of the group tasks during the creative workshops.

(iii) There were sometimes low levels of concentration among artisan youth who were often torn between finding job opportunities and participating in the workshops. As most jobs in these industrial spaces are casualized and unreliable, most youth tended to be mobile in searching for work opportunities while others would multitask in order to boost their day's earnings. This consequently affected the number of young people willing to participate in the workshops and those who did could sometimes only attend for two hours. Clearly, this accounts for the several instances of absenteeism and low motivation due to work-related stress and other pressures related to their personal welfare. This was despite compensating those who consented to fully participate in the workshops with provision of breakfast or lunch and transport costs.

(iv) The timescale of the project meant that it was impossible to gauge its impacts on both the attitudes and behaviour of participants, and on wider social impacts on young people living

and working in informal industrial areas. Similarly, the scale of ambition of the participatory engagement with young people means that there are limitations in what it could achieve in transforming behaviours and livelihoods or curbing the rising rates of HIV infections among the youth. However, as the feedback from dissemination events (discussed in Chapter 7) suggest, there is evidence of participatory social sculpture having potential to inspire discussion of taboo subjects, which may have positive effects. Moreover, the project has brought to the foreground the effectiveness of applied sculpture in highlighting the need to support young people at risk of HIV/AIDS. While limited in scale and scope, by examining what young people reveal in unguarded moments of personal interactions of the social realities of life and work in marginal areas of Kampala the project also highlights the need for follow up work to assess the longer-term impacts on participants, as well as the potential benefits of this kind of participatory research with other young people living precarious lives.

### **8.3 PROPOSED POLICY RECOMMENDATIONS**

In response to the third research question informing this participatory project, the following recommendations have been proposed in relation to the national HIV/AIDS policy strategies in Uganda: (i) broadening the key population boundaries of at risk groups to include young people; (ii) furtherance of marginalised youth engagement for HIV/AIDS prevention and awareness through applied social sculpture; and (iii) future directions for collaborative scholarships in creative practice for HIV prevention and awareness.

#### **8.3.1 Broadening of the definitive boundaries of key populations to build an inclusive youth HIV/AIDS intervention strategy**

Although Uganda's HIV epidemic is generalized as affecting all population groups, there are key populations that are more susceptible because they are in more precarious situations that put them at a higher risk of HIV infection (UAC, 2016). The definition advanced by the Ministry of Health regarding key at-risk populations conspicuously excludes vulnerable young people working in informal areas of the economy, yet they are also disproportionately at risk of HIV/AIDS in Uganda.

Research on the demographics and dynamics of the epidemic among young people is needed to guide appropriate future actions, interventions, and support. Otherwise, if left unattended,

rising infection rates among this group are likely to create a significant dent in efforts to turn the tide against new infections in the urban communities in the country. As already mentioned, the Uganda national HIV prevention strategy as designed and implemented under the Ministry of Health pays significant attention to only five major categories of people described as key populations. They include (i) Sex workers and their partners),<sup>99</sup> (ii) Fisher folks/fishing communities,<sup>100</sup> (iii) Uniformed services<sup>101</sup> e.g., armed forces (UPDF), the Uganda Police, Prisons, etc., (iv) Long distance truckers<sup>102</sup> and (v) Injecting drug-users (IDU) and Men who have Sex with Men (MSM) (Ministry of Health, 2011; UAC, 2011). This list excludes the critically vulnerable young people working and living in peri-urban industrial settlements in the fringes of major cities like of Kampala, yet they typically share, more or less, similar levels of precarity that generate risk and allow HIV to flourish.

It is particularly important to point out that whereas the national HIV prevention strategic policy sets clear milestones to realise its main objectives,<sup>103</sup> there remain several gaps in the coverage and comprehensive implementation of its mandate to ensure a population that is free from HIV, to contribute to the ambitious global targets of end HIV related deaths, move

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<sup>99</sup> Sex workers and their clients; according to the Ministry of Health, it is estimated that sex workers, their clients and partners of their clients contribute 10% of new HIV infections in Uganda. The high HIV risk among sex workers arises from extensive multiple sexual partnerships with very complex networks involving their clients, partners of their clients and eventually bridge to the general public

<sup>100</sup> Fisher folks or fishing communities' vulnerability stems from their perceived hyper-masculinity norms and sub-cultures of risk-taking. Fisher men are often detached from their families for long periods and have little appreciation of marriage and fidelity. They tend to have daily cash incomes-high liquidity – they use for commercial sex and casual sexual relationships. Their fishing/landing sites also attract sex workers while their health-seeking behaviours are very poor. Also compare (Macpherson et al., 2020; Mafigiri et al., 2017)

<sup>101</sup> Uniformed services, who include people in armed forces such as Uganda people's defence forces, the Uganda Police, and prisons, are often subject to deployments away from their homes and places which are not adequately reached by essential health services. Wages are often wasted on alcohol consumption and casual sex, which increases their susceptibility to HIV infections (UAC, 2011).

<sup>102</sup> Long distance truckers continue to constitute a special group of mobile men with money that often-spread HIV through engagements with multiple partners along major transit routes. While information about men who have sex with men (MSM) and those who inject drugs (IDUs) remains scant, it is claimed that these risks exist widely in the different parts of the country (UAC, 2011).

<sup>103</sup> There are five objectives set by the Ministry of Health towards attaining maximum benefit of its national HIV and AIDS prevention policy. They include (i) To increase adoption of safer sexual behaviours and reduce risk-taking behaviours (ii) To expand to critical coverage and utilization of biomedical prevention interventions, (iii) To create a sustainable enabling environment that mitigates the underlying socio-cultural and structural barriers of the epidemic, (iv) To achieve more coordinated HIV prevention response and (v) To strengthen information systems for HIV prevention at all levels (UAC, 2015).

towards zero new HIV infections, and eradicate stigma and discrimination by 2030 (Doshi et al., 2018; UNAIDS, 2020c). This research project is, in part, a scholarly contribution towards exploring the potential of applied artistic practice in strengthening and complementing the Ugandan Ministry of Health's existing strategies towards realising full attainment of its national HIV prevention strategic objectives. Mounting evidence in social science research (Tukundane & Zeelen, 2015) shows that the Ugandan youth have embraced awareness and prevention campaigns, yet statistics continue to show that young people remain one of the most vulnerable groups. Studies from UNAIDS (UNAIDS, 2014, 2017, 2020c) and TASO also point to this. Importantly, several challenges related to social economic disparities causing the rising HIV infections among the youth in this research illustrate that there are gaps in the awareness campaigns, specifically at the grassroots level in informal spaces where marginalised youth largely inhabit. The youth are largely to be found living and working in the poor suburbs of Katwe, Kalerwe, Nassana, Nakulabye and Ndeeba. This study has shown that they urgently need a medium they are familiar with to engage them in discussion of the respective challenges they face in their day-to-day life, especially within the context of HIV/ AIDS. Participatory sculpture workshops provided this familiarity and enabled the circumvention of taboos to promote discussion of sex and HIV. The exhibition of the everyday objects created as artworks in these participatory workshops to wider Ugandan audiences proved to be an effective method for drawing attention to vulnerable youth and proposing responses for strengthening efforts towards eradicating HIV/AIDS in the country and beyond – in line with the current national strategic policy of involving young people in the HIV programmes (UAC, 2017). The research has demonstrated that despite the shifts in the rates of HIV infections and gaps in the interventions (Management Science for Health, 2017; UAC, 2020), there is still an urgent need for young people to remain a priority target in the new National HIV/AIDS Strategic Plans.

### **8.3.2 Proposed furtherance of engagement applied social sculpture with communities, NGOs, and policy makers.**

The National policy on HIV/AIDS (Uganda Aids Commission, 2017) in Uganda provides several Guiding Principles for policy implementations which include: non-discrimination, confidentiality, promotion of prevention, testing treatment care and support, greater involvement of people living with HIV/AIDS, and gender concerns at work. With the primary

goal of the policy being to prevent further spread of HIV and the mitigation of the social-economic impact of the epidemic in the world of work, creative participatory research becomes an important platform for realising the desired impact especially among key populations in the country. Specifically, as this research has shown, it (i) helps in bringing young people together to share, learn and talk about their experiences which, in turn, enables them to develop better ways of expressing themselves. This provides a starting point towards tackling the stigma and other precarious experiences in their social spaces; (ii) enables young people to acquire creative skills with both preventative and livelihood benefits. I envisage greater advantages in directly liaising with HIV parent organisations such as the Uganda AIDS commission (UAC) and other non-governmental organisations such as TASO, Mildmay and others in advancing improved health programmes across the country while focusing on HIV prevention and empowerment among vulnerable young people. I, therefore, propose the following.

There is a need for collaborative engagement with medical professionals. I suggest that building collaborative links among artists, local artisans, and health experts in HIV/AIDS is important in the present context of intervention programmes in Uganda. Liaising with health professionals around HIV/AIDS during the participatory workshops was not possible, which left several questions unanswered and information gaps in the whole process of transformation for better health decision and wellbeing among the participants. By design, the project was intended to explore possibilities of building creative synergies with young people towards tackling their own problems, but there is a need to further develop close collaborative links with health experts to realise the full potential of visual approaches in transforming young lives in both rural and urban informal spaces.

Notably, several participants would occasionally raise medical questions which needed the intervention from relevant HIV experts who could readily provide answers to participants. For better results perhaps, health experts in HIV/AIDS programming and information need to work with visual artists (applied sculptors) to deliver impactful mutual health and livelihood benefits to the participants in research projects involving grassroots communities. This also may necessitate linking applied social sculpture to health outreach activities with medical support teams (including doctors, counsellors, community health workers (CHWs), also known as

village health teams (VHTs), etc.) to counter the likelihood of misinformation. This would involve, for example, providing accurate information about innovations such as oral HIV self-testing kits, and challenging discrimination and stigma. As the findings of this project reveal, community health workers (CHWs), played a vital role in identifying potential HIV positive participants and supporting the participatory workshops. Therefore, I recommend comprehensive HIV prevention collaborative campaigns involving teams of volunteers in the visual arts, medical experts/practitioners, and local community-based organisations to synergise efforts towards supporting the youth overcome the twin challenges of informality and HIV/AIDS. Most importantly, this should be done in complementary ways that boost existing programmes initiated by government and NGOs in the country. This research has also demonstrated that applied social sculpture has the potential to bring young people together and to open up spaces for conversation, especially on critical health and social issues, which paves the way for medical interventions and responses. With a wealth of scholarly evidence attesting to the value of artistic processes in exploring complex social and health issues, we ought to acknowledge, for instance, that;

“The act of making, in and of itself, should also not be underestimated as a technique for enabling difficult conversations and disclosures, which might otherwise be too painful to articulate”

(Coombes, 2019, p. 147)

Indeed, this participatory study has demonstrated its capacity in provoking honest conversations, countering silence, discussing AIDS-related social injustices, and navigating young people’s every day experiences of encountering stigma and other barriers to prevention and awareness. Additionally, in more specific terms, partnering with local NGOs such as NGEN+, TASO, UNYPA<sup>104</sup>, would enable promotion of collaborative activities to design HIV benches or bikes as pedagogic tools that can be cheaply mass-produced and widely distributed to disseminate HIV prevention messages. Such artworks can help relay information regarding

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<sup>104</sup> Uganda Network of young people living with HIV & AIDS (UNYPA) is a youth HIV organisation in Uganda started in 2003 to provide leadership and coordinate the greater and meaningful involvement and participation of YPLHIV in Uganda in the national, regional, and global HIV and AIDS response. UNYPA advocates improving the quality of life of young people living with HIV in Uganda and as a network. UNYPA is driven by the needs of young people living with HIV and implements an evidence informed national programme and advocacy for YPLHIV to lead healthy and productive lives (<https://unypa.org/>).

adherence and compliance with complex drug regimes; they could also encourage the youth to acquire creative skills, practice safe sex, change their attitudes towards better health and wellbeing, and engage in other livelihood-enhancing practices.

#### **8.4 AREAS FOR FUTURE INQUIRY**

There are several study areas that have been identified as potential ends for further research having been recognised as issues that need special attention. These include; (i) Analysis of why men blame women for the spread of AIDS (ii) Future directions for art-geography collaborations in health-related research and (iii) Longer-term impacts of applied social sculpture on young people's incomes, their crafting skills, and promoting behavioural change.

##### **8.4.1 Further research into assumptions about why young men blame women for the spread of HIV/AIDS**

Having identified far-ranging critical social issues affecting young people in informal spaces, and specifically, the masculine ideals of misogyny, there is a need to further interrogate circumstances in which these masculine perceptions arise and synchronize the long-standing strategies of dealing with the epidemic in urban settings. As this research reveals, because of high levels of alcoholism, multiple sexual relationships and other masculine ideals/perceptions, young men are inclined to claim that women provoke them into risky sexual behaviours and encounters, especially when they get drunk. This also manifests as strongly prejudiced against women, even misogynistic, in blaming them for the spread of HIV/AIDS, yet men are deemed primary actors in its transmission. Since these assumptions were not explored in depth nor substantiated during participatory interactions with young people, it remained speculative and unfounded as one of the key factors for increased HIV transmissions in informal spaces. It is against this background that qualitative action research is needed to explore and tackle such misogyny perpetrated among young men in informal communities. This is a form of social injustice arising from the masculine ideals of sexuality and the perceptions of manliness where young men intentionally participate in unprotected sex and pass the blame to women. Reducing infection rates will be difficult unless this misogyny and disinformation is tackled through education and training.



