Allowable Death and the Valuation of Human life
A study of People Living with HIV and AIDS in Zimbabwe

A thesis submitted to the University of Manchester for the degree of
Doctor of Philosophy in the Faculty of Humanities

2016

FORTUNATE MACHINGURA

GLOBAL DEVELOPMENT INSTITUTE
SCHOOL OF ENVIRONMENT, EDUCATION AND DEVELOPMENT
TABLE OF CONTENTS

1 INTRODUCTION ..........................................................16
   1.1 Overview and research questions ....................................16
   1.2 Conceptual and theoretical underpinnings of the study ..........18
   1.3 Philosophical and methodological underpinnings of the study ....19
   1.4 Major concepts and their application in this study ..............19
   1.4.1 Frame ...................................................................20
   1.4.2 Value .....................................................................20
   1.4.3 Allowable death ........................................................21
   1.5 Thesis outline ............................................................22

2 THE ZIMBABWE HIV/AIDS CONTEXT ..................................25
   2.1 Introduction ................................................................25
   2.2 Global overview of the HIV/AIDS epidemic ......................25
   2.3 HIV/AIDS in Sub-Saharan Africa ..................................26
   2.4 HIV/AIDS in Southern Africa ........................................28
   2.5 The Zimbabwe HIV/AIDS epidemic ................................29
   2.5.1 HIV/AIDS and key affected populations ......................29
   2.5.2 HIV/AIDS policy and legal framework .......................36
   2.5.3 HIV/AIDS health outcomes ......................................36
   2.5.4 Zimbabwe poverty and HIV/AIDS .............................38
   2.6 Conclusion ..................................................................39

3 PROBLEMATISATION OF THE VALUATION OF HUMAN LIFE .......40
   3.1 Introduction ................................................................40
   3.2 The problematisation of the value of human life ..................40
       3.2.1 Human rights perspective ........................................41
       3.2.2 Health economics perspective .................................46
       3.2.3 Morality Perspective ...............................................54
   3.3 Theoretical frameworks for investigating the value of human life ...56
       3.3.1 The social determinants of health and the value of human life ...56
       3.3.2 Governmentality and the value of human life ............58
   3.4 Research questions and the study’s conceptual framework ......62
       3.4.1 Episteme: Policy and the legal framework for HIV/AIDS as governmentality ..........66
       3.4.2 Techne: Calculative devices as governmentality ............67
       3.4.3 Ethical government of the self: Discursive framings of HIV/AIDS as governmentality ....68
       3.4.4 The research questions .............................................69
   3.5 Conclusion ..................................................................69

4 METHODOLOGY .............................................................71
   4.1 Introduction ................................................................71
   4.2 Philosophical underpinnings: Constructivist epistemology .......72
       4.2.1 Episteme of government: Policy and legal framework of HIV/AIDS ..........74

TABLE OF CONTENTS ..............................................................2
LIST OF TABLES ......................................................................5
LIST OF FIGURES ....................................................................6
LIST OF PHOTOS ....................................................................7
LIST OF BOXES ......................................................................8
LIST OF ABBREVIATIONS AND ACRONYMS ..............................9
ABSTRACT ...........................................................................11
DECLARATION .......................................................................12
COPYRIGHT STATEMENT .......................................................13
ACKNOWLEDGEMENTS ........................................................14

74
72
71
71
69
68
67
66
65
64
63
62
61
60
59
58
57
56
55
54
53
52
51
50
49
48
47
46
45
44
43
42
41
40
39
38
37
36
35
34
33
32
31
30
29
28
27
26
25
24
23
22
21
20
19
18
17
16
15
14
13
12
11
10
9
8
7
6
5
4
3
2
1
4.2.2 Techne of government: Institutions and their calculative devices 74
4.2.3 Ethical government of the self: Formation of identities through discursive framings 75
4.3 Methodology: Qualitative case study design 77
4.3.1 Study design 78
4.3.2 Study sites 80
4.4 Methods 85
4.4.1 Participant observations 86
4.4.2 Document analysis 88
4.4.3 Elite interviews 89
4.4.4 Semi-structured interviews and life history interviews 93
4.4.5 Focus group discussions 104
4.4.6 Summary of research methods and field activity timeline 105
4.5 Research ethics 107
4.6 Positionality 109
4.7 Data analysis 112
4.7.1 Data collation 112
4.7.2 Coding 113
4.7.3 Descriptive themes 113
4.7.4 Analytical themes 113
4.8 Conclusion 114
5 THE WAYS IN WHICH HEALTH POLICY SENIOR GOVERNMENT OFFICIALS FRAME THE VALUE OF PEOPLE LIVING WITH HIV AND AIDS 115
5.1 Introduction 115
5.2 Valuation of human life as a rational and thoughtful process 115
5.2.1 PLWHA are equal citizens protected by the right to health 116
5.2.2 PLWHA are legal citizens protected by HIV/AIDS laws and policies 118
5.2.3 PLWHA are political citizens who can federate for collective identity 123
5.2.4 Expert power can be a source premature deaths 125
5.3 Valuation of human life as a calculative rationality 127
5.3.1 Cost-effective analysis: A shopping list 127
5.3.2 Disability adjusted life years (DALYs) 131
5.3.3 Results and Statistical based rationalities 133
5.3.4 Market-based rationalities 136
5.4 Conclusion 141
6 FRAMING THE VALUE OF HUMAN LIFE: HOW DOES SOCIETY FRAME THE VALUE OF PEOPLE LIVING WITH HIV AND AIDS? 143
6.1 Introduction 143
6.2 Valuation of PLWHA as identity formation – governing others 143
6.2.1 PLWHA are equal, legal and political citizens protected by the law 144
6.2.2 [De]valued bodies and expendable populations: Religion as a double-edged discourse of love versus condemnatory judgement 147
6.2.3 Degraded and demeaned: Labelling of Opportunistic Infection clinics 155
6.2.4 Undervalued, underpaid and frustrated 158
6.3 Conclusion 160
7 THE FRAMING OF THE VALUE OF HUMAN LIFE: HOW DO PEOPLE LIVING WITH HIV FRAME THEIR OWN VALUE? 162
7.1 Introduction 162
7.2 Demographic profiles of PLWHA interview participants 163
7.3 Ethical government of the self 167
7.3.1 Devalued bodies: Homosexual PLWHA as expendable people 167
7.3.2 Disgust and worthlessness [Kusemesa ne Kufa sembwa] 172
7.3.3 Undervalued, poor and feeling mad 177
LIST OF TABLES

Table 2:1: Ranks for top 10 causes of YLLs 1990-2010, Zimbabwe .............................................30
Table 2:2: Population estimates (Census 2012) and HIV/AIDS estimates (2013) ..........................33
Table 3:1: Macro rationing of health care Resources .....................................................................52
Table 3:2: Key issues in understanding the VoHL ...........................................................................66
Table 4:1: Ways of thinking: Episteme dimension .......................................................................74
Table 4:2: Ways of acting: Techne dimension ..............................................................................75
Table 4:3: Ways of forming identities: ‘Ethical government of the self” dimension .................76
Table 4:4: Suitability of case study to the current research .........................................................79
Table 4:5: Comparison of Chitungwiza and Goromonzi Districts .................................................81
Table 4:6: Summary table of utility and triangulation of the research methods .........................85
Table 4:7: Seeds recruited for the study ..........................................................................................97
Table 4:8: Summary of research methods used in the study, numbers of participants and selection of participants .............................................................................................................106
Table 5:1: Key legal provisions for HIV and AIDS responses in Zimbabwe .........................120
Table 5:2: HIV spending by funding source 2005–2011 ..............................................................138
Table 6:1: Religious characteristics of the Zimbabwean population by sex ..............................147
Table 7:1: Age Group by sex .........................................................................................................164
Table 7:2: Highest level of education by sex ................................................................................164
Table 7:3: Religion by sex .............................................................................................................165
Table 7:4: Marital status by sex ....................................................................................................165
Table 7:5: Symbolic constructs of value of PLWHA: Defeat and hopelessness .....................176
Table 7:6: Symbolic constructs of value of PLWHA: Victory .....................................................196
Table 8:1: Results summary .........................................................................................................200
LIST OF FIGURES

Figure 2.1: Prevalence of HIV among adults aged 15–49 (%) [2005; 2009;2013] .................................28
Figure 2.2: Zimbabwe HIV prevalence rate by place of residence .......................................................31
Figure 2.3: New HIV infections in all ages 1990-2014 .....................................................................37
Figure 3.1: Mapping out the study’s conceptual framework and research questions ......................64
Figure 3.2: Model for understanding the valuation of human life .....................................................65
Figure 4.1: Location of Chitungwiza District in Zimbabwe .................................................................82
Figure 4.2: Location of Goromonzi District in Zimbabwe .................................................................83
Figure 4.3: An overview of the process of identification and recruitment of study participants ....101
Figure 5.1: Example of statistics contained in the national health profile (Table) .........................134
Figure 5.2: Example of statistics contained in the national health profile (Map) ............................135
Figure 5.3: HIV spending by funding source 2005–2011 .................................................................139
Figure 7.1: Source of ARVs ..............................................................................................................166
Figure 7.2: Employment status of PLWHA interview participants ..................................................166
LIST OF PHOTOS

Photo 5:1: Signpost on no-user-fees .................................................................140
Photo 6:1: A rural health centre in Goromonzi District..................................................157
Photo 7:1: Takesure and his basket at Chikwanha Shopping Centre in Chitungwiza –Zengeza.....189
Photo 7.2: Nutritional gardens for PLWHA by PLWHA – the project spearheaded by G108 – Goromonzi, Mwanza Ward.................................................................193
Photo 7:3: Muuyu tree was taken along the road between Chipinda Pools Camp and a turn-off to Masasanya Dam, Gonarezhou National Park. Zimbabwe .................................................194
### LIST OF BOXES

<p>| Box 4:1 | Positionality difficulties: case example in the field (G073) .................................................................110 |
| Box 5:1 | Quotes from senior government officials on CEA .....................................................................................................128 |
| Box 5:2 | Development organisation-led HIV programmes 2010–2015 ...............................................................................129 |
| Box 5:3 | Interview with E1:5 (Excerpt) ............................................................................................................................129 |
| Box 5:4 | Health statistics and surveillance tools and products in the MoHCC ..................................................................133 |
| Box 7:1 | Tino’s Case – Goromonzi (LHIG078) ....................................................................................................................167 |
| Box 7:2 | Tatenda’s case – Chitungwiza (LHIC025) .............................................................................................................169 |
| Box 7:3 | Sex worker’s case – Goromonzi (G077) ..................................................................................................................173 |
| Box 7:4 | Out-of-pocket costs (C056) ..................................................................................................................................177 |
| Box 7:5 | Excerpt – Bernard’s story – Goromonzi (LHIG075) ...............................................................................................178 |
| Box 7:6 | Costs of getting ‘free’ ARVs from Chitungwiza Central Hospital .........................................................................179 |
| Box 7:7 | Lost all brothers to AIDS and cost impeded access to health care (LHIG111) ......................................................180 |
| Box 7:8 | Excerpt – Mai Shingi’s case (LHIC013) ................................................................................................................184 |
| Box 7:9 | Clara’s case – Chitungwiza (LHIC011) ..................................................................................................................189 |
| Box 7:10 | Symbolic expressions: Baobab tree (G108) ............................................................................................................192 |
| Box 0:1 | Appendix 13 - Tino’s Case – Goromonzi (LHIG078) ............................................................................................294 |
| Box 0:2 | Appendix 13 - Bernard’s Full Story – Goromonzi (LHIG075) ...............................................................................294 |
| Box 0:3 | Appendix 13 - Mai Shingi’s Full case (LHIC013) ....................................................................................................295 |</p>
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAC</td>
<td>AIDS Action Committees</td>
</tr>
<tr>
<td>ACRWC</td>
<td>African Charter on the child’s Rights and Welfare</td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral Therapy</td>
</tr>
<tr>
<td>ARV</td>
<td>Anti-retroviral</td>
</tr>
<tr>
<td>CBA</td>
<td>Cost Benefit Analysis</td>
</tr>
<tr>
<td>CD4</td>
<td>a cluster of differentiation 4</td>
</tr>
<tr>
<td>CEA</td>
<td>Cost Effectiveness Analysis</td>
</tr>
<tr>
<td>CEDAW</td>
<td>Convention on the Elimination of all forms of Discrimination Against Women</td>
</tr>
<tr>
<td>CIA</td>
<td>Cost Identification Analysis</td>
</tr>
<tr>
<td>DAC</td>
<td>District AIDS Coordinator</td>
</tr>
<tr>
<td>DALYs</td>
<td>Disability Adjusted Life Years</td>
</tr>
<tr>
<td>DFID</td>
<td>U.K Department for International Development</td>
</tr>
<tr>
<td>DHS</td>
<td>Demographic and Health Survey</td>
</tr>
<tr>
<td>EI</td>
<td>Elite Interviews</td>
</tr>
<tr>
<td>FGD</td>
<td>Focus Group Discussion</td>
</tr>
<tr>
<td>GFATM</td>
<td>Global Fund to Fight AIDS, Tuberculosis and Malaria</td>
</tr>
<tr>
<td>GoZ</td>
<td>Government of Zimbabwe (GoZ)</td>
</tr>
<tr>
<td>HAART</td>
<td>Highly Active Anti-Retroviral Therapy</td>
</tr>
<tr>
<td>HISS</td>
<td>Health Information and Surveillance Systems</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>ICCPR</td>
<td>International Covenant on Civil and Political Rights</td>
</tr>
<tr>
<td>ICESR</td>
<td>International Covenant on Economic, Social and Cultural Rights</td>
</tr>
<tr>
<td>INGO</td>
<td>International Non-Governmental Organisation</td>
</tr>
<tr>
<td>ISIS</td>
<td>Islamic State of Iraq and Syria</td>
</tr>
<tr>
<td>LGBT</td>
<td>Lesbians, Gays Bisexuals and Transgender persons</td>
</tr>
<tr>
<td>LHI</td>
<td>A life history interview</td>
</tr>
<tr>
<td>MIMS</td>
<td>Multi-indicator Monitoring Survey</td>
</tr>
<tr>
<td>MoHCC</td>
<td>Ministry of Health and Child Care</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Full Form</td>
</tr>
<tr>
<td>--------------</td>
<td>-----------</td>
</tr>
<tr>
<td>MRCZ</td>
<td>Medical Research Council of Zimbabwe</td>
</tr>
<tr>
<td>MSM</td>
<td>Men who have sex with men</td>
</tr>
<tr>
<td>NAC</td>
<td>National AIDS Council</td>
</tr>
<tr>
<td>NAPOVC</td>
<td>Action Plan for Orphans and Other Vulnerable Children</td>
</tr>
<tr>
<td>Non-PLWHA</td>
<td>People who are not living with HIV</td>
</tr>
<tr>
<td>OI</td>
<td>Opportunistic Infections</td>
</tr>
<tr>
<td>PEPFAR</td>
<td>United States President's Emergency Plan for AIDS Relief</td>
</tr>
<tr>
<td>PICES</td>
<td>Poverty Income, Consumption and Expenditure Survey</td>
</tr>
<tr>
<td>PLWHA</td>
<td>People Living with HIV/AIDS</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of Mother to Child of HIV Transmission</td>
</tr>
<tr>
<td>PO</td>
<td>Participant Observation</td>
</tr>
<tr>
<td>RDC</td>
<td>Rural District Council</td>
</tr>
<tr>
<td>RDS</td>
<td>Respondent Driven Sampling</td>
</tr>
<tr>
<td>SGO</td>
<td>Senior Government Officials</td>
</tr>
<tr>
<td>SGSS</td>
<td>Second Generation Surveillance Systems</td>
</tr>
<tr>
<td>SSA</td>
<td>Sub-Saharan Africa</td>
</tr>
<tr>
<td>STI</td>
<td>Sexually Transmitted Infections</td>
</tr>
<tr>
<td>SW</td>
<td>Sex Workers</td>
</tr>
<tr>
<td>TAC</td>
<td>Treatment Action Campaign</td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>UDHR</td>
<td>Universal Declaration of Human Rights</td>
</tr>
<tr>
<td>UN</td>
<td>United Nations</td>
</tr>
<tr>
<td>UNGASS</td>
<td>United Nations General Assembly Special Session on HIV/AIDS</td>
</tr>
<tr>
<td>VoHL</td>
<td>The value of human life</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
</tr>
<tr>
<td>WSW</td>
<td>women who have sex with women</td>
</tr>
<tr>
<td>YLD</td>
<td>Years Lost due to Disability</td>
</tr>
<tr>
<td>ZNASP</td>
<td>Zimbabwe National HIV/AIDS strategic plan</td>
</tr>
<tr>
<td>ZNBDC</td>
<td>Zimbabwe National Burden of Disease Committee</td>
</tr>
<tr>
<td>ZNNP+</td>
<td>National Association of People living with HIV</td>
</tr>
</tbody>
</table>
ABSTRACT

Fortunate Machingura

The University of Manchester, Ph.D. Development Policy and Management

September 2016

With more than 75% of its population experiencing poverty, Zimbabwe was in 2012 considered one of the world’s poorest countries. The country sits at the centre of the global HIV/AIDS epidemic and remains one of the hardest hit countries accounting for 5% of all new infections in sub-Saharan Africa. Zimbabwe’s 15% HIV prevalence rate was 19 times the global average by 2012, and the total years of life lost due to premature mortality increased by over 150% between 1990 and 2010 because of HIV/AIDS. This study draws on notions of ‘governmentality’ to ask how the ‘framing’ of the value of PLWHA has influenced their treatment by the Zimbabwean government and society. Four questions are posed: first the study asks, in what ways do health policy decision-makers in Zimbabwe frame the value of people living with HIV/AIDS (PLWHA)? Secondly, the study questions the ways in which people not infected by HIV (Non-PLWHA) frame the value of PLWHA. Thirdly, the study turns to PLWHA and asks how they frame their own value. Finally, the study investigates the implications of valuing PLWHA, for their lives, or conversely, their deaths. The study draws upon primary research undertaken through interviews, focus group discussions, observations and document review. While there are some contradictions within and between groups of study participants in the ways they frame the value of PLWHA; the study finds consensus within and between these groups in the manner in which they tend to value PLWHA. Analysing these findings, there are five ways people in Zimbabwe frame the value of PLWHA.

Firstly, from a ‘citizen’ perspective, PLWHA are both legal and political citizens who can identify as equal members of society like other citizens. They have social rights; participate, belong and can access HIV treatment that can reduce risks of death. Secondly, from a ‘client’ standpoint; PLWHA are customers, gaining access to health services through individual monetary payments or social payments such as Government budget allocations. This introduces a degree of ‘rationing’, forcing the clients (PLWHA) to behave in ways that increase their chances of receiving services. Those with lower purchasing power struggle to access expensive life-saving anti-retrovirals, thus individual wealth confers value on the lives of the wealthy. Thirdly, framing from a Statistical Representation perspective - through statistics, PLWHA can be used as a means of bargaining for government to gain access to international funding, to increase the chances of survival for PLWHA by bringing services such as antiretroviral therapy (ART). Fourthly, the ‘Expendable populations’ perspective views subgroups of PLWHA who fail to adhere to norms of behaviour prescribed by the government, including those unable to purchase services, such as the poor and homosexuals, sex workers and prisoners, as populations that may be allowed to die. Finally, the study shows that PLWHA lament the discursive space of technocrats with a counter-narrative of their value in which they emerge not as expendable victims but as victors reframed as an indefatigable population - ‘Resiliencers’. PLWHA create a narrative of disobedient materiality, challenging totalising notions of governmentality. This study concludes by considering the relevance in the Zimbabwean context of the concept of ‘Allowable Death’ as a premature, avoidable death despite consciously crafted narratives that the death happened because nothing could have been done under the prevailing conditions to prevent it.
DECLARATION

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning;

Fortunate Machingura September 2016
COPYRIGHT STATEMENT

i. The author of this thesis (including any appendices and/or schedules to this thesis) owns certain copyright or related rights in it (the “Copyright”) and she has given The University of Manchester certain rights to use such Copyright, including for administrative purposes.

ii. Copies of this thesis, either in full or in extracts and whether in hard or electronic copy, may be made only in accordance with the Copyright, Designs and Patents Act 1988 (as amended) and regulations issued under it or, where appropriate, in accordance with licensing agreements which the University has from time to time. This page must form part of any such copies made.

iii. The ownership of certain Copyright, patents, designs, trademarks and other intellectual property (the “Intellectual Property”) and any reproductions of copyright works in the thesis, for example graphs and tables (“Reproductions”), which may be described in this thesis, may not be owned by the author and may be owned by third parties. Such Intellectual Property and Reproductions cannot and must not be made available for use without the prior written permission of the owner(s) of the relevant Intellectual Property and/or Reproductions.

iv. Further information on the conditions under which disclosure, publication and commercialisation of this thesis, the Copyright and any Intellectual Property and/or Reproductions described in it may take place is available in the University IP Policy (see http://documents.manchester.ac.uk/DocuInfo.aspx?DocID=487 ), in any relevant Thesis restriction declarations deposited in the University Library, The University Library’s regulations (see http://www.manchester.ac.uk/library/aboutus/regulations ) and in The University’s policy on Presentation of Theses.
ACKNOWLEDGEMENTS

Although this thesis has my name on its spine to represent my work at the keyboard and in the field, it is misleading that research of this breath and scope can only be an effort of a single person. My Ph.D. experience has been like a journey across a vast desert-plain of uncertainties, and such a journey cannot be undertaken without the support of many participants. It is with great zeal and humility I acknowledge the help that I received from a great many participants, whose inputs in many ways are invaluable and priceless for keeping this thesis on track and seeing it to the end.

At the outset, I wish to express my deep sense of gratitude to the Leverhulme Trust for funding my doctoral education, without whose support, I could never have completed this study.

I am extremely thankful to my supervisors Professor Phillip Woodhouse (Director, Brookes Doctoral College - Global Development Institute, also Director at the prestigious Leverhulme Centre for the Study of Value (LCSV), University of Manchester) and Dr Admos Chimhowu (Deputy Director, Brookes Doctoral College - Global Development Institute) for their valuable academic guidance, unwavering support and encouragement that extended throughout the period of my research work. They both espouse and live the beliefs and practices about which we read as efficient. Throughout my journey they remained the voice in the back of my mind, always reminding that this research is mine and that decisions were mine to take and know that they would support me. They have been my colleagues, instructors and mentors; I could not have completed this study without their relentless support and patience. They gave me a unique opportunity for a rewarding and rich learning experience. Thank you, Phillip Woodhouse, for all those comprehensive comments, long hours of discussion, mentorship and for being very generous in sharing your rich and valuable knowledge about ‘Value’ of human life. You always motivated me and you understood me at so many levels. Admos, thank you for making my time a memorable experience. Words can never express my gratitude to you both.

It is with great pleasure and immense gratitude that I wish to acknowledge Professor Sarah Bracking, Research Director at the Leverhulme Centre for the Study of Value (LCSV) and also South African Research Chairs Initiative (SARChI), Chair in Applied Poverty Reduction Assessment at the University of KwaZulu-Natal; for her guidance and continuous encouragement which have provided a cushion for my Ph.D. tenure. Professor Bracking is an amazing person in too many ways. Thank you, Sarah Bracking for the mentorship.

I have immensely benefitted from the LCSV team during my doctorate tenure. Jim Igoe (Professor of Anthropology at the University of Virginia in the United States); Dan Brockington (Professor and Director at the Sheffield Institute for International Development, UK); Patrick Bond (Professor at the University of Witwatersrand); Sian Sullivan (Professor of Culture at Bath Spa University, UK) and Dr Aurora Fredriksen (University of Manchester) for their sincere efforts, dedication and hard work and helping me to critically engage with notions of governmentality in my research and especially at the earlier years of my project. Many sacrifices were made by them to develop and maintain a highly engaging network of international researchers to work on a global project questioning ‘Value Frontiers.’ I am privileged to have been mentored and supported by some of the world’s finest academics.

I wish to acknowledge the valuable co-operation of men and women living with HIV in Chitungwiza and Goromonzi Districts of Zimbabwe. I am grateful that they have shared many interesting and complex stories and have allowed me to share them with you to glean important
life lessons about the value of human life. To these men and women, thank you, this thesis is for you.

I owe a debt of gratitude to my examiners, Professor Lauchlan T. Munro (Director, School of International Development and Global Studies, University of Ottawa, Canada) and Dr Anthony Simpson (School of Social Anthropology, University of Manchester, United Kingdom) for an intellectually stimulating and enjoyable oral examination on a rainy spring afternoon at the University of Manchester.

I am very much indebted to my Zimbabwean academic comrades for their wits, wisdom and support throughout the period of this work. Dr Bernard Manyena and Professor Marvellous Mhloyi, thank you, I doubt that I will ever be able to convey my appreciation adequately. Mai Takaendesa, Mayita Tamangani, Wesley Nyabaya, Professor Rudo Gaidzanwa, Gibson Mhlanga, Faith Mutepa, Larry Wood, Dr Brian Maguranyanga, Henry Chidawanyika, Portia Manangazira, Esther Sharara, Dr Douglas Ncube, Dr Heather Chingono, Rose Musesengwa, Tongai Chokuda, Itai Makumbe, William Mufuka, Agnes Daizi, Donald Mujiri, Tony Sox, Tonderai Kadzere, Itai Rusike and Va Nyakani are greatly acknowledged for their constant support. I owe them my eternal gratitude.

The road to my Ph.D. started with coaching at the: Training and Research support Centre (TARSC) within the Regional Network for Equity on health in the east and southern Africa (EQUINET); then at the Zimbabwe Ministry of Health and Child Care (MoHCC) where RTI International seconded me. I take this opportunity to acknowledge and express my heartfelt thank you to Dr Rene Loewenson, Ms Barbara Kaim and Mr Zvikomborero Mlambo from TARSC for providing excellent training on health, health equity, health policy, health systems and HIV/AIDS - issues that became central to my thesis. I owe a great deal of appreciation and gratitude to my RTI international colleagues for their moral support. I want to extend my appreciation to Ms Rita Sembajwe, Mr Henry Chidawanyika, Mr Gordon Cressman, Dr Elizabeth Randolph, Ms Eileen Reynolds, Mr Absolom Masendeke and Mr William Mufuka for their encouragement, especially during difficult times.

To Dr Admire Nyamwanza, thank you, friend, for holding my hand during my first days in Manchester despite your busy schedule making preparations to defend your thesis at the time. Carlo Vavassori and Mayita Temangami, you have always been there, through thick and thin. Thank you. Malunga, Emmanuel, Rebecca Pointer, great friends who knew what to say when the going got tough, despite having to deal with their own Ph.D. anxieties.

There are no words to convey how much I love you Tinashe, my son. You have been strong throughout. You have been my supporter, and you have unconditionally loved me during my good and bad times. “Mommy you got this,” those words my son, have been instrumental in instilling confidence. Thank you. To my family, my mother, brothers and sisters, Faith, Larry, Tecla, Phillip, Takesure, Terrence, Silvia, Maurizio, Bomber, McDonald and Constance, thank you for sticking by my side, even when I was irritable and depressed. I thank everyone who has played a part in this academic pursuit of mine and helped me to put a full stop to the last sentence of this thesis. Above all, I thank ‘Mwari, Musikavanhu’ [God] for all the blessings. May ‘Vadzimu ne Mhondoro’ [the ancestors and Clan Spirits] continue to bless. Finally, to reinforce my clan identity and solidarity, I would like to thank you Dube [my Totem]. I will recite this detembo [Clan spirit praise poetry] in the Shona language, as there is simply no other way to go about this: ‘Dube iwe, Maita Tembo; Maita Samaita, Maita Mutasa, Maita Mbizi, Maita, Mhuka isina ukasha kana hundwa; Rudzi rune mutupo usina kwausiri, Vene ve Pasi’.
1 INTRODUCTION

1.1 Overview and research questions

The value of human life (VoHL) is a subject that appears to be present in various contexts: in the Middle Ages during the most prevalent times of leprosy, lepers were devalued to the extent of being declared ‘legally dead’ before their actual deaths (Rawcliffe 2006). The rituals of separation between the leper and the ordinary members of society were modelled on the rituals of the dead. The lives of medieval lepers carried less value as they were abandoned by their families, cast out into the streets and left alone to suffer and die (Rawcliffe 2006). Today, perceptions of the value of lepers have not changed much. Depending on the severity of disfigurement, people with leprosy are devalued, and still encounter discrimination, humiliation and ostracism (Rafferty 2005). Similarly, in the thirteenth century during the era of trans-continental microbial pneumonic bubonic disease (Black Death), which claimed over 7,000 people per day in Egypt and over a quarter of the population of China, plague victims were not valued. They were left to die and were denied last rites because the remaining holy men feared infection (Benedict 1996). Despite the appreciation of what bacilli caused the Black Death, and partial information of its transmission, the stigma that the plague carried was not as easily eradicated, and continues today (Benedict 1996). Also, the historical slave trade, the Chinese famine of 1961 and the contemporary violence against homosexuals by the Islamic State of Iraq and Syria (ISIS) are some of the cases and contexts in which particular social groups have not been valued enough to be counted, even when they die.

It is not my intent in this study to reiterate these arguments; rather, I will engage the debate from the perspective of people living with HIV/AIDS (PLWHA) in Zimbabwe. The study investigates the ways in which the value of human life is framed by using the Zimbabwe HIV/AIDS case study. As will be discussed in Chapter Two, although the HIV/AIDS epidemic has received attention in academic scholarship, very few, if any, studies have attempted to understand how the value of PLWHA is framed in health policy and in the communities in which they live, including the implications of these valuations on the lives or, conversely, the deaths of PLWHA. While HIV/AIDS has been debated as one of the most problematic medical (Dube et al. 2003), developmental and scientific (Collins and Rau 2000)
challenges of modern public health, understanding HIV/AIDS-related deaths from the ways in which PLWHA have been governed in the past three decades, especially in Sub-Saharan Africa, has lagged behind. But progress has been made, through the current lifesaving antiretroviral therapy (ART), in treating HIV/AIDS (Cohen et al. 2011), although the longevity of PLWHA is impeded by poor access to ART (UNAIDS 2014b). Also, ART remains expensive, with unbearable side effects, and has had minimal impact among the vulnerable social groups such as sex workers, homosexuals, prisoners and poorer groups in Sub-Saharan Africa that struggle to access this lifesaving treatment (Clark 2008, Cohen et al. 2011, UNAIDS 2014a).

As HIV/AIDS treatment barriers persist, the ART coverage for those needing lifesaving treatment remains low, and HIV continues to be one of the leading causes of death in Sub-Saharan Africa (IHME 2014c). As shall be clear in Chapter Two, Zimbabwe provides an exceptionally dynamic and conducive environment to understand how PLWHA are understood and how their value is framed. The country sits at the centre of the global HIV/AIDS epidemic, and remains one of the hardest hit countries, accounting for 5% of all new infections in Sub-Saharan Africa by the end of 2013 (UNAIDS 2014c). Considered one of the world’s poorest countries, with more than 75% of its population experiencing poverty and a 95% formal unemployment rate, Zimbabwe had an HIV prevalence ratio nineteen times the global average by the end of 2012 (ZimSTAT 2012a, WHO 2014a). Single-handedly, HIV remained one of the top leading causes of premature mortality since 1990 in all ages in Zimbabwe, with one in every seven citizens living with HIV by 2012 (IHME 2014c). There now appears to be a real need for new perspectives and new concepts, which can extend, expand and/or enrich the debate on HIV-related premature mortality to be responsive to the highly dynamic and uncertain contexts of the twenty-first century. To do this, the study specifically asks:

- In what ways do senior government officials (SGOs) in health policy frame the value of people living with HIV/AIDS (PLWHA) in Zimbabwe?
- In what ways do people not infected by HIV (non-PLWHA) frame the value of PLWHA in Zimbabwe?
- In what ways do PLWHA in Zimbabwe frame their own value?
- What are the implications of valuing PLWHA, for their lives or, conversely, their deaths?
1.2 Conceptual and theoretical underpinnings of the study

To gain insight into the concept of the VoHL and the ideas underlying it, this study draws upon a wide range of literature: from a human rights perspective, a health economics standpoint and a moral position. As discussed in detail in Chapter Three, the human rights, health economics and moral pillars from which the literature is drawn collectively contribute towards the problematisation of the VoHL. Using these three distinct but overlapping pillars, Foucault’s concept of governmentality provides a starting point for grasping the human rights, economic, and moral framings of the value of PLWHA. The politics, economic rationalities and moral narratives as to who gets what, when, how and why (value assigning), with implications for life and death, are well encompassed in the concept of governmentality. Contrary to the human rights view, which claims that human life contains an inherent value, Foucault implicates health experts, who decide whose lives matter (Foucault 1982). As shall become clear in Chapter Three, governmentality provides a lens to gain insight into policy and its implementation, rationing of resources and use of language in everyday interactions as a discursive practice.

My intention in using a governmentality approach is both to engage with the framing of the VoHL in the contexts of human rights and rules of law (policy and human rights), management techniques (within institutions and their calculative rationalities) and the ethos (discursive framings). Foucault’s ideas on governmentality highlight both the actions by governments over people, and the rationalities used to make these actions appear normal (Dean 2010). Governmentality is understood not only regarding the government’s action on the conduct (the people) but also in terms of any ‘conduct of conduct’ (governing others and ourselves) (Dean 1999, p. 10) and incorporates the idea of attitudes and language (discursive framings). It is about how governments frame and manage people, and, in turn, how people frame and manage each other. Governmentality includes an understanding of the ways in which conduct (people and their actions) is governed, not just by governments and its institutions, but also by the practices by which an institution – its managers and belief systems – act to shape the mentalities of others and ourselves that normalise these (Foucault 1991, Dean 1999). As shall become clearer in Chapter Three, the study draws upon three analytics of government – episteme, techne and the ethical government of the self (Dean 2010) – as an
analytical and methodological lens through which we can investigate and understand the ways in which the value of PLWHA is framed. These analytics of government are exceptionally well-suited to explain the dynamics in each of the pillars upon which the VoHL is understood because they not only provide the methodological lens (Section 4.2) to investigate VoHL in policy and society, but also provide the analytical lens (Section 3.4) to understand everyday actions as governmentality.