#### 8.4.2 Future directions for art-geography collaboration in health-related research

This research has argued for the importance of creative visual practices and multidisciplinary scholarship that brings together theories and practice of geography, anthropology, and the expanded field of social sculpture in addressing issues related to critical spatialities, health and participation in developing contexts. The project enabled fusion of methodological approaches, including a range of applied artistic practices and ethnographic methods and involving interpretation of narratives and the analysis of co-produced artworks (described as ‘doings’ by social geographers such as Hawkins and Holloway 2019). It could be argued that:

“The ‘expanded field’ of geographic knowledge-making now takes in creative practitioners<sup>105</sup>, seeing their creative practices as part of the ‘doing’ of geography. While geographers are becoming makers and collaborators, creative practitioners are undertaking geography PhDs, and geography is developing an increasingly diverse methodological tool-kit of creative research practices”

(Hawkins & Holloway, 2019, p. 963)

Using applied social sculpture confirms the importance of the furthering collaborative research that can contribute significantly to open conversation about critical social issues affecting society beyond health and cultural geographies of young people and inadequately served communities. Within geography, the creative turn pairs what have also been termed experimental and art-full geographies with a wider spatial turn within arts and humanities scholarship and practice. Different forms of the relationship between art and geography, in particular, are well documented (e.g. Watson & Till, 2010; Hawkins, 2011a; Clammer, 2014).

This research, therefore, adds to the growing body of creative collaborations where artists and geographers work together, and where arts and social sciences are brought into dialogue, to “make-work, carry out research, develop social practice linking with exhibitions or practice various different creative techniques” (Hawkins, 2011, p. 465). Thus, I propose the utilization of applied sculpture for the social and creative engagement of young people, tapping into their inherent abilities, local skills, and materials to enable them to become agents and advocates for improving their livelihoods and wellbeing in the contexts of HIV/AIDS and precarity. This project has demonstrated the utility of applied social sculpture in breaking down social taboos,

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<sup>105</sup> Also see similar efforts towards tackling pandemics like Covid -19 by graffiti artist in Uganda - <https://satisfashionug.com/lumiimamawugwe-an-exhibition-by-xenson-opens-on-6th-november/>

enabling young people infected with and affected by HIV/AIDS to speak about sex and sexuality, risk factors and prevention, and the precarity of their lives that makes them vulnerable.

The artworks co-created through collaboration have an immediacy and an ability to communicate about critical social and health issues related to HIV/AIDS awareness and prevention. Co-creation provided opportunities for skills development and bettering personal skills that could have benefits for improved livelihood prospects among young people. Indeed, art and creativity, as demonstrated in this study, taps into potentially enriched ways of disseminating relevant health information pertinent to HIV prevention and awareness) to broader public audiences in three dominant formats explored in this chapter namely dissemination exhibitions, collective tasks and participatory workshops (e.g., Barry, 2019)

The primary concern in the discussion here, stems from my experiences as 'artist-geographer' emerging from my fieldwork engagements with young people, with co-creative work as inquiry, as knowledge sharing and as part of larger, multi-disciplinary research efforts towards tackling HIV/AIDS among the youth in the peri-urban settings of Kampala city. This encapsulates a hybrid space that is based in a collaborative undertaking that emphasises creative engagement with the youth through scholarship that utilises their artistic skills for social economic empowerment, but most crucially to engage them to participate in seeking solutions to their own problems (Kapoor & Jordan, 2009), particularly those related to HIV/AIDS. Additionally, their collective participation as artisans (some as expert crafts people), helped them realise their creative potential in addressing their own social and health (HIV-related) problems. This may mean that in future they will become highly sought after by others in their industrial spaces. There is thus a need to broaden support for the development of a research environment that is characterised by mutual engagement; where professional diversity, career track and role in collaborative research are valued, encouraged, and embraced; and in which equality, inclusivity and involvement of young people are seen as significant in health and cultural geographies of pandemics.

#### **8.4.3 Extra assessment of the impact of the applied social practice to the livelihoods, industrial crafting practices, behaviours, and wellbeing of young people in the informal economy**

There is need to assess the short term and long-term impact of the participatory sculpture on the livelihood, lives, and skills development of the research participants and the community in which the participatory workshops were conducted. As I noted earlier, it was impossible to make an exhaustive evaluation of the lasting benefits of acquiring new skills because of the short time I was able to stay with the groups and the industrial communities in which they operate. This perhaps calls for an added inquiry into the possible change of ways of work social engagement, attitudes, and behaviours of the young people in the context of AIDS prevention in informal spaces. While participants seemed to claim to have acquired a variety of artistic skills and preventative knowledge/information about HIV/AIDS, it still remains rather unclear as to whether they have continued to put into practice what they learnt after the project, both in terms of behaviour change and using the skills they developed. Indeed, a further review of the potential of applied social sculpture as a participatory approach to transforming lives or supporting young people for better livelihood opportunities and engendering health-enhancing behaviours ought to be put to further scrutiny for tangible and foreseeable long-term benefits, especially in light of the need to curb the spread of HIV/AIDS in the informal spheres of Kampala and beyond. Present statistics and projections suggest that AIDS will continue to increase for the foreseeable future (Bunn et al., 2020; UNAIDS, 2019). Applied social sculpture has potential for positively impacting the lives of young people, imbuing them with creative skills and knowledge for their wellbeing and health, and providing a positive additional social/health function to grassroot communities.

Further research is also needed to explore additional benefits of social sculpture, such as (i) contributing to the beautification of the environment (art as an end in itself: see for example. *Error! Reference source not found.*), (ii) providing creative, collaborative and employment opportunities to disadvantaged young people, artists, and social scientists, and (iii) in some cases turning artists into community AIDS activists (iv) making young people agents of social change in the own lives/ workspaces. Certainly, the value of applied social sculpture demonstrated in this research seems to suggest a great deal of potential in these areas.

## 8.5 CONCLUSION

The findings of this study clearly suggest that it is important to support young people to overcome informality and HIV/AIDS related challenges using participatory art as one of the engagement approaches. Here, in particular, I incline to the proposition of engendering applied sculpture as a social practice to empower them to freely express themselves, share, boldly confront, and directly participate in mitigating the socio-cultural, economic, and other contextual barriers to HIV prevention which curtail their health and wellbeing in marginalized social settings. As one scholar puts it:

Broadly speaking such a research approach is expected to produce new forms of knowledge which would not be accessible without an active engagement from participants, and which, crucially, can be used to bring about social change in some way - perhaps within the immediate research context or at a policy level. (Jupp, 2007, p. 2832)

As a ground-breaking approach, applied social sculpture is not yet well defined, researched or applied, but owing to the findings of this study, it is suggestive of a formidable creative platform intended to stimulate open communication, collective engagement, and creativity among young people. As demonstrated, it enabled young people in Kampala to reveal and appreciate their everyday precarious existence and encouraged them to confront issues that might lead to better health and wellbeing. The method has proved instrumental in contributing towards enhanced creative thinking and practice intended to enable young people to engage in HIV/AIDS prevention and awareness process, skills development and transformative learning towards the critical-emancipatory struggle for greater social justice in informal contexts (Chevalier et al, 2019). While I acknowledge that applied social sculpture alone cannot single-handedly end the spread of HIV/AIDS in marginalised communities, the research has demonstrated that it can be effective and creative in evoking conversation about the critical social issues affecting the youth. In many ways, while indirectly responding to the several of the UN's Sustainable Development Goals (SDGs), especially SDG3, 4, 5, 8 and 17,<sup>106</sup> the

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<sup>106</sup> **Goal 3: Ensure healthy lives and promote well-being for all at all ages** (breaking the silence about the precarious experiences and HIV/AIDS towards engendering health-enhancing behaviours among the youth in Marginalized peri-urban spaces): **Goal 4: Education enables upward socioeconomic mobility and is a key to escaping poverty**

approach sought to empower and sustainably engender collaborative action with young people towards tackling the various social economic factors that have allowed HIV to flourish in informal spaces of Kampala. This thesis has highlighted several follow-up areas for further research and attention, for instance (i) interrogating why young men perpetually blame young women for spreading HIV (ii) the assessment of the immediate or long-terms impact of the applied social practice to the incomes, crafting methods, behavioural change (Health-enabling actions) and wellbeing of young people informal spaces and (iii) why the young women and adolescent girls are still highly vulnerable in spite of the mounting evidence pointing towards national prioritisation of ‘women and adolescent girl’s sexual and reproduction health in relation to the fight against HIV/AIDS in Uganda

With respect to answering the third research question of this study<sup>107</sup>, it has been shown from the analysis that, despite a few shortcomings, applied sculpture is a valuable social practice intended for influencing and improving HIV programming and policy making HIV/AIDS awareness and prevention, especially through youth engagement in marginalized peri-urban areas. It has drawn particular attention to the fundamentals of applied artistic practice and literacy in which issues of self-expression e.g. (Mitchell, 2006), skills acquisition, and knowledge-sharing towards HIV awareness and prevention. Additionally, it has also proved very helpful in the understanding the social realities, especially gender injustices and taboos, that continually allow the epidemic to flourish among young people in the fringes of Kampala city and beyond. In a way, the power of applied social sculpture as a creative approach

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(thrusting applied social sculpture as a pedagogical tool for HIV awareness, prevention and youth empowerment in space where opportunities for formal education are limited): **5<sup>th</sup> Goal: “Achieve gender equality and empower all women and girls”** - ensuring young people, especially young women and adolescent girls make their own informed decisions regarding sexual relations (Sexual and reproductive health). **Goal 8: “Promote... productive employment and decent work for all”**, with special emphasis on the need to reduce youth unemployment (practically Sharing and learning creative skills and knowledge while harnessing hidden artistic talents among the youth, helping them realise better livelihood opportunities). **Goal 17: Revitalize the global partnerships for sustainable development** (This project is result of an institutional partnership between Makerere university and Durham university via conducting research through a GCRF (Global Challenges Research Fund) - PhD studentship towards supporting marginalized young people navigate hard realities of informality and HIV/AIDS for better health and wellbeing.

<sup>107</sup> How might applied artistic practices inform policy makers and providers of health information, and advance new approaches to improve HIV/AIDS awareness, prevention, and empowerment among young people/artisans in Uganda?

potentially lies in how it engenders young people's participation in the fight against HIV/AIDS, thus continuing the long tradition of socially engaged art production in Uganda and sub-Saharan Africa as a whole. This research has shown the potential of utilizing visual and textual rhetoric of the HIV/AIDS prevention efforts in ways that directly involve the youth in seeking solutions to their own problems in informal spaces. However, just as it is impossible to ascertain exactly how much the artistic avenues have enhanced health-enabling behaviours among the participants in this study, it remains equally futile to "measure" in full depth the effectiveness of the applied social sculpture in transforming livelihoods and wellbeing of young people without a follow-up undertaking to interrogate the various assumptions arising from some of the debates it has generated. These include questions about misogyny, creativity and youth livelihood transformation, elimination of poverty, behavioural change and so on. It is also important to recognise that this project alone cannot achieve any radical change of masculine or negative mentalities towards health or low self-esteem, or radically change Ugandan men's sexual behaviour. However, it proposes that the creative process (Gray et al., 2010) that evokes the expression of voice, open communication and development of creative skills to reduce stigma and empower young people to better their livelihoods, while encouraging them to seek the support and treatment, may have potential to change behaviour and attitudes, and save lives, if incorporated on a larger scale into efforts to combat HIV/AIDS among marginalised youth.