1.3 Philosophical and methodological underpinnings of the study
As outlined in Section 4.2, this study was informed by a constructivist epistemology which maintains that there is more than one reality and there are multiple understandings of the phenomena (Guba and Lincoln 1994). It is concerned with understanding the meanings that people give to actions, settings, language and the conduct of others (Cohen et al. 2007), and how these understandings in turn define the context of valuation of human life. Constructivist epistemology stems from the belief that knowledge is built and co-constructed between the researcher and her respondents through experiences as opposed to being discovered (Von-Glaserfeld 1989). This understanding of knowledge co-construction is significant because investigating the ways in which VoHL is framed is an issue of asking ‘how?’ and ‘why?’, which implies that study participants construct the value of PLWHA not only through their actions but also through what they say, how they say it and what they use (e.g. calculations). These attributes attend to the social nature of construction by viewing it as joint action or co-construction (Crotty 1989). Using methods grounded in qualitative methodology, as elaborated on in Chapter Four, the study employed an extensive document review, interviews, life histories, focus group discussions and observations.

1.4 Major concepts and their application in this study
Three concepts emerge as keywords in this study: ‘frame’, ‘value’ and ‘allowable death’. These three concepts are central to this study and I will explore in more detail the understanding of Value of Human life (VoHL) as we find it in the literature drawn from human rights, health economics and morals in Chapter Three and further discussed in Chapter Eight. The three concepts are briefly explored here, each in turn, to allow a clear presentation of how they have been applied and the entry points used to investigate the VoHL in the study.
1.4.1 Frame
In its noun form, the Oxford English Dictionary defines the term ‘frame’ as a supporting case or structure that encloses or surrounds an object. In its verb form, the term refers to creation or formulation of a concept or system; to explain, articulate or to construct something new by putting together parts of various elements (Oxford English Dictionary). Consistent with its verb usage in daily language, the concept of frame is used in this study to mean articulate, construct, present or say. The term frame is used in the three research questions that point to the ways in which social groups frame the value of PLWHA in Zimbabwe (see Section 1.1 above).

1.4.2 Value
The concept of ‘value’ has obscure etymological origins. In the English language, the term value is rooted in the metaphors of value as wealth and value as health. The etymology of the word can be tracked back to the thirteenth century. It is derived from the French noun, valeur, and Latin verb, valere, meaning ‘worth’ and ‘to be in good health’ respectively (Oxford English Dictionary). Value is also understood to correspond with worth or the regard within which something is held (Oxford English Dictionary). As such, value is a homonym, with more than one meaning – but not necessarily its etymological division, which restricts it to just two of possibly more meanings. This homonymity is also evident in the African conceptualisation of the term, where spatial metaphors for value and valuation create many meanings. Value is conceptualised as a noun, and as a practice of value assigning or value production, or both. For instance, in Ndebele, spoken in Zimbabwe, South Africa and parts of Namibia, value is ukuqakathekisa (making significant), ukuhlonipha (to respect, to honour). In Shona, spoken in Zimbabwe and parts of Mozambique, value is metaphorically understood as hukoshi (importance), huremu (worth), mweru, (standard/principles), mutengo (pricing), rukudzo, chiremera (respect worthy / honouring), hunhu (personhood). In Chichewa, spoken in Malawi, Zambia and parts of Zimbabwe, expressions of ulemu (respect), ulemelero (worth) and malinzi (cost) mean value.

Drawing from these various forms of meaning, this study understands the concept of value as multi-attributed – it encompasses both measurable and immeasurable aspects (see Dewey 1939, Gold et al. 1996, Boardman 2006). Although the value of human life lacks tangible
properties that can easily be measured (Dewey 1939), it is implicitly measured in valuing health, using approaches such as cost-effectiveness analysis (refer to Section 3.2.2 and see Gold et al. 1996, Boardman 2006). Also, other implicit ways of valuing human life can include the words that people say, how they articulate those words, the context in which the words are said, why the words are said, for example; these ways also establish agreed-upon socially constructed nuances of valuing human life (Kleinig 1991). As Helgesson and Muniesa (2013) observe, value or worth is simply socially constructed.

1.4.3 Allowable death
The concept of allowable death is novel; its application or use is, therefore, novel. This concept emerges as a major implication of valuing PLWHA by SGOs and non-PLWHA (see Chapter Eight). As discussed in Chapter Eight, allowable death tackles one of the core paradoxes of health policy administration: that the battle to end premature mortality in Zimbabwe shares the moral grammar (human rights, statistics, cost sharing) that sanctions allowable death and excludes the ill, particularly the poor and sexual minority groups, that it purports to serve.

Using the Zimbabwe HIV/AIDS epidemic, the study illustrates that our very understanding of the value of PLWHA is premised upon the unchallenged devaluation of populations living with HIV. The valuing-down of PLWHA is not only an outcome of the actions by the government itself, but also how society in general and especially people not infected by HIV respond to PLWHA. PLWHA, who tend to be viewed as other citizens in society who may not be living with HIV, or they may also be viewed as homosexuals, people who have been in prison, or sex workers – and all of these circumstances are compounded by high levels of poverty in Zimbabwe (75% of the population) – experience multiple legal, economic and social challenges to access ARVs, support and care. With little help available from health service providers and other people not living with HIV/AIDS in the community, PLWHA and especially sex workers and homosexuals are left to their own devices. Simply, they are allowed to die. Allowable deaths not only occur because of costs of health care and poor translation of rights to action, but also materialise within the social experiences of those PLWHA who fail to live by the norms determined by governmentality.
The study concludes by defining allowable deaths in Section 8.5 as deaths that occur under conditions that could have been avoided (amenable to change), but there is a conviction on the part of the institution (government, community, clinic, household) that the deaths occur because nothing could be done under the prevailing conditions to prevent them. From this understanding, allowable death can be interrogated in diverse contexts including warfare, human medical experiments, global health governance, migrants and refugees, disasters, racism, religious conflicts and anti-homosexuality narratives. Noteworthy, however, is that this understanding of allowable death is meant to aid the understanding of how those left-behind in development, the poorest, sex workers, homosexuals, and prisoners living with HIV/AIDS are understood, how they are valued and how they see this conferring on them an allowable death.

1.5 Thesis outline

Following this introductory chapter, the thesis is organised around eight more chapters as follows:

Chapter Two describes the study’s HIV and AIDS context. Given the enormity of HIV and AIDS, the chapter examines the HIV/AIDS literature at the global scale, Sub-Saharan African level, and narrows it down to the Zimbabwean level. The chapter aims to provide the rationale for why the Zimbabwean HIV/AIDS epidemic is especially useful to understanding VoHL. The chapter reveals the dynamics of HIV/AIDS service delivery in Zimbabwe. The chapter concludes by showing that the focus of response to HIV/AIDS has been towards the address of immediate determinants (symptoms), and less on the root causes (structural, political, discursive) embedded in factors such as hunger, poverty and homophobia or criminalisation of sex workers and homosexuals.

Chapter Three provides a review of the main study concepts and relevant literature on the VoHL. Understanding these concepts was crucial in building a platform for their application in this study. The chapter provides the analytical framework to understand the VoHL and discusses Foucault’s notions of governmentality as a means of understanding ways in which the VoHL is framed. Besides examining the utility of these concepts in developing analytical
Chapter Four presents the methodology. It explores the philosophical underpinnings of the study; presents the study sites and justifies the case study approach selected to investigate VoHL; outlines the qualitative methodology and the methods to gather data, as well as how the data was analysed. The research timing and timeline, challenges encountered during the fieldwork, my positionality and ethical issues are also presented.

Chapter Five commences the empirical analysis of the ways in which senior government officials (SGOs) in health policy decision-making frame the value of PLWHA. The chapter presents the ways of valuing from a human rights perspective and from a health economics perspective. It also identifies the specific idiosyncratic words, phrases, laws and policies mentioned by SGOs to articulate how they view, treat and provide services for PLWHA. The chapter discusses the interlocking nature of these peculiar factors and their implications for the VoHL. This chapter identifies three main ways of framing the value of PLWHA drawn from the human rights and health economics perspective. Drawing on the human rights perspective, PLWHA are valued as political, legal and moral citizens with rights, and who can exercise their power as equal, legal members of society. Secondly, drawing from a health economics perspective, PLWHA are valued as clients, who purchase services. Thus, PLWHA with lower purchasing power struggle to access life-saving antiretroviral drugs due to costs implications. Therefore, individual wealth can confer value on the lives of the wealthy. By virtue of using statistics and surveillance, SGOs who are also experts also tend to value PLWHA from a statistics perspective, presenting PLWHA as statistical representations.

Chapter Six explores the ways in which non-PLWHA – people not infected with HIV at the community level, including representatives from community groups such as churches, traditional authorities, local government, clinics, traditional healers, families and individuals in the community who interact with PLWHA – frame the value of PLWHA. Although there were inconsistencies among non-PLWHA participants on ways of valuing PLWHA, drawing from the human rights perspective, the chapter shows that there was a consensus on framing
PLWHA firstly as equal legal citizens who can federate locally to gain access to their citizenship (discussed in Chapter Five). Secondly, and as discussed in Chapter Six, drawing from notions of morality, non-PLWHA value PLWHA as expendable people whose lives can be allowed to end. Sex workers, homosexuals, (ex) prisoners and the very poor are implicated in this categorisation of value. These subgroups are subjected to normative regulation that can undermine their citizenship and allow them to die.

Chapter Seven is the final empirical analysis on the ways in which PLWHA value themselves. In this chapter, the findings show that PLWHA strive to create a counter-narrative around their value and emerge not as victims (as framed by non-PLWHA and by SGOs) but as ‘Resiliencers’. They try to redefine their value by fighting for survival on a daily basis. They also do so by federating through creating groups that challenge the government to account and by internationalising their cause through networks.

Chapter Eight discusses the implications of valuing PLWHA presented in Chapters Five, Six and Seven, for the lives or deaths of PLWHA. The chapter provokes thinking around the explicit and the implicit ascription of value to PLWHA in society at both the policy level and the community level. The chapter discusses how the framing of value of PLWHA and its normative criteria of valuation is naturalised and universalised at the policy level and at the everyday level. What comes out of this analysis are the deepened insights of how allowable death manifests as subtle or silent violence against prisoners, sex workers and homosexuals living with HIV, and how this violence is made to seem natural and necessary through the very instruments that purport to value PLWHA.

Chapter Nine provides the summary, as well as analytical and conceptual conclusions of the study. The chapter revisits findings from the four research questions pursued and makes reflections on analytical and methodological perspectives advanced in the study.
2 THE ZIMBABWE HIV/AIDS CONTEXT

2.1 Introduction
This chapter establishes the context of this research in the HIV/AIDS epidemic in Zimbabwe. While the burden of HIV/AIDS has generally been reduced, at least at the local level, and more generally at the national and international levels, examining the burden of, and the responses to, HIV/AIDS may provide an opportunity to understand the ways of framing the VoHL in Zimbabwe.

To set the scene, the chapter begins by providing an overview of the HIV/AIDS epidemic at a global level and then narrowing the review to the Zimbabwean context. Given the enormity of HIV/AIDS, it was useful to review the literature on the global scale, Sub-Saharan Africa (SSA) level, and the Zimbabwean context for at least two reasons. Not only does examining the literature at multiple scales provide the rationale for why HIV/AIDS is especially useful to understand VoHL, but it also offers opportunities to identify research gaps, thus allowing new perspectives and knowledge on the VoHL to emerge. The chapter then proceeds with an investigation of the nature and dynamics of poverty and service delivery in Zimbabwe, which identifies factors that shape the consequences of HIV/AIDS for individuals in Zimbabwe. As this chapter demonstrates, the HIV/AIDS focus in Zimbabwe has been towards addressing HIV/AIDS policies and legal framework for HIV/AIDS, and less on addressing the plight of social groups experiencing exclusion, poverty or isolation, such as homosexuals, who are criminalised for their homosexuality and who also struggle to access HIV/AIDS services. Overall, as the chapter will show, these factors combined make Zimbabwe a suitable case study for this thesis.

2.2 Global overview of the HIV/AIDS epidemic
Not since the fourteenth century bubonic plague has there been a calamity as devastating as HIV/AIDS. For over three decades, HIV/AIDS has ravaged populations, with an estimated 78 million infected and 39 million dead since the start of the epidemic in 1981 (UNAIDS 2014a). It represents one of the first infectious diseases considered a global public health security threat in the twenty-first century (WHO 2007). Between 1990 and 2010, the burden of HIV/AIDS rose by 354% and increased global years lost due to disability (YLD) by over
105% (Vos et al. 2012). Years lost due to disability (YLD) is an indicator that quantifies the burden of non-fatal health outcomes, conditions or consequences (put together as disabilities) that people live with, such as conditions resulting from side effects of treatment (WHO 2015a). Using YLD in the HIV/AIDS discussion is especially crucial to understand how well health systems respond to problems related to HIV/AIDS (WHO 2008).

The global YLD from HIV/AIDS alone was much higher than the 3% increase in total YLDs from all causes by the end of 2010 (Vos et al. 2012). In 2011, HIV/AIDS deaths had increased at a steady pace in almost 100 countries and dominated as the single largest cause of mortality in about 20 countries (IHME 2014c). It has caused enormous grief (as families lose their loved ones) and has precipitated economic catastrophe for households, communities and countries (UNOCHA [undated], UNDP 2009).

2.3 HIV/AIDS in Sub-Saharan Africa

Sub-Saharan Africa (SSA) is the region hardest hit by the HIV/AIDS epidemic (UNAIDS 2014c). It accounts for more than half of all PLWHA (24.7 million) and 70% of the global total of new HIV infections (UNAIDS 2010, Murray et al. 2012). By the end of 2013, 73% of all people who died from AIDS-related causes worldwide were from SSA. The region has lost more than a third of its economically active and reproductive age group (15 to 49) to HIV/AIDS in three decades (Murray et al. 2012). Since the early 1980s, SSA experienced reductions in gross domestic product, and increased food security threats due to the epidemic (FAO 2001, Pennap et al. 2011).

Although Highly Active Antiretroviral Therapy (HAART) only reduces (treats), but does not eliminate (cure) HIV/AIDS, it facilitated the gradual evolution of HIV infection from a life-threatening, fatal condition to a manageable, chronic health condition (Brenchley et al. 2004, Brown et al. 2009, Marin et al. 2009, Donnell et al. 2010, Cohen et al. 2011, CDC 2014). Before 1995, the average life expectancy of an HIV-infected individual was in the order of 10–15 years, but with ARVs, life expectancy has increased to more than 40 years (Marin et al. 2009). ARVs have reduced the risk of premature mortality because they increase the count of CD4 cells (a measure of how the body’s immune system responds to infection) and HIV ribonucleic acid level (the amount of virus in the blood/viral load) (Marin et al. 2009, Cohen
et al. 2011). HAART also produced declines in HIV incidence (new HIV infections) (Das et al. 2010) and opportunistic infections, such as tuberculosis (Grinspoon and Carr 2004). By mid-2014, more than 20 antiretroviral regimens for use in HIV-infected adults and adolescents were licenced in SSA (CDC 2014).

Despite these treatment advances in SSA, there is an emerging scholarship that argues that the emergence of new comorbidities resulting partly from ART and partly from the virus itself represent a new problem in medical practice and resource allocation (Brown et al. 2009, Marin et al. 2009, Funk et al. 2010, Palmisano and Vella 2011). For instance, HIV persistence heightens the risk of organ damage and can accelerate ageing, despite the use of ART (Lodi et al. 2010, Palmisano and Vella 2011). Such evidence signals the need for a multi-disciplinary and a multi-agency approach to avert or reduce premature mortality. But, to do so, policy questions concerning when to initiate HIV treatment, with what combination of HIV treatment and for how long or at what cost, become central to policy decision-making.

While epidemiologists (see Brown et al. 2009, Marin et al. 2009, Funk et al. 2010) have addressed these treatment gaps, there is very little evidence to explain why some subgroups of PLWHA such as sex workers, homosexuals and prisoners still experience high HIV prevalence, higher HIV comorbidities, low access to ARVs and harsh treatment from health workers at the point of care (Cowan et al. 2013). This area needs further insight and opens an opportunity for understanding how PLWHA are valued both at the policy level and at the point of care.

Although the Global Fund to Fight AIDS, Tuberculosis and Malaria (GTAFM), United States President's Emergency Plan for AIDS Relief (PEPFAR), the World Bank, and bi/multi-lateral donors and corporations (among others) have expanded ART programmes in SSA, some PLWHA remain without access (Schneider and Garrett 2009, Fidler 2010, UN 2011). The UNAIDS reports that more than 60% of all adults living with HIV are still not able to access lifesaving ART in SSA (UNAIDS 2014a). Similarly, by the end of 2013 fewer than 25% of all children living with HIV in SSA received ARVs (UNAIDS 2014a). Nearly 70% of all women living with HIV in SSA still struggle for ART (UNAIDS 2014a). While the cost of accessing health care, distance to the clinic and human resource shortages have been cited as factors impeding the expansion of HIV treatment in SSA (Machingura et al. 2011, Vos et al.
very few empirical studies attempt to identify the social groups living with HIV that are left out in ART programmes. This gap opens up opportunities to understand how both policy and communities frame the value of PLWHA, particularly the poor, homosexuals, and sex workers.

2.4 HIV/AIDS in Southern Africa

The countries in Southern Africa include Zimbabwe, Zambia, Swaziland, South Africa, Mozambique, Botswana, Malawi, Lesotho and Namibia. Southern Africa constitutes only a little more than 5% of the world's population but accounts for more than 50% of HIV infections worldwide (UNAIDS 2014c, WHO 2014a). As Figure 2.1 shows, the HIV/AIDS epidemic remains one of the leading causes of mortality in Southern Africa, with adult HIV prevalence in all the aforementioned nine countries above 10% (Murray et al. 2012, IHME 2014a, UNAIDS 2014a). AIDS mortality among adults in the first two decades of the epidemic in these countries resulted in high orphanhood (90% of all orphans were orphaned by AIDS) (USAID 2001). Similarly, between 1990 and 2012, life expectancy fell by almost 20 years from 62 to 47 years respectively (WHO 2004). Life expectancy indicates the total years a person would live from birth if mortality trends prevailing at birth remained the same, and measures the overall population health status of a country including the people’s quality of life (UN 2013).

Figure 2.1: Prevalence of HIV among adults aged 15–49 (%) [2005; 2009; 2013]

Source: (WHO 2014b)
The reasons why HIV prevalence rates are highest in Southern Africa have not been conclusive, and no consensus has emerged in response. Cultural practices and societal norms may have played a role, and the reasons for such have been extensively documented (USAID 2001, CIA 2011, UNAIDS 2014c, Salaam 2015).

Demographer John Caldwell, from his extensive work in Africa, suggests the presence of genital ulcerative sexually transmitted infections (STIs) as probably the single most important reason contributing to the rapid spread and thus higher prevalence of HIV in Southern Africa (Caldwell and Caldwell 1996). Genital ulcerative STIs (Chen et al. 2000), syphilis and chancroid (Ballard 1999, Steen 2001), serve as efficient conduits of HIV and other infections. In addition, the discrepancy in HIV severity is also attributed to the link between lack of male circumcision and HIV infection (Halperin and Bailey 1999, Weiss et al. 2000, Bailey et al. 2001, Auvert et al. 2005, Halperin 2006). Scholars argue that the nature of concurrent sexual partnerships found in Southern Africa facilitates the rapid spread of HIV and increases the risk of premature death (see Hudson 1996, Morris and Kretzschmar 1997). They show that African men and women often have more than one concurrent sexual partnership that can overlap for several months or years (Leclerc-Madlala 2003, Epstein 2004, Halperin and Epstein 2004). The nature of these partnerships differs markedly from that of the pattern of one-off casual and commercial sexual encounters (Hudson 1996) or serial monogamy (Hudson 1996, Morris and Kretzschmar 1997).

2.5 The Zimbabwe HIV/AIDS epidemic

This section explores the HIV/AIDS epidemic in Zimbabwe over four sections, each discussed in turn as follows: HIV/AIDS in Zimbabwe; HIV/AIDS policy and legal framework, HIV/AIDS health outcomes, HIV/AIDS and poverty.

2.5.1 HIV/AIDS and key affected populations

Zimbabwe sits at the centre of the global HIV/AIDS epidemic, and remains one of the world’s hardest hit countries with approximately 1.4 million PLWHA (See Table 2.2.) (UNAIDS 2014d). Its HIV prevalence rate of 15% (ZimSTAT and ICF 2012) accounts for 5% of all new infections in SSA (UNAIDS 2014c) and is nineteen times the global average (WHO 2014d). When Zimbabwe identified its first HIV case in 1985, there was no clear
indication of the nature, magnitude and direction of the epidemic that was to follow, and the response was slow (NAC 2010). While lower respiratory infections, tuberculosis (TB), malaria and diarrhoea diseases were in 2010 some of the top five causes of total years of life lost due to premature mortality (YLL) as Table 2.1 shows, their total burden combined was less than that of HIV alone (IHME 2014b).

Table 2.1: Ranks for top 10 causes of YLLs 1990-2010, Zimbabwe

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of YLL in thousands</th>
<th>% of total YLL</th>
<th>Rank 1990</th>
<th>Rank 2010</th>
<th>Number of YLL in thousands</th>
<th>% of total YLL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>541</td>
<td>13.0</td>
<td>2. Lower respiratory infections</td>
<td>2. Lower respiratory infections</td>
<td>895</td>
<td>11.7</td>
</tr>
<tr>
<td></td>
<td>281</td>
<td>6.8</td>
<td>3. Diarrhoeal diseases</td>
<td>3. Diarrhoeal diseases</td>
<td>455</td>
<td>6.0</td>
</tr>
<tr>
<td></td>
<td>259</td>
<td>6.2</td>
<td>4. Preterm birth complications</td>
<td>4. Tuberculosis</td>
<td>318</td>
<td>4.2</td>
</tr>
<tr>
<td></td>
<td>154</td>
<td>3.7</td>
<td>5. Tuberculosis</td>
<td>5. Malaria</td>
<td>275</td>
<td>3.6</td>
</tr>
<tr>
<td></td>
<td>97</td>
<td>2.3</td>
<td>7. Congenital anomalies</td>
<td>7. Road injury</td>
<td>189</td>
<td>2.5</td>
</tr>
<tr>
<td></td>
<td>98</td>
<td>2.4</td>
<td>8. Malaria</td>
<td>8. Self-harm</td>
<td>179</td>
<td>2.3</td>
</tr>
<tr>
<td></td>
<td>80</td>
<td>1.9</td>
<td>10. Road injury</td>
<td>10. Protein energy malnutrition</td>
<td>148</td>
<td>1.9</td>
</tr>
<tr>
<td></td>
<td>75</td>
<td>1.8</td>
<td>11. Meningitis</td>
<td>11. Neonatal encephalopathy</td>
<td>130</td>
<td>1.7</td>
</tr>
</tbody>
</table>

Source: IHME 2014b.

As Table 2.1 summarises, HIV remains the number one cause of total YLL; it claimed at least a third of all cases of YLL between 1990 and 2010, and increased mortality overall in the past 25 years in Zimbabwe (1990–2015) (IHME 2014c).

---

1 YLL measures premature mortality by considering the age at which deaths occur. It assigns greater weight to deaths at a younger age and lower weight to deaths at the older age (WHO 2015a).
The Zimbabwe HIV/AIDS epidemic has a generalised heterosexual transmission and reached its highest peak of 36% between 1995 and 1997 (NAC 2010). In urban areas, HIV prevalence rates are slightly more advanced than in rural areas (see Figure 2.1) (ZimSTAT and ICF 2012, UNAIDS 2014b). The explanation for the positive association between HIV and urban areas remains inconclusive in the literature, although demographers tend to base the correlation on the theory of economics of sexual behaviour. They postulate that the adverse future life chances of poor urbanites are likely to increase their readiness to take risks today (see Brockerhoff and Brenan 1998, Magadi et al. 2003, Holmqvist 2009, Montgomery 2009, Magadi 2013).

**Figure 2.2: Zimbabwe HIV prevalence rate by place of residence**

![HIV Prevalence by Place of Residence](image)

Source: ZimSTAT and ICF International 2012

This high (15%) prevalence of HIV/AIDS is resulting in a lower life expectancy at birth in Zimbabwe. For instance, between 1990 and 2012, life expectancy fell by almost 15 years from 62 to 47 years respectively (WHO 2004). Today, Zimbabwe’s average life expectancy is less than the SSA’s average of 53 years, at a time when life expectancy in high-income countries continues to exceed 80 years, almost 30 years more (UN 2013, WHO 2014c). The impact of the epidemic on the immediate family environment, communities and the wider economy are well documented (see Over 1992, Over and Ainsworth 1996, Kwaramba 1997, UNAIDS 1998). Despite this weight of evidence, however, adoption of HIV management
policies in the first 15 years of the epidemic in Zimbabwe was painfully slow. The reasons for the slow response to HIV remain vague and need further interrogation. More Zimbabweans continue to die prematurely (IHME 2014c, UNAIDS 2014b), especially populations that have been termed key affected populations (KAP). KAPs are populations that are known to have a higher risk of HIV/AIDS infection, including adolescents, women, sex workers, homosexuals and prisoners (Ferrand et al. 2010, ZimSTAT and ICF 2012, Cowan et al. 2013, UNAIDS 2015).

2.5.1.1 Adolescents and HIV/AIDS in Zimbabwe

Infection of more than half of Zimbabwe’s PLWHA occurs during adolescence (15–19) and young adulthood (20–24) (UNICEF 2013). In 2011, adolescent girls (15–19) in Zimbabwe had an HIV prevalence of 4%, which almost tripled (11%) before girls reached 25 years. The prevalence of HIV subsequently increased to 20% among young women (25–29) (ZimSTAT and ICF 2012). Adolescent boys and younger men are also impacted. HIV prevalence among adolescent boys aged 15–19 years in 2011 was at 3%. However, this was lower than that of girls of the same age (4%). While variances in HIV prevalence between boys and girls have been attributed to differentials of age at first sex between women and men, girls, unlike boys, experience gender-based violence, and lack access to education opportunities and health services, as well as social protection (UNAIDS 2014c). A review of about 50 studies from SSA revealed that intergenerational sex between older men and younger women was common and was associated with low condom use (Idele et al. 2014). In 2010, approximately half of hospitalised adolescents were likely to be HIV-infected, and HIV remained the cause of acute admission and in-hospital death in Harare, Zimbabwe (Ferrand et al. 2010).

Similarly, about 25% of all Zimbabwean adolescents are likely to be orphaned children (UNICEF 2013). The most recent Zimbabwe Poverty, Income, Consumption and Expenditure Survey (PICES) conducted in 2011–12 reports orphanhood at 19% among all children aged below 18 (ZimSTAT 2013). At the end of 2012, about three-quarters (75%) of all orphaned children had lost one or both parents to HIV/AIDS (see Table 2.2below) (UNICEF 2013). Overall, 38% of households in Zimbabwe are caring for foster and/or orphaned children (ZimSTAT and ICF 2012). These figures make Zimbabwe the country with, arguably, the largest burden of orphans in SSA, and the magnitude remains high. Also,
as Munro (2015) argues, such levels of orphanhood increases children’s vulnerability to neglect, abuse and early sexual debut.

Table 2:2: Population estimates (Census 2012) and HIV/AIDS estimates (2013)

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total population of Zimbabwe</td>
<td>12,973,808</td>
</tr>
<tr>
<td>Population of males</td>
<td>6,234,931</td>
</tr>
<tr>
<td>Population of females</td>
<td>6,738,877</td>
</tr>
<tr>
<td>Number of people infected with HIV</td>
<td>1,400,000</td>
</tr>
<tr>
<td>HIV prevalence rate of adult persons aged 15 to 49 in Zimbabwe</td>
<td>15%</td>
</tr>
<tr>
<td>Number of adults who are aged 15 and up living with HIV</td>
<td>1,200,000</td>
</tr>
<tr>
<td>Number of women living with HIV and aged 15 and up</td>
<td>720,000</td>
</tr>
<tr>
<td>Number of children aged 0 to 14 living with HIV</td>
<td>170,000</td>
</tr>
<tr>
<td>Number of deaths due to AIDS</td>
<td>64,000</td>
</tr>
<tr>
<td>Number of children aged 0 to 17 orphaned by AIDS</td>
<td>890,000</td>
</tr>
</tbody>
</table>

Source: UNAIDS 2014d, ZimSTAT 2012a

2.5.1.2 Women and HIV/AIDS in Zimbabwe

The estimated number of women infected with HIV has been higher year on year, consistently, since 1989 (WHO 2005). At the end of 2013, women in Zimbabwe (52% of the population) were disproportionately affected by HIV/AIDS (60% of PLWHA), with 18% of women compared to 12% of men living with HIV (ZimSTAT 2012a, ZimSTAT and ICF 2012, UNAIDS 2014b). Data from the national routine surveillance system show a decline in HIV prevalence among pregnant women from 26% in 2002 to 21% in 2004 and to 18% in 2012 (ZimSTAT and ICF 2012, UNAIDS 2014d). An analysis of HIV prevalence rates shows that women still acquire infection at younger ages than men and maternal mortality ratios² are still high (CSO and Macro International 1995, UNDP 2011, ZimSTAT and ICF 2012, IHME 2014b, PEPFAR 2014, WHO 2015b). HIV prevalence tends to increase with age for both women and men but it peaks at ages 30–39 for women (29%) and later for men at ages 45–49 (30%) (ZimSTAT and ICF 2012). The under-five mortality rates (the probability of dying between birth and the fifth birthday) increased from the period 1983–1988 to the period 1993–1998 from 75 to 102 deaths per 1,000 children surviving to the first birthday (CSO and

² Maternal death is the death of a woman in pregnancy or within 42 days of termination of pregnancy, irrespective of the duration and site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management but not from accidental or incidental causes (WHO 2015b)

2.5.1.3 Sex workers and HIV/AIDS in Zimbabwe

Current assessments of sex workers (SW) in Zimbabwe show that HIV prevalence ranges from 51% to 70% in border towns (Cowan et al. 2013). Data from elsewhere in Africa (Malawi, Namibia and South Africa) provide similar evidence supporting high HIV prevalence amongst SW with an increasing prevalence of STIs (Wojcicki and Malala 2001, Pauw and Brener 2003). HIV prevalence as high as 60–90% was reported for SW in Kenya (Kreiss et al. 1986), Central and East Africa (Quinn et al. 1986) and Rwanda (Piot and Laga 1988). Current data suggest that SW in Zimbabwe, like other African countries, have HIV prevalence 10–20 times higher than the general population (WHO 2011b, Baral et al. 2012, Vuylsteke et al. 2012). In addition, sex workers have a high prevalence of other STIs that further increase the risk of contracting and transmitting HIV (Cwikel et al. 2008).

Despite long-standing acknowledgement of their enhanced risk, SW continue to be largely neglected by HIV programmes in Zimbabwe (Cowan et al. 2005, WHO 2011b, Cowan et al. 2013). Criminalisation of sex work in Zimbabwe further complicates service delivery with reports of police extortion, confiscation of condoms, and sexual assault (Wojcicki and Malala 2001, Pauw and Brener 2003, Scorgie et al. 2011). Stigma, marginalisation and abuse of human rights have also been highlighted as key determinants of reduced access to health care including ART among SW in Southern Africa (Arnott and Crago 2009). Historically, data on SW access to services and ART, including how health workers treat them, are scant, although sub-optimal when reported (Kriitmaa et al. 2010). The dearth of such literature could be telling of underlying systematic abnormalisation of the (devalued) lives of SW in HIV programmes.

2.5.1.4 Homosexuals, prisoners and HIV/AIDS in Zimbabwe

In 2012, HIV epidemics were found to be expanding among women and men who engage in same-sex behaviour, globally, in both low-income and high-income country settings. About 5–10% of global HIV transmission is estimated to result from same-sex behaviour (Okal et al. 2009, Baral et al. 2009, Muraguri et al. 2009). A meta-analysis of surveillance in low and
middle-income countries noted that men who have sex with men (MSM) are 19 times more likely to get HIV infection than the general population (Baral et al. 2007, WHO 2011a). Evidence coming from SSA has also shown high levels of HIV prevalence among this vulnerable population: Malawi 21%, (Baral and Phaswana-Mafuya 2012), Botswana 20%; Namibia 12% (Kreiss et al. 1986). Despite the evidence of this disproportionate burden, HIV among MSM or women who have sex with women (WSW) or bisexuals continues to be understudied, under-resourced, and inadequately addressed. Moreover, inasmuch as epidemiologists have identified behavioural, biological and structural factors of vulnerability for lesbians (WSW), gay men (MSM), bisexual people and transgendered people (LGBT3), HIV/AIDS programmes continue to turn a blind eye to them (WHO 2011a, Baral and Phaswana-Mafuya 2012). There is an ongoing systematic exclusion of LGBT in Zimbabwe, despite increased evidence of their contribution to the overall HIV prevalence rate on the continent (Baral and Phaswana-Mafuya 2012, Beyrer et al. 2012, UNAIDS 2012).