### **Giving voice to the voiceless through applied art**

Being an applied sculptor is a key part of my own identity. For me, making an artwork has a social, physical, and emotional impetus that permits me and others to find a visual and metaphoric voice. Like Berman (2018), I see the creative process as driven by a need to translate personal and social responses to our life experience into a mediated expression of a public communication. Similarly, applied social sculpture uses multidisciplinary modes and contemporary artistic approaches to understand and document the complex realities of HIV/AIDS and to open lines of communication about the virus and protective measures. Like the Siyazama project (Wells, 2012, 2016) in South Africa (where rural traditional women from Kwazulu-Natal were helped to express their concerns about HIV/AIDS in their communities),

the dissemination exhibits and the project as a whole centred on inspiring confidence and candid dialogues to challenge young people's precarious existence in the context of HIV/AIDS. Furthermore, based on the collaborative engagements with young people (affected by and infected with HIV) in Kampala, there is an urgent need to recognize the inclusion of applied social sculpture into mainstream approaches designed to engage and involve active participation of the youth. This is based on its potential for facilitating social change and economic empowerment in vulnerable and excluded communities as a form of 'pragmatism at work' (Buckles et al., 2019). This relates to other visual approaches such as body mapping in southern Africa (MacGregor, 2009; Solomon, 2007) and the Siyazama project and its extension to Uganda (Wells, 2012, 2016). Broadly speaking, it is imperative to promote the incorporation of applied social sculpture into national HIV programs and initiatives as a way of achieving meaningful involvement of young people, especially in areas where skills development initiatives in the critical areas of vocational development, livelihoods improvement, agency, HIV/AIDS advocacy, and community mobilization are needed. These are aspects that have been at the heart of participatory engagements with the youth in this study, and conspicuously, align with the National HIV and AIDS Priority Action Plan (UAC, 2018) as a key strategy to reducing infection rates and ultimately defeating AIDS as a public health threat by 2030 (UAC, 2016; UNAIDS, 2019, 2020c). In this research, applied social sculpture affirms and arguably positions itself among those arts-based scholarships that uphold the notions of art having the capacity to move beyond the spaces of galleries into an expanded field, and thus, beyond the visual and into the social spheres (See Nabulime, 2007; Nabulime & McEwan, 2011). This research sought to promote positive health practices by engaging the youth in participatory exchanges while simultaneously offering them life-skills/tools for positive behavioural choices regarding their work, gender, sexuality and HIV/AIDS (E.g., Sánchez-Camus, 2009). This thesis has presented applied sculpture as a crucial channel for young people to find their individual voices and to become their own agents for change in the arenas of HIV/AIDS awareness and prevention.

Applied social sculpture is an important multidisciplinary pedagogical tool in providing a desirable creative platform that can help raise silent voices and restore human dignity, wellbeing and livelihood eroded by suffering and other barriers that perpetuate the spread of

HIV/AIDS among young people in marginalised informal spaces. As shown in the analytical chapters, it provides a formal space for making sense of ordinary every-day experiences, finding meaning and crafting clarity of young people's lived experiences in the context of HIV/AIDS. Ultimately, applied social sculpture is a relatively new approach to helping marginalized young people to rethink alternative ways of confronting their precarious situations; it also helps them to recreate and view themselves as producers of knowledge, social advocates, and empowered actors in transforming their livelihoods and wellbeing in informal contexts. Moreover, this research suggests that applied artistic practice can allow power to be decentralized to participants through interactive processes such as open group dialogues, collective visualisation of ideas through drawing, and co-production of artworks. These processes were intended to encourage and inculcate better health practices and add to livelihood benefits within their own settings in consideration of the wider context of informal geographies. This narrative triangulates around three participatory aspects (i) collective creativity and co-production of applied objects for creative practice and social cohesion (ii) sharing of creative skills and knowledge for open communication, capacity building and knowledge production and (iii) potential change of attitudes to work, health, and wellbeing among the participants, crucially paying attention to the positive outcomes of this in the context of HIV/AIDS prevention.

Overall, the research attempted to explore and demonstrate the centrality of applied social practice as a multi-dimensional tool intended to invoke open dialogue, confidence-building, social change and economic emancipation regarding HIV/AIDS and its prevention among young people in the informal peri-urban areas. The thesis has also shown that creatively stimulating dialogue and fostering information-sharing with relevant target audiences through applied artistic approaches can create wider dialogue about both the HIV/AIDS and Covid-19 pandemics. Applied social sculpture alone cannot solve the complex problems associated with either disease (or any other social phenomenon). Concerted efforts from all social, academic, political, and economic fronts remain vital and must be fully explored to stem the tide of disease. Much as the project has shown its potential towards opening new avenues for provoking thought, discussion, innovation, and probing preventive actions, there is more room for further inquiry into aspects that are critical in transforming young lives in the context of the epidemic in Uganda and the greater sub-Saharan region.



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## APPENDIX 1

### LIST OF PLATES



*Plate 1: A shanty settlement with slums, narrow corridors, dilapidating houses built with mud and wattle, rusty iron sheets full of dry leaves and stones with very old dirty clothes on top, rusty corrugated iron sheets. (Field diary photo, Katwe industrial area, 17<sup>th</sup> August 2020)*



*Plate 2: A makeshift structure made from a container and timber panels in Bwaise: These double as business points during day and dwelling place at night (Field diary photo, Bwaise industrial area, 29<sup>th</sup> March 2020).*





*Plate 3: Shanty dwellings (Field diary photo, Bwaise industrial areas, 31<sup>st</sup> August 2020).*



*Plate 4: Exhibition; 7000 Oak, Documenta 7 the Museum Fridericianum, Kassel, Germany, 1982 (Google photos)*



Plate 5: One of the artworks produced by Tanzanian and Zambian women telling their HIV stories in 2006 (CATIE-Canadian AIDS Treatment Information Exchange, 2006): Source: CATIE website



Plate 6: Translucent soap sculptures, Nabulime Lillian, 2004 (Source: Lilian Mary Nabulime, Permission granted)



*Plate 7: Soap sculptures by Lillian Nabulime (Source: Lilian Mary Nabulime, Permission granted)*



*Plate 8: Applied sculpture portraying for function and beauty: A Pulpit, Ssewanyana Robert, 2018*



Plate 9; Bead dolls and imbenge, 2002, Google photo

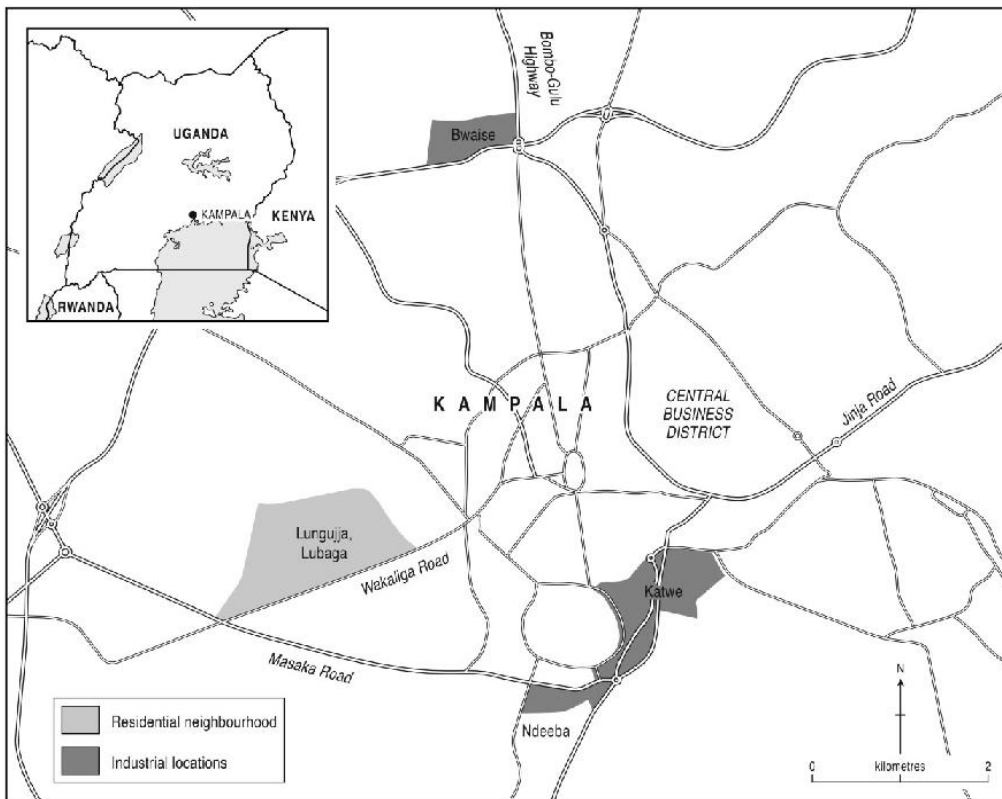


Plate 10: Map for study sites in Kampala (Source: Chris Orton, Durham Cartographic Unit)



*Plate 11: Direct participation with young people in Katwe industrial area in August 2020*



*Plate 12: Art and creativity workshop with HIV participants (storytelling and drawing session)*



Plate 13: Researcher interacting with attendees, HIV Exhibition at TASO Mulago, Uganda (17<sup>th</sup> - 20<sup>th</sup> February 2021)



Plate 14: A muddy road in Bwaise industrial area (Field diary photo, Bwaise industrial area, 17<sup>th</sup> January 2020)

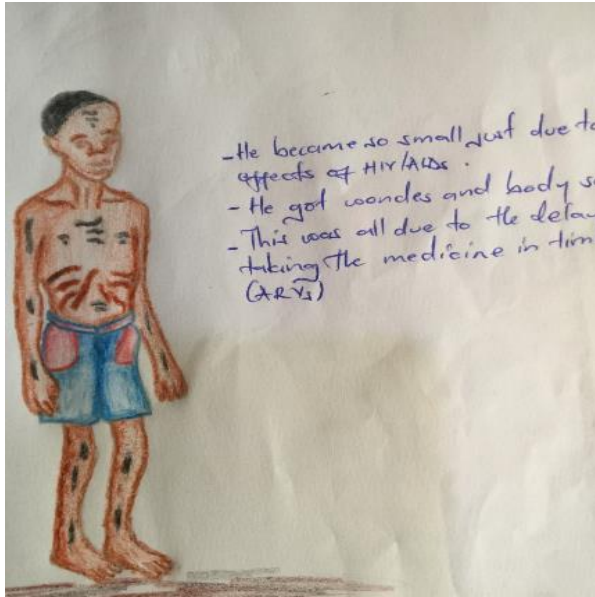


Plate 15: The AIDS patient: Illustration by a participant K (Art and creativity HIV awareness workshop, June 2020)



Plate 16: A view of Bwaise industrial area, Kawempe Division, Kampala



Plate 17: Book cover for a local saving group for artisans in Bwaise industrial area (Field diary photo, 6<sup>th</sup> August 2020)



Plate 18: Drawing/discussion session in progress inside a makeshift carpentry workshop on 20<sup>th</sup> October 2020 (NB. Those who could not write shared their stories with participants who translated them into written scripts or artistic images)



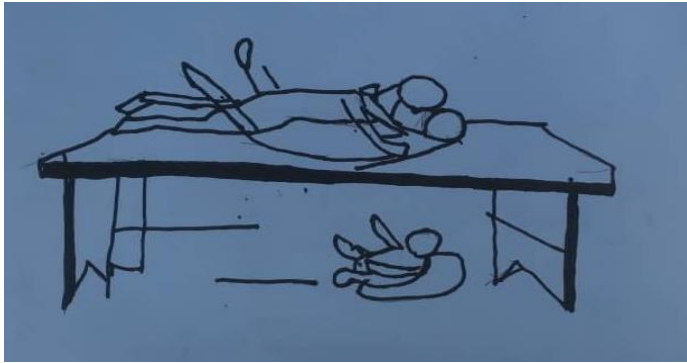


Plate 19: 'Sex in the workshop'- A drawing by Participant 'M' during a participatory workshop held on 22<sup>nd</sup> October 2020



Plate 20: Participants developing 3D HIV prevention concepts/designs in soap.



Plate 21: Workshop participants in a group discussion (21<sup>st</sup> October 2020)



Plate 22: 'Malaaya vva kumutembeyi'(drawn by participant P on 22<sup>nd</sup> October 2020)



Plate 23: Illustration showing hotspots of sex trade in and around Ndeeba by participant P



Plate 24: Participants discuss sex and HIV-related experiences while sanding wood pieces for artwork in plate 23



Plate 25: Participant P displays female shapes out of plywood and assembles them on a board to indicate hotspots of sex work in informal spaces. He includes a few men in long trousers to demonstrate that young men are part of the sex trade



Plate 26: Finished relief artwork (42' x 25') showing hotspots of sex worker in and around Ndeeba industrial area

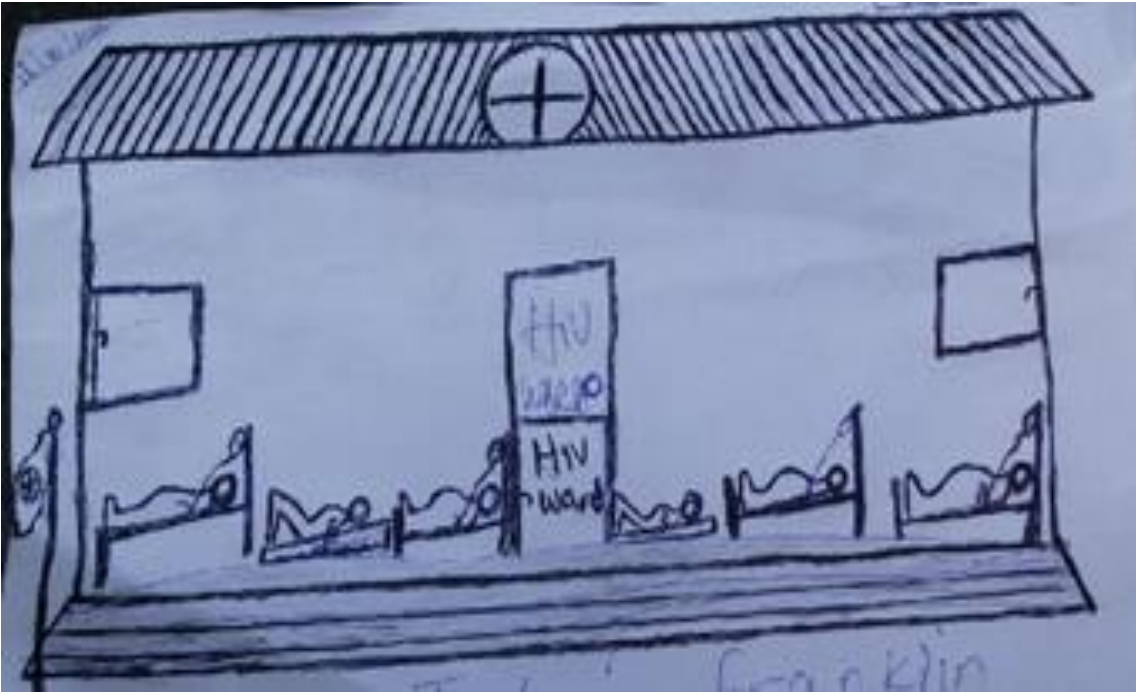


Plate 27: A simple illustration of the HIV ward by participant Q.

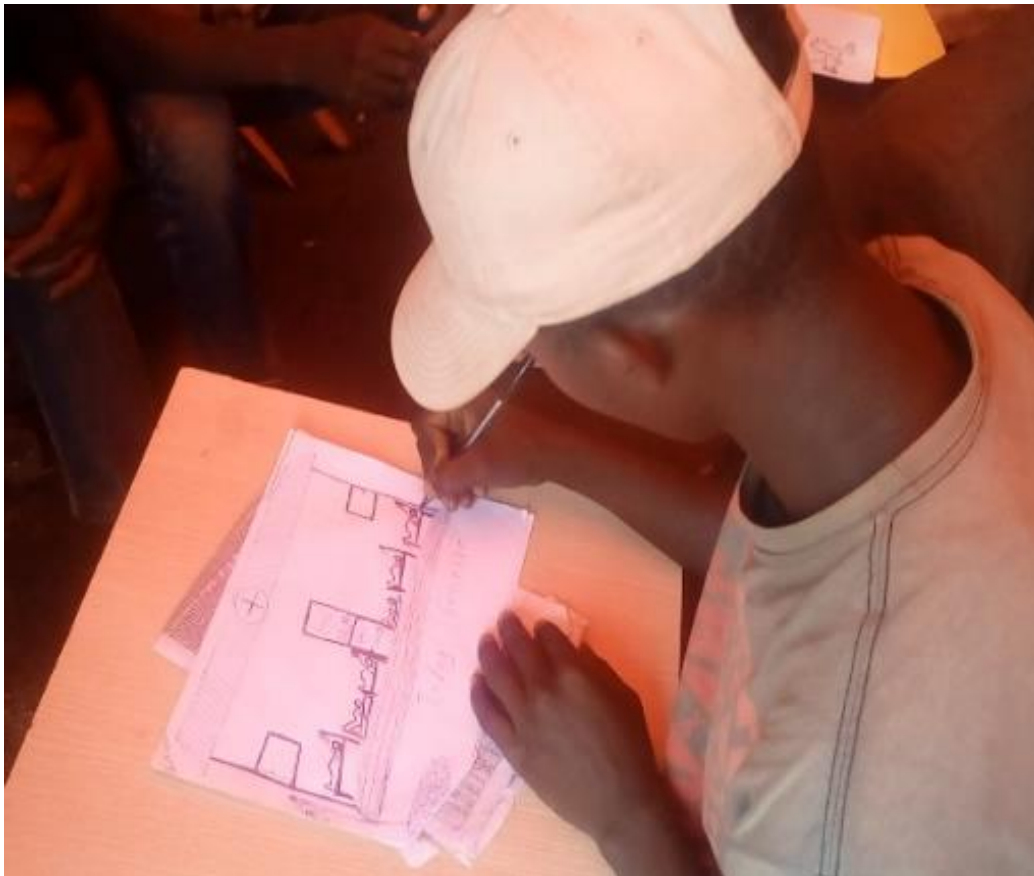


Plate 28: HIV patients on drip': Participant Q illustrating his concept of the HIV ward



*Plate 29: 3-Dimensional presentation of HIV corpses lying on beds in a hospital*



*Plate 30: The co-production process; participants jointly crafting the HIV ward*



Plate 31: A figurative structure of the HIV ward with patients lying on the bed and others on the floor



Plate 32: Artwork D: The beer party in Ndeeba drawn by a 29-year-old carpenter (Participant A)



Plate 33: Artwork E: A crafted bench showing male genitals affected by Herpes by participant Y (Lunguja, 20<sup>th</sup> May 2020)

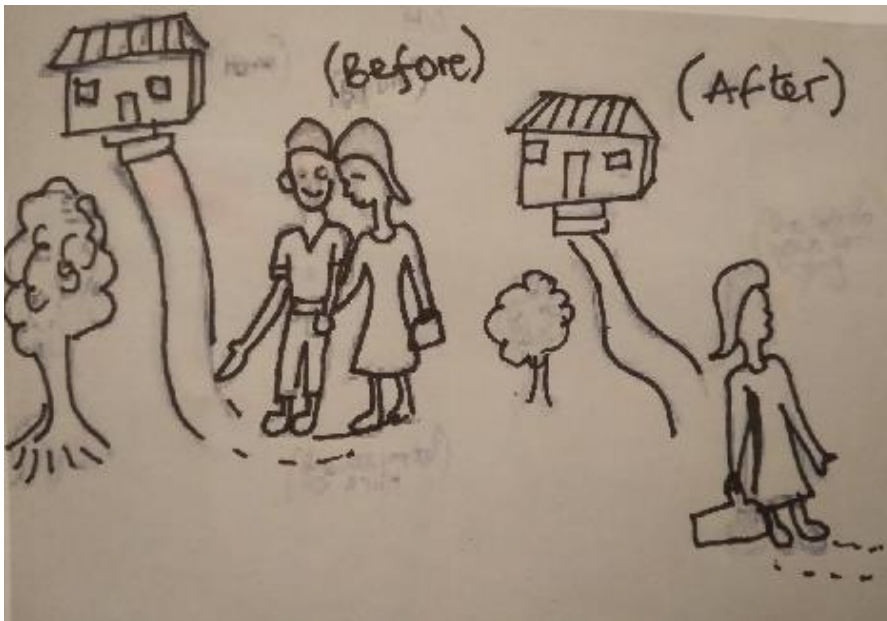


Plate 34: Artwork F: My love, let others wait: A depiction of a girl going home with her new boyfriend by participant S (25<sup>th</sup> October 2022)



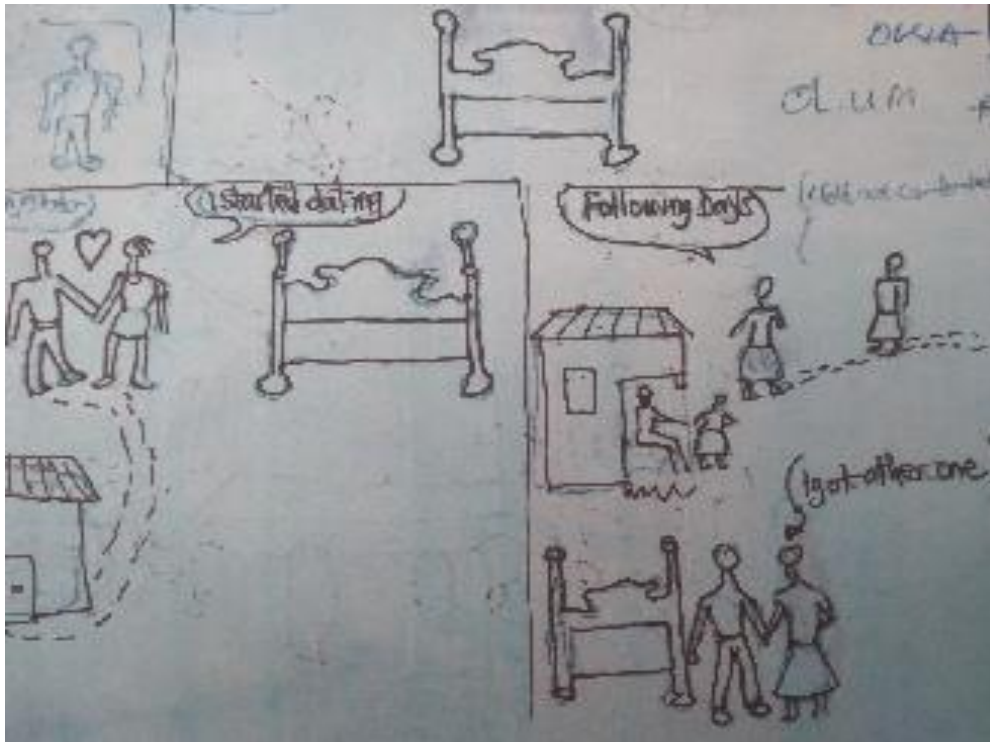


Plate 35: Artwork G: Multiple dating; Participants R depicts young men swapping women endlessly, Ndeeba, 25<sup>th</sup> Oct 2020



Plate 36: 'Tetukuta'; A figurative depiction of multiple dating in industrial spaces (Drawn by participant B, 25<sup>th</sup> October 2020)



Plate 37: Artwork H: A relief carving depicting 'Omutima gw'omulenzi gubeera Eno eneeri' (A heart of a young man is always back and forth) - Ndeeba, 24<sup>th</sup> October 2020



Plate 38: Participants making drawings from their stories while maintaining social distance due to Covid-19 (8<sup>th</sup> May 2020)

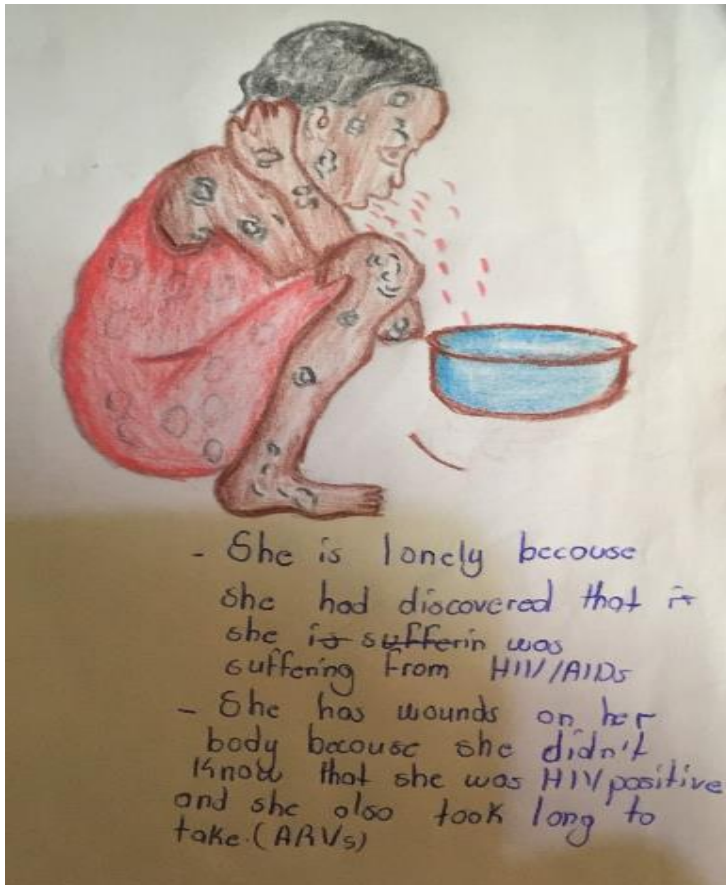


Plate 39: Drawing of person suffering from HIV related fever by participant H, 25<sup>th</sup> May 2020



Plate 40: HIV benches with various prevention messages



Plate 41: The HIV bed: 'Omutima gw'omulenzi guli eno neeri' (Design concept by participant T)



Plate 42: Participants crafting the wooden benches with the help of a local artisan in Lunguja, May 2020



Plate 43: Participants' sketching HIV messages/words on to the wooden benches



Plate 44: A busy trading centre in the outskirts of Kampala (Lunguja Kitunzi)<sup>108</sup>

<sup>108</sup> A busy Scene from a local trading centre (Near Lunguja-Kitunzi market) in Kampala captured on 17<sup>th</sup> Jul 2020 during a participant identification survey. Its typically one of those ideal sites where HIV awareness forms/benches can be placed for their visual and functional impact in relation to HIV/AIDS awareness and prevention