The vulnerability of MSM to HIV has been attributed to factors, which include limited knowledge of the risks associated with anal sex, poor knowledge and access to appropriate HIV prevention services and transactional sex (Sanders et al. 2007, Baral et al. 2009, Smith et al. 2009). Transactional sex between men has been cited as common in prison settings, between men who would not consider themselves gay. In 2011, HIV prevalence among 14,000 male prisoners in Zimbabwe was high (27%), nearly twice the national average (Department of State 2011). There is a dearth in literature on HIV in prisons in Zimbabwe, signalling the need for future research, particularly among men and women engaging in same-sex behaviour.

But the criminalisation of same-sex behaviour presents further challenges, including stigma, discrimination, violence, rape by both sexual partners and law enforcement agents, which increases LGBT vulnerability and risk of HIV infection as they are denied recourse to justice

3 LGBT is a broad term that covers a range of settings and contexts in which male and female same-sex behavior takes place and this includes gay, bisexual, transgendered and heterosexual men who have sex with men but do not express their sexual orientation as gay for a variety of reasons. It also includes lesbians, bisexual, transgendered and heterosexual females who have sex with other females (WHO 2011a3).
(Sanders et al. 2007, WHO 2012). In essence, stigma and discrimination have been cited as factors that prevent LGBT from disclosing their sexual orientation when seeking health services and have stifled the design of interventions that meet the specific needs of this most at-risk population in African settings (WHO 2012). Stigma and discrimination against sexual minorities are among the foremost barriers to HIV prevention, treatment, care and support because they lead gay men and lesbians to deny being homosexual or may cause them to have unwanted long-term relationships with the opposite sex (Boyce 2007, Okal et al. 2009). This evidence suggests that same-sex behaviour could be playing an unacknowledged yet significant role in HIV transmission in Africa where the key driver of the HIV epidemic has been identified as heterosexual transmission (Boyce 2007, Okal et al. 2009, Muraguri et al. 2009, Beyrer et al. 2010). Additionally, understanding how LGBT PLWHA are valued could open up opportunities for identifying entry points for research and perhaps the most appropriate research methods to gather data from and for this vulnerable population.

2.5.2 HIV/AIDS policy and legal framework

Zimbabwe is a signatory to numerous international commitments to health service delivery. These include the Millennium Declaration (2000); the Abuja Declaration (2000); the International Conference on Population and Development (ICPD) (1994) and the Ouagadougou Declaration (2008). Central to all these international commitments is the improvement of population well-being, standards of living and reduction of poverty and disease. At the domestic level, the Parliament of Zimbabwe enacted the National AIDS Council (NAC) in the year 2000, following the approval of the National Policy on HIV and AIDS in the preceding year (GoZ 2000a). Accordingly, the adoption of some policies, action documents, bills and acts ensued – to respond to the rising epidemic. See Table 5.1 and Section 5.2.2 which captures the primary HIV policy instruments in Zimbabwe from the start of the epidemic in 1985 up to 2015.

2.5.3 HIV/AIDS health outcomes

With a supportive policy and legal framework outlined in the preceding section (Section 2.5.2) and in Section 5.2.2, Zimbabwe made strides in reducing new HIV infections from as high as 200,000 in 1990 to only 71,000 in 2014 (UNAIDS 2015). The decline in HIV
incidence rates has been quite visible, from approximately 6% to below 1% between 1992 and 2013 respectively (UNAIDS 2014b) (see Figure 2.3).

Figure 2.3: New HIV infections in all ages 1990-2014

Source: UNAIDS 2015

The early prevention information, including safe sex through condom use, faithful sexual partners and abstinence among adolescents, was widespread in all provinces of Zimbabwe (GoZ 1999). The messages shared through local newspapers, on radio and television and in local languages were used to relay the messages to the public (GOZ 1999a). The enactment of the HIV policy at the end of the second decade of the epidemic, the proclamation of HIV as a state of national disaster and the subsequent access to ART to those needing it were amongst the noteworthy gains (UNAIDS 2008). Additionally, the behaviour-change education programmes, prevention of mother to child of HIV transmission (PMTCT), post-exposure prophylaxis and paediatric HIV treatment were among the life-changing responses to the epidemic in the 2000s (UNAIDS 2014b). In essence, more than 60% of pregnant women were receiving ART for PMTCT by the end of 2011 (UNDP 2015). In 2011, Zimbabwe the contraceptive prevalence rate (about 60%) was above the SSA average of about 30% (USAID 2014). The contraceptive prevalence rate measures the capacity of health systems to provide reproductive health services to its population (USAID 2014).
2.5.4 Zimbabwe poverty and HIV/AIDS

Death (mortality), a common outcome of many health problems, is often lower amongst advantaged individuals or social groups – a pattern observed across and within many countries, including those offering universal health coverage (see Eames et al. 1993, Feinstein 1993, Veugelers and Yip 2003, Pampalon et al. 2009, Exeter et al. 2011, Mackenbach 2012, Borrell et al. 2014). In Zimbabwe, the wealth quintile into which a child is born relates to its survival. For example, Zimbabwe’s under-five mortality rate is substantially lower in the highest wealth quintile (58 deaths per 1,000 births) than in the lower quintiles (81–88 deaths per 1,000 births) (ZimSTAT and ICF 2012). Relatedly, expectant mothers in Zimbabwe’s highest wealth quintile in 2012 had nearly double (90%) the likelihood of delivering in a health facility than expectant mothers in the lowest wealth quintile (46%) (ZimSTAT and ICT International 2012). Such socioeconomic inequalities have been argued to increase premature mortality amongst the poor (see Kawachi et al. 1997, Mackenbach et al. 2003, Marmot and Wilkinson 2008, Mikkonen and Raphael 2010, WHO 2008). This evidence shows that, in general, the lower an individual’s socioeconomic position, the worse their health.

As poorer people experience worse health outcomes, Zimbabwean poverty presents itself as an important determinant of HIV/AIDS, especially so when Zimbabwe has become home to the worst poverty levels in the world. In 2015, the UNDP (2015) reported that the majority of Zimbabweans (75%) lived in poverty while one in every four Zimbabweans (25%) suffered deprivation in rudimentary health and education services. Also, UN data reflects that one-quarter of Zimbabweans struggle for essential core services, and their standard of living is poor, signalling extreme poverty. By the same token, the FEWSNET (2014), Helliwell and colleagues (2013) also note that 75% of Zimbabweans lack not only income but also assets and happiness, while at least one in every four households has lost at least one child. The likelihood of having a malnourished child among those that remain was reported as high (45%), with poor living standards contributing almost 60% of deprivation to overall poverty (UNDP 2015, OPHI 2015).

Overall, this evidence suggests that the poorer social groups access little or no service, and the risk of mortality is higher than their wealthier counterparts. But, as shown by the Chronic
Poverty Research Centre, both the GoZ and the private sector often neglect the needs of Zimbabwe's poor (Bird and Shepherd 2002). Bird and Shepherd (2002) argue that populations that experience chronic poverty are adversely incorporated as much as socially excluded. But, little is documented to show how the poor, and especially the poor living with HIV/AIDS, are valued, and how the valuation interacts with longevity or, conversely, their deaths. Investigating the VoHL is key to understanding HIV/AIDS outcomes in Zimbabwe.

2.6 Conclusion

This chapter explored the Zimbabwe HIV/AIDS epidemic to show the context in which the VoHL can be investigated and understood. As the chapter has shown, Zimbabwe, as one of the poorest contexts in the world, one of the hardest hit by HIV and with the bulk of its population unemployed, provides an especially conducive environment to understand how the value of PLWHA is framed by policy, PLWHA themselves and others in the community. The review not only looked at the Zimbabwean HIV epidemiology, responses and challenges, but also explored the level of the epidemic in Southern Africa, Sub-Saharan Africa and at the global level. The chapter invoked demographic considerations in Zimbabwe, as well as differentiated impacts on social groups, to understand the scale and trend of the HIV and AIDS epidemic in the country. As the chapter illustrates, no known studies have connected HIV/AIDS with the value of human life, but a deliberate attempt to connect the value of human life to HIV/AIDS is key to understanding HIV/AIDS outcomes in Zimbabwe. In the next chapter, the thesis examines the conceptual understanding of the value of human life and makes connections with theories that could be used to investigate it in HIV/AIDS contexts.
3 PROBLEMATISATION OF THE VALUATION OF HUMAN LIFE

3.1 Introduction
Assigning a value to a human life is not new. The first public slave auction held in 1655 at New Amsterdam (now called New York) provides the most vivid illustration of valuing a human life in modern history. Humans (as commodities) had neither a standard nor a fixed price attached to them, signalling challenges with pricing human life. However, the bidders’ value assessments, preference constructions and decision-making dynamics in the exploration of the value determined how much the human commodity was worth. Thus, the value of human life (VoHL), it can be argued, depended on the assessments by the valuator or the bidder. At each stage of bidding, the value of the human life, the commodity, would change. The change in the value was not because the human had physically changed in appearance at that specific moment, but because of the decisions made by the bidder to assign a higher or lower value, or possibly no value at all. The assigning of value had implications of life or death. Despite the breadth and depth of literature on the history of slavery, it does not provide sufficient theoretical conceptualisation to understand how the valuation of human life is framed, which may have implications for the wider contemporary world.

What is new, as well as central to this study, is the way assigning a value to a human life is framed, and the outcomes of such valuations. This chapter discusses the literature on the VoHL and the analytical framework to understand the VoHL. It is organised into three sections. Firstly, I explore the literature on the VoHL from a human rights perspective, in health economics and from a reading of moral perspectives. Secondly, I discuss Foucault’s notions of governmentality in relation to the three literature domains of understanding VoHL: human rights and policy, health economics and morality. Third, arising as the logical consequence of the preceding discussion, the chapter ends by stating the study research questions, followed by a conclusion.

3.2 The problematisation of the value of human life
One of the questions at the heart of this study is: What is the value of a human life and what human life claims value? Although this question sounds familiar, answering it is complex. Civil courts tend to consider such questions when awarding compensation to the families of
deceased victims of someone’s malice or negligence; or when assigning some particular monetary value such as in vaccine injury/death compensations, workers’ compensation benefits and military death gratuities (Friedman 1982, CDC 2011, Burrelli and Corwell 2006). But this is not limited to civil courts: public policies also tend to consider the same questions when making decisions about the allocation of resources where benefits and costs need to be expressed in one standard unit (Mishan and Quah 2007). Only then is it possible to compare the relative value of saving human lives with achieving competing policy objectives. The rationale becomes the primary logic for assigning dollar values to human lives (Mishan and Quah 2007).

These examples of assigning value to human life beg the question: How is the calculation of a person’s worth (or compensation or value) reached? For example, using the case above, how does the monetary figure in the vaccine, workers, and military compensations equate to the VoHL? Also how does the VoHL calculated in cost-benefit analysis compare people of different age, sex, education, geography, race and behavior? Are they the same? What about people living with chronic infections such as HIV or cancer – do they claim the same value as those without? What is the logic behind the calculations?

In order to investigate how such questions have been discussed in the literature, the following sections draw from the expertise of different disciplines including a) human rights, b) health economics and, c) moral perspectives.

### 3.2.1 Human rights perspective

Grounded on legal assumptions of equality, there is consensus in the human rights literature that human life carries an intrinsic value, not because the human being is a rational being or has a conscience, but because human life in itself is considered to have an inherent worth (see UN 1945, Rice and Cooper 1967, Riga 1981, Henry and Merrills 1993, Alberti and Emmons 2001 and Feldman 2002). Providing the strongest support for the claim that human life has an inherent value, the United Nations (UN) Universal Declaration of Human Rights (UDHR), adopted by the UN General Assembly in 1948, stands above many (UN 1948). Although religious books, such as the Holy Bible and the Holy Koran, are littered with expressions of the sanctity of life, it was not until 1945 when the UN Charter became the first
international expression of human rights, which clearly affirms the inherent value of human life (UN 1945). This seminal historical document was signed at San Francisco in 1945. The preamble, purpose and principles of the 1945 UN Charter notes:

We the people of the United Nations… reaffirm faith in fundamental human rights, in the dignity and worth of the human person, in the equal rights of men and women and of nations … to promote social progress and better standards of life in larger freedom…The Purposes …are… promoting and encouraging respect for human rights and for fundamental freedoms for all without distinction as to race, sex, language, or religion. (UN 1945)

The text in the UN Charter affirms that the life of a human being has an inherent dignity, worth and value. It also appears to assert that everyone has entitlements to this kind of life through the protection of the human rights law. It is through the 1945 UN Charter that the drafting of the international bill of rights was possible. The bill of rights first came out as a non-binding declaration from which the UDHR adoption ensued in 1948 and later became a legally enforceable covenant in 1966. It first came out as non-binding, posing challenges for countries to establish the mechanisms for the implementation, enforcement and monitoring of violations of the bill (Kunz 1949, Hand 1965). Recognising the challenges, it was later in 1966 when it was considered that a legally enforceable covenant to make member states commit to the bill of rights through ratification or accession was more binding to those governments that had ratified it or acceded to it (Amar 1998, Alston 1999, Clapham 2006).

In its preamble, the UNDHR contains the ‘recognition of the inherent dignity and the equal and inalienable rights of all members of the human family’ and Article One states, ‘All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood’ while Article three observes ‘Everyone has the right to life liberty and security of person’ (UN 1948). At the heart of these articles are, as Morsink (2000) argues, not mere enlightenment responses, but empirical and experiential observations discovered during the Holocaust. The experiences warranted pen and paper to articulate the need for the protection of not only the right to life but also the value which ‘life’ carries (Morsink 2000). Today, the Holocaust continues to be a reference point of how human life was undervalued and how people were allowed to die. Then, the Holocaust policies allowed deaths through forced euthanasia, medical experiments on prisoners, torture and execution of the old, the mentally unstable, those with incurable diseases and with eating disorders (Morsink 2000). Such disregard for the value of human
life during the Holocaust was profound to the extent of bringing the world together to forge the UDHR.

It is in this UDHR that the provision of the right to life provides a compelling justification for the proposition that, because human life matters, it has a normative intrinsic value which we all know and uphold (Alston 1999, Clapham 2006). To this end, there is a worldview understanding spanning across nations that the life of every human being is equally worthwhile, regardless of any differences whatsoever (see Amar 1998, Alston 1999, Morsink 2000, Clapham 2006). Corroborating the assumption that human life has an inherent value, more recently and from legal philosophy, is Ronald Dworkin’s book *Taking Rights Seriously*, which argues strongly from an end of life (death) lens, asserting that the life of a human, and not necessarily its living body cells, claims an ‘inherent value’ (Dworkin 1978). Although the death of living body cells is inevitable and discernible, as Dworkin (1978) argues, human life constitutes the experiences and memories carried by the living, about the deceased. It is in this understanding of life (outside the living cells) that the argumentations on the legal and ethical considerations around termination of life, including abortions (Belshaw 1997); euthanasia (Buhrmann 2008); clinical human experiments (Petryna 2009); judicial murder and capital punishment (Slovic 2007), are drawn. Across this literature, although there are various strands around abortion and capital punishment, the value of human life appears to be a common thread and appeals as something for which value is due. Central to these debates on the value of life, human life also appears as something in which a particular privilege seems to inhere. In essence, life appeals as an obligation and a duty that not only individuals and communities owe to themselves but something which the government has an obligation to protect (Kunz 1949, Hand 1965, Morsink 2000). It appears that, in many ways, it is in this sense that the idea that human life has an inherent value serves as the overarching principle of the modern day right to life. The right to life became an international, national, community and individual concern and obligation. Thus, it can be argued that it is reasonable that death should be prevented as far as possible and that no life should be allowed to be lost.

Following a universal recognition through the UDHR that human life has inherent value, the adoption of the International Covenant on Civil and Political Rights (ICCPR) and the
International Covenant on Economic, Social and Cultural Rights (ICESCR) ensued in 1966. The ICCPR provides for the right to life. Article Six (subsection one) of the ICCPR affirms that ‘Every human being has the inherent right to life. Law shall protect this right. No one shall be arbitrarily deprived of his life’, and Article 10 appeals to the inherent dignity of humans (UNHR 1966a). Both Articles 6 and 10 enunciate the right to life as an inherent and inalienable right, as did the UDHR. In addition, Article 12 (subsection one) of the ICESCR provides for the right to health, stating that ‘The States Parties ....recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health’ (UNHR 1966b), where health, as defined in the constitution of the WHO, is a complete state of well-being, including the social, physical and the mental state (WHO 1946). Article 12 of the ICESCR espouses that for a human being to live with dignity, they would need to enjoy their right to health, and thus the right to health links to the realisation of other human rights, including rights to life, food, education, dignity and equality (UNHR 1966b). It appears that the provisions of both the ICCPR (Article 6 and 10) and the ICESCR (Article 12) affirm that the right to life comes from the intrinsic value that human life itself carries, and not necessarily from legal provisions that countries offer. However, while the ICCPR and ICESCR have each been ratified by a significant number of countries (UNHCHR 2006), critics argue that most of these countries have not been particularly successful in upholding the rights contained in the treaties. See Peffer (1978), Sohn (1982), Holmes and Sunstein (2000), and Joseph (2013) for the criticisms.

The criticisms have value as they signal the gap between ratification and implementation. The government can influence the fulfilment of positive rights such as those in the ICESCR; for example, the right to food, housing, and health. Positive rights are rights whose fulfillment is specific to government action, and, therefore, amenable to political action. See Neuborne (1988), Sunstein (1993), Hershkoff (1999) and Fredmen (2008) for discussions on positive rights. Negative rights are rights that the government may struggle to take away such as the right to free speech (Kreimer 1984, Gerhardt 1990). Critics argue that most governments put in little effort to conform to the provisions of the ICCPR and the ICESCR, and that negative rights in both treaties are vague and susceptible to manipulation; see Peffer (1978), Sohn (1982), Holmes and Sunstein (2000). Ssenyonjo (2008) and Joseph (2013) argue that while the ICCPR and the ICESCR have encouraged Western countries to adopt rights for their
citizens, they fail to bring about similar manifestations of rights in nations where the need is highest. The failure in fulfilling rights has implications on life and death of other individuals – for instance the failure to fulfil the rights to health, food or shelter can compromise the fulfillment of the right to life.

To this end, it is within the contexts of human rights that governments express their obligation to protect and prolong life, and prevent death, as in the application of international conventions, national constitutions and domestic laws and policies (UNHR 1966b, Sohn 1982, Neuborne 1988, Ssenyonjo 2008). Governments carry a legal obligation to protect (the value of) life, in-line with the human rights ratifications made and through domestic law (Sohn 1982, Kreimer 1984, Neuborne 1988, Sunstein 1993, Ssenyonjo 2008). They also tend to employ legislation that prohibits killings, murders and suicides, including the application of the national bill of rights, which guarantees personal freedoms and integrity. The VoHL is also upheld by government actions and services that promote human well-being, such as dignity or happiness.

Similarly, prohibition of violent deaths and deaths without dignity, and prevention of premature mortality are policies common among nations (UN 1948). A human rights framework is documented as a pathway that provides the mechanisms for government to design, implement and monitor health programmes and policies that may enhance health outcomes (Johnson 2003, Silva 2003). There is extensive evidence highlighting the connections between uptake of health rights approaches and positive health-related outcomes. Typical examples include the UNICEF human rights programming framework, which views the health rights as a reference point for all its activities (Johnson 2003); Silva (2003) discusses the shared understanding among the different UN agencies about the utility of a rights-based approach in policies. Also, the literature linking the value of human life to health rights and PLWHA is extensively implied in the debates around discrimination. To be precise, Crawford (1994), Parker and Aggleton (2003), Campbell et al. (2005), and Castro and Farmer (2005) discuss discrimination as a negative identity on PLWHA arising from their involvement in social actions and relationships that devalue them. Discrimination amounts to a failure to respect human dignity by devaluing those affected, often adding to health inequalities (Parker and Aggleton 2003, Goudge et al. 2009). Also, Mbonu, et al.
(2009) note that discrimination fuels social inequalities of particular social groups, and ultimately shapes both the distribution of diseases and the course of health outcomes among those already suffering. The ICESR enlists non-discrimination as one of the most central principles of human rights law and prohibits any form of discrimination in health care access on the grounds of health status, including HIV/AIDS and sexual orientation, among other characteristics (UNHR 1966b).

Central to all these prohibitions is the encouragement to the care, preservation and prolongation of life, which individually and collectively combine elements of personal worth, self-integrity, and the clinical, legal, social and/or political tools for governing life and death (UN 1948).

Although there is a consensus in the human rights literature that human life has an inherent unique value, there is no conclusive empirical evidence to demonstrate that people recognise the ‘inherent unique value’ of human lives in practice and especially in health care. Also, there has been little investigation into the connections between the VoHL, human rights and the ability of PLWHA to access treatment and resist social interactions that devalue their VoHL. One exception that resonates with the study’s conceptualisation of ‘value’ argues that people are able to counter discrimination to the extent that they have access to social responsibilities; and enjoy their rights as equal citizens in a society to which they can ascribe positive value and meaning to their lives (Goudge et al. 2009). This insight provides a springboard for the investigation of how the human rights framework creates a pathway to frame the value of human life.

3.2.2 Health economics perspective

There are two major schools of thought regarding life and death in medical sciences. The first comes from medicine, which argues that public health has transformed death from a fate into something which could be viewed as a ‘risk’, managed through planning, although only within limits because we all will inevitably die (Rothman et al. 1995, Porter 1997, Bynum 2008). This school of thought is consistent with the objective of the human rights perspectives on the VoHL (see section 2.2.1 above), that human life has inherent value, which should be protected through policy and government interventions. The second school of thought comes
from health economics (Culyer 1989). The health economics perspective argues that valuation of health care through evaluation of costs, benefits and other mathematical approaches informs decision-making, including allocation and rationing of health care resources. Both schools of thought have implications for health outcomes, the survival of individuals, and protection of people’s dignity and VoHL. I will review each in turn.

### 3.2.2.1 Public health and the value of human life

The increase in the average life expectancy at birth during the twentieth century is one of society’s chief achievements in modern history. Thus, events once perceived as accidental or unavoidable are, through public health programmes, now interpreted as preventable hazards (Lupton 1999).

These improvements are part of a major global transition in human health. They reflect a decline in infectious and parasitic diseases and a generalised increase in life expectancy. Immunisation against the major killer diseases like measles, smallpox and polio, improved water supply and sanitation, and progress in nutrition are some of the major public health landmarks of the twentieth century; see Ehreth 2003, and WHO, UNICEF, World Bank 2009 for this literature. These victories, combined with improvements in medical technology and medical surveillance, are associated with the progressive increases in survival. By the same token, global population projections show that the life expectancy of people will continue to grow; with the global number of people above 100 years old projected to multiply tenfold between 2010 and 2050. Suzman and Beard (2011) argue that life expectancy projections transformed the odds of living from birth to a centenary from an estimated 1 in 20,000,000 to 1 in 50 for females over the course of human history (UNDESA 2012). The longevity of females may increase even faster than current projections assume – previous population projections often underestimated decreases in mortality rates among the oldest of old people (Suzman and Beard 2011). Such evidence suggests that medical advances that increased survival appear to have generated interest among modern day demographers. Most notable is the work of Rutstein and colleagues (1976) who argue that the quality of medical care can reduce cases of unnecessary disease and avoidable death. Avoidable mortality is a measure of the quality of medical care, which assesses deaths from selected disease groups considered either treatable or preventable (Rutstein 1976, Nolte and McKee 2004). The seminal work of
Charlton and colleagues (1983) corroborated Rutstein’s findings, and argued that previously taken for granted threats to life are manageable and are controllable risks, and thus mortality was amenable to change.

Such mortality, resulting from causes that are treatable or from amenable social conditions, is what Charlton and colleagues termed ‘amenable mortality’ (Charlton et al. 1983). Amenable mortality is only a subset of conditions from Rutstein’s work; it is a measure of health system performance (Gay et al. 2011, Tobias and Yer 2009). It separates causes that are responsive to medical intervention through treatment and secondary prevention, from causes that are responsive to actions beyond health care services, such as smoking or alcohol abuse (Newey et al. 2004). The concept of ‘mortality amenable to health care’ maintains that a premature death should not occur in the presence of timely and known efficacious medical treatment (Nolte and McKee 2008, Gay et al. 2011). In the same light, Nolte and McKee (2004) argue that avoidable deaths and amenable mortality are unnecessary and unjust and therefore, in a sense, premature deaths. They argue that medical knowledge, coupled with extant societal expectations of longevity, makes premature death a preventable risk. Thus, from the perspectives of Nolte and McKee (2008) and Gay et al. (2011), it would appear that when premature mortalities amenable to health care persist, then deaths have been allowable because the deaths could have been prevented.

3.2.2.2 Health economics and the value of human life

The UDHR, the ICCPR and ICESCR principles on the right to life establish systems for national obligations to ensure the institutionalisation of that right in many aspects of government policy (UN 1948, UNHR 1966a and 1966b). Thus, promoting human health and establishing systems for preventing premature death and increasing chances of survival are among the most important responsibilities of government, as already discussed in Section 3.2.1 (UNHR 1966a and 1966b). Such responsibility encompasses a range of actions rooted in different contexts, such as improving air, water and sanitation and cultivating a secure food and nutrition security system, providing a reliable health delivery system, preventing war, creating employment and minimising conflict (UNHR 1966a, Tang et al. 2004). Recognising these responsibilities, the health economics school of thought maintains that estimating the magnitude of health benefits and reductions in premature mortality helps policy-makers to
decide whether particular interventions merit the expected costs associated with achieving benefits and inform their choices among alternative strategies (see Hall 1997, Daniels 1998, Whitehead et al. 2001, Thomas and Weber 2004 and Rowden 2009). On one hand, this position gives the impression that calculations are done to determine how much money the state must raise to implement actions to protect everybody. On the other hand, it appears that only after policy and decision-makers are willing to spend to save a person from dying can the life be saved or be considered worthwhile. Only then can the ever-problematic question be asked: What life claims the value of being saved?

It appears that valuing health through economic evaluation to inform resource allocation in health care systems is argued as a standard mechanism to measure and assess benefits of health care provision, as well as costs that must be incurred (McCulloch 2003). In practice, health valuation is a process through which choices in the health sector are made (McCulloch 2003). As argued by Sleeth and colleagues (2012), policy-makers and decision-makers alike value health as a proxy for valuing human life. But scarcity is a real phenomenon that senior government officials, donors and others have to deal with, and thus consensus on principles that tell them what is fair, or even when they have general principles but are burdened by reasonable disagreements about how they apply, need to be explicitly provided. The doctrine of the progressive realisation of rights, especially for resource-intensive economic and social rights, such as the right to health, is a mechanism through which the human rights community deals with the problem of scarcity. For instance, Article 2 (1) of the ICESCR requires governments to take steps to provide the maximum amount of the resources that are available to ensure that they achieve progressively the full realisation of rights (UNHR 1966b). At its core is the reference to the availability of resources, which reflects a recognition that the realisation of the right to health can be hampered by resource scarcity and this is only achievable over an extended period. Equally, it also suggests that governments’s compliance with its mandate to take appropriate steps is assessed in the light of unavailability or scarcity of resources. The progressive realisation of the right to health over extended periods should, however, not be interpreted as depriving the role of government to move forward expeditiously towards the full realisation of the right. Rationing is one such way of doing so, as argued by Sleeth and colleagues (2012), who contend that the government employs rationing to share scarce health resources. Health care resources, including money,
consumables and staff, are the means that are available to a health care system for delivering services to the population (Sleeth et al. 2012).

Rationing of such health system resources implies the distribution of any needed but scarce resources or procedures to those in need, in accordance with an existing set of rules that assure fair distribution (Redwood 2000, Williams et al. 2012). Jonsen and Edward (1998) understand it as inequity in resource distribution based on ability to pay, as does Rai (1997), who understands rationing as denying others opportunities to access services because the services are categorised as expensive. Klein, Day and Redmaynes (1996) divide rationing into two: micro and macro rationing. Macro rationing is concerned with the setting of priorities about the kind of care that will be provided and where it will be provided – called the first level of resources allocation. And micro-rationing is concerned with the rationing of care at an individual level – creating the second level of resource allocation.

**Micro rationing**

Micro rationing occurs as health workers decide the resources to allocate to individual patients. In micro-rationing, health workers may use their judgements to evaluate the patient’s clinical needs (Hughes and Griffiths 1997). The judgements may include technical assessments to determine the seriousness of the disease and hence the needs. Hughes and Griffiths (1997), however, argue that the clinical evaluations can shift to social or moral assessments, such as when health workers ration the time they are available to provide health care services – which can be more personal than scientific rationing. Personal rationing may include the ability to function competently and the ability to offer quality service (Hughes and Griffiths 1997). This usage of personal rationing appears to be so embedded in the everyday use of ‘scientific based (economic) rationing’ that it may be difficult to identify and quantify. It could be that personal rationing, as argued by Hughes and Griffiths (1997), signals the suitability (deserving and worthwhile) or the unsuitability (undeserving and unworthy) of individuals. Personal rationing practice as micro-rationing is predominantly an action of using common sense to make rational decisions (Hughes and Griffiths 1997, Scheunemann and White 2011). This is significant to the question of value of human life, because it means that the micro-rationing decisions are subjective and they differ from one health carer to another, depending on one’s feelings and mood. But such approaches
employed in micro-rationing can fail to function when choices such as rationing inpatient care bed units, medicines or which patient to serve first from a queue in the emergency department are to be considered (Jonsen and Edward 1998). For instance, between a five-year-old who has broken limbs, an adolescent with an advanced genito-urinary infection and an old person with renal failure.

One similar controversial resource allocation issue, debated in USA Seattle (1962) over the use of social worth, as a criterion to decide patient's eligibility to receive lifesaving dialysis treatment, concluded that micro rationing mechanisms are often subjective and unfair, particularly where social worth is considered (Rescher 1969). Jonsen and Edward (1998) also argue that the nature of such assessments using ‘social worth’ as a tool can lead to unfair conclusions, as those patients who are more popular, educated, wealthier based on social worth could benefit; while gender (women), social class (poor) and religious devoutness could determine exclusion and suffering. The decisions around application of social worth, consider the social utility value of the patient to determine whether the patient should live or should die (Scheunemann and White 2011). Churchill (1987) and Hiatt (1987) argue that micro rationing has been conducted less explicitly and informally on the bases of social class, value for money, immediate availability of health resources and the circumstances of the patient, making it an unfair approach (Blank 1988). By the same token, Marmor et al. 1994 argue:

Suggestions for rationing the health care of people who are members of a demographically identified category be it age, race, ethnicity, religion, gender, or other characteristics – start us down the clichéd slippery slope to a moral abyss. Any of us is vulnerable to social constructions that classify us an unworthy. Any of us is subject to becoming the scapegoat [any of us who is poor or lives with a chronic problematic condition can be allowed to die] (Marmor et al 1994, p. 168)

Here, Marmor and colleagues (1994) suggest that a conscious decision is made to make resources unavailable to others and available to some. Thus, those who get the resources may lead longer, healthier lives at the expense of those who are denied the resources and allowed to die. Rationing remains important in the health sector to share the ever scarcer resources for health, but it has not been as explicit and is, especially in low income countries, hardly open to public scrutiny. It is this lack of transparency in rationing scarce commodities that becomes problematic, as it renders some social groups more equal than others.
Macro rationing

Macro rationing occurs at the policy level of the health system. Here, health valuation techniques or macro rationing methods (see Table 3.1) are used to value health as a proxy for valuing human lives based on costs of health care (Klein et al. 1996, Skowronske 2001). The most discussed are found in the works of Gafni (1989), Jamison et al. (1993), Morrow and Bryant (1995), McCulloch (2003), Dolan (2008) and Holmes (2013). Across this body of work, there are three major macro-rationing techniques: 1) cost identification analysis (CIA) 2) cost-effectiveness analysis (CEA) and 3) the cost benefit analysis (CBA). See Table 3.1 below.

Table 3:1: Macro rationing of health care Resources

<table>
<thead>
<tr>
<th>Economic methods for valuing health</th>
<th>What valuation question does the approach attempt to answer?</th>
<th>What are the main assumptions, goals or use?</th>
<th>What is the weakness?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost identification analysis (CIA) (Duenas 2013)</td>
<td>• What is the cost per individual intervention?</td>
<td>• Aims to select the least costly option. Assumes health outcomes are the same for two interventions</td>
<td>• Ignores benefits or health outcomes</td>
</tr>
<tr>
<td>Cost-effectiveness analysis (CEA) (Loomes and McKenzie 1989, Gold et al. 1996, WHO 2003, CDC 2015)</td>
<td>• Of the two interventions proposed, how much would it cost for the intervention A to produce outcome X and for intervention B to provide the outcome Y? • How much would it cost for the intervention A to produce X life-years of survival or quality-adjusted life years (QALYs) and for intervention B to provide the Y QALYs?</td>
<td>• CEA includes both costs and outcomes • CEA outcomes may include lives saved; cases of the disease prevented • CEA tests to see if health outcomes are the same for two interventions. If the intervention A is cheaper and more efficient regarding its outcomes, it prevails. On the other hand, if the intervention is costlier but more effective, it might be that the extra benefit justifies the extra cost • Measures outcomes in life-years of survival or quality-adjusted life years (QALYs)</td>
<td>• CEA only compares interventions whose benefits are in the same measured units of effectiveness • CEA cannot inform decisions about how much to spend on such issues as livelihoods, protection or food in relation to health care or HIV and AIDS care</td>
</tr>
<tr>
<td>Cost benefit analysis (CBA) (Boardman 2006, EU 2008, Dunn 2009)</td>
<td>• Is the benefit worth the extra cost?</td>
<td>• CBA has a broader application than CEA • CBA is used to inform decisions about how much to spend on such issues as livelihoods, protection or food in relation to health care or HIV and AIDS care</td>
<td>• Aggregates all effects (benefits and costs) into dollar amounts. This can be controversial: it involves putting a monetary value on human life or asking consumers what they are willing to pay to avoid death from AIDS • CBA provides no difference between cost and outcome</td>
</tr>
</tbody>
</table>
The objective of applying the rationing methods inevitably contradicts the arguments put forward in the human rights framework. The methods seem to ignore individuals whose needs appear costly for the government, as Calabresi and Bobbitt (1978) argue:

[S]carcity is not the result of any absolute lack of a resource but rather of the decision by society that it is not prepared to forgo other goods and benefits in a number sufficient to remove the scarcity (Calabresi and Bobbitt 1979, p. 273).