Plate 45: Bench A; Say 'No' to unprotected sex (Size: 1ft x 6ft x 18ft)



Plate 46: Bench B and C: 'Genda wekebeze' and 'Mira edagala' respectively (1ft x 2ft x 1.5ft)



Plate 47: Encouraging disclosure is a creative essential for the safety of others



Plate 48: Bed supports with messages to confront reckless sexual behaviours



Plate 49: Figurative artworks – **Image I:** A clay piece as a marquetry for the covid house: **Image II:** Covid house (22'x 33' x 22') dubbed as 'Abuser within': Perpetrator of domestic violence lockup with the victims in homes



Plate 50: The Covid bikes (85' x 54') as figurative artworks representing the travel hardships faced by PLHIV



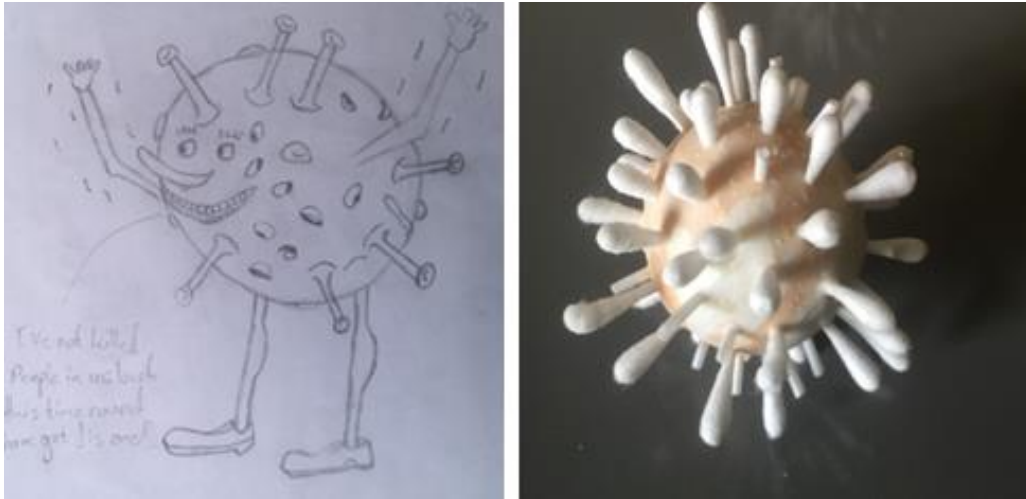


Plate 51: Image Y: A caricature a caricature of the corona virus Image Z: A 3D model of the corona virus developed by the participants in Lunguja using soap with cotton swabs (2<sup>nd</sup> - 5<sup>th</sup> June 2020)



Plate 52: Semi-circular relief models of soap showing the engraved imagery/design of (i) the covid bike and (ii) two HIV couples as created by participants, 10th June 2020



Plate 53: The process of welding the covid bikes, Katwe industrial area, July 2020



Plate 54: Images showing the collaborative performances that led to the creation of HIV prevention artworks



*Plate 55: Close observation: The HIV Benches exhibited next to furniture products, Ndeeba industrial area (1<sup>st</sup> - 2<sup>nd</sup> Nov. 2020)*



*Plate 56: Open conversation: A participant points at the genital image as a candid stance towards talking about sensitive topics - sex and HIV/AIDS.*



Plate 57: HIV/AIDS signage anchored on one of the participants' makeshift workshop 27<sup>th</sup> March 2021



Plate 58: Bed concept (5' x 6') created by Participant T, Ndeeba participatory workshop, September 2020.



*Plate 59: HIV ward jointly executed by participants using scrap wood in Ndeeba, October 2020*



*Plate 60: Research participants anchoring the Covid bike on to one of the art gallery walls at Makerere University, 3rd January 2021*



Plate 61: HIV artworks displayed in the middle section of the gallery. hand-woven foot rug with the words 'HIV kill'



Plate 62: Last section of the gallery with the Covid-19 artworks.



Plate 63: Official Launch of the reception event: Attendees at the reception event/HIV/AIDS artworks exhibition, Makerere University art Gallery, 4th January 2021, 3pm.



Plate 64: The researcher talking to one of the guests at the exhibition event, 4th January 2021



Plate 65: Exhibition participants interacting with the HIV bed inside the gallery



Plate 66: Researcher explaining the HIV bed concept to the guests at the exhibition (17<sup>th</sup> February 2021, 11am)





Plate 67: Attendees interacting with the exhibits in one of the tents after it was officially opened, 17th February 2021



Plate 68: A guest taking time to read the information on a poster besides the covid house inside the tent (17<sup>th</sup> February 2021)



Plate 69: TASO medics looking at the HIV benches displayed inside one of the tents at Mulago, 17th January 2021



Plate 70: Internship students from Mulago hospital viewing one of the exhibits - the HIV ward



Plate 71: Young people listening to the researcher at TASO Mulago, Kampala (17th February 2021)

# Artistic twist to HIV awareness



Ssewanyana plays a game of Ludo with guests at the exhibition, depicting the everyday life of many urban youth. PHOTOS/ DENIS NSUBUGA

The fight against HIV/Aids has not stopped and last week artist and Mak lecturer Robert Ssewanyana showcased some pieces of art to create further awareness of the disease using everyday objects used in urban life.

BY DENIS NSUBUGA

Artist Robert Ssewanyana's latest work expands the conversation on the awareness of HIV/Aids. In his signature art form dubbed *Applied Sculpture*, Ssewanyana uses functional objects such as benches and beds to promote awareness of the disease which has tormented Uganda's urban youth over the years.

Messages on HIV/Aids prevention and treatment are aesthetically inscribed on the objects used in everyday life. The exhibition that took place at TASO Mulago on Wednesday last week, saw the artist who identifies as an Applied Sculptor, showcase works intended to stimulate the youth on their sex life.

Phrases such as 'Be Faithful' and 'Aids Disrupts Your Future' are some of the engravings on benches placed at a Ludo game joint. This, according to Ssewanyana, is "effective in delivering awareness and prevention messages for local communities especially in busy trading centres where young people usually gather."

The Research Dissertation Exhibition under the theme, 'Art and creativity in HIV/Aids prevention and empowerment among young people', was the culmination of Ssewanyana's continued exploration into the

subject of art as a tool of advocacy.

The lecturer at Makerere University's School of Fine and Industrial Arts, engaged young artisans in industrial neighborhoods in Kampala, including Ndeeba, Lunguja and Bwaise. And in the 12 months of his research that ended in November 2020, artisans co-produced works in the context of HIV/Aids.

One of the works that fascinated viewers at the exhibition was titled *Omutima Gwomulenzi Guli Wano Neeri*, which is a carving on the headboard of a wooden bed. It depicts a heart with a dove in the middle. According to Ssewanyana, it is a creation of 24-year-old artisan Izevo Chan, who was depicting a love life typical in the society she lives in.

"The big heart is (symbolic of) the lovely boyfriend who has a darling described in the dove, but he will keep on getting concubines," Ssewanyana said. The concubines are portrayed as silver cyprinid (*mukena*) engraved on the polls of the wooden bed.

#### The sexual network

"They destabilise the relationship, Chan says", adding that the web grows into a sexual network. While the man heads for the *mukena*, the woman seeks solace from other men," he explained.

Ssewanyana says they used the bed because it is traditionally known as marital space, so it can help send the messages.

"So the bed is very symbolic," visual artist Lillian Nabulime said, adding: "Usually, people get infected while having sex on the bed, sometimes because they have forgotten about protection. When they have a bed like this, they will reflect more on the protection."

Lillian Sande, a viewer at the exhibition, said the unconventional way of awareness



The piece depicting life under lockdown.



Guests view a sculpture of the HIV ward.

is plausible because "for information to be prominent among the people, it should be developed from stuff they use every day."

The event was attended by various dignitaries in the HIV/Aids advocacy fraternity, including Michael Etukoit, the executive director of TASO Uganda, who tackled the conservation on enhancing new local knowledge for empowerment, awareness and other challenges associated with the epidemic.

But, at least to the knowledge of the curators, the exhibition could not go without tackling one of the most prevalent health and social issues, Covid-19, and how it has affected human life. Art works addressing the pandemic were also showcased.

The piece, *Abuser Within*, is a portrayal

of the undesirable situation brought about by the lockdown effected early last year. According to Ssewanyana, from research, the wooden sculpture of a house with a Covid-inspired lock peddle and nails on the sides depicts the life of many people in crowded industrial zones.

"Lockdown meant locking up with difficulties such as sexual abuse, gender-based violence, and economic hardships. How Covid-19 impacted livelihoods, people could not get health services, basically struggling to survive," he explained, adding that it also overshadowed efforts to fight HIV/Aids.

editorial@ug.nationmedia.com

Plate 72: An article published in the Daily Monitor, a local newspaper in Uganda about the art exhibition at TASO Mulago ("Artistic twist to HIV awareness")<sup>109</sup>



*Plate 73: Covid bike anchored on to a wall in one of the homes in Lunguja for beautification*

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<sup>109</sup> <https://www.monitor.co.ug/uganda/magazines/life/artistic-twist-to-hiv-awareness-3300138>

## APPENDIX 2

### SAMPLE INTERVIEW TEMPLATES

#### (i) Interview guide for artisans and other industrial related workers<sup>110</sup>

Title of research; “A participatory approach towards art and creativity for HIV/AIDS awareness, prevention and empowerment of young people in Uganda”

Objectives;

- i) Use participatory applied sculptural practice with young artisans in marginalised industrial areas in Kampala to generate knowledge about their personal and every day working experiences and how they relate to HIV/AIDS awareness and prevention.
- ii) To initiate collaborative partnerships between the researcher (Applied Sculptor) and young artisans to co-produce applied sculptural/functional forms and explore their potential in improving HIV/AIDS awareness and prevention and economic empowerment in marginalised communities.
- iii) To demonstrate the value of applied sculptural practices generating information for policy makers and providers of health information and services concerned with HIV/AIDS awareness and prevention among young people.

Bio-data of participant

Pseudo Name/code .....

Ethnicity/Tribe.....

Age.....

Sex .....

Marital status .....

HIV status ..... Have you ever tested? .....

Place of residence ..... Did you migrate to this place/area?  
..... If yes, why? .....

Place of work.....

Employment status .....

---

<sup>110</sup> This is a sample template. During the course of the interviews themselves and during the course of the fieldwork in general, questions were modified according to the nature and place of work of the participant, the answers given, and the context.

Years of experience.....

Field training/ Area of expertise

1. What is the highest level of education .....
2. List of qualifications; Name of institution and field of study.....
3. What training or apprenticeship have you received in this work space?  
.....
4. How has your level of training influenced your income and performance levels? Are you satisfied with both .....

Employment Background

1. For how long have you been engaged in this current job/ activity/ industrial area?  
.....
2. How did you get the opportunity to work in this industrial area/ current job? .....
3. How would you describe your current job in terms of your aspirations and achievements so far? .....
4. What socio-economic challenges do you encounter in your work space? Could HIV/AIDS be one of these challenges?  
.....
5. What are the key factors affecting youth engagement and performance in your work areas?  
.....

HIV/AIDS awareness and prevention among young people in industrial areas

1. Are you aware of your HIV/AIDS status? If yes and positive, how have you been able to cope with it in this work space?
2. Is HIV/AIDS among the major challenges you face in this community? If yes, how do you/ have you dealt with it?
3. Are there specific strategies designed by your employers to deal with stigma and other HIV-related challenges? What are these strategies?
4. Do you engage with colleagues who are HIV+ in work spaces? How do you help/relate with them during work?
5. What do you think are precarities that have perpetuated the spread of HIV among young people in your community?

6. Are there organisations in your community that offer support services/testing and counselling or any other help to HIV/AIDS victims? What services do they offer?
7. What advice would you have for young people living with HIV/AIDS in your work environment?
8. What else would you like to share about HIV/AIDS and work in your work spaces?

#### Applied sculpture and intervention strategies for tackling HIV/AIDS in artisan communities

NB: Applied sculpture is the art of creating 3D object in tangible materials such as clay, cement, etc for both aesthetic and functional reasons.

1. Have ever engaged in any HIV/AIDS intervention activities in your work spaces? What are some of those intervention?
2. What collaborative activities have you done for awareness and prevention of HIV/AIDS while empowering young artisan with skills for a better livelihood in your community?
3. How could the art of applied sculpture be integrated with artisanal activities
  - a) To co-produce works that communicate about the challenges of living with HIV/AIDS
  - b) Encourage social and economic empowerment?
4. How would you utilize and promote co-produced products in tackling stigma and other HIV-related challenges in your community?
5. What other collaboration ideas would you advance/done for tackling challenges associated with HIV/AIDS in your community?
6. To what extent have HIV/AIDS organisations been helpful in the fight against the spread of HIV/AIDS among young people in this community?
7. What would you suggest as alternative ways of addressing HIV/AIDS challenges among young artisans in this area?



**(ii) Interview guide policy makers, Ministry of Health, and related NGOs<sup>111</sup>**

Research title: A participatory approach towards art and creativity for HIV/AIDS prevention, awareness, and empowerment of young people in Uganda’s informal sector.

**Background data;**

Name of organisation; .....

Name of Official; .....

Job title/ Expertise; .....

Years of experience; .....

Date of Interview; .....

**Information about HIV and AIDS policies in Uganda**

1. Uganda was heralded for drastically reducing HIV prevalence from 18% in 1990s to 6% in the 2000s. Today, new research studies indicate that this trend in the reverse gear. What could be the factors leading to this reversal?
2. What are some of the mitigative strategies that Government is putting in place to avert this trend and perhaps aligned with the UN-shared vision of ending AIDS by 2030 (Zero new infections, zero discrimination and zero HIV- related deaths).  
Do you think there need for policy review or creating new ones
3. Are there policies for HIV/AIDS and work in Uganda? What are these policies? Are they inclusive for all key populations? How effective have they been? Who designs these policies?
4. Are there policies designed and implemented in support of UN shared goal of ending HIV/AIDS by 2020? Yes/NO. If yes which one are those?
5. There is too much complacency over HIV among young people and its one of the reasons why HIV rates are rising today. What is your comment on this statement?

---

<sup>111</sup> This is a sample template. During the course of the interviews themselves and during the course of the fieldwork in general, questions were modified according to the nature of the NGO, the answers given, and the context.

6. Do you think government still has the political will and capacity to avert these worrying trends of infections among young people and other key populations? Please cite some Examples.
7. Is Uganda bound or a signatory to any/ by any international declarations on Fighting HIV/AIDS in the recent past? Which ones for example?
8. Are there special intervention programmes implemented through ministries say Gender, Labour and social Development, Education, and sports or any other for key population particularly in the informal sector?
9. Do you have any contacts you know or would recommend for information regarding young people and HIV/AIDS in Uganda?

**Thank you for participating**

## APPENDIX 3

### ETHICS DOCUMENTS

#### (i) Durham Ethics Letter

#### **Ethical Approval: GEOG-2020-05-07T06:43:01-hqbv35**

Ethics <no-reply@sharepointonline.com>

Fri 12/06/2020 13:58

To:

- SSEWANYANA, ROBERT

Cc:

- LESHEM, NOAM;
- MCEWAN, CHERYL

**Please do not reply to this email.**

Dear Ssewanyana Robert,

The following project has received ethical approval:

Project Title: *A participatory approach towards art and creativity for HIV/AIDS awareness, prevention, and empowerment of young artisans in Kampala, Uganda*

Start Date: *01 February 2019*


End Date: *31 January 2022*

Reference: *GEOG-2020-05-07T06:43:01-hqbv35*

Date of ethical approval: *12 June 2020.*

Please be aware that if you make any significant changes to the design, duration, or delivery of your project, you should contact your department ethics representative for advice, as further consideration and approval may then be required.

(ii) Taso Ethics Letter



**The AIDS Support Organisation  
(TASO) Uganda Ltd.**

**TASO Headquarters**  
Mulago Hospital Complex  
P.O. Box 10443, Kampala-Uganda  
Tel: +256 414 532 580/1  
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Website: [www.tasouganda.org](http://www.tasouganda.org)

30<sup>th</sup> July, 2020

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**TASO COLLEGE OF HEALTH SCIENCES (TASOCS)**  
Katyanya DR Oculia Road,  
Ako Akomoni  
P.O. Box 10443, Kampala  
Tel: +256 414 532 537  
Fax: +256 414 588 704  
Email: [info@tasouganda.org](mailto:info@tasouganda.org)

**SUPPORT CENTRES**

**TASO ENTebbe**  
Plot 15-17 Lugoli Avenue  
P.O. Box 25, Entebbe  
Tel: 0414 256500/274 155  
Email: [entebbe@tasouganda.org](mailto:entebbe@tasouganda.org)

**TASO GULU**  
Plot 4 Malwa Lubwa Road  
P.O. Box 147, Gulu  
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Email: [gulu@tasouganda.org](mailto:gulu@tasouganda.org)

**TASO IRRA**  
Jinja Referral Hospital  
P.O. Box 57, Jinja  
Tel: 020200 1170752 774 145  
Fax: 0434 12002  
Email: [irra@tasouganda.org](mailto:irra@tasouganda.org)

**TASO KASABA**  
Wakiso Hospital  
P.O. Box 1076, Wakiso  
Tel: 0392 745 566/752 774 145  
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**TASO MAKINDI**  
Makindil Hospital  
P.O. Box 117, Makindil  
Tel: 0465 425 224/0752 774 144  
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**TASO MUKONO**  
Mukono Hospital  
P.O. Box 2596, Mukono  
Tel: 0454 451 511/0752 774 137  
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**TASO NAKURU**  
Plot 29 and 27 Hospital Road  
P.O. Box 1016, Nakuru  
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Email: [nakuru@tasouganda.org](mailto:nakuru@tasouganda.org)

**TASO NALUOTO**  
Nalungu Hospital  
P.O. Box 71485, Kampala  
Tel: 0414 532 538/0752 774 130  
Fax: 0414 541 283  
Email: [naluoto@tasouganda.org](mailto:naluoto@tasouganda.org)

**TASO RUMWEE**  
Rumwee Road  
P.O. Box 210, Rumwee  
Tel: 0488 442 222/0752 774 141  
Fax: 0488 442 072  
Email: [rumwee@tasouganda.org](mailto:rumwee@tasouganda.org)

**TASO SOROTI**  
Soroti Hospital  
P.O. Box 422, Soroti  
Tel: 0454 461 260/752 774 143  
Fax: 0454 461 242  
Email: [soroti@tasouganda.org](mailto:soroti@tasouganda.org)

**TASO TORORO**  
Plot 21, Coa Road  
P.O. Box 777, Tororo  
Tel: 0454 442 222/0752 774 145  
Fax: 0454 445 224  
Email: [tororo@tasouganda.org](mailto:tororo@tasouganda.org)

**SECURITY PROJECTS**  
**GRANTS MANAGEMENT UNIT / GLOBAL FUND**  
House of Hope, Plot 18  
Wakiso Road  
P.O. Box 10443, Kampala  
Tel: 0414 259 888/0752 774 148  
Email: [smu@tasouganda.org](mailto:smu@tasouganda.org)

**TASO-KARABOLA PROJECT**  
Plot 10, Independence Avenue  
P.O. Box 181, Makwa  
Tel: 0752 744 732  
Fax: 0454 440 234  
Email: [karabola@tasouganda.org](mailto:karabola@tasouganda.org)

**TORORO LABORATORY HUB**  
P.O. Box 777, Tororo  
Tel: 0454 442 222/0752 774 133  
Fax: 0454 445 224  
Email: [tororo@tasouganda.org](mailto:tororo@tasouganda.org)

Our Ref: TASOREC/008/2020-UG-REC-009

Mr. Robert Saewanyana,  
Durham University, United Kingdom  
[robert.saewanyana@durham.ac.uk](mailto:robert.saewanyana@durham.ac.uk)

Dear Robert,

**RE: RESEARCH APPROVAL "A Participatory Approach to Art and Creativity for HIV/AIDS Awareness, Prevention and Empowerment of Young Artisans (15-24 Years) in Uganda."**

Thank you for responding to the committee's request for further information.

On behalf of the committee, I am pleased to confirm that your correspondence bearing the revised documentation on 23<sup>rd</sup> July 2020 with responses to additional initial review comments of 26<sup>th</sup> June 2020, met the requirements for approval.


TASO REC, through its full meeting gave a favorable ethical opinion of the research, annual approval has been granted, effective 30<sup>th</sup> July 2020, valid until 25<sup>th</sup> July 2021.

**Final list of documents reviewed and approved:**

Document Type	Date	Version
1. The Study Protocol.	23/07/2020	2.0
2. Informed Consent Form with Translation.	23/07/2020	2.0
3. Data Collection/Observational Tools.	23/07/2020	2.0
4. COVID-19 Risk Management Plan.	23/07/2020	1.0
5. TASO REC Research Review Application and DOC of Interest.	30/01/2020	1.0
6. Introductory Letter, Makerere University, CEDAT	18/07/2019	
7. Admission Letter, Durham University, UK.	05/11/2018	

**After ethical review:**  
 Amendments: All proposed amendments to the study (including personnel, procedures, or documents) must be approved by the REC in advance before the study commences.  
 Adverse Events/Unanticipated Problems: It is your responsibility to inform the REC of any adverse consequences to participants that occur in the course of the study.  
 Site Monitoring Visits: shall be undertaken to verify that only approved procedures are being implemented, to ensure that the rights and welfare of participants are being protected.  
 Study Reports: It is a requirement by the REC that you submit timely progress reports.  
 Renewal of the study approval: This should be through submission of the Annual Report and a Continuing Review Application, at least 60 days prior to expiration date.  
 Protocol documents which contain the REC-stamp (if applicable), must be utilized during recruitment of participants, obtaining informed consent and data collection processes.  
 We recommend that you proceed with the registration and final clearance of your study by the Uganda National Council of Science and Technology (UNCST) before commencement.

Yours sincerely,



Approved, Valid Until: \_\_\_\_\_  
 Dr. Adnan Jiruko, LL.D  
 Chairperson, TASO RESEARCH ETHICS COMMITTEE (REC)  
 CC: Executive Director, TASO (U) Limited  
 CC: Uganda National Council for Science & Technology (UNCST)

**(iii) Certificate of consent**

I have been invited to participate in the research about art and creativity for HIV/AIDS awareness, prevention, and empowerment of young artisans’ project in Kampala, Uganda.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked to have been answered to my satisfaction. I hereby confirm that I Live and /or work in this industrial area and I consent voluntarily to be a participant in this study

Print Name of Participant.....  
.....

Signature of Participant .....

Date \_\_\_\_\_

**If illiterate.**

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness ..... Thumb print of participant  
Signature of witness .....  
Date .....



**Statement by the researcher/person taking consent**

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

- 1. Face to face interviews*
- 2. Action-group Discussions/ fora*
- 3. Co-production of works and exhibition*

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

#### **(iv) Information Sheet**

Date; 2<sup>nd</sup> July 2020

Address; Geography Department, Durham University, UK

#### **INFORMED CONSENT FORM FOR YOUNG ARTISANS IN KAMPALA**

This is an informed consent form for artisans in industrial areas of Kampala-Bwaise, Ndeeba and Katwe who are invited to participate in this research about art and creativity for HIV/AIDS awareness, prevention, and empowerment of young people project.

**Principal investigator;** Ssewanyana Robert

**Name of organisation;** Durham University

**Name of project;** Art and creativity for HIV/AIDS awareness, prevention, and empowerment of young people in the informal sector in Uganda.

#### **INTRODUCTION**

I am a postgraduate researcher from Durham University doing research about how art and creativity through applied sculpture can help tackle challenges associated with HIV/AIDS, promote awareness while empowering young people with knowledge and skills for better lives. This will be done by way of sharing knowledge and skills through collaborative partnerships with young artisans in industrial settings in Kampala. It is conceivable that the partnership formed for this research will yield co-produced works that will be used as tools of communication about HIV/AIDS and how to deal with stigma among young people while encouraging social and economic transformation within your community.

I am going to provide you with information and invite you to be part of this research. You don't have to decide today whether or not to participate in this research. Before you decide, you can talk to any one you feel comfortable with about this research.

If this consent form contains details you don't understand please ask me to stop as we go through the information, and I will take time to explain. If you have any questions as we move along please don't hesitate to ask me.

#### **PURPOSE OF RESEARCH**

HIV/AIDS is still as deadly as ever before. It has had devastating effects on many communities across the world particularly in Saharan African- poverty, stigma, social discrimination, orphans, death and so on. Today, young people are most-at-risk populations in many informal settings in developing countries including Uganda.

I want to find ways of contributing to the already existing efforts to wipe out HIV/AIDS from our communities by way of sharing your lived experiences of the disease in your community and how it affects your everyday experiences in industrial settings in Kampala. I believe this will be instrumental in collectively devising ways of overcoming this epidemic while empowering your community socially and economically. Through action groups with young people, I want to use applied sculpture to co-produce works inspired and informed by your everyday experiences in the context of HIV/AIDS and seek new pathways of how learning and sharing knowledge and skills can transform livelihoods for you and your community. I would also like to know more about how you deal with this devastating disease in your community and how local health practices have been used to control its spread in the community and later the country as a whole.

### **TYPE OF INTERVENTION**

This research will involve your participation as a young person/ artisan forming groups of 5 to 10 people called action groups. These groups will be engaged in this research through interviews and co-production of artworks for HIV/AIDS awareness, prevention and empowerment.

### **PARTICIPANT SELECTION**

You are being invited to take part in this research because I feel that your everyday experiences as a young artisan can contribute to our understanding and knowledge about tackling challenges and stopping the spread of in our communities HIV/AIDS.