Dror (1967, p. 198) argues, ‘Invasion of public decision-making by economics is both unavoidable and beneficial, but fraught with danger’. The use of economic principles (economisation) can be, according to Dror (1967), beneficial because it facilitates ‘critical decision-making processes’, particularly in the context of scarcity, and also constructs death as a preventable risk. On the contrary, Thomas and Weber (2004) argue that such positivist objective methods of economic calculation (see Table 3.1) signal that death can be amenable to political management and economic profit-making (as health insurance calculations).

Corroborating, Fourcade (2011) and Kjellberg and colleagues (2013) argue that use of economic calculative devices in valuing health care not only lacks the capacity to deal with conflicting non-commensurate values other than by ignoring them, but also lacks the metric units that evaluate personal motivations, irrational behaviour and selfish individual idiosyncrasies of decision-makers. Taking these arguments together, it appears that economic valuation may also violate the fundamental principles of human rights by valuing objects which Fourcade (2011) terms ‘peculiar goods’, such as calculating the worth of human life.

Similarly, given that most causes of death are entrenched in politics and governance (such as lack of potable water, or shortages of medicines and diagnostic equipment), those populations who make noise about such causes of death may not be treated well by those who govern (Ericson et al 2000, Thomas and Weber 2004). It is here that we also locate the role of organisations such as hospitals, clinics and the National AIDS Council (NAC) in valuing PLWHA through the tools used in valuing health, such as those listed in Table 3.1. There is a dearth of literature on the connections between rationing and the VoHL.
3.2.3 Morality Perspective

The view that certain illnesses are a punishment for immoral behaviour is not a new phenomenon. Once it concerned syphilis, and today, to some extent, involves obesity, smoking-related diseases and mental illnesses that result from drug abuse. See Jabbour (2000), Alexander and Roberts (2003) and Ulijaszek and Eli (2014) for these moral arguments. Sexually transmitted infections (STIs) and especially HIV/AIDS have not been spared in these arguments. The works of Earl and Shelp (1992), Caltabiano and Ricciardelli (2012), Liamputtong (2013) and Pope and colleagues (2014) are replete with views and debates on HIV and immorality, promiscuity, sin, punishment and guilt. The moral narratives in the early 1980s by the then moral majority was that the virus was either punishment or an indication of how immoral one has been in their behavioral conduct (Earl and Shelp 1992, Pope et al. 2014). In addition, often, the spread of HIV is associated with preventable social factors implicated through arguments involving religious and cultural morals.

HIV infection is viewed through the ‘prism of sin’, and those infected by it as deserving punishment for sinful behaviour associated with sex work, homosexuality and/or multiple concurrent partnerships (Liamputtong 2013). Anthony Simpson (2009), in his book Boys to Men in the Shadow of AIDS: Masculinities and HIV Risk in Zambia, especially stresses the condemnation of homosexuality in Zambia and how homosexuals who may be living with HIV are especially seen as deserving punishment from God. Describing his experience interviewing his respondents, Simpson (2009) notes,

In discussions with me, several men were clearly anxious to distance themselves from even the remotest suspicion of a homosexual orientation. They prefaced their remarks …If they acknowledged knowing someone who was thought to be homosexual, they were usually at pains to stress the very tenuous nature of the acquaintance (Simpson 2009, p. 131)

Similarly, Uganda's notorious penal sodomy code forbids same-sex sexual conduct as well as sex work, describing the practices as crimes against morality. When compounded by discrimination and stigma, this impedes access to HIV/AIDS services for these social groups (Amnesty International 2013). To this end, most PLWHA experience rejection from family members and experience stigma and discrimination in all aspects of their lives (Liamputtong 2013). Also, many countries (78), particularly in Africa, criminalise homosexual acts between consenting adults through sodomy laws (Lennox and Waites 2013). Sodomy is
understood as sexual acts deemed ‘unnatural’ or ‘immoral’ (Lennox and Waites 2013). People involved in homosexual acts can face incarceration, the death sentence or mob justice, all of which violate the right to life (Amnesty International 2013). The same argument is equally applicable to sex workers and prisoners who experience stigma because of judgements by the moral others (Lennox and Waites 2013). See Section 2.5.1 for a broader review of homosexuality, sex work and prisoners in Zimbabwe.

A contradiction arises when the modern state, which has the ultimate goal of prolonging life and warding off mortality, is armed with the legitimate means to inflict immiseration and death (Foucault 1982, Dean 2010). Noting the persisting salience of state monopoly over the legitimate use of power to increase the risk of mortality in certain populations (criminalisation of sex workers, prisoners, LGBT and PLWHA, for example), Giorgio Agamben has argued that political power is shaped by its exclusive privilege to define homo sacer: life that may be taken with impunity (Agamben 1998, pp. 6 and 8). In this sense, there is no distinction between autocratic medieval emperors and modern democracies (Agamben 1998, p. 9).

The conceptualisation of death as a manageable risk has a normative bearing on how we live our lives and how others perceive our actions. Thus, not only the legal human rights frameworks and health economics need consideration in understanding the valuation of human life and its health outcomes, but also the language that people use, their attitudes and behaviours towards PLWHA – simply put as discursive framings. The latter entails understanding the ways that the government and society, in general, frame the problem of HIV infection (and therefore the solutions that may be contemplated for it). This problematic opens a gap in the literature, very little is documented to explain the extent that the framing of PLWHA include or exclude them as part of society?

These moral arguments and questions present the most important aspects that may conflict with the right to life of PLWHA and the inherent value of their lives. The ways in which HIV/AIDS is understood in society provides an opportunity to understand how society weights value of life between those who deserve sympathy, help, support and/or treatment, and those who do not. HIV provides a useful lens through which to analyse such processes.
because of the uniquely acute moral judgements involved in policy and broader social terms. It also raises questions about critical perspectives on framing of the value of the life of PLWHA through language as discursive formations. This area of enquiry has not been addressed in the literature. It is also not clear if and how decision-makers in policy draw from their moral perceptions to inform rational decisions and implicitly allow the death of those seen as deserving of punishment.

3.3 Theoretical frameworks for investigating the value of human life

This section traces evolving thinking in relation to understanding the VoHL, and identifies models that could be used not only to empirically investigate the concept of VoHL, but also to analyse it. But the application of the concept of VoHL in global health, and especially in HIV/AIDS studies, is new, and theoretical models that can help to investigate the concepts are scarce and far between. Although the theoretical approaches are scarce, two approaches are discussed here to assess their utility and limitations to investigating the VoHL: the social determinants of health (SDH) framework and the Foucauldian concept of governmentality. I will review each in turn.

3.3.1 The social determinants of health and the value of human life

One of the most widely known models to understand health inequities is Dahlgren and Whitehead's model which contributed to the first health for all strategy for Europe (Dahlgren and Whitehead 1991). The model is built around the principles of the social determinants of health (SDH) framework and identifies how social contexts produce health outcomes through social stratifications or hierarchies. Didierichsen’s model of – ‘the mechanisms of health inequality’, like Dahlgren and Whitehead's (1991), provides a persuasive account of how health inequities can account for premature mortality (Didierichsen 1998). Building on Didierichsen’s (1998) model, Brunner and Marmot's model is another that is increasingly cited (Brunner and Marmot 1999). Also widely discussed in the literature is Najman's model (Najman 2001). Other examples include Evans and Stoddart's model and Hertzman's framework for human development (Evans and Stoddart 1990, Hertzman 1999). The most recent model, which builds on these models, is the World Health Organisation (WHO) Commission on Social Determinants of Health (CSDH) framework, established in 2008 (WHO 2008a). The CSDH framework identifies health inequities as factors that can
undermine health rights, and highlights how social hierarchies are created, and the resultant conditions of daily life (WHO 2010). But, all these models work in a series of three similar basic steps:

- Social environments create social hierarchies and assign individuals to different social stratification.
- Social stratification, in turn, produces differential vulnerability and exposure to disease-causing conditions and resource availability.
- Social stratification equally provides differential consequences of ill-health. Wilkinson and Pickett (2009) also argue that there is a life expectancy gradient, with people in higher socio-economic positions living longer than those slightly lower than themselves.

These models explain the causes of health inequities and show the dysfunctional and harmful effects of the stratification of society, including how that stratification can benefit the wealthy and powerful at the expense of the poor. For instance, in 2008, the WHO Commission on Social Determinants of Health found evidence that demonstrated that the poor fare worse than those deprived a little less than them, who are also, in turn, worse off than those with slightly average incomes. The WHO described the phenomena as a social gradient observable across the globe (WHO 2008b). In their seminal 2009 publication – *The Spirit Level* – Richard Wilkinson and Kate Pickett also argue strongly about the social gradient, noting that the wealthier do better on a range of outcomes across society globally. They highlight that the social gradient in health exists and entails that moving up the socio-economic ladder leads to an increase in health outcomes (Wilkinson and Pickett 2009). Also, there is a broad range of empirical scholarship that shows that inequities cause differentials in access to health resources, and can cause illness, even premature death (Hills 1998, Kuzanzsky et al. 2001). The arguments for developing health policy that promotes health equity by addressing SDH are persuasive in the literature (see WHO 2008a, MoHCW 2009, WHO 2010, Leppo et al. 2013).

But, this scholarship is silent on how these inequities connect with the VoHL. Similarly, the SDH framework is contested for its failure to provide a compelling political narrative to
facilitate its implementation in public policy (Clavier and de Leeuw 2013a, Kickbusch 2013). Tellingly, a new public health discipline, health political science, is emerging (Kickbusch 2013) where the concept of VoHL in health care could be assimilated relevantly. VoHL could be applied because the elements of health political science that are crucial to investigating VoHL but absent in the current SDH framework include the role of economics, rights and morals, including the role and power exercised by policy actors and individuals in governance (Clavier and de Leeuw 2013b).

3.3.2 Governmentality and the value of human life

Michel Foucault’s conceptualisation of governmentality offers a model for understanding not only the ways of framing the VoHL, but also the implications of valuation of life. This is because Foucault’s definition of governmentality captures the three elements through which the literature tends to understand the VoHL. As discussed in Section 2.2 above, the VoHL is framed from a human rights perspective, a health economics standpoint and at personal interaction level through moral perceptions. In the same fashion of understanding VoHL through multiple strands, in his lecture titled: Security, Territory and Population, Foucault (2004) was also interested in framing governmentality from multiple strands that seem to resonate with the VoHL strands. Foucault (2004) conceptualises governmentality as a concept enjoining governing (‘gouverner’) and modes of thought (‘mentalité’), suggesting the significance of investigating power through an analysis of the political thinking underpinning it. Here, there is a second important aspect relevant to the investigation of VoHL:

Foucault uses the notion of government not only in its political sense as administrative control over populations, but also in its economic and philosophical view as a means of (in)justice (Lemke 2002). This aspect of government, is significant because it resonates with the VoHL perspectives in human rights and health economics that speak to notions of how governments govern populations through rights and economics. In addition to administration, ‘government’, according to Foucault (2004), also signifies issues of self-governance, management of the family and the household, directing one’s spirit and behaviour. This aspect of governing each other and the self resonates with aspects of morality discussed in the VoHL (see Section 3.2.3). It is for this reason that Foucault (2004) defines government
as ‘the conduct of conduct’, meaning governing populations, others, and the self (Dean 1999, p. 10). All in all, governmentality shows how the state and individuals co-determine and shape each other’s existence.

Also, at the very core of governmentality and central to understanding the VoHL is the role of ‘power’, which works by managing communities and individuals, also referred to by Foucault as ‘biopower’. Although he was not consistent in his conceptualisation of power throughout his lectures, at the centre of his definitions Foucault (1998) presents power as both exercising control and dominance over others or over resources, and the collective action earmarked for achieving control through joint action with others (Foucault 1982). This is important for this study as it helps in understanding the intentionalities of such aspects as rationing of health resources in health economics (see Section 3.2.2). In this context, biopower, according to Foucault (1982), represents the way in which modern governments exert control over people to promote life in order to gain from it. The main practice that Foucault (1991) identifies, through which governments exercise control over people and gain from them, includes statistics, valuation, probabilities and surveillance – all central to legal, economic and moral valuations.

Using the analogy of the panopticon (an instrument of surveillance), Foucault argues that through biopower, people are subjected to surveillance in order to normalise their subjectification to calculations aiding governments in gaining power ‘over’ people by generalising the ways of governing individuals and populations (Foucault 1977, Foucault 1991, Foucault 2004). Therefore, biopower works as an administrative tool to manage life, deployed with the aim of optimising, multiplying and prolonging life – as it also suppresses freedom through control, surveillance and subjectification. Biopower provides the conditions under which governmentality operates and, as such, governmentality’s expression requires biopower.

This is significant for investigating the VoHL because governmentality unravels the practices of government such as who gets what, when, how and why (value assigning), implicating the actors in institutions and individuals – on themselves and each other – aspects that are central to the social construction of value (see Section 1.4.2). Contrary to the human rights view,
which claims that human life contains an inherent value, Foucault’s governmentality implicates experts, who can defend and protect it or allow it to be lost (Foucault 1991). Here, governmentality would seem to both promise the VoHL, withhold the right to live, and also be responsible for the ways in which resources are managed and distributed. Governmentality helps to understand how the value of people is assigned through the actions of government policy or decision-makers in their allocation and distribution of resources. It implicates organisations their tools and their interface with individuals at the point of care or at community level. Governmentality also implicates the interactions among individuals themselves by understanding language use and its mundane applications in daily interactions (Foucault 1982).

But governmentality is not without criticism. It has been criticised for being rigid in viewing power as top-down and paying little regard to transformative power processes that often result in revolutions and struggles from below (Kerr 1999). In his critique of governmentality, Kerr (1999) argues that Foucault’s notions of governmentality are top-down because they disregard subjective experiences of individuals in their everyday lives. For Kerr (1999), governmentality tends to concentrate on the role of institutions of power and how they shape everyday human conduct. But this view is also invalidated by Dean (2010), who argues that Foucault’s governmentality is not just about how institutions of power shape human behaviour but also about how individuals exercise power on each other – to shape everyday struggles.

For this study, governmentality provides the most persuasive theoretical framework that embraces the major elements identified in the problematisation of the VoHL in Section 3.2, above. Taken together, these notions of governmentality are found, as Foucault (2004) argues, on a continuum scale in relation to each other as practices of government, both in a forward and backward track – and intermeshed with each other with some overlapping features. The forward track requires the government to have the knowledge to govern individuals, while the backward path requires governance that makes the government enable individuals and communities to conduct themselves. Together, these practices of government are termed regimes of government practice, which involves methods that produce knowledge that shapes particular identities of people, and comprises many forms of technical and
calculative rationalities to justify government action (Dean 2010). To analyse government, Dean (2010) identifies analytics of government, which can be used to understand regimes of government practice. The analytics of government are significant in the investigation of the VoHL because they provide a flexible guide (not rigid template) to both investigate and analyse the human rights aspects of VoHL (which also embrace policy and legal frameworks) – *episteme*; health economics – *techne*; and morality – government of the self.

- **Episteme dimension of government: policy and legal framework** – These are the ways of thinking and questioning that create the many diverse forms of knowledge that inform the activity of governing. This regime of practice relies on laid-out principles, procedures and rationalities, such as the constitution, policies, human rights and rules. These are all things that would normally be understood as ‘institutional arrangements’ under institutionalist frameworks (Hurwicz 1994, Crawford and Ostrom 1995) – or even as ‘assemblage’ (Fredriksen et al. 2014) (see Section 3.4.1). This is where the art of good government (one that can form desired citizens) is contained (Dean 2010).

- **Techne dimension of government: calculative devices** – The practice of calculative rationalities as the means, instruments and systems from which government governs populations and ourselves (Dean 2010). This axis of an ‘analytics of government’ is also a means of strategy on the part of government, and as such equally understood as an institutional arrangement. Thus, there is an overlay of institutional arrangements between Episteme and Techne axes. This is where the art of governing institutions, communities and individuals is contained.

- **The ethical government of the self**; this is a practice that forms individual and collective identities formed by actions of government. The dimension locates ‘attitudes and language’ (discursive framings) of people as they manage each other (conduct of conduct). The ethical government dimension of government denotes the forms and identities that people assume when they are governed and when they govern others.
This conceptual understanding of governmentality appears most appropriate to understanding the framing of the value of PLWHA. Specifically, these three analytics of government – episteme, techne and government of the self respectively – correspond with aspects that shape understanding of the VoHL in the literature. Policy, legal framework, calculative devices (institutional arrangements) and discursive framings (morals) form the essential elements from which the VoHL is understood, as discussed extensively in Sections 3.2.1 to 3.2.3 above. Thus, governmentality is about how governments frame people’s worth or value and, in turn, how we form individual and collective identities of value of others and ourselves. Governmentality includes an understanding of the ways in which conduct (people and their actions) is governed, not just by governments, but also by others and ourselves (Dean 1999, p. 16).

3.4 Research questions and the study’s conceptual framework

Reflecting on the HIV/AIDS epidemic in Zimbabwe (see Chapter Two) and the main debates in the literature on the VoHL (See Section 3.2.1 to 3.2.3), very few governmentality studies (e.g. Craddock 2000) have contributed to extending empirical research on the governmentalisatation of HIV/AIDS. Also, even though the sheer volume of work originating from governmentality research manifests the methodological and analytic potential of governmentality research (see Rose and Miller 2008, Dean 2010, Bröckling et al. 2011), governmentality research has not yet achieved its full analytical potential, especially not in HIV/AIDS research.

Also, no published studies have attempted to investigate the VoHL from an HIV/AIDS perspective, despite a vast scholarship on HIV/AIDS globally. Very little is known about the roles that actors in government policy (senior government officials) play in framing the VoHL in general, and PLWHA specifically, despite the enormity of the HIV/AIDS burden across the globe. Thus investigating how the human rights framework and health economics approaches, including calculation approaches used in the rationing health care (Section 3.2), frame the VoHL becomes ever more important in establishing what works for development policy.
Also, very little is known about the ways in which people who are not infected with HIV/AIDS (non-PLWHA) frame the value of PLWHA, and how the valuation interacts with PLWHA’s everyday conduct. While these questions may open up opportunities for understanding how power ‘over’, or ‘top-down’ power, frames the VoHL in general, and for PLWHA in particular, they also open up opportunities to understand how PLWHA value themselves. Although Kerr (2009) has criticised governmentality for being too top-down (see Section 3.3.2), very little has been done empirically to show how governmentality can(not) explain ‘bottom-up’ power from those whose value is framed by others. Thus, questions about how PLWHA value their lives become central to understanding the valuation of human life by the self – ‘bottom-up’ power.

As already discussed in Section 2.5.1, although key affected populations (KAPs) (including homosexuals, prisoners and sex workers) are disproportionately affected by HIV/AIDS and struggle to access HIV/AIDS services, very little is known about how SGOs value the lives of these KAPs, and how this shapes the chances of the longevity of KAPs, or, conversely, their deaths, in Zimbabwe. Overall, and as illustrated in Figure 3.1 below, this study draws out the following key research questions:

• In what ways do health policy decision-makers frame the value of people living with HIV/AIDS (PLWHA) in Zimbabwe?
• In what ways do people not infected with HIV (non-PLWHA) frame the value of PLWHA in Zimbabwe?
• In what ways do PLWHA in Zimbabwe frame their (own) value?
• What are the implications of valuing PLWHA, for their lives or, conversely, their deaths?
Figure 3.1: Mapping out the study’s conceptual framework and research questions
As Figure 3.1 (above) illustrates, grounded in the HIV/AIDS context in Zimbabwe, the study investigates the VoHL from three strands of literature: human rights, health economics and morality. Each of these strands, as already explored in Sections 3.2.1 to 3.2.3, can be examined by applying the concept of governmentality.

This study acknowledges that governmentality has its limitations, and thus the study will not use governmentality in a straitjacket approach, but will adapt it by intermeshing the three analytics of governmentality: techne, government of the self and episteme. Taken together, these analytics of government create the model through which the VoHL can be investigated and analysed (see Figure 3.2).

**Figure 3.2: Model for understanding the valuation of human life**

*Source: Author*
Table 3.2: Key issues in understanding the VoHL

<table>
<thead>
<tr>
<th>Dimension of government</th>
<th>Key context issues through which the VoHL is understood</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Episteme</strong></td>
<td>Includes sources of knowledge, such as policies and the legal framework for HIV/AIDS for governing people (VoHL). Also includes the experts who turn the knowledge into implementable policies, programmes and activities (Dean 2010). Policies, human rights and laws for HIV/AIDS in Zimbabwe are viewed as institutional arrangements (Fredriksen et al. 2014).</td>
</tr>
<tr>
<td><strong>Techne</strong></td>
<td>Includes the tools and approaches used by experts for governing populations and for people to govern each other. These tools include statistics and statistical representations and calculations. I refer to these as calculative devices. These are also viewed as institutional arrangements (Polski and Ostrom 1999).</td>
</tr>
<tr>
<td><strong>Ethical government of the self</strong></td>
<td>Includes the language, discourse, attitudes and behaviour of individuals towards each other. Refers to self-governance of people NOT infected and those infected by HIV and between each other. But it also acknowledges the agency of PLWHA by considering the government of the self can be both conduct of conduct and counter of that conduct.</td>
</tr>
</tbody>
</table>

The following sections will each outline the different axes of the analytical framework as understood in this study.

3.4.1 Episteme: Policy and the legal framework for HIV/AIDS as governmentality

Drawing from the review of VoHL and governmentality in Sections 3.2 and 3.3 respectively, and from the HIV/AIDS context in Zimbabwe (Chapter Two), such aspects as human rights, policies and laws for PLWHA work as government action that controls and manages its populations. Here, the legal framework for HIV/AIDS is understood not simply as a form of rights, rules or laws, disseminated by economic and political elites in government, nor as the framework which PLWHA can utilise to protect themselves from injustice or harm, but rather as a system of meaning that constitutes institutions, beliefs and identities. Fredriksen et al. (2014) view institutions as rules, policies, norms and strategies that form incentives for behavioural conduct, that can exist individually or in a set of other related arrangements. A set of institutional arrangements coordinated by participants who have set aims and objectives is viewed as an organisation (Polski and Ostrom 1999). An organisation includes such entities as the health ministry, the non-governmental organisations, faith-based organisations, the United Nations, clans, social networks and families. Organisations use institutional arrangements to steer conduct (Polski and Ostrom 1999). This is significant because the policies that support rights are implemented and enforced by organisations through their participants (also viewed as experts) (Hurwicz 1994). Indeed, Foucault’s governmentality provides a useful way to problematise how government specifies its needs.
through the invocation of individual choice, or exerting force through institutional arrangements and individuals to conform to the norms of the market – what Foucault terms responsibilisation (Foucault 2008). Responsibilisation strategies of rule, found in various realms of policy, agriculture, health or welfare organisations, encourage citizens to see themselves not only as individualised, but also as active, self-sufficient individual citizens, responsible for enhancing their well-being (Dennis 2014). Foucault (2008) argues this form of governmentality has an exceptionally diffuse form of control whereby strategies of government control are not only distributed through everyday media but also implicated in the most mundane everyday life of individuals (Foucault 2004).

The implementation of responsibilisation implicates everyday experts, such as nurses and doctors (in the case of this study), who aid individuals to undertake an exercise in self-government by providing knowledge and expertise on staying healthy (example) or taking ARVs consistently with food (Oksala 2013). Although the government may not provide the ARVs or the food, the person living with HIV, who has learnt the importance of taking ARVs with food, is made to become a responsible citizen and, therefore, should buy both the ARVs and the food to stay healthy. The part of ourselves we seek to improve (immune system, for example), the ways by which we do so (taking ARVs with food), and the person we hope to become (healthy active, responsible citizen), are largely motivated by responsibilisation (Dean 1999). The motivations, according to Dean (1999), are underpinned by governmentality mechanisms that aim to transform people into self-sufficient, active and autonomous people. Thus, using governmentality can help in understanding how government action can create a system of winners (valued people) and losers (devalued people), maintained through capitalism. This study unravels the policy space of HIV/AIDS to understand how that is implicated in the valuation of human life.

### 3.4.2 Techne: Calculative devices as governmentality

To understand the relationship between institutional arrangements as calculative devices (see Table 3.2 above) and governmentality, it is useful to differentiate between government action and the particular institutional arrangements that are associated with these actions of government. To begin with, the concept of ‘institution’ as underscored by Foucault (2002) is an ensemble, which may refer to the government itself and its obligation for the protection
of life. Ensemble could also refer to hospitals, clinics, NGOs, communities and the household level (Foucault 2002), and their values, belief systems and roles in valuing life. Ensemble, here, is defined in the same way as organisations have been understood in Polski and Ostrom (1999) (see 3.4.1). Kress (1989) defines institutions as social constructions framed through discourse. As already highlighted in Section 3.4.1, institutional arrangements may be thought to include notably the government policies, laws and programmes; government actions are a clear set of ways in which government goes about doing things (Dean 1999). Thus, calculative rationalities used in health policy, such as through economic calculations and statistics (see 3.2.2), can also be viewed as institutional arrangements steered through government actions. These government actions, such as delivering ARVs or enforcing the criminalisation of homosexuals, are typically linked to specific institutional arrangements and specific organisations (Dean 1999). What is not clear, and what is investigated in this study, is what role calculative devices play in calculating the value of human life, and how this intermeshes with other axes of the analytics of government to prevent or allow death. What Dean (1999, p. 20) describes as an ‘analytics of government’ offers the means by which to appreciate this complexity and intermesh of VoHL and outcomes of such valuations. This is so because such analytics seek to unravel distinctive ways of thinking and questioning (knowledge tools such as calculative devices), and ways of forming subjects. In this arm of the framework, I use techne as the dimension of government (that is, involving use of calculative devices. See Section 4.2.2) to illustrate the ways of calculating the value of PLWHA and the implications of such valuations for the lives of PLWHA, or, conversely, their deaths.

3.4.3 Ethical government of the self: Discursive framings of HIV/AIDS as governmentality

The concept of ‘discursive framings’ describes the ways of representation, use, and habits of language that produce and reproduce certain fields of meaning located in culture and history (Foucault 1971). Discursive framings are shaped by both language and the ways in which people think and act, providing a basis to understand the values, belief systems and intentionalities of organisations and institutional arrangements (Fairclough 1992, Phillips et al. 2004). Organisations working on HIV/AIDS (for example) interact and come to accept shared definitions of reality through language. It is through language that descriptions of
reality are prescribed, produced and reproduced (Phillips et al. 2004). Foucault presents discursive formation as a concept that can aid the analysis of institutions and their approaches to framing and shaping what becomes truth and reality. Foucault’s discursive formation gives meaning to what people talk about at different periods of time and history (Foucault 1971). Thus, discursive framings constitutive of the dimension concerning the ethical government of the self (see Section 4.2.3) exist in the mundane, everyday space of PLWHA, and overlap, intermesh and connect with the techne and episteme dimensions.

3.4.4 The research questions
These three separate ‘axes’ of analysis outlined from sections 3.4.1 to 3.4.3 can occur individually and collectively so that each analytic of government, or a combination of more than one, applies to each of the ways of ‘framing’ the VoHL. The episteme dimension identifies institutional arrangements, such as health rights, policy and laws for HIV/AIDS in framing the VoHL (Section 3.4.1). The techne dimension prompts investigating framing of VoHL from a calculation perspective (Section 3.4.2), while the ethical government of the self mainly identifies the normative meanings of VoHL through discursive framings. All three of these separate axes intermesh in such a way that there is an overlay between them because they all partially exist within organisations. Although episteme and calculative devices exist as separate axes, their distinction is blurred as they can also be viewed as institutional arrangements. They have been separated in this study because the techne dimension (calculative devices) frames the VoHL in ways different to human rights, policies and laws contained in the episteme dimension.

Taken together, these three axes of the analytical framework prompt four empirical questions already highlighted in Section 3.4 above and restated here as: In what ways do (i) senior government officials (SGOs) in health policy (ii) PLWHA (iii) people not infected with HIV (non-PLWHA) frame the value of PLWHA in Zimbabwe? What are the implications of valuing PLWHA, for their lives or, conversely, their deaths?

3.5 Conclusion
This chapter began by reviewing the main arguments around the concept of value of human life, drawing from the human rights perspective, the health economics view and the moral
narratives, thereby clarifying the importance of developing and understanding arguments in this study. This was followed by an examination of Foucault’s concept of governmentality, which helps to unravel the political, economic and moral arguments on the value of human life. The chapter also explores how a governmentality perspective can be used to take the enquiry of valuation of human life in health policy in light of the gaps and weaknesses in the current HIV/AIDS and value literature. By so doing, the chapter drew out a conceptual framework and a set of research questions by using the existing scholarship on the value of human life and governmentality to answer some of the gaps in the literature. This created opportunity to relate the study’s findings to those of other scholars working on HIV/AIDS, value and governmentality. Overall, this chapter shows that the valuation of human life creates new analytic space for social science research on the politics of global health, particularly in the area of HIV/AIDS. In the chapter that follows, I discuss the methodological approach for this study, including its philosophical underpinnings, methods, ethical considerations and my positionality.
4 METHODOLOGY

4.1 Introduction
This chapter discusses the methodological aspects of the study to answer the research questions: i) in what ways do (a) senior government officials in health policy decision-making (SGOs) (b) non-PLWHA and (c) PLWHA frame the value of PLWHA and ii) what are the implications of valuing PLWHA, for their lives, or, conversely, their deaths? The chapter highlights the philosophical underpinnings of the study, discusses the methods, data analysis, ethical considerations and the researcher’s positionality. As explored in Chapter Three and as shall become clear in Section 4.2.1–4.2.3 below, analytics of government (Dean 2010) provide both the methodological and analytical lens to shape the major themes around which the actual questions used during the fieldwork process were formulated. The study employed a qualitative case study design because, as Patton (2002) and Yin (1994) argue, a case study allows the depiction of major story elements that often give a picture of what happened, how, why, with whom and with what results. For this study, a case study was especially persuasive because:

- The use of analytics of government to investigate the ways in which the value of PLWHA is framed requires the researcher to ask questions of how and why, which are central to both case study designs and governmentality studies (Yin 1994, Dean 2010). Thus, a case study design provides a reasonable approach to answering the research questions.

- Exploring value of PLWHA in health policy, a new knowledge frontier in health research, can be problematic as it may require designs that are novel to lead to new frontiers of knowledge; thus understanding contextual conditions was crucial because they may be important to the phenomenon under study. As Yin (2003) argues, a case study is best suited when contextual factors are essential to understanding phenomena, and when the boundaries are not clear between the phenomena and context – thus a case study design provides a persuasive rationale for its use.

The qualitative methods used include documentary analysis, participant observation, semi-structured interviews, life histories, elite interviews and focus group discussions. These methods allowed the researcher to understand emotions, stories, reasons, intentionalities, and...
attitudes – all central to understanding the VoHL. Also, the study employed thematic
synthesis, a method for data analysis which involved the formation of descriptive themes
from primary data, followed by the formation of analytical themes that were subjected to the
study’s analytical framework.

This chapter is organised as follows: following this introduction in 4.1 is the study’s
philosophical underpinnings in 4.2. Section 4.3 provides an outline of the qualitative case
study methodology, followed by 4.4 with an outline of study methods. Section 4.5 presents
a summary of all the methods used and the field timeline. Sections 4.6 to 4.9 look into
research ethics, positionality, data analysis and conclusions respectively.

4.2 Philosophical underpinnings: Constructivist epistemology
For this study, understanding how SGOs, PLWHA and non-PLWHA frame the value of
PLWHA demands not only an understanding of the analytics of government but also an
epistemological claim that acknowledges that consideration should be given to perceptions,
attitudes, emotions, intentionalities of actors, context and actions in order to understand
reality. This is because, first; an analytics of government is concerned with thought of
government as it is embedded in everyday programmes, activities, strategies and technical
means of shaping conduct (Dean 2010). And second; beyond consideration of analytics of
government, the study acknowledges that the world is not homogenous and that reality is
contextual, ever changing and emergent. Thus, an analytics of government is not to be
considered as a straitjacket approach from which there is no escape, but simply as a guide.
This reasoning framed the basis upon which I adopted the constructivist epistemology rooted
in a constructionist ontology, as it helps to answer the research questions:

- In what ways (how) is, the value of PLWHA framed by a) senior government
  officials, b) non-PLWHA and c) PLWHA)?
- What are the implications of valuing PLWHA, for their lives or, conversely, their
deaths?

Constructivist epistemology maintains that there is more than one reality and multiple
understandings of phenomena (Guba and Lincoln 1994). It is concerned with understanding
the meanings which people give to actions, settings, language and the conduct of others
(Cohen et al. 2007), and how these understandings in-turn define the context of framing the
VoHL. Constructivist epistemology stems from the belief that knowledge is built and co-
constructed between the researcher and her respondents through experiences as opposed to being discovered (Von-Glaserfeld 2001).

The study adopted constructivism as it brings into consciousness the hidden political, economic, moral and social forces and structures critical to understanding the framing of the VoHL. To answer the questions, of -in what ways is the value of PLWHA framed is also a question of asking how people’s value is framed. These questions also entail asking such further questions as ‘how do (are) we govern(ed)?’, ‘what do we become when we (are) govern(ed) (what value)?’, examining all that is necessary, as well as uncovering the historical and cultural contexts in which people experience reality (Creswell 2009, p. 8, Dean 2010). An enquiry about governing and being governed implies that investigating ways of framing the value of PLWHA should first detect the government knowledge and actions that present PLWHA as a meaningful objective of social intervention. After all, the possibility to make PLWHA an objective of government intervention depends on the combination of different types of knowledge, such as: how PLWHA are perceived; how the needs of PLWHA are integrated into overall government policy and activities; how the needs of PLWHA either motivate or impede other government competing priorities; by whom and for what reasons HIV/AIDS programmes should be carried out.

Following governmentality scholars (see Dean 2010, Nadesan 2008) who have made the first attempts towards systematising empirical notions of governmentality, the study employs an analytics of government. To do so, the study applies episteme, techne, and ethical selves as three essential dimensions of an analytics of government (see Lemke 2007, Nadesan 2008, Dean 2010, Marttila 2013). As already outlined in Sections 4.3.5 to 4.3.6, these three analytics of government are constitutive of the study’s analytical framework. The application of these three dimensions provides both the analytical and methodological framework for this study, rooted in a constructivist epistemology for an empirical investigation of the value of PLWHA in Zimbabwe. Below, I further the discussion on each corresponding axis of an analytics of government from a methodological perspective.
4.2.1 Episteme of government: Policy and legal framework of HIV/AIDS

To answer the research question ‘In what ways do SGOs frame the value of PLWHA in Zimbabwe?’ the study considered the thought processes of government, represented through various practices of governing. The episteme dimension of government is outlined by thought processes, such as ideals for equality and human rights, that denote the final goals and objectives of government, including its sources of knowledge (Dean 2010). Consistent with Dean (2010), such forms of knowledge as policies, human rights, laws, strategies and plans can be categorised under this episteme dimension as it not only identifies the sources of knowledge but also sets out the ‘telos’ (broader goal) of government (Dean 2010 p. 42, p. 44). Like Foucault (1991, p. 93), who argues for government to be constantly directed toward a ‘series of specific finalities’, the works of Rose and Miller (1992, p. 179) also point to such finalities as ‘justice, equality, mutual responsibility… citizenship …economic efficiency’. To this end, the policy and legal framework of HIV/AIDS contained in this study’s analytical framework contains the episteme dimension of government (see Section 3.6.1). Thus, the following set of questions that Dean (2010) proposed, helped to guide the questions that SGOs in the Zimbabwe Ministry of Health and Child Care were asked; see Table 4.1.

Table 4.1: Ways of thinking: Episteme dimension

<table>
<thead>
<tr>
<th>Governmentality literature (Dean 2010)</th>
<th>Questions for health-policy decision-makers in the GoZ Health Ministry</th>
</tr>
</thead>
<tbody>
<tr>
<td>What ideals, principles, sources of knowledge or rationality are employed in practices of governing?</td>
<td>• What HIV/AIDS policies, human rights, plans are employed in governing PLWHA and in what ways does this frame the value of PLWHA?</td>
</tr>
<tr>
<td>How do these practices of governing render particular issues or problems governable?</td>
<td>• What ethos or goals does the health ministry use to establish appropriate and inappropriate public sector interventions for HIV and AIDS?</td>
</tr>
<tr>
<td></td>
<td>• How does the method of choice take into account the extent to which the intervention treats people with dignity?</td>
</tr>
<tr>
<td></td>
<td>• Have there ever been major disagreements about the policy of how to distribute resources fairly or is everyone agreed on the means to do this?</td>
</tr>
</tbody>
</table>

4.2.2 Techne of government: Institutions and their calculative devices

To answer the research questions i) in what ways do SGOs frame the value of PLWHA in Zimbabwe?, and ii) in what ways do non-PLWHA frame the value of PLWHA?, the study investigated the technical means used by government to govern its populations. The technical means included such aspects as organisations and their strategies, reasoning, means, instruments, procedures, economic models, mathematical calculations that government and
institutions employ to control subjects and that subjects in-turn will use to govern other subjects (Dean 2010, Marttila 2013). Taken together, these aspects represent the techne dimension of government (Dean 2010). Techne is an interconnected and heterogeneous grouping of techniques, with intentional means of government; it is often not chosen voluntarily by the government but reflects both the history and context ingrained around the governed subjects (Foucault 1998, Marttila 2013). The dimension provides the basis for the choices of government and the justification of governmental action (e.g. privatisation, marketisation of health care) (Marttila 2013). Another aspect of techne is ‘visibilisation’ (Dean 2010, p. 41) that reflects the means to picture who and what is being governed, what problems need solutions, and how relations of authority and obedience are constituted in space, such as through statistical surveillance, descriptive statistics, graphs and charts found in routine health information and surveillance programmes. Following Foucault (2004), statistical surveillance was a strategic means for governing and rule. Using the analogy of Bentham’s panopticon, Foucault (2004) argues that statistical calculations revealed mortality figures, prevalence and incidents rates, showing not only the body and its limitations but also locating the person within a visible space of social and political spaces. To this end, the following set of questions, proposed by Dean (2010), helped to answer the research questions; see Table 4.2.

Table 4.2: Ways of acting: Techne dimension

<table>
<thead>
<tr>
<th>Governmentality literature (Dean 2010, p. 42)</th>
<th>Questions for study participants</th>
</tr>
</thead>
</table>
| By what means, mechanisms, procedures, instruments, tactics, techniques, technologies and vocabularies is authority constituted and rule accomplished? | • What decision-making techniques do you use to assess the trade-offs between interventions in cases where multiple objectives or competing interests exist and are PLWHA treated differently?  
• How does the method of choice take into account the extent to which the intervention treats PLWHA with dignity?  
• Have there ever been major disagreements about the method/techniques you use? |

4.2.3 Ethical government of the self: Formation of identities through discursive framings

To answer the research questions ‘In what ways do non-PLWHA frame the value of PLWHA’ and ‘In what ways do PLWHA frame their own value’, identities that people claim or attach to others, and the ways in which they are internalised and incorporated by subjects as they govern others and themselves, were considered. Identity is what people become when
they are governed (Dean 2010). The forms of identity that people claim and attach to others rationalise particular practices of governmental action. This includes identities as active self-sufficient citizens, moral self-respectful individuals who use protection during sex, regularly exercise at the local gym, and buy medicines when ill. This understanding is linked to the means of subjectification that Foucault (1988, p. 18) refers to as ‘technologies of the self’ which ‘elicit, promote, facilitate, foster various capacities’ of subjects to the point that subjects begin to experience the technologies as if they were part of their lives. Some of the technologies can submit subjects to (example) having protected sex, buying medicines from the local pharmacy when ill, losing weight when obese or quitting smoking. The ethical government of the self dimension refers to the forms of identity formed by government action, programmes and activities (Dean 2010). As already discussed in Section 3.6.3, the ethical government of the self connects with the discursive axis of this study’s analytical framework (see Figure 3.2). Drawing from the governmentality literature, the following set of questions that Dean (2010) proposed helped to frame the questions that various study participants were asked to answer for the research question; see Table 4.3.

Table 4.3: Ways of forming identities - ‘Ethical government of the self’ dimension

<table>
<thead>
<tr>
<th>Governmentality literature (Dean 2010, p. 43)</th>
<th>Questions for study participants</th>
</tr>
</thead>
</table>
| What kind of people and identities are created by different practices of government and what forms of identities do these practices seek to produce? How are certain aspects of conduct problematised? How are they then to be reformed? | • What are your views on the way policy-makers perceive worth and dignity of PLWHA (value given/attached/projected by others)?  
• If you were to equate the value or the worthiness of your life (for PLWHA) to ‘something’, what would it be? What about the people you have identified (decision-makers/service providers/duty bearers)? What do you think they equate your life to? What value do you think they attach to your life? Why? |
| What status (value) is assumed of those who exercise power (e.g. politicians, government officials and health workers) and those who are to be governed such as (patients, consumers and beneficiaries of welfare)? | • What are the HIV/AIDS services available in your area? And which of these HIV/AIDS services do you use and why? (Why do you prefer these services relative to others – probe why if there is a preference over modern medicines.)  
• Do you think government officials, even those living with HIV, view themselves as any different from PLWHA in this community? Why?  
• Do you view PLWHA in the same way as those without? Why? What are they expected to do? Why?  
• How do you value yourself? What is your worth? |
| What kinds of conduct are expected of those who are governed? What (value) duties and rights do those who are governed have? How are people made to identify with other groups to become active self-sufficient citizens? For those who are | • Are there things you have done to improve you HIV/AIDS condition? What are they? Why did you do them?  
• Are there things that needed to improve you HIV/AIDS condition, which you have not done? |
While the questions in 4.2.1 to 4.2.3 were considered in the research instruments used in this study’s research methods (see Sections 4.4.1 to 4.4.6), scholars of governmentality research (see Bröckling et al. 2011, Marttila 2013) have cautioned researchers on the sole application of governmentality research, arguing that it should either be provisional or used alongside other approaches instead of being ‘how-to’ manuals. Similarly, Rose (1999) and Larner and Walters (2004, p. 3), in their works on international governmentality, have argued that governmentality research is largely empirical in its nature. Stäheli (2011) and Marttila (2013) have contradicted this view, claiming that governmentality studies aim to historicise the economy, as well theorising governance of the self. What they imply is that scholars of governmentality do not provide sufficient methodological explanations as to how they construct knowledge. The embeddedness of knowledge in the analytics of government means that governmentality scholars locate empirically observed phenomena within the limits of these analytics of government without admitting to this bias (Marttila 2013). It is for this reason that this study’s approach employs a qualitative case study design (methodology), grounded in a constructivist epistemology (philosophical underpinnings), to combine the theory (governmentality) through analytics of government and everyday life by using qualitative tools (methods) to curb the weakness of governmentality approaches when used alone.

### 4.3 Methodology: Qualitative case study design

Constructivist epistemology adopts qualitative methodologies, such as case study designs (in-depth studies of events or processes over a prolonged period) and ethnography (the study of cultural groups over an extended period) (Stake 1995, Cohen et al. 2007, Merriam 2009, Yin 2012, Flyvbjerg 2011). Also, governmentality study approaches give priority to why and how, questions that sit at the centre of a qualitative methodology approach (Dean 2010). To this end, this study employed a qualitative case study design.
4.3.1 Study design

A case study examines a phenomenon within its context, using multiple data sources to facilitate various features of the phenomenon to be revealed and understood. Stake’s (1995) qualitative case study, situated in the constructivist epistemology, claims that truth is relative and that it is not dependent on one’s perspective, enabling participants and the researcher to co-construct knowledge (Guba and Lincoln 1994). Knowledge co-construction is particularly useful when applying the three dimensions of an analytics of government because it enables voices of the researched to shape the knowledge agenda (Bröckling et al. 2011).

Stake (1995) describes qualitative case study research as an approach that draws together various methods or data sources – a palette of techniques (Stake 1995). Ritchie and Lewis (2003) refer to case studies as an examination of multiple meanings within a natural context. This view of case studies is significant for this study because investigating the VoHL entails uncovering multiple meanings of value in the Zimbabwe HIV/AIDS context. A case study, as Yin (1994, p. 13) suggests, ‘allows an investigation to retain the holistic and meaningful characteristics of real-life events’ such as individual life changes and relationships. This line of thinking is especially critical for investigating implications for valuation of human life. On the same thinking, Merriam (2009) argues that a case study maintains deep connections to core values and intentions, and is ‘particularistic, descriptive’ and ‘inductive’ (Merriam 2009, p. 46). By particularistic, Merriam (2009) refers to focusing on a specific event or process to advance understanding. While the descriptive refers to collation and use of full details relating to the phenomena. The inductive involves the reasoning used to conceptualise meaning that emerges from the data (Merriam 2009). This study adopted the inductive reasoning perspective because this perspective allows us to make meaning of data as it emerges in the context, and is especially useful in understanding the ways in which value is framed.

When considering a case study design, which also underpins this study, Yin (2003) identifies four important factors to which one must relate. Table 4.4 identifies the relevance of Yin’s (2003) factors to the current study.
Table 4.4: Suitability of case study to the current research

<table>
<thead>
<tr>
<th>Why the case study design</th>
<th>Arguments for the current study</th>
</tr>
</thead>
<tbody>
<tr>
<td>The study seeks to answer ‘how’ and ‘why’ questions</td>
<td>• The study examines the ‘ways’ of framing the value of PLWHA. The term ‘ways’, according to the Oxford English Dictionary, suggests ‘mannerisms, modes, behaviour, characteristic or habits’. The conceptualisation of the term ‘ways’ demands an understanding of not only the ‘what’ but also, the ‘how’ and the ‘why’. Also, the second overarching research question enquires on: ‘implications for valuations of PLWHA for their lives or, conversely, deaths’. This research question is a ‘how’ research question. These reasons made a case study the most appropriate research design to take.</td>
</tr>
<tr>
<td>The behaviour of study participants cannot be manipulated</td>
<td>• The case study approach was preferred because it provided a lens through which I could understand behaviour without necessarily having to manipulate relevant conducts of senior decision-makers in the health ministry or community members in the study sites.</td>
</tr>
<tr>
<td>You want to cover contextual conditions because you believe they are relevant to the phenomenon under study</td>
<td>• Understanding decision-making in institutions such as the Ministry of Health and Child Care, and community and social dynamics at social interaction level, was necessary for this study. Understanding these would provide the research with relevant information to answer the ‘why’ dynamics in the study’s research questions. Thus, the contextual conditions were relevant to understand valuation of human life.</td>
</tr>
<tr>
<td>The boundaries are not clear between the phenomenon and context</td>
<td>• The ways in which value is framed cannot be separated from the reasons for framing value – these overlaps are difficult to isolate. Thus, the boundaries between valuing of the lives and the influence of the context in which they occur were narrow.</td>
</tr>
</tbody>
</table>

As already discussed extensively in Chapter Three, valuation of human life is located in policy decision (episteme), within institutions and their behaviour (techne), and among people in their personal interactions (ethical government of the self). Thus, valuing human life requires an interactive method of inquiry, which enables the researcher to have a personal interaction with respondents within their context. Understanding the context in which HIV/AIDS decision-making can constitute the framing of the value of people infected with HIV was necessary for this study. Thus, it would have been difficult to have an accurate picture of how value is framed without considering the context within which it occurred. Such a consideration also informed the qualitative design of the study methods.

Case study research, however, has been criticised, primarily because of its lack of statistical generalisability. The case study critics (Miles and Huberman 1994, Cornford and Smithson 1996) argue that the richness and complexity of the data gathered are open to diverse
interpretations, and researcher biases. However, case study sympathisers (Denzin and Lincoln 1994, Yin 2003) argue that the multiplicity of respondents, methods and/or multiple settings can suggest plausible generalisability. These contending views indicate the need for data method triangulation, given that research methods often have limitations. As shall become apparent in Section 4.4. on methods, first I employ a sampling approach that aims to engage the most marginalised sub-groups among PLWHA. Second, I triangulate data methods to assess the depth of meanings constructed, and enable the reader to make a judgement regarding the transferability of the research outcomes from triangulation of methods.

Also, Cohen and colleagues (2007) and Scotland (2012) have noted that commonly used methods in constructivist approaches yield insight and understandings of behaviour, an element essential for the investigation of the framing of value of PLWHA. The methods employed for this study included: FGDs, semi-structured, open-ended interviews, elite interviews, life histories, observations and document analysis. The methods provide a greater scope to answer the ‘what ways’, ‘why’ and the ‘how’ of valuing PLWHA.

4.3.2 Study sites
The study was conducted with senior government officials in the Zimbabwe Ministry of Health and Child Care (MoHCC) headquarters in Harare, with participants living with HIV/AIDS, and without (non-PLWHA) aged 18 years or over and residing in Chitungwiza and Goromonzi Districts. As already discussed in Chapter Two, Zimbabwe provides the most persuasive context to investigate the framing of value of PLWHA. With a relatively young population, in which 41% are below the age of 15 and only 4% above the age of 65, life expectancy at birth (length of life estimated at birth) is only about 38 years, and most of the country’s population (67%) resides in rural areas (ZimSTAT 2012a). Thus, the study purposively sampled one each of rural and urban districts with a preference from one of the provinces with a higher prevalence rate and a lower prevalence rate. Although the variations in HIV prevalence are relatively all clustered towards the national 15% HIV prevalence rate, there are smaller differences between provinces. To this end, Goromonzi District in Mashonaland East Province (rural) and Chitungwiza in Harare Province (urban) were
selected. See a map of Zimbabwe in Appendix 14 and comparison of Chitungwiza and Goromonzi in Table 4.5.

Table 4.5: Comparison of Chitungwiza and Goromonzi Districts

<table>
<thead>
<tr>
<th></th>
<th>Chitungwiza District</th>
<th>Goromonzi District</th>
</tr>
</thead>
<tbody>
<tr>
<td>Province</td>
<td>Harare</td>
<td>Mashonaland East</td>
</tr>
<tr>
<td>% (proportion) of national population</td>
<td>3%</td>
<td>2%</td>
</tr>
<tr>
<td>Rural/Urban</td>
<td>Urban</td>
<td>Rural</td>
</tr>
<tr>
<td>Distance from the capital city</td>
<td>30km south</td>
<td>30km south-east</td>
</tr>
<tr>
<td>Population below the age of 15</td>
<td>34%</td>
<td>42%</td>
</tr>
<tr>
<td>Population above the age of 65</td>
<td>2%</td>
<td>5%</td>
</tr>
<tr>
<td>HIV ranking in Zimbabwe</td>
<td>Lowest burden</td>
<td>4th largest burden</td>
</tr>
<tr>
<td>HIV/AIDS prevalence</td>
<td>13%</td>
<td>16%</td>
</tr>
<tr>
<td>Proportion 3–24 years never been to school</td>
<td>10%</td>
<td>17%</td>
</tr>
</tbody>
</table>

Source. ZimSTAT 2012a, 2012b, 2012c

Chitungwiza and Goromonzi are both located no more than 35km from Harare urban, where the health ministry’s headquarters (HQ) offices are located. The Ministry of Health and Child Care’s (MoHCC) HQ is where the policy level decision-making, including on resource prioritisation, is made. As part of the participant observations, and as shall become clearer below, I spent months in these districts, observing everyday routines of PLWHA and non-PLWHA, including participating in high-level meetings at the MoHCC HQ in Harare. Thus, in addition to crucial socio-economic, health and political factors outlined above, both Chitungwiza and Goromonzi were closer to Harare and, therefore, cost-effective study sites for this study.

4.3.2.1 Chitungwiza District

Chitungwiza (see Figure 4.1) is the largest high-density suburb in Zimbabwe with an estimated 3% of Zimbabwe’s total population (ZimSTAT 2012b). Chitungwiza is located about 30km south of Harare city, within the greater Harare province (Table 4.5). Harare, the capital city of Zimbabwe, is the most populous of Zimbabwe’s ten provinces, with a population of just above 2 million; it constitutes about 16% of the country’s 13 million population (ZimSTAT 2012b). Harare province has the lowest HIV prevalence (13%) and contains the most educated populations, where more than 8 in 10 women have attended secondary school or higher (ZimSTAT and ICF 2012). While Chitungwiza city has commercial and industrial enterprises, it offers few economic opportunities, and most
economically active people commute to Harare city on a daily basis. Chitungwiza has an 18% unemployment rate (including formal and informal employment), which is higher than the national unemployment average of 11% among economically active people (ZimSTAT 2012a). More than half (56%) of households in Chitungwiza were lodgers at the end of 2012 (ZimSTAT 2012b).

**Figure 4.1: Location of Chitungwiza District in Zimbabwe**

![Map of Chitungwiza District](image)

Source. Zimbabwe District Health information and Systems Software 2014

Also, Chitungwiza is served by Chitungwiza Central Hospital (Bijlmakers et al. 1998). The hospital is one of the six central hospitals in the country; two are in Harare urban, three in Bulawayo (Zimbabwe’s second largest city) and one in Chitungwiza. Central hospitals offer the highest and most specialised levels of care, with specialty services for HIV, STIs and tuberculosis (TB). Chitungwiza Central Hospital is administered directly by the health ministry, and has a special TB clinic, as well as an opportunistic infections (OI) clinic for PLWHA. Chitungwiza Town Council administers four other municipal clinics: Seke North, Seke South, Zengeza ‘three’ and St Mary’s Clinics (Bijlmakers et al. 1998). Frequent water shortages are common, with some areas having been without potable tap water for years. Furthermore, poor refuse collection services, including of clinical waste, are common challenges in Chitungwiza (CHIRRA 2011). As I drew upon the work of Foucault (1991) on
governmentality, these elements about Chitungwiza seemed crucial to understanding the context of framing the VoHL.

4.3.2.2 Goromonzi District
Goromonzi (see Figure 4.2) is one of Mashonaland East Province’s 11 districts, and it is located about 30km southeast of Harare, in Zimbabwe. Goromonzi District, with about 17% of Mashonaland East’s total population, is the most populous district in Mashonaland East and constitutes about 2% of Zimbabwe’s total population (ZimSTAT 2012c). Mashonaland East Province is home to 10% of Zimbabwe’s population, making it one of the least populated provinces, along with Bulawayo (5%), Matabeleland South (5%), Matabeleland North (6%) and Mashonaland Central (9%) (ZimSTAT 2012a).

Figure 4.2: Location of Goromonzi District in Zimbabwe

Source. Surveyor General’s Office, 2014
Mashonaland East, mostly rural, has almost half (42%) of its population below 15 years old and only about 5% above 64 years old (ZimSTAT 2012c). The 2012 census reports that nearly 70% of the employed people were engaged in agriculturally-related livelihoods, and lived in traditional types of dwelling units (ZimSTAT 2012a). About 98% of Goromonzi District is rural. The province has the fourth largest HIV burden in the country, estimated at 16%, above the national average of 15%. Within the province, the proportions of people aged 3–24 years who had never been to school by the end of 2012 were highest in Goromonzi (17%). The proportion is also higher than the national average of 12% (ZimSTAT 2012c) (see Table 4.5).

Like Chitungwiza, Goromonzi District is headed by a District Administrator, who reports to the provincial administrator and/or governor. Goromonzi District is divided into 26 wards. A ‘ward’ is a sub-unit of the Rural District Council (RDC) and is headed by an elected councillor. A ‘ward’ in Zimbabwe is made up of numerous villages, usually six or more, which are often led by a village head (sabhuku). For this study, part of my stay in Goromonzi was in Mwanza ward, which has about 35 villages in total. Each village can have from 20 to 300 households. The traditional authorities are represented by chiefs (mambo) who have a council in the Parliament of Zimbabwe. Goromonzi District has three chieftainships: Chinhamora, Chinyika and Chikwaka. Chieftainships (madzimambo) are divided into sub-chieftainships, that are headed by sub-chiefs (machinda). The study was conducted across all the madzimambo, masabhuku and machinda areas.

Goromonzi District’s service centre, Bora, also known as Juru Growth Point, offers markets for farm fresh produce, beerhalls, a post office and banking services, brothels, a clinic, district offices and sporting facilities. The area is under Chief Chikwaka in the Mwanza ward. Bora growth point is located along one of Zimbabwe’s busiest trans-border corridors linking Zimbabwe with Mozambique and Malawi. The corridor connects the district to Harare, and is also used by truckers travelling in Southern Africa.

Unlike Chitungwiza, home to a central hospital, Goromonzi District is served by Makumbe Mission Hospital (christian church based hospital) located in Domboshawa’s Chief Chinhamora’s area. There are no direct roads connecting Chikwaka, Chinyika and other areas.
in Goromonzi to Makumbe Mission Hospital. Patients may walk several kilometres or have to find transport to Harare first before connecting to the district hospital. The district has several rural health centres.

Together, these several attributes of Goromonzi District seemed relevant to understanding the district’s context and attendant social and political factors, which, as Foucault (1991) argues, are crucial in understanding the ‘conduct of conduct’, government practice and actions of the governed.

4.4 Methods
As noted earlier, the study utilised a qualitative case study design, which employed multiple research methods that were administered concurrently. The methods included documentary analysis; semi-structured interviews, elite interviews, life history interviews, focus group discussions and participant observations. I will discuss each in turn. Table 4.6 summarises the utility and triangulation of these different research methods during the research timeline.

Table 4.6: Summary table of utility and triangulation of the research methods

<table>
<thead>
<tr>
<th>Research question</th>
<th>Level of focus</th>
<th>Issues covered – These were used to structure the empirical Chapters Five–Seven</th>
<th>Research method</th>
</tr>
</thead>
<tbody>
<tr>
<td>In what ways do policy decision-makers frame the value of PLWHA?</td>
<td>Senior government officials (MoHCC elites; Political elites; Technical elites; Development elites)</td>
<td>Knowledge on how decision-makers decide how to distribute resources that affect the quality of health service delivery. Identifying, tracking and understanding the methods used to make choices about HIV priorities. Where do these methods originate; and how do the methods work – in the sense that they lead to outcomes for patients? Knowledge on any major disagreements about the policy of how to distribute resources fairly or if everyone agreed on the means to do this and why. Tracing the interaction and relationships between institutions and PLWA.</td>
<td>Documentary analysis; Elite interviews; Participant observations</td>
</tr>
<tr>
<td>In what ways do non-PLWHA frame the value of PLWHA?</td>
<td>Hospital and clinics</td>
<td>Understanding the ways people ‘treat’ or ‘value’ each other and value PLWHA in the study sites. The influence of government HIV Programs including policies on the way communities treat PLWHA.</td>
<td>Focus group discussions; Participant observations; Documentary analysis</td>
</tr>
<tr>
<td>In what ways do PLWHA</td>
<td>Individuals</td>
<td>Understanding how PLWHA ‘value’ themselves.</td>
<td>Participant observations</td>
</tr>
<tr>
<td>Research question</td>
<td>Level of focus</td>
<td>Issues covered – <em>These were used to structure the empirical Chapters Five–Seven</em></td>
<td>Research method</td>
</tr>
<tr>
<td>-------------------</td>
<td>----------------------</td>
<td>----------------------------------------------------------------------------------</td>
<td>------------------------------------------------</td>
</tr>
<tr>
<td>frame their own value?</td>
<td>Family/households</td>
<td>• Tracing the interaction and relationships between institutions and PLWHA.</td>
<td>• Life history interviews</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Semi-structured interviews</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Focus group discussions</td>
</tr>
<tr>
<td>What are the implications of valuing PLWHA, for their lives or conversely, their deaths</td>
<td>Individual, Family/households</td>
<td>• How do differential health service outcomes occur?</td>
<td>• Focus group discussions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• What decision-making techniques are used to assess the trade-offs between HIV responses and other health care interventions in cases where multiple objectives or competing interests exist; how and why?</td>
<td>• Participant observations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• How does the way ‘others’ treat PLWHA affect their daily lives?</td>
<td>• Life history interviews</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Tracing the interaction and relationships between institutions and PLWHA.</td>
<td>• Semi-structured interviews</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Documentary analysis</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Elite interviews</td>
</tr>
</tbody>
</table>

### 4.4.1 Participant observations

Participant observation (PO) is a qualitative research method established from cultural anthropology, which enables a researcher to obtain a close and intimate familiarity with the research population in the study sites over an extended period (Spradley 1980). The first thing that I considered upon deciding to apply PO was to reflect on the type of participant observation best suited for the study. Consistent with a constructivist epistemology underpinned by notions of knowledge co-construction between the researcher and the researched, I approached the field as a moderate observer – one who balances between insider and outsider roles, facilitating a mixture of involvement and detachment to remain objective (Howell 1972). This detachment, however, was not rigid as in the approach used by positivist researchers who contend that researcher and respondent should be detached to separate reason from feelings. Instead, consistent with constructivism, the moderate observation allows for a more personal and flexible detachment which allows for capturing meanings in everyday interactions and making sense of what is perceived as reality (Black 2006). I applied moderate observation in study sites throughout the ten months in the field. I attended public meetings convened by *maDzimambo* (chiefs) and *maSabhuku* (village heads).
Participant observation was conducted to appreciate and understand the dynamics of the local context. The process began with sampling of participants and lasted throughout the fieldwork, lasting for almost one year. The method helped to identify the networks of the PLWHA before recruitment of participants. The following are some of the dynamics considered at the beginning of the fieldwork.

- What research methods could be employed to ensure that as much data is collated to answer the research questions?
- In what areas of the study sites could PLWHA be reached and what would be the best way to identify and recruit participants?
- What networks of PLWHA exist in the study sites and what sampling criteria would enable a fair representation or stable composition of these networks in the study?
- What aspects of the districts needed the understanding to build trust within the target population?

Observations also helped to map and identify different actors who would constitute FGD participants in the category of non-PLWHA (see Appendix 7).

In the study districts where I lived (see further notes about my place of residence in Appendix 15), I also went to the rural health centres on the specific dates allocated for PLWHA to collect their ARVs, once every month, to observe the behaviour of both the provider and the recipient of service. At the health ministry HQ level, I participated in meetings coordinated by the health ministry. I also worked with the health ministry’s health information and surveillance department – not as a government-paid worker but attached to a development organisation that worked directly with the MoHCC. Thus, while I was involved with the HQ’s everyday work and established rapport, I remained an outsider and was able to observe phenomena with the necessary detachment. As Hutt and Hutt (1970) recommended, I recorded my personal experiences, thoughts and emotions in a book.

The reflections on my notes made me consider my positionality in the research to reflect on my ethnicity, race, gender, sex, sexual orientation and other factors, which I thought had a bearing on the way I observed reality. Like Spradley (1980), I agree that the presence of the
researcher in the study sites can influence the participants’ behaviour, and as such I employed PO as one of the methods used in the study to triangulate and improve research rigour. Methods triangulation aims to keep a guard on such biases as personal preferences and emotion in order to record meaningful experiences.

4.4.2 Document analysis

Document analysis consisted of exploring Zimbabwe’s history of HIV/AIDS policy, programmes and legal statute changes from 1984 when the first HIV case was confirmed in Zimbabwe to 2015. It also involved a review and examination of relevant published and unpublished documents on the socio-economic, historical, political, cultural and other contextual dynamics on HIV/AIDS in Zimbabwe, in general, and in Goromonzi and Chitungwiza in particular. The documents used included the Government of Zimbabwe (GoZ) acts, policies, and MoHCC published and unpublished documents. Most of the documents were used to understand the context of HIV/AIDS in Zimbabwe, while some materials were used to strengthen the presentation and analysis of findings; see Chapters Five, Six, Seven, Eight and Nine. These documents were obtained from various sources, such as the MoHCC Library and National Archives of Zimbabwe, where historical documents on the dynamics of HIV and AIDS in Zimbabwe are archived. (See Appendix 11 for a full list of documents accessed from the National Archives of Zimbabwe and the Health Ministry Library services)

As Caulley (1983) describes, a document analysis is an exploration of documents to understand actions of people in their social, political, economic and cultural contexts. Also, Bardach (2009) maintains that to understand the policy, the likely sources of data and ideas fall into two general types: documents and people (Bardach 2009, p. 69). Bardach (2009), like Foucault (1982), argues that an understanding of power struggles and governmentality requires an exploration of written story lines and metaphors to locate the sites of discursive struggles. As such, the study sought to examine the behaviour of HIV resource priority-setting among SGOs in policy. Consistent with the three dimensions of analytics of government – episteme, techne and ethical government of the self – document analysis also helped to trace the telos of the government, tracking its ideals, principles of equity and equality in the provision of HIV/AIDS since the 1980s. This intention was consistent with
arguments to understand analytics of government as highlighted in the works of both Bardach (2009) and Foucault (1982). Document analysis helped to question policy-making processes in the health ministry to answer the questions of how we (are) govern(ed), consistent with the study's questions on the framing of the value of PLWHA.

When determining what type of data to collect for understanding SGOs in the health ministry, I took heed of Yanow’s (2007) guidelines which suggest that document analysis is constitutive of participant observation and interviews. Documents can provide relevant background information before elite interviewing, which can then be used to corroborate or refute observational data or shape the dialogue during the interview sessions. Yanow (2007) argues that, in either case, the researcher is equipped with evidence to clarify or, perhaps, to contest what is being told, a role also played by participant observation (Yanow 2007, p. 411). Document analysis informed deliberations in other methods, such as interviews, life histories and FGDs.

Some useful policy documents on the national health plans and other specific government and non-government HIV/AIDS initiatives were obtained from the MoHCC Library, WHO online library and development organisations. Lastly, useful newspaper articles dating back to 1984 on HIV and AIDS were accessed from The Herald Archives in Harare, Zimbabwe. The Herald is the oldest and biggest newspaper company in Zimbabwe.

4.4.3 Elite interviews

A working definition for ‘elite’ was adopted from Amsden and colleagues (2012) as ‘a distinct group within a society which enjoys a privileged status and exercises decisive control over the organization of society’ (Amsden et al. 2012, p. 120). Amsden and colleagues (2012) argue that the elites may not necessarily be wealthy, and neither do they need to belong to the ruling class, but they do influence development, economic, social and/or political outcomes. This section will discuss both the sampling and interviewing of the SGOs, as they are assumed to be part of this elite grouping.
4.4.3.1 **Elite interviewing**

The use of interviews to study influential people at the ‘top’ of decision-making is referred to as elite interviewing. Elite interviews (EI) focus on political and economic notables. The EI are focused interviews, which differ from other interview protocols, such as life history interviews, in that they provide depth to individual first-hand insights on matters that are often regarded as secret or confined to decision-making elites. According to Nader (1972), elite members include decision-makers with proximity to power; those who decide on, or influence, policy-making processes. Along with Nader (1972) and Hughes and Cormode (1998), I also agree that it is just as crucial to study those who influence important decisions in government as it is to research the lives of those affected by these decisions. Critics of EI such as Baxter and Eyles (1997) argue that EI data suffers from poor credibility as they are often sourced from one source, or one type of source. The triangulation of EI with other research methods facilitated the corroboration of data that had been established from other sources, such as document analysis. The EI was also conducted to investigate how decision-makers in HIV/AIDS initiatives think and act. In this way, EI was contributing towards the triangulation of data methods, where collected data was crosschecked through multiple sources to increase the robustness of the findings.