Please note; your participation in this study is entirely voluntary. It's your choice whether to participate or not. If you choose not to participate, all the services and benefits in your workspace will continue and nothing will change. If you don't wish to participate in this study, do you have any questions?

### **PROCEDURES**

#### **For action groups;**

You are going to help me know more about your everyday experiences about work, HIV/AIDS and your community. Am inviting you all to take part in this research project. If you accept, you will be asked to take part in discussions and design processes with 5 to 10 other persons with similar experiences. These sessions will be guided by myself. Each action group discussion will be kick started by myself or a selected member of the group to make sure you are comfortable.

We shall share and learn from each other as we discuss and narrate our everyday experiences and stories which will later inform and inspire our design processes for co-production of works communicative aspects meant to tackle HIV/AIDS among young people in the industrial areas/community. It will help in learning and harnessing talents

and how that might improve your social and economic wellbeing. We will ask questions about HIV/AIDS and give you time to share experiences and your knowledge about precarities you face and how they perpetuate the spread of the epidemic. We shall discuss what young people can do to stop it from spreading across communities, how those infected are being supported and how health service providers have helped in your community to fight the scourge.

The action group sessions will take place in a location near your workshops/ workspaces and no one else but the people who will take part in the discussions and co-production sessions and myself will be present at this meeting. The entire discussion and practical procedures will be videotaped but no one will be identified by name. The tape will be kept safely, and the information recorded will be treated with confidentiality.

#### **For the interviews:**

During interviews, I will sit down with you in a comfortable space at or near your workshop area. If you don't wish to answer any or some of the questions during the interview you may say so and I will move to the next question.

No one else but me (interviewer) will be present unless you would like someone else to be there. The information recorded will be confidential as the entire interview will be tape recorded and no one will be identified by name on the tape. This tape will be destroyed after 3 weeks.

#### **DURATION OF RESEARCH**

This research will take place over 5 months in total. During that time, I will be interacting, working, and interviewing different members of the action groups and individuals with in workshops once every month and each interview will last approximately 1 to 2 hours.

#### **RISKS**

There is a risk that you may be uncomfortable talking about or be traumatised by sharing sensitive personal or confidential information related your experiences and HIV/AIDS by any chance. I DON'T wish this to happen, you don't have to answer any question or take part in activities that may traumatise you or hurt your feelings when they get personal.

#### **BENEFITS**

There will be no direct benefits to you, but your participation is likely to help in finding out more about how to use art and creativity to deal with HIV awareness and prevention while exploring new pathways for youth empowerment and improved livelihoods in your community.



## **RE-EMBURSEMENT**

You will not be provided with any special incentives to take part in this research. I will give you re-imbusement for your transport and other such expenses incurred as a result of participating in this research. On the other hand, protective gear such as gloves, overalls, visors, etc. shall be provided for personal safety during co-production activities in workshops.

## **CONFIDENTIALITY**

The information we collect from this research project will be kept private. Any information about you will have a number on it instead of your name. Only the researcher (myself) will know what your number is and I will lock that information with key and lock. It will not be given to anyone except research sponsor or your clinician, etc.

For action groups; I will ask you and others in the group not to talk to people outside the group about what was said in the group. I will in other words ask each of you to keep what was said in the group confidential. You should know however, that I cannot stop or prevent participants who were in the group from sharing things that should be kept confidential.

## **DISSEMINATION OF RESULTS**

Nothing you tell me today will be shared with anybody outside the research team and nothing will be attributed to you by name. The knowledge I get from this research will be shared with you and your community before it's made widely available to the public.

Participants will receive a summary of results through your action group leaders. There will be small meetings in the community, and these will be announced. Following the meetings, I will publish the results so that other interested persons may learn from the research.

## **REFUSAL/WITHDRAW RIGHTS**

You don't have to take part in this research if you don't wish to do so. You may stop participating in the discussions, interviews, or co-production process at any time that you wish without your job being affected. If you do withdraw, any information you have shared from me will be permanently deleted.

## **CONTACTS**

Local contacts;

Dr. Lillian Nabulime, (CEDAT) Makerere University, Kampala, 0777139996; Email [nabulimekitaka@yahoo.co.uk](mailto:nabulimekitaka@yahoo.co.uk)

Ssewanyana Robert, PGR, Durham University, UK, 0772413507/0705248244

IRB TASO contact; Mr Ojok Mijumbi Andrew, TASO, Mulago, Kampala, 0785037496,  
Email: [ojokandrew@gmail.com](mailto:ojokandrew@gmail.com)

#### **(v) Data management plan**

Research title: A participatory approach towards art and creativity for HIV/AIDS awareness, prevention, and empowerment of young people in marginalized settings in Kampala.

Purpose of the research

This study seeks to engage young people working as artisans in marginalised informal settings of Kampala into collaborative/ co-production of craft forms for HIV/AIDS awareness, prevention, and empowerment in the context of HIV/AIDS. It aims to observe, share, and learn from their lived experiences in order to inform and inspire applied sculptural practices that will (i) raise awareness of and lower the stigma associated with HIV/AIDS among young people; (ii) equip young artisans with the social, moral, and economic capacity to improve their lives, reducing the economic dependency that makes them vulnerable to risky behaviours that perpetuate HIV/AIDS infection.

A data management plan (DMP) has been put in place to help manage generated research data, meet institutional requirements, and help others use your data if shared as explained below;

Research data will be obtained from a number of source particularly through ethnographic sources that will require creating metadata from everyday situations in the selected research sites. Interactive participation with young artisans, coupled with conversations and narratives built around living and working experiences in the industrial areas in Kampala- Bwaise, Ndeeba and Katwe. Besides participant observation as one of the key data methods, Capturing and recording events, processes and daily activities will be done with the help of photography, audio, and video recorders prior to the consent of participating individuals. In the later stages of the study, formation of action-groups will lead to co-production of art/craft forms and knowledge which will be used as modes or tools of communication for new pathways of tackling HIV/AIDS and its associated problem whilst improving the livelihoods of young artisans in industrial areas of Kampala. All the data generated from the above will be managed by the

researcher, processed, archived, and stored in secure servers/files run by Durham University and some at Makerere University.

NB: All Interview data will be recorded and transcribed where participant consent is granted.

Additionally, transcripts and other data such as field notes in hard copies will be stored in a lockable drawer or filing cabinet to which only the researcher has access. Given the potential sensitivity of some data, the database will be accessible only to the PGR researchers and to IT systems administrators, although there would be no need for the latter to access files except in a disaster recovery scenario.

Findings will be made available on the researcher's project website and will also be shared at project workshops with stakeholders, curated exhibitions, in academic papers and conference presentations where consent to do so is granted by research participants.


Data collection will be overseen and planned by the researcher with advice from the two UK supervisors, a Makerere University-based supervisor, NGEN+ and TASO. Important to note is that a secure storage at Makerere University will allow the field data to be accessed by the researcher for two years beyond the end-of-funding date of the PhD and will be destroyed by the end of 5 years from the time of collection.

Sharing and dissemination of data will be done by the researcher with consent from the participants since it was co-produced by both parties. Dissemination will be mainly during conference, academic and workshop presentation organised by the researcher or relevant stakeholders involved in the study. Access to clouded or secured data on servers will be limited to the researcher. IT teams in charge of University servers will only have access to the data only in recovery crisis scenarios and with permission from the researcher.

## APPENDIX 4

### INTRODUCTION LETTERS

Figure 1: Bwaise introductory letters

**INDUSTRIAL AREA VILLAGE**  
**BWAISE 1 –KAWEMPE DIVISION**  
Tel: 0772897447 /0705661755 / 0753604739 /0751865555

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Our Ref.....  
Your Ref.....

Date... 25/7/2019

To whom it may concern.


Dear Sir/Madam


Re. Mr Ssewanyana Robert.

The bearer of this letter in the names above is a student at Makerere university and Durham university united Kingdom he is on research about of his studies at or near.

The purpose of this letter is to recommend him for any necessary assistance from your office any service rendered to him will be highly appreciated

Thank you  
Yours faithfully





BWAISE FURNITURE MAKERS SACCO

09<sup>th</sup>/JULY/2019.

RE: TO WHOM IT MAY CONCERN

This is to certify that Ssewanyama Robert of Makerere University and Durham University has been granted permission to conduct a research on Participatory approach to Art and Creativity for HIV/AIDS awareness, prevention and empowerment of young-artisans in our workshops in Bwaise

We have agreed to cooperate with above student and will render him any assistance including space for his research workshops with ~~consent~~

Yours faithfully,

Kawuki Passal

Chairman

Bwaise Furniture Makers Sacco.



Figure 2: Ndeeba introductory letter



**TOMUSANGE ZONE LC 1 NDEEBA PARISH**  
**RUBAGA DIVISION KAMPALA DISTRICT**  
**TEL: 0772 544404 / 0701 483167**

Date: 26<sup>th</sup> - July 2019

RE: INTRODUCTION MISSIVE

MR. SSEWANYAMA ROBERT, PHD STUDENT  
have introduced himself to our office  
of Tomusange Zone, Ndeeba Parish, Rubaga  
Division, Kampala District.

The purpose of his introduction is to carry  
our fieldwork in the aforementioned zone.

The fieldwork is pertain to youth both HIV  
affected and infected young artisans

Any assistance accorded to him  
is very much appreciated



Figure 3: Katwe introduction letter

**BULIGGWANGA VILLAGE URBAN COUNCIL I**  
**MAKINDYE DIVISION**  
**KATWE I PARISH**  
**Mob No: 0712-718100 / 0755-718100**

**KCCA**  
 KAMPALA CAPITAL CITY AUTHORITY  
 KCCA

Our Ref: 62/1547/08/2019  
 Your Ref: .....  
 Date: 02 AUG 2019

**KCCA** 02 AUG 2019  
 CHAIRPERSON L.C.I  
 KATWE I BULIGGWANGA VILLAGE

TO WHOM IT MAY  
 CONCERN

Rev: SEKIANYANA ROBERT

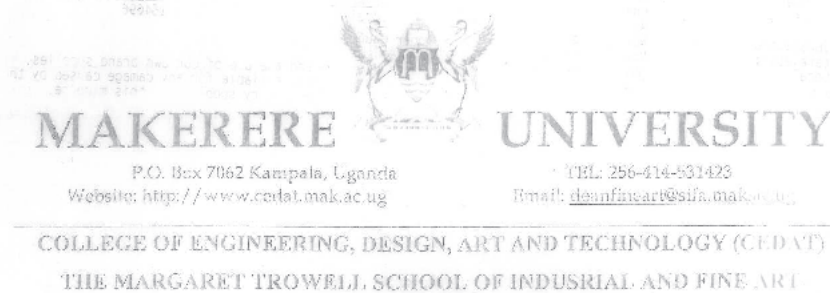
This is to certify that the above mentioned person, who is a student at Makerere University / Durham University, We have received him in our village / zone / area. It has come to our notice that he intend to get more technology from the people working with in our area.

Therefore we recommend him for that matter.

Tours in service  
James Simal  
James Simal

**KCCA** 02 AUG 2019  
 CHAIRPERSON L.C.I  
 KATWE I BULIGGWANGA VILLAGE

Figure 4: Makerere University introduction letter



To Whom it may concern

18th July 2019

Ref: Ethical Clearance

**Mr. Ssewanyana Robert, PhD Student of Makerere University and Durham University**

Mr Ssewanyana is a full time PhD student registered at Durham University, United Kingdom (2019-2023). His research is a sandwiched programme with Makerere University, College of Engineering, Design Art and Technology (CEDAT), under the title:

*"A Participatory approach to Art and Creativity for HIV/AIDS Awareness, Prevention and Empowerment among young Artisans (15-24 years) in Uganda"*

Mr Ssewanyana is conducting field work in Uganda which has been approved by Durham and Makerere Universities in selected Uganda artisan communities affected by HIV/AIDS in areas around Kampala District namely: Bwaise, Ndeeba and Katwe. His research is largely based on collaborative participation with vulnerable young artisan in the above industrial areas for joint knowledge production, sharing creative skills through co-production of HIV/AIDS related interventional concepts geared towards awareness and their socio-economic empowerment.

The purpose of this letter, therefore, is to request for permission (Ethical clearance) to enable him conduct research among the fore-mentioned artisan community affected by HIV/AIDS.

We would be very grateful for any assistance that you can offer to Mr Ssewanyana Robert.

Yours sincerely,

Dr. LilianM Nabulime,

A handwritten signature in black ink, appearing to read "Nabulime L", is written over the printed name.