Spencer (1982), in his case study on US Military at West Point, admits to actively deceiving the elite interview participants, stating that when researching elites, and especially on sensitive and/or controversial issues, researchers often face hostility and suspicion. Spencer (1982) argues that the hostility and suspicion betrays the possible alliance between the researcher and the interviewee. Similarly, Routledge (2002), in his research, masqueraded as a tour operator to obtain information from elites in India’s tourism industry. Lilleker (2003) suggests couching controversial issues in broad terms and flattering the elite to encourage them to speak openly. Cochrane (1998) also argues that creating the right impression, such as by dressing appropriately and establishing a rapport through research into the interviewees’ backgrounds, are important considerations. These examples all suggest that the researchers felt that the powerful position of their elite participants warranted some level of manipulation; a suggestion that gives the idea that the powerful may not require the same level of ethical conduct as other types of research.
I faced similar problems. My research was not only sensitive but also could easily be misinterpreted as one that would pin the elites as people responsible for causing preventable deaths or not valuing human life enough. The SGOs could read the research as a way through which they would be made to account for deaths of millions that had prematurely perished from HIV/AIDS. To address such problems without manipulating the research intentions, I immersed myself within the health ministry’s workspace as both an insider and an outsider. I was an insider because I worked in the National Health Information and Surveillance Unit, in the health ministry, a department that deals with national health data, statistics, and surveillance all central to policy, planning and prioritisation. The unit links with and collaborates with all the departments in the health ministry. I was an outsider because I was not a government employee, but worked through a development organisation that worked directly with the health ministry. This approach of being both an insider and an outsider is part of the participant observation, a research method also employed for this study (see Section 4.4.1). Conducting participant observation as preparatory work for EI, consistent with feminist approaches and collaborative research techniques, was used for three reasons. First, I aimed to identify the actual holders of power. Second, to be known and be trusted. Third, I intended to understand how the holders of power asserted their authority and control. Understanding the dynamics of power in the midst of SGOs and their work made it easier for them to accept my invitation to interview them.

Studying elites such as high-level, powerful SGOs in the health ministry appears, on the surface, to be out of a moral intention to researching real people without having to worry about doing violence to them. However, once I was drawn into the world of the MoHCC’s SGOs, I began to uncover a divided, insecure, unsure, and rather vulnerable group of workers with a range of political and personal dilemmas, as Chapter Five outlines.

The EI provided new information on the attitudes, language and beliefs of decision-makers. The EI guide asked questions about the basis and approaches for HIV/AIDS resource prioritisation and distribution. It also asked where these approaches originated from, who made the decisions about which of the methods were used, how they were applied and if the methods led to fair outcomes. The questions were informed by the episteme, techne and moral analytics of government. The content of the EI guide is shown in Appendix 1.
An official letter was written in advance to inform the SGOs about the research project and the interest in interviewing them. The letter also highlighted the questions that could be asked, the rules, consent issues, anonymity, confidentiality and the time that the conversation was likely to consume. Upon consent, I sent a second letter to thank them for the opportunity to interview them and to establish a date for the meeting.

4.4.3.2 Sampling of ‘elites’

Elites who are senior government officials working in or with the MoHCC to make policy and programmatic decisions on HIV/AIDS were identified through participant observation processes. Three factors that interact with each other and together, to determine the decision-making process by elites in the Zimbabwean MoHCC, were identified. These three types include the internal political commitment (political elites); external influences and non-governmental initiatives (development elites), and health sector and government planning processes (technical elites). Decision-making elites under each decision-making domain were purposively sampled. These SGOs were all selected from the MoHCC Headquarters, where coordination of the development of health policy and setting of national priorities is carried out (MoHCW 2001). At this level, other key functions of the MoHCC that point to strategic decision-making that could have implications for value assignment on human life included the role of consolidating budget estimates, mobilising resources and allocating them, while also instituting expenditure controls, and budget analysis (MoHCW 2001). It must be noted that although SGOs represented officials in policy decision-making, they are also members of society who may on the one hand experience the same challenges that PLWHA face, as they too may have HIV. On the other hand, they may (not) have agency to challenge the calculative devices they apply in decision making (counter conduct), they may be engaged in homosexual conduct, and may have family members or relatives living with HIV.

Appendix 15 outlines the types of SGOs that were carefully selected for this study. Although the study draws largely from the senior government political and bureaucratic elites in the MOHCC (also see Appendix 4), it must be noted that the study acknowledges the power of other sector ministries that play a role in decision-making – with implications for HIV/AIDS.
resource availability. Among other, these include the Ministry of Finance, which determines the MOHCC's annual budget allocation; the Ministry of Education involved in HIV/AIDS through HIV/AIDS school health programmes; the Ministry of Labour and Social Welfare which determines social services for PLWHA; the Ministry of Infrastructure and Community Development which determines the availability of clinics; and the Ministry of Transport and Road Services which determines access to health services through road infrastructure. While these were important, it was beyond the remit of this study to interview the whole of the Government given the complexity of carrying out such a study, with resources and time. Also, it is noteworthy to highlight that although the study focused on the development organisations working directly with the MoHCC on HIV/AIDS, there are other similar development organisations who also work with other sector ministries in their respective remits that may also impact the type and scope of resources available for PLWHA. These limitations may thus overestimate the power of SGOs in MOHCC, who are as much policy takers as they are policy makers, since they must live within a budgetary envelope and a policy environment over which they have little power or even influence.

4.4.4 Semi-structured interviews and life history interviews

The study interviewed PLWHA to answer the question ‘In what ways do PLWHA frame their own value?’ Also, as Servaes (2008) notes, PLWHA, like other vulnerable social groups, occupy a better position to articulate their exclusion rather than the powerful forces that have tendencies of blaming the victims of exclusion rather than querying the models that make them vulnerable. Thus, interviewing PLWHA also gave indications to the ways in which non-PLWHA, including SGOs, frame the value of PLWHA. The study interviewed 111 PLWHA in semi-structured interviews, and 6 in life history interviews. The latter consented from a random selection carried out from the 111 PLWHA interviewed in semi-structured interviews. A very careful process was administered to select a representative sample of PLWHA networks in both Goromonzi and Chitungwiza. As already highlighted in Chapters Two and Three, the HIV epidemic is met with secrecy and derision, blame and shame on the highest rung of the stigma ladder (Maman et al. 2009). As such, reaching PLWHA for research is often associated with difficulties of sampling and recruitment. PLWHA are made up of hard-to-reach populations with no existing sampling frame, particularly at district levels in Zimbabwe. Also, the personal circumstances of PLWHA and
their socio-demographic characteristics makes it harder to access the populations for research. Discriminatory repercussions (Tung et al. 2008) primarily contribute to their reluctance to volunteer personal information. For almost three decades now, HIV-related stigmatisation, discrimination and denial have characterised the Zimbabwean HIV epidemic, where terror and blame are assigned, and from which social responses are derived (Maman et al. 2009). At the personal level, the internalisation of these societal responses may result in PLWHA’s self-exclusion from information. Such difficulties are equally problematic in recruiting this population for research purposes (Todd et al. 2007, Valle and Levy 2008, Shahmanesh et al. 2009).

These implications pointed to possible limitations on the diversity of PLWHA participants for both the semi-structured interviews and life history interviews. From this, there was a realisation that the accrued sample may be neither diverse enough nor sufficiently representative of the wider population of PLWHA to achieve results that can speak concretely about the valuation of PLWHA and its implications for the life of PLWHA. This study did not attempt to make statistical inferences about the wider population as these would not do justice in answering the how and why questions central to analytics of government. Instead, the study used a case study to gain close-up insight on the framing of the value of PLWHA and implications of such valuations on life or death of PLWHA. Even so, according to Creswell (2009), qualitative case studies should have a sample representative enough to constitute a diverse composition for both a focus group discussion and interviews.

To this end, using purposive sampling, PLWHA in either Goromonzi or Chitungwiza Districts did not need to have an equal opportunity of being selected. This meant that only those participants with a medically confirmed HIV-positive status, who were of age 18 or above and willing to participate in a survey, were eligible for the study.

Below I discuss the sampling approach that was used for interviews with PLWHA and its limitations.
4.4.4.1 Sampling: Respondent-driven sampling method

The respondent-driven sampling (RDS) method, first introduced by Douglas Heckathorn in 1997 (Heckathorn 1997), has served as a model for recruiting hard-to-reach populations in research. Hard-to-reach populations may include PLWHA and LGBT, ex-prisoners and sex workers who live with HIV, sub-groups of PLWHA central to this study (Faugier and Sargeant 1997). Scholarly communities in public health, social science and health policy research have come to accept the validity of the methodological assumptions associated with the RDS sampling method. The thinking expressed in the rigour of this modification presents opportunities to prevent biases associated with the snowballing recruitment of participants. Snowballing can result in differential recruitment where the final sample can be over-represented by the features of those participants with wider networks, and simultaneously underrepresented by the features of those with fewer networks – usually the more hidden, hard-to-find social group members (Johnston and Sabin 2010). The RDS data collection method is now widely used in public health behavioural research, and has been widely employed in more than 20 countries (Malekinejad et al. 2008). More specifically, the RDS method is used by the Centers for Disease Control and Prevention (CDC) (Lansky et al. 2007, Lansky and Drake 2009) to track the HIV epidemic in countries where the epidemic is more generalised. For this research, RDS was employed primarily for purposes of participant recruitment to facilitate data collection through interviews. It facilitated examination of PLWHA via a chain referral procedure in which participants recruit one another, akin to snowball sampling where the initially known person living with HIV (the ‘seed’) in either of the districts would use their personal networks to identify more individuals living with HIV and aged 18 or above (Erickson 1979, Heckathorn 1997, 2002, Salganik and Heckathorn 2004).

The central feature of RDS, which largely differentiates it from snowballing, is that the seeds recruit rather than identify participants (Heckathorn 1997). This approach enabled seeds to recruit peers, then peers to recruit peers, exerting social influence where the researcher had none. The recruitment chain was made sufficiently long – meaning that more and more participants were recruited by peers (peer recruiting peer), allowing for deeper penetration of the target PLWHA group networks, reaching the hardest to find. This is one of the key theoretical suppositions proposed by the RDS method, which ensures that the sample
demonstrates agility for representativeness (Heckathorn 1997, Heckathorn et al. 2006, Salganik and Heckathorn 2004). Ensuring representativeness satisfies the assumption of ‘equilibrium’ attainment, where the distribution on the selected variables remains stable or saturated, beyond which point no additional respondents bring in new data (Heckathorn 1997, 2002).

i. **Study seeds**

To apply RDS, the initial participant living with HIV, called the ‘seed’, was purposively sampled based on key traits or distinguishing characteristics, which the literature identify as constitutive of analytics of government or relevant to understanding governmentality and its role in the valuation of human life. Identification of key or essential traits sought to maximise the possibility of attaining a complete social network of PLWHA and that the PLWHA network characteristics reached a stable composition along the recruitment chain. The stable composition was fulfilled when key traits of PLWHA were included in the network to ensure the diversity of composition. Ensuring stable composition suggested a fulfilment of the first RDS assumption of composition saturation. Key traits of research participants were identified based on the literature review and the research questions. The key traits were important in the identification and the subsequent recruitment of seeds. The list that became the guide of the research’s key traits is below:

- PLWHA who had lost a family member to AIDS
- PLWHA who had been turned away from the treatment centre and/or put on a waiting list
- Sex (male or female), sexuality (homosexuality, heterosexuality), key affected populations (LGBT, ex-prisoners, women, adolescent (18–19))
- Physical outlook and well-being of the person (visible side effects from ARVs of worried-well patients)
- Ethical, religious and spiritual belonging
- Urban/rural residence

These traits are highlighted further in Appendix 15, showing the interaction of traits with the specific research question. A participant needed at least one of the traits and not necessarily all the listed traits (see full list of all the SSI respondents in Appendix 10). However, the seeds that began the recruitment process fulfilled at least half of these traits and met the eligibility requirements set up at the outset of the study (medically confirmed HIV-positive status and above the age of 18). Other important traits such as income, employment and CD4 count, while important to consider in the recruitment, were not included because these traits
are considered personal in Zimbabwean culture. Thus, peers or study participants were likely to face difficulties when attempts to disclose such information were made during the recruitment process. However, some of these key traits were traced during interviews and life histories, and were discussed more broadly in FGDs.

ii. **Seeds: Selection and recruitment**

To generate an RDS sample, I began by purposively selecting a small number (three) of initial participants (‘seeds’) from the target population of PLWHA, as recommended by CDC as one of the institutions championing RDS in public health research (CDC 2005). The seeds recruited their contacts in Goromonzi and Chitungwiza. The sampling proceeded with sample participants recruiting the next wave of sample participants. The process continued with interviews administered to eligible recruits at every wave until the desired sample size was reached. Participants were allowed to recruit up to three other contacts to ensure sampling continued, even if some sample members did not recruit. The seeds knew the PLWHA community well which meant that they were connected to a network; they lived with HIV and were above the age of 18. The following describes the recruited seeds in the respective districts.

**Table 4.7: Seeds recruited for the study**

<table>
<thead>
<tr>
<th>Characteristics of seeds</th>
<th>Chitungwiza seeds</th>
<th>Goromonzi seeds</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Chitungwiza seeds</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>She was a former nurse and a founder of a home-based care programme for PLWHA. She lost a husband to AIDS when she was 32 years old. She chaired the local HIV support group and was the focal person for the Zimbabwe National Association of People Living with HIV (ZNNP+). She linked group members to local activities supported by the National AIDS Council’s District AIDS Coordinator (DAC) and other NGOs. Now 39 years old, she had three children and her last-born son, aged seven, was living with HIV. She and her son were both on ART. (C001)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>She was a founder of a local HIV/AIDS support group for young people that were born with, affected by and or infected with HIV/AIDS. Before she began her antiretroviral therapy (ART), she had been put on a waiting list at Harare hospital for 11 months. Before ART initiation, she had advanced HIV, suffered from tuberculosis and developed recurrent retinal opportunistic infections, which led to her losing one eye. She was 49 years old. (C002)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He was born with HIV and had lost both parents when he was seven. His uncle, who had four other children of his own, raised him, but he could not complete secondary school. He was 24 years old, unemployed and hoped to get married once he found a suitable partner, what he termed ‘my true love’. He was also an active community home-based caregiver and was on ART. (C003)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Goromonzi seeds</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>He was incarcerated for eight years in one of Zimbabwe’s prisons (name of prison withheld). He endured homosexual rape as an inmate and reported that other inmates infected him with HIV because of ongoing sexual abuse, while his requests for help from staff were ignored. He reported that his situation was similar to some of the inmates still incarcerated, and those out of prison with whom he still communicated on an ad-hoc basis. At the time of the interview, he was 38 years old, married with one child. His wife was also living with HIV. However, his 13-year-old child was HIV negative. He raised chickens for eggs and sold the eggs for income. (G057)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Seeds had unique traits that I purposively selected to ensure adequate recruitment using the distinctive traits that included the following: first, seeds came from both the rural area (Goromonzi) and the urban area (Chitungwiza), each with three seeds. Second, the total sex composition of seeds was equally distributed with three women and three men overall. Third, approximately 30% of the seeds were not on ART while two-thirds had been initiated. They all had relatively large social network sizes, had the potential to be respected by members of the target population, had the capacity to convince others to participate in the study and had shown interest in the study goals. Furthermore, seeds represented key sub-populations. These were 1) sex workers, 2) apostolic church network, 3) young people born with HIV, 4) ex-prisoners, 5) HIV support group networks, 6) home-based caregiver network, 7) and gay men and lesbians. The subpopulations’ diversity aimed to increase chances of forming a complete social network of PLWHA and to increase the chances for the sample traits (see Appendix 15) to attain a stable composition (equilibrium).

**iii. Recruits of seeds: selection and recruitment**

The RDS seeds were each given three uniquely coded tickets that they submitted back to me at the interview site within five days. The interview sites were my home, in Mwanza, and Seke Unit D, for Goromonzi and Chitungwiza respectively. The recruits of seeds (first wave) recruited their peers (second wave), who in-turn enrolled in the study’s semi-structured interviews and received their own set of tickets to use in recruiting their peers (third wave). This process continued to form an extended recruitment chain comprised of seven waves of participants for each district. A theoretical limitation of RDS is that the choice of seeds can undermine the final composition of the sample given that individuals differentially recruit individuals with traits similar to theirs (referred to as homophily). However, initiating the process with a limited number of three seeds, and limiting the number that each seed recruited (first wave), enabled an extended recruitment chain that facilitated a resemblance of the
underlying population (referred to as equilibrium), curbing the weakness of homophily. Heckathorn (1997 and 2002) proposes that the probability of participants recruiting others who are unlike themselves improves with the length of the recruitment chain, attained at approximately six referral waves. He suggests that at this stage of referral waves, a sample is likely to have reached resemblance of the underlying target population within a geographic area or major demographic characteristic, resulting in an unbiased final sample. The study’s long recruitment chain helped to ensure that the sample satisfied theoretical assumptions that suggest representativeness and attainment of ‘equilibrium’ (Heckathorn 1997, Heckathorn 2002, Salganik and Heckathorn 2004, Salganik 2006).

An interview was carried out for each seed. After completion, the researcher asked if the seed would agree to recruit three other participants. Upon assent to recruit, 15 to 30-minutes of training on the recruitment process ensued. This also included the seed being given three separately coded, irreproducible tickets that the seed (as a recruiter) would give to each prospective participant (recruit) in their networks. The code number on the ticket was linked to the recruiter and the person returning the ticket (the recruit). The seed was also given three consent forms to give to the recruit to read. Each recruit brought back the consent form and ticket to the interview site to complete an interview once I granted eligibility. When eligibility was granted, the recruit was taken through the consent form to ensure that they understood the purpose of the study. Also, consent to participate in life history interviews and an FGD was sought (see Appendix 12 for ethical clearance approval). A participant could consent to partake in the SSI and refuse to participate in a life history interview and/or FGD. Where a participant consented to participate in a life history interview, their details were noted for a possible future call/visit to inform them about the life history interview. In cases where a recruit was interested in the semi-structured interview but could not come to the study site, the recruit flash dialled me as a cue to call back. Where a phone was not available, word travelled by word of mouth and I would travel to the village or homestead to meet the sender of the word. In such cases, the ensuing discussion involved arrangements on alternative interview locations and times. Upon completion of the interview, each recruit went through the process similar to that administered on the seeds, i.e. they were asked to recruit others (recruit became recruiter), recruiters were provided a short training on peer recruitment and
given three irreproducible coded tickets. The process of recruitment continued until seven waves each for Chitungwiza and Goromonzi (111 participants) had been established.

**iv. Recruits: Eligibility to participate in interviews**

The eligibility benchmarks for all the recruits were established to ensure standardisation in recruitment and to ensure recruitment of the actual target participants for the study. The following is a list of the questions that I asked each prospective participant before the survey interview.

<table>
<thead>
<tr>
<th>Question</th>
<th>Eligibility Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) How old are you? Only those participants aged 18 or older were eligible.</td>
<td></td>
</tr>
<tr>
<td>b) How did you find out you were seropositive for HIV? This was a proxy question to determine if one was living with HIV and if this had been confirmed medically.</td>
<td></td>
</tr>
<tr>
<td>c) Describe to me the HIV testing process that you went through. This was meant to determine if the prospective participant had been tested for HIV medically.</td>
<td></td>
</tr>
<tr>
<td>d) Where do you live? Only those participants who lived in any of the wards in the Goromonzi District or any municipality zone of Chitungwiza were eligible for the study. Therefore, those participants who were visiting family or in the area for other reasons and not normally based in these study districts were not eligible.</td>
<td></td>
</tr>
<tr>
<td>e) What language do you speak at home? If I were to interview you what is your language of choice? Only those participants who could be interviewed in Shona, Ndebele or English were eligible.</td>
<td></td>
</tr>
</tbody>
</table>

I paid attention to the manner in which the prospective recruits responded, the logical flow of their responses, and their general knowledge of HIV. This was meant to prevent entrepreneurial participants from enrolling in the study, lest they had been coached on the screening questions beforehand by their recruiter or peers, hoping to get the transport reimbursement. Other distractors or in-depth questions were included where necessary. For instance, when a prospective participant mentioned their initiation on ART, I asked for the names of the medicines being taken, and/or other tests, if any, that were administered to determine their eligibility for ART. Where the prospective respondent failed to give the names of the medicines or to describe the ART eligibility tests, I made the decision to interview or not to interview in full consideration of other selection questions.

**v. Respondent-driven sampling (RDS) recruitment process**

The framework provides an overview of the process to identify and recruit survey participants and FGD participants employed in the study using RDS.
Figure 4.3: An overview of the process of identification and recruitment of study participants

Source. Author
4.4.4.2 Semi-structured interviews

The study administered 111 semi-structured interviews (SSI), 55 in Chitungwiza and 56 in Goromonzi districts, with PLWHA sampled through RDS outlined in Section 4.4.5 on sampling above. These face-to-face SSI ranged from 20 to 60 minutes. Unlike structured interviews, which have a rigid set of questions, the SSI are open, allowing new ideas to be pursued, interrogated and understood (Gordon 1975, Abrahamson 1983). The SSI is grounded in social science research, consistent with the constructivist epistemology which underpinned the current study (Gordon 1975, Bailey 1987, Guba and Lincoln 1994).

The SSI was administered to explore views of PLWHA, their experiences on HIV service delivery, their treatment by service providers, policy and others in the community. The interviews also explored the beliefs and motivations of PLWHA on particular matters like how they value their own lives and how others value their lives. The questions that were asked in the SSI guide are contained in Appendix 2.

The use of the term ‘value’ in the interview was ‘implied’ rather than being used ‘explicitly’, as it did not capture the richness of the concept of value as used in the in Zimbabwe’s Shona culture (see Chapter One, Section 1.4.2). Thus, local terms, including ‘rukudzo’, ‘huremu’, ‘hukoshi’ and ‘udzamu’, were used, and participants used similar terms interchangeably as they can all mean ‘value’ depending on the context in which a story is told. Such explorations provided a ‘deeper’ understanding of social phenomena, which could not have been gathered had a quantitative survey been used (Cormack 984). Such an approach did not imply a deliberate disregard for the opinions and perceptions of people not infected with HIV; rather the perceptions of HIV-negative people were explored through the lens of the infected and through FGD with non-PLWHA. The objectives of the SSI were to understand the ways in which the government managed PLWHA – and the effect those actions had on their lives – from the perspective of PLWHA. Thus, the interviews were semi-structured in format but active in nature – i.e. I treated them as a site of meaning production, with the aim not to elicit the pre-interview and dogmatic views held by the interviewee, but to co-construct the meaning during the interview.
This experience was particularly important given that little, if anything, is known about framing the VoHL in health policy and practice in Zimbabwe. Therefore, SSI was the most appropriate method because, as Bailey (1987) and Barriball and While (1994) argue, SSI are most useful where little is already known about the studied phenomenon and/or when exploring sensitive topics, where participants, for example, feel ashamed to disclose certain information.

4.4.4.3 Life history interviews

A life history interview (LHI) is a research method that employs an intensive interview with a participant who gives an account of his/her life or an aspect of it that has developed over the life course (Devault 1990, Silverman 2000). The interviewee highlights their experiences, life challenges and opportunities. It is more than a description of a discrete experience; it gives the ‘whys’ and the ‘hows’ a life’s course took the form it did. A LHI method is established in social science and anthropology and has become allied to postmodern feminist and constructivist epistemology (Devault 1990). Six selected life histories, one from each of the three chieftainships in Goromonzi and one from each of Chitungwiza’s Seke, St Marys and Zengeza municipalities, were recorded.

The six interviewees were drawn from networks of HIV and AIDS identified through the RDS in both study sites. These included 1) sex workers, 2) visibly ill, 3) young people born with HIV, 4) ex-prisoners, 5) receiving/not receiving ART, 6) support/home-based caregiver network, and 7) gay men and lesbians. The interviews were time-intensive; on average, an interview lasted between 2 and 3 hours, and meetings that started at 1000hrs were adjourned between 1200–1300hrs, with short breaks in between. LHI aimed to understand connections between different aspects of the life of PLWHA and government practice. The relationships included their daily struggles with HIV infection and with society, and how these struggles interacted with death and survival, and why things turned out the way they did. I recorded not only what the individuals said, but also how I felt about what they said, capturing emotions of excitement, shame, sorrow, sobs and laughter – as these too have implications on the VoHL.
4.4.5 Focus group discussions

The rationale of conducting focus group discussions (FGDs) was premised on the need to explore, and to provide clarification on entrenched societal conducts that are often difficult to extract from single face-to-face interviews (Kitzinger 1995, p. 299). FGDs are group discussions conducted on a set of questions in the quest for knowledge (Kitzinger and Barbour 1999, p. 4), offering the researcher a higher level of face validity to confirm the information relayed by participants (Webb and Kevern 2001, p. 800). This is significant for this study because FGDs spoke to an in-depth understanding of the valuation of human life as observed and experienced by the participants who partook in the discussion. Joseph et al. (1984) also corroborates by giving an example of how epidemiologists employed FGDs to gain insight on experiences of people at risk of HIV infection with whom they had little prior experience. Similarly, Krueger (1994, pp. 10–11) defines an FGD as a group interview that elicits environmental behaviours that construct societal meaning from mere group interactions. Asbury (1995) corroborates, noting that FGDs can enable a harvest of data from people’s experiences.

The FGDs were employed to share experience and practice of PLWHA and those not infected with HIV (non-PLWHA), to gain insight to how their life events could collectively conceptualise how they are valued in society and in health systems, and how this had implications on the lives or deaths of PLWHA.

To this end, four FGDs were conducted (two in each district) with PLWHA, along with four with non-PLWHA (two in each district). Multiple FGDs have been argued to provide a platform for the researcher to assess content saturation (Lincoln and Guba 1985; Strauss and Corbin 1990; Morse 1995). Krueger (1994) and Morgan (1997) propose three to six FGDs as adequate to reach both content and theoretical saturation, beyond which data would appear to have no additional interpretive worth.

Each FGD had ten participants to facilitate an in-depth discussion. Once the researcher had granted eligibility to participate in the survey and sought consent, the participant was also asked if they would want to be included as an eligible participant for the FGDs later. The
participants who agreed to participate were listed down as eligible FGD participants and their contact information was noted accordingly.

4.4.5.1 Sampling of FGD participants

Non-PLHWA are people not living with HIV/AIDS in the study sites. These can be subdivided into several categories such as women, youths, children, development organisations, community AIDS service organisations, faith-based organisations, people living with disabilities, gay men and lesbians, and commercial sex workers. This study did not place the non-PLHWA into categories as that was beyond the thrust of this study. For non-PLWHA, 40 participants were purposively sampled from community-based groups, development organisations, Church groups, the police, the clinic, traditional authorities and local government (see Appendix 7 for list).

PLWHA are people living with HIV/AIDS in the study sites. For PLWHA, 27 and 23 participants agreed to be included as eligible FGD participants in Goromonzi and Chitungwiza respectively from the SSI (see a sampling in 4.4.4.1). Among them, 20 participants from each district were randomly selected to constitute two separate focus group discussions in each district. Simple random sampling was employed to recruit the 40 (total) from the pool of 50 (total). Coded cards (27 and 23 from Goromonzi and Chitungwiza respectively) that linked the participant to their contact information were all thrown in a basket, and 40 cards were picked at random (20 from each district). Two FGDs were held in Goromonzi, and two were held in Chitungwiza for PLWHA.

4.4.6 Summary of research methods and field activity timeline

The fieldwork exercise was conducted from September 2013 to July 2014 (see Appendix 8 and 9). Whilst the study was primarily concerned with understanding the framing of value of PLWHA for extended periods (i.e. over 1985 to 2015) as opposed to investigating them at a particular moment in time, the timing of the fieldwork was tailored to capture ‘everyday lifestyles’ and how they connect with policy and society. This involved observing life and death events in ordinary communities with real people going about their businesses. Thus, I needed almost a year to fully witness ‘life of PLWHA’ in their communities. Table 4.8 below summarises the research methods used and the selection of participants, while Appendix 15
gives a summary of the study timeline, along with Appendix 8 which provides a detailed calendar of activities.

**Table 4.8: Summary of research methods used in the study, numbers of participants and selection of participants**

<table>
<thead>
<tr>
<th>Research method</th>
<th>Numbers</th>
<th>Selection criteria</th>
</tr>
</thead>
</table>
| Semi-structured interviews (SSI) | 111 interviews (See SSI guide in Appendix 2) | ● Sampled through respondent-driven sampling (RDS)  
● Resident in Chitungwiza or Goromonzi District  
● Medically confirmed HIV-positive status  
● The interviewee is recruited by one of the six initial RDS seeds (see Table 4.7 and Appendix 10 for a complete list of respondents). The seeds represented the following networks: 1) sex worker 2) homosexual 3) well-to-do (wealthy) 4) religion 5) receiving ART or not 6) lost a relative to HIV  
● Aged 18 and above |
| Focus group discussions with PLWHA (FGDPWA) | 4 focus group discussions (See FGDPWA schedule in Appendix 5) | ● 40 PLWHA randomly sampled from semi-structured interview respondents who gave consent to participate in the FGD  
● Two FGDs in each of the two districts |
| Focus group discussions with non-PLWHA (FGD) | 4 focus group discussions (See FGD schedule in Appendix 5) | ● 40 people purposively selected from the study sites including people not living with HIV, representatives from community-based groups, development organisations, church groups, police, the clinic, traditional authorities and local government  
● See Appendix 7 for a complete description of each participant |
| Life history interviews (LHI) | 6 cases (See LHI guide in Appendix 3) | ● Sampled from semi-structured personal interview respondents – based on the strength of their input in the semi-structured interview  
● Six individuals, one from each of the three chieftainships in Goromonzi and one from each of Chitungwiza’s Seke, St Marys and Zengeza municipalities were recorded. The six interviewees were drawn from networks of HIV and AIDS identified through the RDS in both study sites. These included 1) sex workers, 2) apostolic church network 3) young people born with HIV 4) ex-prisoners 5) not receiving ART 6) Support / home-based caregiver network, and 7) Gay men and lesbians.  
● Willingness of respondents to provide intimate details of their lives  
● See Appendix 6 for a LHI schedule and description of each each respondent |
| Elite interviews (EI) | 10 interviews (see EI Guide in Appendix 1) | ● Purposely selected from senior officials in positions of policy, high-level policy decision-making in the government’s MoHCC and relevant non-governmental entities working directly with the MoHCC  
(See Appendix 4 for the elite interview schedule and description of each respondent) |
| Document analysis | - | ● Relevant published and unpublished material from the Ministry of Health and Child Care (MoHCC) Library  
● National Health Information and Surveillance Unit (NHISU) databases  
● National Archives of Zimbabwe Library  
● WHO and UNAIDS websites  
● Development organisations libraries and The Herald print newspaper archives  
(See Appendix 11 for a list of documents sourced from the national archives and the MoHCC library) |
Research method | Numbers | Selection criteria
---|---|---
Participant observations | - | **Policy decision-maker level**
- Key MoHCC policy and planning meetings
- National AIDS Council research advisory meetings
- Key national level health programme launches
- Social Determinants of Health whole of government technical committee meetings
- Informal conversations with senior officials at the MoHCC and during crucial meetings
**Society level (community, family, individual)**
- Randomly selected community members and key informants

### 4.5 Research ethics

There were three main complementary options used to ensure ethical issues were above board, given that this study employed intrusive data collection methods. The methods were in the form of semi-structured personal interviews, life histories, elite interviews and observations that involved personal and interpersonal interactions. A checklist, information sheet and/or a consent form were considered to ensure ethical issues were observed. Given that English is a second language in study sites, a consent form, where participants could read the contents before appending their signatures to the form, was provided in Shona, the sites’ primary language. Information was also explained verbally in Shona to ensure that the participant understood the objectives of the research. Consistent with Patton’s (2003) recommendations, I used consent forms and information sheets that were based on appropriate moral and legal principles. These were included for all FGDs and interviews.

The information sheets and consent forms were consistent with both the University of Manchester Code of Good Conduct Research Policy (2012) and the Ethical Practice Policy and Guidance (2012) guidelines. Both policies emphasise applying both beneficence and non-maleficence ‘to do good’ and ‘not to do harm’ respectively. The policies advocate honesty and integrity in research publication, respect for the rights of others, and justice and fair treatment of others during the study. Therefore, information provided to participants was adopted from the University of Manchester’s policy guidelines. Some of the ethical matters considered are listed below.

- **Purpose of the study:** Explaining the purpose of the study in simple, local language, and identifying any possible benefits of the study to the participants.
• **Risk assessment:** Conscious of the psychological stress the interviews or observations might cause, particularly for PLWH, or SGOs that may make resources available to some and scarce or unavailable to others in Zimbabwe.

• **Confidentiality:** Emphasis was made that participants’ identities would remain confidential and anonymous in the study documents. This was particularly important in the socially and politically polarised Zimbabwean environment at the time of the study.

• **Informed consent** before and during participation was sought. Participants were able to withdraw their consent at any point.

Pseudonyms were used both during the fieldwork exercise and in the writing up of the thesis, to uphold the principles of anonymity and to protect the privacy of participants. Participants whose identities were difficult to anonymise, such as elite interviewees (SGOs) from the health ministry, were clearly informed of that fact before the interview so that they could decide whether to continue or not given that position. While I emphasised that no name would be written, the fact that the SGOs in the health ministry are few and could easily be identified meant that the SGO had to be informed of this fact before the interview (see the full list in Appendix 4). Data collection exercises, including elite interviews, semi-structured interviews and life histories, as well as names of participants and study sites, were anonymised to avoid participants being identified by third parties. Examples of pseudonyms used during the fieldwork exercise are shown in Appendix 15.

I also continually asked for the permission of respondents to use an audio recorder before each interview. While participants who were interviewed had signed a consent form, I regularly asked for consent throughout the dialogue in all interviews and FGDs. During and after the research, all data was, and has since been, stored with security safeguards against loss, unauthorised use, modification or disclosure in personal password-protected computers.

It should be noted that the Medical Research Council of Zimbabwe (MRCZ), which is also the National Ethics Committee, established in terms of Zimbabwe’s Research Act of 1959, provided the extra ethical clearance needed for my research in Zimbabwe. In addition to having had my research cleared by the University of Manchester Research Ethics Committee,
I sought clearance through the MRCZ in Zimbabwe – a process that took three months (see Appendix 12 for Zimbabwe clearance). It was the MRCZ’s clearance that was acceptable to local authorities in study sites and the health ministry HQ offices. Thus, it was the first formal engagement tool that I used to introduce the research in the study sites.

4.6 Positionality

One of the ethical limitation issues that I came across in the field had to do with my position and how it influenced the way I engaged with research participants, and perhaps how I understood reality and constructed knowledge from the information that I had gathered. First; my positionality as an African and Zimbabwean woman, whose relatives perished from HIV, contributed to partiality. In practice, this means that I showed emotion in some of the stories as they could relate to my experiences losing friends and relatives, compromising, perhaps, the way I interpreted the meaning of particular interviews. It could have also affected the way the participants told their story.

Secondly, my work experience in HIV/AIDS issues contributed to subjective interpretations of reality. This is because, before the research, I had worked on HIV/AIDS issues for a long period. Formal engagement on HIV/AIDS matters began when I was an adolescent doing my undergraduate studies at the University of Zimbabwe. Just before commencing my Ph.D. studies, I also worked at the policy level in the Zimbabwe Health Ministry’s, National Health Information and Surveillance Unit, as part of a project that was integrating HIV/AIDS and TB information systems with the main national information system to coordinate national information systems. Though I had engaged at the policy level, I had not sat on high-level resource allocation decision-making tables and had always wondered what they discussed and how decisions on HIV resources were made. Prior to my work in the health ministry, I worked with communities in six African countries (Tanzania, Namibia, Malawi, Mozambique, Zimbabwe and Botswana), leading on participatory research on an African, Caribbean, Pacific and European Union project on community-based systems for HIV treatment, for over four years. I had also been part of an HIV movement in Africa, including the Treatment Action Campaign (TAC) and the People’s Health Movement, since 2005 as part of my health activism work in Africa. I trained hundreds of people in the east and southern African rural and urban communities in health and HIV treatment literacy between
2006 and 2012. I had worked across all ten provinces of Zimbabwe with people living with HIV, homosexuals, sex workers, women and youths. Thus, my study was not just a piece of academic work, but a part of my work and study interests.

Thirdly, the manner in which people, in general and research participants in particular, viewed me affected my positionality. Consistent with feminist epistemologies that argue that the sort of meaning made to any pieces of knowledge depends on who its makers are (see Haraway 1991 and Harding 1993). The ever-growing literature on situated knowledge, reflexivity and positionality grounded in feminist epistemologies emphasises the importance of researchers to acknowledge their partiality, subjectivities and biographies through reflexivity (Harding 1991, Gibson-Graham 1994, Steinberg 1994 and Nightingale 2003). Doing so can support researchers to grasp the dynamics of the research process, participants and the research context, which have an impact on knowledge production. For instance, one experience I encountered in the field that brought an ethical positionality difficulty to my study was a statement uttered by one of the participants from the semi-structured interviews (G073). See Box 4.1 below.

Box 4.1: Positionality difficulties - case example in the field (G073)

After having checked all the eligibility benchmarks to assess whether the participant recruited through respondent-driven sampling was eligible for the interview, we sat on a Rukukwe (reed mat) under a tree, and I switched on my black Sony tape recorder between us, and we began to talk. With what appeared to look like fine lines, thin as cobwebs covering her beautiful dark face, aging her, and wrinkling her skin she hid them with a broad smile. She was quite alert and looked very keen to begin to talk, although frail and tired. She smelled of confinement, soap and sweat. I began to think that she had probably walked in the sun which made her sweat after her bath. She had close-cropped short natural hair, and she was not dressed like most women I had seen in G, and she appeared to show no apprehension. She wore a pink, snug fitting modest bodice tank-top, and a flared green skirt with a hem that fell inches above the knee. As I had just begun to interview her, a friend of hers, a younger man from the local bar walked past us waving at her. She shouted, ‘ndichakuona kana ndapedza, ndichambo intavhiyuwiwa nevakuru, mikana yeupenyu wangu, haufanirwi kupfluurwa nezvakadai, zvinhu zvinogona kungondichinjira waona, ndozokuona’. This can be loosely translated as ‘I will see you when I’m done, just getting interviewed by vakuru [powerful, respected, valued, elite, knowledgeable], these are life opportunities never to be missed, you never know when life can change for the better, see you later’. She was laughing and glowing with excitement as she sent off her friend who had stopped to listen to her speak. I laughed with her too and shared her excitement, but I did not know what she was excited about.

The statement has bothered me since then and caused me to reflect on a number of elements. I have many uncertainties about it - why did she refer to me as vakuru? Vakuru is a complex Shona term with multiple meanings. It can refer to a senior citizen; it can refer to someone more powerful with the ability to change things. It can also mean someone wealthy, or a
politician. Is this how she viewed me? Did she view me as a powerful elite from the health ministry? Which one from these multiple meanings did she mean? Overall, she had high expectations of me and I believe these expectations influenced how she prepared for the interview, her excitement, what she said and how she felt after saying what she communicated to me.

The questions reflect the difficulty or challenge of reflexivity that has been advocated by supporters of feminist epistemologies as a strategy for situating knowledge to avoid a falsification of neutrality and universality of so much academic knowledge. See Haraway (1991), Katz (1996) and Harding (2004) for a few examples.

Although positionality seemed to have limitations in the ways above, it also had its upside. The activist epistemology, which can be argued to be a component of the feminist epistemology, argues that researching one’s own, or people who have lived in the context in which the researcher has experienced or seen, has substantial justification arguments. Fonow and Cook (1991) argue that activists from marginalised social groups can confront and challenge research approaches that are steeped in inquiry (finding-out), by incorporating understanding not only in the research agenda but into the ways of acquiring the knowledge (informing respondents). This is significant because it also helped to inform the qualitative design and methods used in the study. For activists, the primary purpose of qualitative research is to effect change iteratively by providing information to respondents, which should, arguably, lead to empowerment – empowering one’s people and not just reporting phenomena. See Fonow and Cook (1991) and Lather and Smithies (1997) for these arguments.

Activist epistemologies argue that the approach to just report phenomena is in itself unethical (Fonow and Cook 1991). Hence, it can be argued that just reporting phenomena where the inability to empower a participant (through information for example) can lead to harm or death can also be unethical. Hard-to-reach and stigmatised social groups such as PLWHA, ex-prisoners and LGBT communities may be aware of the oppressive social structure and can resist being researched by the privileged group. By the same token, Lather and Smithies (1997), who wrote about women living with HIV/AIDS, argue that making people tell their
stories and writing those stories as direct speech helps to tell an actual story instead of diluting
the stories using ‘expert’ and academic language. For these reasons, I tried to keep the depth
of stories as they were told by participants – see extracts of life histories from Chapter Seven.
This suggests an intent to empower those being researched, based on witnessed reality and
acknowledgement that academic writing would not ‘fully’ and accurately tell their true
stories as they told them. As a black intellectual, an African woman and an activist coming
from an HIV-stricken country, I also used the study as a space for informing PLWHA how
to access HIV treatment and counselling, where to go and whom to contact if they needed
help – in ways that could inform PLWHA to effect change.

However, to deal with competing strands of positionality, as I have already highlighted in the
sections above, the study adopted the method triangulation approach. The approach
triangulated research methods to counterbalance the deficiency of a single method and
address possible positionality biases, thereby increasing the ability to interpret the findings.

4.7  Data analysis
The thematic synthesis approach was used to analyse data. Stake (1995) argues that the
researcher whose priority is to merge the findings between cases or study sites (rural and
urban) should use this particular method and ensure any differences identified between sites
are noted. The thematic analysis involved identifying patterns from the primary data collected
from multiple methods towards answering the study research questions (Thomas and Harden
2008). For this study, three steps were implemented that illustrate the process and outcomes
of this approach. It must be noted that while the stages are elaborated in steps, the analysis
process did not necessarily follow a linear process; it was a ‘messy’ and sometimes ‘clumsy’
process, muddling through themes, collapsing themes into bigger ones. The process was in
constant flux. Where gaps were identified, I went back to the field to fill the gaps and the
analysis process continued in that continuous fluid state.

4.7.1  Data collation
This process involved gathering all the data from the various methods used in the study. The
data relates to tape recorded interviews, notes from FGDs and participant observations. Data
was transcribed through repeated careful listening of the recorded tapes as an essential and
important first step in my data analysis. The process encouraged familiarity with data, a process that facilitated the initial stages of realising the ideas emerging in the data. The process was partly a data cleaning process that overlapped with data transcription, reading and re-reading the data, noting down initial ideas. The process of transcription of data took place while I was the field. The re-reading of data continued post field work.

### 4.7.2 Coding
Step 1: the transcribed data was analysed and arranged such that data addressing similar concerns and activities was ‘extracted’ and organised into specific sub-themes as guided by the study’s research questions.

### 4.7.3 Descriptive themes
Step 2: Text was coded using the ‘line-by-line’ approach in order to organise it systematically into coherent ‘descriptive themes’. The descriptive themes were very much close to transcribed primary data. Information was tabulated to allow identification of prominent themes and to provide structured ways of dealing with the data in each identified theme. Differences were also marked and recorded. The frequency of mention was one of the indicators of the relevance of a content point, but not the only one, as argued by Thomas and Harden (2008). Specific outliers or issues were noted with the context and nature of the person making them. ‘Themes’ included processes/relationships/dynamics and content issues, to reflect how categories of issues affected the lives of PLWH and their ability to access services.

### 4.7.4 Analytical themes
Step 3: The themes and sub-themes were examined and explored to capture finer nuances using the analytical framework outlined in Section 3.8. The analytical framework helped to understand the finer nuances in the sub-themes, including any outliers. The analytical framework characterised a stage of meaning construction and interpretation responsible for the generation of interpretive constructs of valuing human life. The analysis for each theme was organised to address a research question, and each theme was subjected to each of three analytics of government/regimes of practice;

a. Episteme – means of thought: policy and legal frameworks for valuing human life
b. Techne – means of calculating: institutions and technologies of power
c. Ethical – means of forming selves, identities, people - discursive practice

The thematic synthesis process began during fieldwork – as information would be arranged, questioned, examined, summarised, queried, and interpreted in an iterative process. The thematic synthesis facilitated the identification of patterns, themes and consistency in ideas. Manual analysis of qualitative data was preferred to computer programs designed for managing and processing qualitative data because I found it more sensitive to make associations between everyday actions, emotions, attitudes, language of respondents and framing the VoHL (Terre Blanche and Kelly 1999).

4.8 Conclusion

Respondent-driven sampling (RDS), developed less than two decades ago by Douglas Hackathon in 1997 as part of his work with the USA Connecticut HIV/AIDS project, has the potential of being extended and adapted for qualitative sampling to recruit hard-to-reach populations in most qualitative research. For this research, it must be noted that recruiting PLWHA was not an easy task, primarily because there is no standard sampling frame for PLWHA, and because the chronic condition remains stigmatised. Also, subpopulations who may be living with HIV, such as LGBTs and sex workers are criminalised in Zimbabwe. This chapter outlined the study’s philosophical underpinnings, the qualitative case study design and the employment of multiple research methods. The content of the different types of interviews is referenced to the appendices. The chapter articulated the purpose of the different methods triangulated in the study. The triangulation strategy was applied to research methods to ensure research rigour. Triangulation facilitated the capturing of the various complexities inherent in a study that was intrusive, in order to explore ‘truth’ in the narratives of life and death. This chapter outlined how the study was subjected to feminist epistemologies, particularly to articulate my positionality, and provided a rounded picture of how knowledge was created and co-created between researcher and participant. The acknowledgement of situated knowledge, reflexivity and positionality in the study was consistent with the constructivist epistemology underpinning this study, which is important in studies seeking to answer ‘how questions’ – governmentality studies. The data collected was comprehensive and accurate enough to address the research questions.
5 THE WAYS IN WHICH HEALTH POLICY SENIOR GOVERNMENT OFFICIALS FRAME THE VALUE OF PEOPLE LIVING WITH HIV AND AIDS

5.1 Introduction
This chapter commences the empirical analysis of the study by addressing the research question ‘In what ways do health policy decision-makers in Zimbabwe frame the value of PLWHA?’ To answer this question, interview responses from senior government officials (SGOs), who coordinate the design, implementation, and verification of HIV/AIDS policy and programme choices, were examined from a governmentality perspective using thematic analysis. Although SGOs in the health ministry were the primary sources of data to answer the research question, data was triangulated with findings from document analysis, and participant observations (see Table 4.6 and Appendices 1–6 for a detailed list of the study’s sources of data).

The ways of framing the value of PLWHA highlighted in this chapter not only provides mixed, sometimes contradictory, results, but also the overlaps that were manifest. By way of simplifying the complexity of the responses, I divide the chapter into three sections. The first section investigates the policy, legal framework and rationalities employed by SGOs on HIV/AIDS activities and how the activities render particular issues of HIV governable. The second section examines the means and calculative techniques used in HIV/AIDS decision-making (refer to Sections 3.6.2 and 4.2.2). Finally, the conclusion summarises emerging observations and findings on the analytics of government and their implications on the ways in which PLWHA are valued by SGOs in Zimbabwe.

5.2 Valuation of human life as a rational and thoughtful process
Although there were subtle differences in expression and nuance, when asked: What ideals, beliefs or goals does the health ministry use to establish appropriate interventions for HIV and AIDS and what are the implications for this kind of governance/management? there was consensus among SGOs that the constitutional provision of the right to life, HIV/AIDS expertise, law, and policy presents and views PLWHA as equal, legal and political citizens. Other SGOs identified expert power as a source through which PLWHA can either access or fail to access the needed HIV/AIDS services and thus emerge as a determinant of health
inequalities experienced by PLWHA. Together, these presented the ways through which the value of PLWHA is framed as a rational and thoughtful process by which decision-makers adopt visions and objectives of what they seek to achieve. Discussion here touches on the epistemic dimension of government and presents narratives from SGOs on *kodzero* (rights), *mitemo* (laws and policies), *kubatana* (organising politically by forming campaigning groups) and their expertise (*expert power*) on HIV/AIDS issues in Zimbabwe.

5.2.1 **PLWHA are equal citizens protected by the right to health [Kodzero]**

The narratives from health policy SGOs reveal that the consideration of, and respect for, rights of PLWHA is one of the critical elements in shaping HIV/AIDS policy and related decision-making. Like other citizens without HIV, PLWHA, despite their HIV status, are viewed as equal people, born with a ‘prerequisite right of all rights’, the right to life, which gives meaning to the right to health and other rights. EI: 1, SGO said:

…Just last year, Parliament passed our new constitution that most people endorsed in those chaotic stakeholder conferences and the um February to March referendum last year. In this [new] constitution munhu wese, mwana wevhu, [everyone is a child of the soil]. Murombo, mupfumi, mwana, chembere, harahwa, Mukadzi murume, anorwara, akaremara, mutano, everyone mwana wevhu anekodzero youpenyu [the poor, wealthy, child, old woman, old man, woman, man, the ill, the handicapped, the healthy, everyone is a child of the soil with a right to life]… (EI:1)

Consistent with EI:1, EI:2, an SGO working in the health ministry for 20 years, said ‘the [new] *Constitution of Zimbabwe now protects the right to health of all including for HIV-positive people. It was tricky before because the [old] Constitution didn’t clearly provide for that [right to health]’*. EI:7, as did EI:4 and EI:8, spoke about the role of the health ministry in ensuring the respect, protection and fulfilment of the right to health care, especially for PLWHA. Specifically, EI:7 noted:

we ensure that our facilities take-in all patients with HIV. No one should be barred from service, if there are facilities doing it, they are not only being notorious but also dangerously malicious because we have said it again and again, no one should be denied care if they can’t pay, ikodzero yavo [it’s their right]. (EI:7)

EI:4 corroborated,

we respect their [PLWHA] rights, that’s our philosophy here in the ministry. That’s why you see us trying by all means to prevent violations of health rights. So where we have been reliably informed that Mapostori ekwaMarange [African Apostolic Church] are stopping young women from condom use or there is encouragement for child marriages we intervene, because tinoziva kodzero dzavo [we know their (PLWHA) rights] (EI:4)
Similarly, EI:8 observed, ‘we strive to ensure that every expecting mother with HIV gets PMTCT [Prevention of Mother to Child Transmission of HIV/AIDS]. We do the same for all those living with HIV as a rights issue. I know we still have gaps because we do not have the money but we really, really try very, very hard to ensure that those rights are fulfilled depending on what we have’.

These accounts suggest that the right to health is presented as both a means and a goal to make the GoZ accountable for its actions toward PLWHA. By preventing the barring of PLWHA who cannot afford services, EI:7 is suggesting that the GoZ respects rights of PLWHA by not violating the right directly. EI:4 is suggesting that the GoZ, through its health ministry, protects the rights of PLWHA by preventing violations such as those found among religious objectors. Although EI:8 claims that the health ministry fulfils the rights of PLWHA by ensuring the provision of HIV treatment and especially PMTCT to expecting mothers, he also suggests that the shortages of HIV/AIDS financial resources make it impossible for the GoZ to immediately and completely fulfil the rights of PLWHA. From EI:8’s perspective, it seems that managing policy through mere commitment to rights of PLWHA requires more than statements in constitutions. EI:9 noted that while there did not exist specific rights targeting only PLWHA, rather targeting everyone, all the global human rights mechanisms that monitor government activities express their commitment to the rights of PLWHA by exploring the implications of HIV/AIDS for the GoZ obligations. Specifically, EI:9 argued:

…you see, there aren’t specific HIV rights so to say, but we monitor government commitment to rights of positives [PLWHA]. So it’s very important for the government to continuously find ways of incorporating this new constitutional right to health to the needs of PLWHA in very clear, assessable practical ways…(EI:9)

Similarly, EI:1, who has worked in the GoZ for 30 years (see Appendix 4), viewed human rights as the primary ethical form of knowledge employed by the GoZ to inform decision-making on HIV/AIDS since the 1980s, at the onset of the epidemic. Using a metaphorical term, Mongo, a Shona term, which means bone marrow, EI:1 said,

there has been great deal of investment in HIV/AIDS and especially on its connections with rights of those infected, ndiwo mongo wedu [that’s our bone marrow] in principle, not just since the 80s here in the Ministry, but we have also made political commitments via the UN resolutions and guidelines. So these folks [PLWHA] have always been rights holders ever since. (EI:1)

Even though Zimbabwe is a signatory to most international human rights commitments as EI:1 suggests, its constitution suggests that any international commitments that are not
provided for in law through an Act of Parliament are not binding, despite the ratification of that international treaty. For instance, its constitution states, ‘an international treaty which has been concluded or executed by the President or under the President’s authority— (a) is not binding unless approved by Parliament; and (b) does not form part of the law of Zimbabwe unless incorporated through an Act of Parliament’ (GoZ 2013a, p. 125). Thus, the ratification of international treaties can, in principle, denote commitment of government, but the domestication of these commitments signal a promise to protect the rights of citizens and, to some extent, signify the valuation of human life.

5.2.2 PLWHA are legal citizens protected by HIV/AIDS laws and policies [Mitemo]

Some of the interviewees (SGOs) did not specifically mention the constitution on the right to health of PLWHA, but referred instead to other contracts between the Government of Zimbabwe and its citizens, which are embedded in the city by-laws, statutory instruments and policies. A development elite (E1:3) stated ‘historically, the Ministry [of Health and Child Care] bases its HIV decisions on policy priorities, for example, mutemo we [the policy on] OI [opportunistic infection] clinics for people with HIV was to protect their rights to privacy because of the stigma associated with the condition. So a law was befitting for such a cause’. This could suggest that the policy-makers view PLWHA as citizens who are legally protected by the law because of their (PLWHA) vulnerabilities to stigma. Implicitly this could infer that PLWHA are respected (valued). Media reports also reveal that PLWHA tend to be viewed in the same way as others without infection – as legal citizens. The Zimbabwe Herald (23 October 2013) states,

‘…the Health Professions Authority secretary general and chief executive Mr Shepherd Humure unpacks the Zimbabwe Patient’s Charter, which protects the rights of patients within a health institution. He said the charter was developed after the Consumer Council of Zimbabwe and the Government recommended some form of protection to patients in an effort to improve service delivery… patients have a right to access the health system at the time of need, both as non paying and paying patients…’ (The Herald, 23 October 2013)

The GoZ SGOs argue that workplace policies, the national AIDS policy, the AIDS levy and other legal provisions (Section 2.5.2) frame PLWHA not only as rights holders but also as socially competent people with social, political and economic rights. But, there is a paradox between the role of government to uphold the rights of PLWHA as legal equal citizens and the narrative of PLWHA to fulfil their responsibilities to defend the right to health, as articulated by political elite E1:6:
‘…yes people living with HIV have their rights which we respect and which we’ll always respect, but rights come with responsibilities and not just those of government but also from the people themselves to prevent HIV in the first place and if you already have it, you need to take care to get well. If a person has a right, then one takes the duty to fulfil that right…’ (EI:6)

But, as document analysis suggests, although some gaps in legal provisions still exist, Zimbabwean SGOs have made strides in asserting the rights of PLWHA – as discussed in Section 2.5.2 and summarised in Table 5.1 below.

In addition, Zimbabwe is also a signatory to numerous international instruments that commit governments to creating an enabling environment for the delivery of health services to their citizens. These include the Millennium Declaration (2000), the Abuja Declaration (2000), the Ouagadougou Declaration (2008) and the International Conference on Population and Development (ICPD) (1994) which Zimbabwe ratified. These provisions are all central to the commitment of the health ministry through its SGOs to improve well-being, standards of living and the reduction of poverty and disease amongst PLWHA. These efforts, according to SGOs (EI: 1, 4 and 7), signal the tendency to uphold, in principle and in policy, the position of PLWHA as equal legal citizens that are free to act according to the law and who have the right to claim the law's protection. Implicitly this could infer that PLWHA are respected (valued). The right to claim the law’s protection tends to be viewed as an aspect, which reinforces the elements of being a citizen (citizenship), that not only guarantees rights to people but also demands their responsibility to ensure that the rights are fulfilled.

In addition to the key policy and legal provisions, Zimbabwe ratified several International Labour Organisation conventions to protect the labour rights of workers on HIV matters. These include the 1981 Convention on the Occupational Safety and Health (No. 155) (ILO 1981) and the 1985 Occupational Health Services (No.161) (ILO 1985). Both provide for the management of HIV in the workplace, and especially the human rights of PLWHA on employment and non-discrimination without prejudice on the grounds of their HIV infection. While these conventions came out promptly at the time of the first cases of HIV in the 1980s, both were inoperative until Zimbabwe ratified them over a decade later, on the 9th of April in 2003 (ILO 2014).
<table>
<thead>
<tr>
<th>Year</th>
<th>Law/Policy</th>
<th>Highlights of rights of PLWHA as legal and equal citizens</th>
</tr>
</thead>
<tbody>
<tr>
<td>1980</td>
<td>The Public Health Act (1980) (GoZ 1980)</td>
<td>The Public Health Act (PHA) (1980), despite 19 amendments, does not address emerging epidemics (Goz 1980). It is not rights-based and contains labelling of humans as dirty and verminous persons (Section 28) (Goz 1980). The Act is an amended version 19 of 1924 revised at independence in 1980. In 2011, the Zimbabwe Public Health Advisory Board (PHAB) reviewed the 1980 amendment 19 of the 1924 PHA Act and subsequently identified provisions to address social determinants of health and promote justice and equity (PHAB 2011). In 2015, the revised PHA bill still awaited approval and enactment in Parliament. It suggests potential to assign a value to humans as useless, dirty or poisonous if they have an infection.</td>
</tr>
<tr>
<td>1984</td>
<td>Planning for equity in health strategic Plan (MoHCW 1984)</td>
<td>The strategic plan made equity a central policy principle and organised the Zimbabwe health delivery system around primary health care (PHC) (Loewenson and Masotya 2009).</td>
</tr>
<tr>
<td>1999</td>
<td>National Policy on HIV and AIDS</td>
<td>The policy upholds the rights and dignity of all people regardless of their HIV status. It asserts the promotion of equality and asserts non-discrimination of PLWHA (GoZ 2000a).</td>
</tr>
<tr>
<td>1999–2007</td>
<td>Planning for equity and quality in health, National Health Strategy 1999–2007 (MoHCW 1999)</td>
<td>Places health equity and PHC at the centre of all health systems strategies in the MoHCC. Operations and measures were taken to strengthen access and of public services to redistribute resources to areas of higher deprivations (Loewenson and Masotya 2009).</td>
</tr>
<tr>
<td>2000</td>
<td>National AIDS Council Act</td>
<td>Guides policy direction and national coordination of all HIV/AIDS activities in the country and ensures that the rights of PLWHA are promoted in service provision, community and programmes (GoZ 1999b).</td>
</tr>
<tr>
<td>Year</td>
<td>Law/Policy</td>
<td>Highlights of rights of PLWHA as legal and equal citizens</td>
</tr>
<tr>
<td>------------</td>
<td>----------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>2006</td>
<td>Children Protection and Adoption Amendment Act: 2006</td>
<td>Provides for the rights of testing for HIV in children up for adoption (GoZ 2006b).</td>
</tr>
<tr>
<td>2007</td>
<td>Domestic Violence Act: 2007</td>
<td>It criminalises all forms of violence including sexual, physical, social and psychological violence (GoZ 2007).</td>
</tr>
<tr>
<td>2009–2013</td>
<td>National Health Strategy 2009–2013, Equity and quality in Health, A People’s Right (MoHCW 2009)</td>
<td>Although health equity and PHC were central to all planning in the health ministry since 1980, there was a shift in emphasis from comprehensive PHC to selective PHC, efficiency and cost recovery measures. Meanwhile, equity and social justice remained the core policy principles (Sanders 1990).</td>
</tr>
<tr>
<td>2011–2015</td>
<td>2011–2015, the Zimbabwe National HIV and AIDS Strategic Plan (ZNASP)</td>
<td>Both the ZNASP 2006–2010 and the ZNASP 2011–2015 map the strategies for the government to fully operationalise the principles of involvement of PLWHA as equal legal citizens. The document outlines the actions that government and its stakeholders need to take to improve treatment and care, protection and rights and access to adequate services for PLWHA and those affected people (NAC 2011).</td>
</tr>
<tr>
<td>2013</td>
<td>The Zimbabwe constitutional provision of the right to health (GoZ 2013a)</td>
<td>The new Zimbabwe constitution outlines an authoritative interpretation of the right to the highest attainable standard of health (referred to as the ‘right to health’). Since the adoption of the new constitution in 2013, the right to health became a constitutionally protected right (Mulumba et al. 2011). The constitution of Zimbabwe prevails over any other national legislation or statutory instruments. The inclusion of the right to health marks the government’s obligation to uphold principles of justice, equity, fairness, benevolence and altruism (WHO 2011c). These principles are in consonance with the respect, protection and fulfilment of human rights. In addition, the constitutional provision of the right to health is in line with the International Covenant on Economic and Social Rights in which Article 12 obligates member states to recognise the right to health (UNHR 1976).</td>
</tr>
<tr>
<td>2013–2018</td>
<td>2013–2018, the Zimbabwe Agenda for Sustainable Socio-Economic Transformation (ZIMASSET) (GoZ 2013b).</td>
<td>The ZIMASSET economic blueprint’s treatment on the rights of PLWHA lacks coherence and practical steps towards fulfilment of planned interventions for HIV/AIDS. It is silent on the rights of PLWHA and abandons poverty reduction as one of its inclusive objectives, despite poverty being a structural determinant of not just HIV, but other conditions including access to education, health and nutrition (Munro 2015)</td>
</tr>
</tbody>
</table>
In 1998, the Government of Zimbabwe (GoZ) regulated the Government Labour Relations statutory instrument 202 (GoZ 1998) under the Labour Relations Act (Chapter 28:01) of Zimbabwe (GoZ 2006c), to guide employer–employee conduct on HIV/AIDS matters in the workplace. The subjects include HIV/AIDS education to employees, risk management, rights to benefits and compassionate leave (GoZ 1998).

To strengthen this Labour Relations statutory instrument of 1998, the GoZ criminalised the wilful transmission of HIV and AIDS, including between married couples, under the Criminal Procedure and Evidence Act Amendment of 2000 (GoZ 2000b). Intentional transmission of HIV, particularly through rape, attracts a stiff penalty of 20 years in prison. But empirical studies that have documented the extent of enforcement of the Criminal Procedure and Evidence Act in correctional facilities such as prisons are scarce. For instance, Cornell University Law school (2012) reports that NGOs in Zimbabwe said that half of all inmates at the Chikurubi maximum-security prison in Harare were living with HIV by the end of 2011. On the same point, the United States Bureau of Democracy, Human Rights and Labor reported a daily mortality rate of 40 inmates out of an estimated total of 14,000 prisoners at Zimbabwe’s Chikurubi prison in 2009 (Department of State 2011). Although the report concludes that malnutrition, tuberculosis and HIV/AIDS were the primary causes of mortality, it is also reasonable to assume that detainees could have been living with HIV before their incarceration. It is also sensible to suppose that others get infected with HIV in prison. The nature of the HIV epidemic in Zimbabwean prisons is unknown; the transmission of HIV in prisons is also undocumented. Zimbabwe’s inmate population ratio of (129 inmates/100,000) is almost 40% higher than the average of the Sub-Saharan Africa region (91 inmates/100,000) (UNDP 2015).

In addition to the criminalisation of wilful HIV transmission, the Children’s Protection and Adoption Act (Chapter 5:06) was adopted in 2001, and amended in 2006, to protect the rights of children living with HIV/AIDS. The act was accompanied by the 1999 National Policy on HIV/AIDS (see Table 5.1), and an action plan for orphans and other vulnerable children (NAPOVC) (GoZ 2004) was enforced in 2004 following the adoption of an orphan care policy in 1999 (GoZ 1999c). In addition to intensifying efforts to implement, coordinate, monitor and evaluate all in-country legislation for children, the NAPOVC sought to enforce the Children’s Protection and Adoption Act and the Zimbabwe National Orphan Care Policy of 1999 (GoZ 2004). Furthermore, Zimbabwe

Although these policies and the legal framework exist, the ever-changing environment of the epidemic has since overtaken the HIV/AIDS policy, last reviewed in 1999. The emphasis is now on mainstreaming actions to combat HIV/AIDS into other sectoral policies. Relatedly, the Zimbabwe National Strategic Plan 2011–2012 (NAC 2011) argues that this approach can expand the scope of the national response.

Overall, the current legal and policy framework on HIV/AIDS suggests that Zimbabwe has made strides in asserting the rights of PLWHA, as well as providing an environment for their improved health outcomes. However, the World Health Organisation (WHO) Global Health Observatory data repository shows that the estimated antiretroviral coverage among people with HIV infection in Zimbabwe is still below half (48%) (WHO 2015c).

5.2.3 PLWHA are political citizens who can federate for collective identity

Kubatana (organising politically by forming campaigning groups) or Federation was another recurring theme in the interviews with SGOs. There was a general consensus concerning the notion that PLWHA are actors who actively federate as small groups in communities and nationally to advance their needs. The federation of PLWHA was seen as a political expression of their rights, as equal, legal citizens. EI:8, as did EI:6 and EI:10, gave reference to the AIDS Action Committees (AACs) which are coordinated by the National AIDS Council, the Zimbabwe National Association of PLWHA (ZNNP+) and the Zimbabwe AIDS Network (ZAN), all of which allow PLWHA to organise politically by forming campaigning groups. According to EI:8, membership of AACs gives access to information bottom-up and top-down from the PLWHA to the SGOs and from SGOs to the PLWHA respectively. Membership of groupings such as the ZNNP+ and ZAN also
gives access to allegiance from other members of the group, guaranteeing not only loyalty and support but also as an expression of political freedom.

EI:8, who worked with the National AIDS Council for 15 years (see Appendix 4), described how the GoZ was working with chiefs and traditional authorities to embed HIV care within contexts of deep-rooted ‘private’ Shona traditions such as *Doro re Matare evarwere*, groups that had created the clan spirit federations organised by PLWHA and their families, including senior village members, to summon the clan spirits (*madzitareguru*) to help the ill. *Doro re Matare evarwere* is a ceremony which incorporates singing, drum beating, ululating, humming and minimal dancing in the early hours of the morning. Seeking to understand how *Doro re Matare evarwere* expressed political freedom, EI:8 argued that, ‘*nemhaka yokuti tsika dzedu dzepasichigare, hunganidzwa dzedu hadzitariswi sedzinematro, zvoita sedambe munhau dzematongerwe evhu, zvoita sekunge munhu atsikiriwa asi kwete, handizvo, kana uchida enda unobvunza kumaruwa kwaunoitatsvakiritso yako*’. This is translated as ‘because the traditional sense of federation is no longer regarded as the most democratic expression of political freedom, most people neither talk nor write about it, that’s why it’s not as common, if you want you can go and find out where you are doing your research’.

After my interview with EI:8 which I administered in Harare on the 19th of June 2014, I spent a week making preparations to meet a Chief-Gor whom I met on the 26th of June 2014 in Goromonzi. The intention was to ask if I could attend one of the ceremonies. I could not attend one in Goromonzi because the next ceremony was to be held in 2015, after my field work. Chief-Gor noted that the *Doro re Matare evarwere* involved dancing of those living with HIV as a way of bringing to life *Matateguru* (spirits) through dance, and that they would embody PLWHA and communicate what should be done using their (PLWHA) bodies to articulate the attitude embedded in the personality of the spirits. This explanation is analogous with Carens’ (2000, p. 166) view of psychological citizenship, in which a particular community's collective identity, such as *Doro re Matare evarwere*, in our case, can facilitate a sense of belonging to the same political community, which could also strengthen social cohesion and contribute to social integration of PLWHA. Cohesion or integration of PLWHA, however, does not guarantee expression of equal legal citizenship of PLWHA because it is only the PLWHA who can characterise their own attachment to the wider political community. The *Doro re Matare evarwere* operates as a secret ceremony which, according to non-PLHWA participants in FGD-GorB, attracts
many people from the city. It is performed in the night, starting soon after midnight and ending at the first light at dawn. According to non-PLWA in FGD-GorB, the ceremonies attract flexible alliances held together by the influence of powerful chiefs and *Masvikiro ne Midzimu* (spirit mediums).

### 5.2.4 Expert power can be a source premature deaths

As already discussed in Section 2.5.2 and in Section 5.2.3 above, Zimbabwe’s health policy and legal framework reflects a political consideration, a human rights recognition, and legal expression of commitment to the right to health for PLWA. Although most SGOs tend to frame PLWA as equal, legal and political citizens based on the policy and legal framework for PLWA, some SGOs contested the framework as a mere political game which has consistently failed to translate into tangible benefits. To this end, ‘experts’ was another theme that was often used by participants who opposed the view of framing the value of PLWA as citizens who can claim the law’s protection.

In participant observations in Goromonzi, one male participant at one of the Rural District Council (RDC) meetings observed the importance of experts in the lives, or conversely, deaths, of PLWA when he said: ‘the experts say these people [PLWA] have rights, but in real life, it is the same experts who decide what needs to be done. No health workers, no medicines, and you say people with HIV have rights?’ Also, EI:4 argued that before the advent of HIV, Zimbabwe’s health service structure was ideal to respond to the threat of HIV once it became apparent in 1985. However, it was not clear, at the time, whether the HIV/AIDS resources (financial, human, medical, sundry, psychosocial) were available. Nor was it clear whether the political will was present to make them available. Commitment of resources is a factor of SGO (experts) decisions and actions as they determine the rationing of resources. While HIV/AIDS was still a far-fetched idea for most policy-makers in the 1980s, as already shown in Section 2.5.1, the reluctance and absence of explicit policies, resources and interventions put in place in the ten years between 1985 and 1995 seem to suggest contradictions with the generous accounts about the right to health for all, including for PLWA – suggesting that PLWA are framed as equal citizens. Explicitly, EI:4 observed:

‘...the basis for decision-making is informed by the policies made by experts in the Ministry of Health, but there were no HIV specific policies in the 80s and the greater part of the 90s. I wasn’t in the ministry at the beginning of the epidemic, but those who were here did very little around HIV, we used radio and posters to make people aware of HIV at a time when the sexually active African, was largely illiterate and many did not own radios. That’s when the HIV problem spread like veld fire. What we saw and felt in the 1990s was a combination of damage already done in the 80s and new infections, we should have cared more…’ (EI: 4)
On reflection, the phrase ‘we should have cared more’ does not only suggest discomfort in the actions of government experts and/or the decision-making at the time, but also implies acknowledgement of inaction. Again, the sensitivities around HIV/AIDS between 1985–1995 may account for some of the reluctance to act, as it meant raising controversial topics. The narratives in the media note:

we are obviously perturbed that despite all the rumours that have been floating in Harare and other cities, it has taken until now to confirm that AIDS has finally hit Zimbabwe. We should have been told earlier. We applaud the Ministry of health for finally acknowledging that AIDS is now a problem in Zimbabwe. Certainly, we would have been much happier if the warning had come much earlier (The Herald, 28 February 1988)

These expressions of denialism by experts in the 1985–1995 period have in fact been commonly softened and almost inaccessible beyond those in the know, as observed by EI:1. ‘It’s not that we didn’t know that AIDS was killing people; we just weren’t fully equipped to address that. It was happening in America. So to us, it was a disease of the well-to-do, varungu [white people]. There wasn’t enough information to convince all the experts here to act. I guess, it’s one of those things where you have more important things to do for the newly independent us, like training nurses and deploying them to prevent Kwashi (kwashiorcor). So I think, that’s where we lost it’. EI:1, an expert, was somewhat acknowledging, or perhaps justifying, the inaction in that period. Rather than making HIV/AIDS a primary policy concern in the 80s and 90s, perhaps the most significant period for public health intervention and creating motivation needed to assert the rights to health for PLWHA and help change perceptions of sex, marriage, and contraception, the government devoted its financial support to other competing issues. The lack of attention in the first years of Zimbabwe’s HIV/AIDS epidemic speaks to denialism and stigma that contradict the notions of asserting citizen rights. Consequently, by the end of the 1985–1995 period, the epidemic had tripled to more than 25% (see Section 2.5), creating immense negative effects on life expectancy and mortality rates; but clear HIV/AIDS policy was yet to be put in place.

While there were significant changes from inaction in the 80s–90s period to ‘action’ in the 2000–2015 period – especially in instituting HIV/AIDS policy framework, including the introduction of a dedicated fund for HIV AIDS activities – the AIDS levy (see Table 5.1), and the HIV/AIDS activities in Zimbabwe remain inadequately funded through the national budget (see Box 5.2 in Section 5.3.1 below). Largely, the inaction in policy in the 1985–1995 period is comparable to the lack of commitment of financial resources
seen between 2005 and 2013 (see Table 5.2). Such inaction, which largely depended on the actions of experts in the MoHCC, could mirror steadfast political denial, and a reluctance to engage on meaningful and timely approaches to combat HIV. These accounts seem to suggest that the value of PLWHA is contingent upon the reasoning and actions of decision-makers, the experts. The accounts about experts here suggest that the power wielded by the experts and the power of government itself appear difficult to separate, and therefore it appears that the power of policy experts can be the source of health inequality or premature deaths. Contrary to Sections 5.2.1 to 5.3.3, which show that the policy and legal framework of HIV/AIDS presents PLWHA as equal, legal and political citizens, the actions of the GoZ, mirrored through experts in the MoH policy, do not seem to always agree that PLWHA have full citizenship.

5.3 Valuation of human life as a calculative rationality

As already discussed in Chapter Four, SGO participants were asked: What decision-making techniques do you use to identify the appropriate interventions for HIV/AIDS and to assess the trade-offs between interventions with competing interests? Are PLWHA treated differently from other social groups? Why? The themes that emerged include cost-effectiveness, disability adjusted life years, results and market-based rationalities.

5.3.1 Cost-effective analysis: A shopping list

For the SGOs who suggested cost-effectiveness analysis (CEA) as a method used by Zimbabwe’s MoHCC for decision-making, one of the follow-up questions I raised was, ‘how is this cost-effectiveness analysis done? What is your role in this, or the department that is working on this?’ I asked these questions so that I could get a sense of their understanding of CEA to unpack underlying objectives or intentionalities of choosing this approach. As a way of recapping CEA already discussed in Section 3.2.2.2 and Table 3.1, I will briefly highlight its key features here. CEA is an economic evaluation tool that is used to inform planning and priority-setting by measuring the efficiency of service delivery. It can be used to assess the costs of the proposed HIV/AIDS interventions for decision-makers to make the best use of the fewer resources. As Section 3.2.2.2 shows, the term ‘efficiency’ in CEA implies that the best and most outputs of the intervention are achieved at minimum costs. CEA involves identifying costs and summing them, and then dividing them by the health impact to obtain a fraction or ratio that can be compared with other interventions (see Section 3.2.2.2 for CEA).
Half of all of SGOs talked about cost-effectiveness as a tool used in the MoHCC; see Box 5.1 below.

<table>
<thead>
<tr>
<th>Box 5.1: Quotes from senior government officials on CEA</th>
</tr>
</thead>
<tbody>
<tr>
<td>• We base our decisions on what is cost-effective, because we have very little resources so we want what works (EI:6)</td>
</tr>
<tr>
<td>• We conduct an analysis of cost-effective interventions then we do the work (EI:1)</td>
</tr>
<tr>
<td>• We normally consider our work based on cost-efficiency for example what is out there that is needed by people with HIV and what can we afford? Then we go to do that (EI:7)</td>
</tr>
<tr>
<td>• I’m not really sure if we have something systematic but it should be based on effectiveness of the cost of the intervention (EI:2)</td>
</tr>
</tbody>
</table>

Although SGOs talked about cost-effectiveness, none of them were sure exactly what CEA was. Instead, as EI:4 put it, CEA is understood as ‘a shopping list approach here, people think its listing what you want to do and then funding those things based on how much you have in the pocket’. Others like EI:1 did not know what it was: ‘I’m not an economist, in fact, we do not have trained economists in the whole ministry, so we have not done that’. EI:4 uses the phrase ‘shopping list’ to refer to what SGOs refer to as ‘CEA’. A shopping list is simply a list of things needed by a consumer from a shop, and when used figuratively it refers to a list of written items (Oxford English Dictionary). This understanding of a shopping list could suggest that the CEA is in fact not a real CEA as it is applied in the health ministry. In CEA, the computations are more than just a list of written items. For a shopping list, it may be compiled immediately before the actual shopping, or cumulatively as the need arises. It may be on a scrap of paper or something more comprehensive. This could suggest that whatever method is being referred to as CEA is indeed unsystematic; it can be developed immediately when needed or cumulatively and without any guiding principles. Despite this, on the outside, the GoZ SGOs thought they were employing CEA, but, in fact, they were not sure!

Other participants put it differently as follows. EI:8 noted, ‘we just use WHO recommendations for CEA because we do not have the expertise here’. EI:2, like EI:8, identified international experts as the specialists in deciding cost-effective HIV interventions for Zimbabwe. ‘You just choose what you think is the best depending on what the donor wants because we do not have money here, so to us here, we use cost-effectiveness as a way of deciding what’s cheaper or where it’s cheaper to do. We have no studies that we conduct on our own’, as EI:2 had suggested. Indeed, some leading development organisation-led programs had the largest funding for HIV/AIDS in Zimbabwe (see Box 5.2).
Box 5.2: Development organisation-led HIV programmes 2010–2015

- Zimbabwe Health information systems support project (ZimHISP): $9 million USD 2010–2015 (CDC/PEPFAR)
- Zimbabwe Population HIV Impact Assessment (ZimPHIA): $7.5–8.5 million USD since 2014 (CDC/PEPFAR)
- Surveillance, Evaluation, Assessment and Monitoring (SEAM): $10 Million USD since 2011–2016 CDC/PEPFAR

Source. Field notes from EI:8

Such donor reliance could suggest that development organisations have the most influence on the choice and priority of local HIV interventions. Furthermore, the variation in the selection of priority issues between the international donors who wield power from the money they hold, and the GoZ and the aid recipient may contribute to wider gaps in HIV/AIDS care. These differences in choice can influence the priority-setting decisions because of the varying evidence and intentions by both. Also, as reflected in Section 4.4.3, other sector ministries such as the Ministry of Finance, Ministry of Education; Ministry of Labour and Social Welfare, and the Ministry of Transport among others have a role to play in shaping the environment in which SGOs in the MoHCC work, as they too shape the (un)availability and accessibility of HIV/AIDS resources.

Relatedly, EI:5 was more explicit about the limitations of economic evaluations of health in the GoZ MoHCC. Box 5.3 is an excerpt from an interview held with EI:5.

Box 5.3: Interview with EI:5 (Excerpt)

**EI: 5**: CEA. Ha! Hahaha. what? CEA! We don’t have ma health economists chaiwo [real health economists]. It’s a gap, Big one! Here, most confuse it [CEA]with health accounting.

**Me**: But why do you say that?

**EI: 5**: The real CEA or even Cost Benefit Analysis has been on our agenda for long, for the 12 years I have been in government we have not seen one or done one. What’s worse is those people in the academia do their research and publish but do not share their findings with us [health ministry]. That’s why need drives most of our programmes, we are reactive instead of being proactive. We firefight! We just make our decisions based on a number of criteria.

**Me**: A number of criteria? Such as?

**EI: 5**: It’s a difficult question that you have asked me because we have nothing systematic that I can say we do here. But suffice to say we have no real CEA for health programmes let alone for HIV in Zimbabwe at least from the health ministry itself. Maybe they do at the University or with donors; we do not know. All HIV programmes that require cost-benefit analysis or CEA done in other countries like South Africa; that’s where we borrow because we assume that the context is the same.

**Me**: But has CEA ever been done here even before 2002?

**EI: 5**: I’m yet to see a proper CEA. What we do have here is simple as this: How much is it? How much do we have? but I don’t think that’s what CEA is all about. We have never done proper systematic studies that link costs to DALYs that’s for countries like England, not here, it requires resources such as money and knowledge, and we lack in both at the moment. I’m sure things will get better in the future. Maybe there are some professors from the University [of Zimbabwe] that have done these things, but when they do, they are working as consultants engaged by NGOs, or some university professors from USA or UK who come here and partner with local NGOs and do their studies and go. Now I think no one knows how much is needed to run a responsive HIV/AIDS system in Zimbabwe.
The discussion with EI:5 summarises the limitations as a lack of specialised expertise, know-how and money to conduct economic valuations. Based on EI:5’s responses in Box 5.3, the lack of CEA seems to be blamed on these factors. This could suggest that should the needed resources be availed, economic valuations would remain the option of choice for decision-making. Implicit in the limitations identified by the EI:5; EI:4, EI:1, EI:8 and EI:2 is the failure to evaluate costs and consequences, along a time horizon that extends over a lifetime. Without empirical data, assumptions regarding indirect expenses, such as those incurred by the caregivers, user fees burden, equipment, drug and human resources costs, fail to be captured.

EI:5 specifically mentioned DALYs (disability adjusted life years) (refer to Section 5.3.2). This is a composite indicator of cost and utility measured in terms of gains, which involves the incorporation of morbidity and mortality measures into a single comparable unit (IHME 2014c). The DALY is borrowed from the WHO’s global burden of diseases, and combines information on the years of life lost (YLL) due to premature death, and total years lived with disability (YLD). The computation of DALYs according to the IHME (2012) is as follows:

\[
\text{DALY} = \text{YLL} + \text{YLD}
\]

An indicator based on the number of years of life lost gives unduly greater human life value to the death of a younger person in comparison with that of an adult (refer to Table 2.1 in Section 2.5.1 and Section 5.3.2) (Jelsma et al. 2002, IHME 2014c).

Indeed, in the document analysis of Zimbabwe HIV literature between 1984 and 2014, there appears to be very limited HIV/AIDS studies on the improved health-related quality of life (HRQL) that can be applied in HIV cost-utility analyses in Zimbabwe. Most of the research by the health ministry and/or led by partners describes the economic impact of HIV at the household level (The Policy Project 1999). Others describe it at the community level (Kwaramba 1997) and the wider economy (Matshe and Pimhidzai 2008) level. But, such data is of little use as input to economic valuations. These studies may provide valuable information for clinical considerations or for identifying strategies to the development of community systems on HIV treatment and for monitoring treatment, as well as development of individual PLWHA. However, for the economic evaluation, the outcome units used are of limited value because they are not comparable across the topic areas. In addition, they cannot be used to assess the extent of quality of life improvement,
i.e. quality (worth, dignity) and quantity of life (years lived) cannot be measured on the same metric.

Furthermore, when the assumptions regarding remote costs are unavailable or are unreliable, the economic valuations may collapse under the weight of uncertainty. At the time of the research, the donor-funded routine health data system was reported to have been functioning ‘fairly well’ (EI:9). However, it was yet to establish cohort studies that tracked large cohorts of PLWHA longitudinally for decades, to provide more accurate predictions of future costs of HIV and consequences, as argued by EI: 9;

we have only managed to integrate the previously parallel health information systems. We are now tech friendly, and all our clinics are now on the mobile phone-based health information systems. Every clinic is now connected to DHIS2 [District Health Information and Surveillance Software Version 2]. That was the first step. We now need to make sure that IMMIS [Inpatient Morbidity and Mortality Information System] is functioning then commence longitudinal studies with large cohorts of people with HIV… (EI:9)

EI:9 argued that the cohort designs that enrol a representative sample of entire populations of PLWHA and follow it (the cohort) over time are needed as they are crucial for HIV CEA or other economic valuations. The studies would also track CD4 counts and viral load tests, alongside comprehensive health and cost questionnaires that could be repeatedly administered over time. Furthermore, EI:9 highlighted that such cohort studies would examine the costs of ARV drug toxicities, opportunistic infections, behaviour, and mental health disorders. However, the health ministry had neither the human capacity nor the money to do so. At the time of the research, the interviews showed that there was little knowledge of the relative cost-effectiveness of HIV services offered in the Zimbabwean public health care sector, despite the rather carefree use of the term ‘cost-effective’ by SGOs. The tendency to use such terms in this fashion casts doubt as to whether they knew what they were doing as they used these ‘cost-effective’ economic terms.

5.3.2 Disability adjusted life years (DALYs)
From document analysis, the Zimbabwe Global Burden of Disease Study 2010 (GBD 2010), which measures the disease burden between 1990 and 2010 (IHME 2012), is one of the few available reports that estimate the national burden of 291 diseases and injuries, and 67 risk factors disaggregated by age and sex (HIV among them). The GBD report by the Institute of Health Metrics provides data on years lost due to premature deaths and disability, necessary for economic valuations in Zimbabwe. When asked if this report had been ‘used to assess the trade-offs between HIV responses interventions in cases where
multiple objectives or competing interests existed, all the interviewed elites bar EI:9 (development elite), did not know about such calculations nor the report, and had never heard of the Institute of Health Metrics.

However, a defunct committee (at the time of the research), established in 1997 and coordinated by the WHO country team, the Zimbabwe National Burden of Disease Committee (ZNBDC), previously provided technical support for computing disability adjusted life years (DALYs) in the late 1990s. See the computation of DALYs in section 5.3.1 above.

In 2002, ZNBDC led the Zimbabwe National Burden of Disease Study with financial aid from the UK Department for International Development (DFID) and the Danish International Development Agency. In the study, ZNBDZ compared how Zimbabwean society valued health at different ages with DALYs to measure years of life lost (Jelsma et al. 2002). The study assessed if the age-weighting function used in the calculation of DALYs in Zimbabwe reflected the value attached to a life saved and to a year lived in full health at different ages. Furthermore, the ZNBD study also investigated if factors such as age, sex and the educational level of Zimbabweans determined value of a life lived at different ages. The results of this study showed that when the respondents could choose only one person to save among people of different ages, the younger person tends to be given preference. However, when the exercise required more deliberation, the 15-year-olds were valued more than the ages 1, 30, 45 and 70 because of their ability to contribute economically (Jelsma et al. 2002). The study concluded that the calculation of DALYs should be context-specific, and developed locally, based on judgements and priorities of local people. The study’s findings seem to have implications for the priority-setting of HIV interventions despite not having been used in the GoZ MoHCC.

Interviewees were asked if the DALYs recommendations from the ZNBDC had been used to assess the trade-offs between HIV responses interventions in cases where multiple objectives or competing interests exist’ in the health ministry. Only EI:6 and EI:4 remembered the ZNBDC, but could not recall if the results from the study were used in any planning platforms in the health ministry. EI:4 argued that the DALY weights in most research in the region (Southern Africa) have insufficient evidence basis, which made it difficult to use learning from elsewhere to inform priority-setting in Zimbabwe. ‘We know
the DALYs are important, but we know that the WHO disability weights are difficult to adapt to our [Zimbabwean] context' (EI:4).

Indeed, the WHO disability weights used in the DALY calculations are standardised and based on expert views rather than the preferences of PLWHA or population samples (IHME 2014c). These accounts show that little is known in Zimbabwe about how PLWHAs’ quality of life responds to HIV treatment over time. The lack of knowledge in these computations could also be telling of ‘little care’ or ‘little value’ accorded to PLWHA by the GoZ.

5.3.3 Results and Statistical based rationalities
‘Results’ was another theme mentioned by two SGOs: EI:3 and EI:5. As EI:3 said, ‘We also use the World Bank Results Based Financing on funding mainly rural facilities that perform well’. Similarly, EI:5 said, ‘we focus on the statistical results that we get from the routine health information to determine where the need is higher’. The SGOs referred to two types of results-based techniques: results-based financing (RBF) and the statistics from the national routine Health Management Information and Surveillance System (HMIS). The HMIS coordinates the collection, collation, aggregation, and analysis of health data collected from all health facilities across Zimbabwe (MoHCW 2001). The statistics are analysed at the MoHCC headquarters in Harare to inform decision-making. According to EI:5, routine statistics are used alongside clinical research conducted with the MoHCC and development organisations for generation of evidence to impact decision-making. The statistics are presented in the form of graphs, histograms, health profiles, technical reports, and blogs on the health ministry website to advise the citizenry of HIV/AIDS information. According to EI:9, the health Ministry’s HMIS Unit is responsible for the systemic expertise, collation, management and analysis of all HIV statistics in the MoHCC. Box 5.4 summarises some of the HIV-specific surveillance and statistical data.

<table>
<thead>
<tr>
<th>Box 5.4: Health statistics and surveillance tools and products in the MoHCC</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Surveillance systems</strong></td>
</tr>
<tr>
<td>• <strong>electronic Early Infant Diagnosis</strong> – HIV/AIDS notifications for infants. It uses mobile technology to transmit information in a timely fashion. For each sample collected, a health facility can inform the laboratory in advance, allowing the laboratory to communicate if samples are not received in time. Sample results are automatically sent back to health facilities by mobile phone text message as soon as they are released from the lab.</td>
</tr>
<tr>
<td>• <strong>electronic Maternal and Perinatal Death Notification system</strong>: to track maternal mortality (death of pregnant woman during pregnancy or 42 days after birth because of pregnancy related reasons)</td>
</tr>
</tbody>
</table>
and perinatal death (stillbirth) by capturing, transmitting and analysing maternal and perinatal death notifications that occur in all health facilities in Zimbabwe. It works alongside the already existing paper death notification forms, current information flows and data review.

- **Laboratory Information Management System** – to relay information related to HIV Polymerase Chain Reaction testing for early infant diagnosis of HIV.
- **Health Facility Registry** – serves as the central registry/authority that collects, manages, stores and shares health facility specification data including health facility that tests for HIV and initiates ARV treatment.

**Reports**

- **Weekly Disease Surveillance Report** – Rapid Disease Notification System – weekly collation of all notifiable diseases. Introduced in 1991 as a system to monitor epidemic-prone conditions. Health facilities collect data on a weekly basis listing diseases and conditions and transmit the data to the district, provincial and national levels. Although HIV/AIDS is not notifiable, the collated statistics can inform timely programming for HIV/AIDS.
- **Monthly health programme statistics for HIV** – monthly collation of selected disease profiles including for HIV/AIDS
- **Quarterly health profiles** – three-monthly collation of selected disease profiles including for HIV/AIDS
- **National Health Profiles** – annual collation of all disease profiles including for HIV/AIDS systems

**Maps, graphs, pie charts, time series analysis and other descriptive statistics on:**

- Prevalence (proportion of PLWHA divided by the population)
- HIV incidence (new infections of HIV)
- Prevention of mother to child transmission of HIV
- Coverage of HIV testing and counselling services
- HIV related maternal, neonatal and prenatal mortality deaths
- HIV in pediatrics

**Surveys**

- Demographic and Health Survey (DHS)
- Gender and Health Survey
- Poverty Income, Consumption and Expenditure Survey (PICES)
- Multi-indicator Monitoring Survey (MIMS)
- Global AIDS Response Country Progress Report

Source. Field notes, MoHCC national HMIS

Figure 5.1, showing the coverage of HIV Testing and Counselling Services, and Figure 5.2 showing the 2013 HIV Prevalence in Zimbabwe, are examples of data that is captured in the national health profiles

**Figure 5.1: Example of statistics contained in the national health profile (Table)**

Source. MoHCC, 2013
The World Bank-led results-based financing (RBF) programme is neither funded nor coordinated by the GoZ health ministry. Musgrove (2010) defines results-based financing in health as health financing programmes where financial incentives finance health programmes as rewards upon the achievement of a predefined set of results. In Zimbabwe, Cordaid a Dutch development organisation, works with the health ministry as the principal agent who coordinates the programme across the country. The RBF aims at setting incentives for rural health centres to deliver good performance on set indicators, and payment takes place against achievement of the set indicators. The RBF is sponsored by the government of Norway and the UK’s Health Results Innovation Trust Fund. It began in 2013, and by the end of 2014 RBF was implemented in almost 50% of the health districts in Zimbabwe, focusing on results and strategic use of data (Crown Agents 2014). The project does not specifically mention HIV/AIDS, but could have an impact on the delivery of HIV services. For instance, the focus on health worker incentives and retention schemes may have a direct effect on the provision of HIV/AIDS services. Although the RBF programme may have involved the MoHCC’s SGOs, only one (EI:5) mentioned it in the interviews and could not articulate how it informed decision making in MoHCC, and if it was at all useful in rationing scarce HIV/AIDS resources. EI:5 highlighted that it
was better to have RBF than nothing at all because of inadequate funding to help the rural clinics function. Thus, the RBF was seen as a way of cushioning health facilities that had no funding, and not as a tool for rewarding results through financial incentives or as a management or resource allocation technique as it should.

5.3.4 Market-based rationalities

Several terms, ‘customers’, ‘clients’, ‘pay’, ‘costs’, ‘fees’, and ‘expensive’ were frequently used by SGOs during interviews. Taken together with the approach of cost containment (see the discussion in Section 5.3.1 about the ‘shopping list approach’), the outsourcing of HIV resources through international donor support (see Table 5.2) and transfer of fees to users, it seems that the value of PLWHA is framed within an economised health care system. Although these terms can easily be perceived in different ways, they are all characteristic of economisation of health care, based on Ewert’s (2009) definition of economisation of care. Ewert (2009) views economisation of health care as the existence of economic motivations and intentions in the ways through which health care is provided. While no policy drives the economisation of health care in Zimbabwe, the GoZ through its attendant MoHCC strives to control centrally a cost system, such as fee-for-service payments and the user fee policy that prohibits charging fees to children below the age of five, older citizens above the age of 65 and physically challenged people.

From the interviews, it appears that a remarkable characteristic of Zimbabwe’s health care system is shortage, which is visible in the composition of a range of HIV/AIDS-related services, ARV treatments, and HIV/AIDS products to be offered to PLWHA. The ‘shortage’ characteristic is consistent with Ewert (2009), who argues that the paradigm of economisation of health care implies a visible shortage of services, expertise, treatment and quality. The government makes excuses for its resources or introduces health care reforms that cut on health spending and treatment, and programmes or services are judged according to overarching criteria that involves cost-effectiveness analysis or a shopping list approach. Therefore, as Ewert (2009) argues, an economised health care system has numerous managerial rationales put in to homogenise the rationing of care. A good example is the introduction of user fees implemented at the height of the HIV epidemic which led to the reduction in health care expenditure (GoZ 1990, Chisvo and Munro 1994, Honogoro and Chandidwana 1994). EI:5 identified the effects of user fees and explicitly said;
we started collecting money from our clients [user fees] as far back as 1993 not to punish anyone, but to sustain clinics. There wasn’t enough money from the government to help, so we agreed that we would share costs with the public. I’m not saying people had money, no. I’m saying it was necessary to share costs, and so people started paying to get health service. Just a dollar at first and we have now increased it to US$5, well some pay US$10, because of inflation…’ (EI:5)

Here, EI:5 unambiguously identifies the user fee policy as an approach that led to cost sharing with users and he also brings out the concept of clients suggesting that clients (PLWHA and other patients) purchase services; the service provider (MoHCC and other private entities) supply the service and the health workers (employees) manage the everyday demands of the system. But there is also a role here for overall reduction in health care budget as a consequence of the World Bank itself hollowing out the MoHCC by providing the technical support or expertise in (how to) cutting spending in order to increase the role of the private sector, whose aim is to make profit. This narrative allows for the clients to be problematised as a construct that should take responsibility for their own health, and not expect the government to do so. Connected with this, EI:4, like EI:5, raised concerns over the impact of fee-for-services, highlighting that

…the huge reductions in people who came in the hospital was so evident in the 1990s and we thought things would get better. But I think most people who had AIDS failed to go to the hospitals because relatives might have feared that they would be asked to pay, even though most people in rural areas were not asked to pay. Even these days, most people don’t go to the clinic because of costs of bus fares or card fees [User fees] or whatever money that the hospital asks, we see it on statistics of maternal deliveries…’ (EI:4)

In 1991, the fee-for-services (the user fees to which EI:4 and EI:5 referred) was enforced, resulting in significant increases (tenfold) in out-of-pocket costs (Basset et al. 1997). The enforcement of fee-for-service co-payments coincided with higher levels of HIV prevalence (above 25% in 1997) and the decentralising of health services to local authorities that set up health service delivery as a private good, accessed through payments rather than a publicly funded good (Basset et al 1997). Thus, the lowered funding for health care might have contributed to increased HIV/AIDS mortality (Basset et al. 1997, GoZ 1997).

Document analysis raises some reasons for the Zimbabwean government to maintain economised health care. Honogoro and Chandiwana (1994) argue that the post-independence policies that aimed to ensure equity in access to health care and expanding primary care facilities almost doubled health care expenditure from about 5% in 1980 to 9% in 1984 of total national envelope. Thereafter, until the end of 1990, the health budget allocation from central government declined, leaving most rural areas supported by donor
aid (Honogoro and Chandiwana 1994). Since then, through to today (2016), personal payments and donor aid provides most of the support for HIV/AIDS services.

Paradoxically, although the health ministry adopted the economisation of health care by adopting a user fee policy, it did not abandon its policy of achieving equity in health. One would expect equity not to be an issue. EI:1 said, ‘We have always tried to put principles of equity and equity in access of health care at the centre of all our [MoHCC] policies, look at all our health strategies’. The tendency for the MoHCC to always put emphasis on equity in access to health care may re-emphasise the framing of PLWHA as equal, legal citizens, but the redesign of health programmes to recover costs produces effects opposed to principles of equity. For instance, in order to recover costs, in addition to enforcing user fees, the health ministry allows the Parirenyatwa Group of Hospitals\(^4\) to retain a share of its collected revenue instead of redistributing the proceeds to poorer health facilities in remote rural areas where need is higher.

Relatedly, from document review, an analysis of figures on HIV spending by source (see Figure 5.3 and Table 5.2) shows that the bulk of the funding has been sourced from the international donors. This raises questions about the value that the GoZ attaches to PLWHA given that domestic public funding of HIV has in every year been a fraction of international funding.

\(\textbf{Table 5.2: HIV spending by funding source 2005–2011}\)

\[
\begin{array}{l|c|c}
\text{Year} & \text{International (US$)} & \text{Domestic Public (US$)} \\
\hline
2005 & 74,732,191 & 14,700,000 \\
2006 & 66,079,626 & 63,437,000 \\
2008 & 26,989,448 & 354,661 \\
2009 & 61,552,177 & 8,883,551 \\
2010 & 160,000,000 & 20,833,554 \\
2011 & 170,000,000 & 28,642,838 \\
2012 & 220,000,000 & 34,573,569 \\
2013 & 220,000,000 & 34,347,820 \\
\end{array}
\]

Source. UN data 2015

\(^4\)Parirenyatwa is Zimbabwe’s largest central hospital. In addition to being the country’s teaching hospital, it is also largely equipped with curative high-tech equipment, highly skilled expertise and is relatively well funded.
Figure 5.3: HIV spending by funding source 2005–2011

The domestic funding allocated to HIV and AIDS may suggest that if it were not for the international community, Zimbabwe might not have experienced the reduction in: mortality, HIV prevalence and new cases. Should the international community reduce funding in HIV in favour of other pressing priorities, such as non-communicable disease, it may be that premature mortality from AIDS could increase.

In addition, the Health Services Fund, also known as the Social Development Fund set up in 1992 to function as a community-level health insurance scheme to collect revenue from households and to maintain any donor funds, signals the tendency to transfer financial responsibilities to users through cost-sharing policies. These elements of liberalising health facilities by giving them autonomy to function as suppliers of commodities re-enforce the notions of economisation of health care, a phenomenon which appears to have impacted negatively on PLWHA at the time (see Chapter Seven).

Although the cost of HIV treatment was mentioned consistently by PLWHA participants (see Chapters Six and Seven), some of the SGOs, like EI:6, did not agree with narratives of cost of HIV treatment as a barrier to treatment, arguing that ARVs were free in hospitals and clinics across Zimbabwe: ‘the ARVs are now available in government hospitals for free. The only money that an HIV positive person pays is bus fare to get to the hospital to get the tests done [diagnostics tests] and for the ARVs chete [only]’. Indeed, it was the user fees and out-of-pocket costs, such as ‘bus fare, food, lodging, diagnostic
tests’ that most PLWHA could not afford – a situation impeding PLWHA’s access to ARVs.

These coherent narratives about an economised health system could be pointing towards the key processes of commodification of the health sector as an organic way of societal selection of who is valued and who is not, including the tools for valuation. Media reports reveal that the GoZ privatises health care, a process that impedes access to HIV services:

…of late there has been concern from the public over allegations of privatisation of service which make health care expensive for ordinary Zimbabweans. But Chitungwiza Central Hospital Chief Executive