PhD Supervisor  
Senior Lecturer, Department of Fine art, School of Fine Art,  
College of Engineering, Design, Art and Technology,  
Makerere University, Kamapala, Uganda.  
Email: [nabulimekitaka@yahoo.co.uk](mailto:nabulimekitaka@yahoo.co.uk)


Mobile: +256 777 139 996

**Co-supervision:**

Professor Cheryl McEwan (Geography Department) and Prof. Hannah Brown  
(Department of Anthropology), Durham University, United Kingdom



Figure 5: Uganda AIDS Information letter



**AIDS INFORMATION CENTRE - UGANDA**

**Head Office**  
Musajja - Alumbwa Road  
P. O. Box 10446, Mengo-Kisenyi, Kampala-Uganda  
Tel: 0393 264454/3  
Email: [informationdesk@aicug.org](mailto:informationdesk@aicug.org)  
Website: [www.aicug.org](http://www.aicug.org)

---

**AIC Regional Branches**

**Kampala Office**  
Musajja - Alumbwa Road  
P.O. Box 10446, Mengo - Kisenyi  
Tel: +256 393 264 454/3  
Email: [aickampalabranch@aicug.org](mailto:aickampalabranch@aicug.org)

**Mbale Office**  
Plot 2 Mugisu Walker Hill, Pallisa Road  
P.O. Box 1838 Mbale  
Tel: +256 393 264 454/3  
Tel: +256 780178605 / 704 667800  
Email: [aicmbalebranch@aicug.org](mailto:aicmbalebranch@aicug.org)

**Arua Office**  
Plot 148 Awindir, Crescent Road  
P.O. Box 550 Arua  
Tel: +256 393 264 454/3  
Tel: 0780178606/0704667899  
Email: [aicaruarbranch@aicug.org](mailto:aicaruarbranch@aicug.org)

**Kabale Office**  
Plot M24 Rwakiseta Road Kirigime  
P.O. Box 373 Kabale  
Tel: +256 393 264 454/3  
Tel: 0780178604/0704 667866  
Email: [aickabalebranch@aicug.org](mailto:aickabalebranch@aicug.org)

**Mbarara Office**  
Plot 11 Ruharo,  
P.O. Box 1055  
Tel: +256 393 264 454/3  
Tel: +256 780 178603/704 667844  
Email: [aicmbararabranch@aicug.org](mailto:aicmbararabranch@aicug.org)

**Jinja Office**  
Plot 17 Bell Avenue West,  
P.O. Box 2159 Jinja  
Tel: +256 393 264 454/3  
Tel: +256 780 178610/ 704 667812  
Email: [aicjinjabranch@aicug.org](mailto:aicjinjabranch@aicug.org)

**Soroti Office**  
Plot 2 Ocuiji Road  
P.O. Box 62 Soroti  
Tel: +256 393 264 454/3  
Tel: +256 780 178608 / 704 667855  
Email: [aicisorotibranch@aicug.org](mailto:aicisorotibranch@aicug.org)

**Lira Office**  
Plot 5 Dokolo Road,  
P.O. Box 156 Lira  
Tel: +256 393 264 454/3  
Tel: +256 780 178607 / 704 667899  
Email: [aiclirabranch@aicug.org](mailto:aiclirabranch@aicug.org)

**Karamoja Office**  
Plot 22 Loruk Road,  
P.O. Box 62  
Tel: +256 393 264 454/3  
Email: [aickaramojabranch@aicug.org](mailto:aickaramojabranch@aicug.org)

8<sup>th</sup> August 2019

The PHD Supervisor,  
College of Engineering Design, Art and Technology  
Makerere University and Durham University

Dear Sir/Madam,

**RE: ETHICAL CLEARANCE OF MR SSEWANYANA ROBERT TO CONDUCT HIS RESEARCH STUDY**

In response to your letter received on the 1<sup>st</sup> August 2019 requesting for Ethical clearance to conduct a research study with the support of AIDS Information Centre Kampala.

This is to certify that Mr. Ssewanyana Robert who is a student of Makerere University and Durham University has been ethically cleared by AIDS Information Centre to enable him conduct his research study among the artisan communities affected by HIV/AIDS.

AIDS Information Centre further pledges that it will professionally and technically support Mr. Ssewanyana Robert to conduct his field work research in the selected artisan communities affected by HIV /AIDS in areas around Kampala District namely Bwaise, Ndeeba and Katwe.

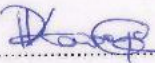
Where an HIV Counselling and testing outreach shall be required to be conducted to the mobilized artisan communities, AIDS Information Centre shall provide a team of eight (8) service providers consisting of Five (5) counsellors, (2) Laboratory technicians and one (1) prevention officer at a fee of 50,000/= Uganda shillings per service provider per day, fueling of the office vehicle amounting to 60,000/= and a professional fee of 100,000/=.

For an HIV/AIDS sanitization talk, a prevention officer shall be paid a Perdiem of (120,000/=) one hundred twenty thousand shillings per day so as to conduct such an activity to the mobilized community.

We are looking forward to support you so as to achieve your academic objectives.

Thank you.

Yours Sincerely,



Richard Kawooya  
Prevention Officer (AIC Kampala Regional Office)  
0782-724212/0701-906593

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**28 Years of Quality HIV Counseling and Testing**

*Vision Statement: Population free of HIV and AIDS and other preventable health problems*  
*Mission: To provide sustainable, collaborative and integrated HIV and AIDS and other related services in Uganda*

Figure 6: NGEN+ introduction letter



# NGEN+

STANDING TOGETHER TO IMPROVE THE QUALITY OF LIFE

National Guidance & Empowerment Network of People Living with HIV/AIDS

Ref: NGEN+/General/0916/54/72

19 August 2019;l

The PhD Supervisor  
Senior Lecturer, Department of Fine Art,  
School of Fine Art,  
College of Engineering, Design, Art and Technology  
Makerere University, Kampala, Uganda.

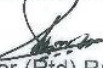
Dear Madam,

**RE: ETHICAL CLEARANCE FOR MR. SSEWANYANA ROBERT, PHD  
STUDENT OF MAKERERE UNIVERSITY AND DURHAM UNIVERSITY.**

We are in receipt of yours dated 18<sup>th</sup> July 2019 in which you introduce to us the above mentioned PhD student who intends to carry out his field work in selected Ugandan artisan communities that are affected by HIV/AIDS in and around Kampala.

We are happy to inform you that Mr. Ssewanyana has been accepted to carry out his field work with us and we shall have no problem in giving him the assistance he may require to meet the various groups in all the communities that we are associated with in Uganda.

Yours Sincerely,

  
for Major (Rtd) Rubaramira Ruranga  
Chief Executive Director (NGEN+)

Xlrowoza Zone Road,  
Near Uganda Christian University, Mukono  
P. O. Box 24950, Kampala  
Tel: +256 414 273 528/256 752 303 397  
Email: [ngenadm@gmail.com](mailto:ngenadm@gmail.com)  
[ruranga@gmail.com](mailto:ruranga@gmail.com)

Bringing together people living with HIV/AIDS, empowering them to participate in HIV prevention and AIDS care activities in the country.

## APPENDIX 3

## APPENDIX 5

### SAMPLE INVITATION LETTER

Figure 7: Official Invitation card for guest to the dissemination/exhibition event

The invitation card features a header with four logos: Durham University, the Ugandan national emblem, NGEN+ (National Gender and Empowerment Network), and Sustainable Development Goals. The main text is centered and reads: "RESEARCH DISSEMINATION EXHIBITION" in bold black letters, followed by the subtitle "Art and Creativity for HIV/AIDS prevention and Empowerment of Young People(15-24Yrs) in Uganda." in red. Below this, it says "Makerere Art Gallery invites the company of" followed by a dotted line. The event details are: "to a RESEARCH DISSEMINATION EXHIBITION by Robert Ssewanyana at Makerere University Gallery from Monday, 4th January - Saturday 30th January, 2021". At the bottom left, it lists the sponsor "GCRF" (Global Challenges Research Fund). At the bottom center, it provides contact information: "R.S.V.P Robert Ssewanyana Tel: 0772 413 507/ 0705 248 244". At the bottom right, it features the "MAKERERE ART GALLERY MIHCR" logo.

Durham University

NGEN+  
National Gender and Empowerment Network  
of People Living with HIV Aids Uganda

SUSTAINABLE DEVELOPMENT GOALS

**RESEARCH DISSEMINATION EXHIBITION**  
"Art and Creativity for HIV/AIDS prevention and Empowerment of Young People(15-24Yrs) in Uganda."  
Makerere Art Gallery invites the company of

.....

to a **RESEARCH DISSEMINATION EXHIBITION** by Robert Ssewanyana at Makerere University Gallery from Monday, 4th January - Saturday 30th January, 2021

Sponsor:

R.S.V.P Robert Ssewanyana Tel: 0772 413 507/ 0705 248 244

GCRF  
Global Challenges Research Fund

MAKERERE ART GALLERY  
MIHCR

## APPENDIX 6

### SOME OF THE RESEARCH PARTICIPANTS IN WORKSHOPS

Table 3: Ndeeba Industrial Area

No.	Participant (Pseudonym)	Sex	Age	Location (Study site)	Occupation
1	Participant A	Male	27	Ndeeba- Betania	Carpenter
2	Participant B	Male	18	Katwe/Nateete	Scrap collector (HIV+)
3	Participant C	Female	23	Ndeeba- Railway	Sander
4	Participant Q	Male	20	Ndeeba-Railway	Engraver
5	Participant T	Female	23	Ndeeba-Betania	Sander
6	Participant P	Male	21	Ndeeba-Railway	Carpenter
7.	Participant S	Female	21	Ndeeba Betania	Wood sander (HIV+)
8.	Participant V	Male	23	Katwe	Carpenter
9.	Participant W	Male	20	Ndeeba-Betania	Wood sander

Table 4: Lungujja-Kitunzi Residential Precincts

No.	Participant (Pseudonym)	Sex	Age	Location (Study site)	Remarks
1.	Participant G	Male	25	Lungujja-Kosovo	HIV +
2.	Participant H	Female	23	Lungujja-Kitunzi	HIV+
3.	Participant K	Male	35	Lungujja-Kosovo	HIV+
4.	Participant Y	Male	22	Lungujja-Busega	HIV+
5.	Participant AN	Female	30	Lungujja-Kosovo	HIV+ (Works with ICWEA as an advocate for sexual reproductive health and rights)
6.	Participant TS	Male	17	Lungujja-Kosovo	HIV + (prenatal)/student
7.	Participant AB	Male	32	Lungujja-Nabisasilo	HIV+
8.	Participant RN	Female	23	Lungujja-Sendaula	CHW/VHT
9.	Participant EN	Female	24	Lungujja- Nabisasilo	HIV+
10.	Participant VN	Female	19	Lungujja-Kosovo	HIV+ (Prenatal)
11.	Participant EN	Male	31	Lungujja-Kosovo	Caretaker of 2 prenatals
12.	Participant GN	Female	36	Lungujja Kitunzi	VHT/CHW (Member of LUCOHECO)
13.	Participant IM	Male	25	Lungujja-Sendaula	Student (HIV-)
14.	Participant RS	Male	27	Lungujja Kitunzi	Youth leader/ Councillor, Rubaga
15.	Participant CN	Female	24	Lungujja-Kosovo	HIV+ (Wife to Participant K)

NB: Participants GN, RN, and RS were my research gatekeepers and also consented to participate in the creativity workshop with HIV positive participants in Lungujja.

Table 5: MEETINGS WITH RESEARCH GATEKEEPERS

NO.	Names	Job description/Title	Date of meeting	Location/ Area	Remarks
1.	Evelyn Nakiryowa	Chairperson, Ndeeba	1 <sup>st</sup> February 2020	Tomusange Zone, Ndeeba LC1 offices	Also works as local mobilizer for JCRC and a peer educator for Rubaga Division, Kampala
2.	Faisal Kawuki	Chairman Bwaise furniture makers association and SACCO	10 <sup>th</sup> February 2020	Bwaise SACCO offices, Mbaawo zone	Also, carpenter and workshop owner
3.	Retired Major Rubaramira Ruranga	National Guidance and Empowerment Network for People living with AIDS (NGEN+)	22 <sup>nd</sup> February 2020	NGEN+ Head offices, Kamwokya, Kampala	Also, Chairman, Operation Wealth Creation (OWC) in Uganda
4.	Grace Kabuubi	Community health worker/VHT	31 <sup>st</sup> March 2020	LUCOHECO Office, Lungujja, Kitunzi	Nurse with LUCOHECO and HIV/AIDS counsellor
5.	Paul Kajubi	Community health worker	15 <sup>th</sup> April 2020	Council offices in Rubaga	Village Councillor
5.	Resty Namulindwa	Community health worker	20 <sup>th</sup> April 2020	Private residence	Youth mobilizer, LC1
6.	Richard Kawooya	Prevention Officer	28 <sup>th</sup> February 2020	AIC Kampala regional Offices, Mengo, Kisenyi	Community outreach programmes support office
7.	Tom Mark Ssebunya	Chairman, Ndeeba furniture makers' Group/SACCO	28 <sup>th</sup> September 2020	Ndeeba carpentry workshop, Betania zone	Also, carpenter and workshop owner
8	Paul Mulangila	Katwe metal worker's group	10 <sup>th</sup> August 2020	Katwe metal workshop, Ring road, Mengo	Metal lathing and drilling

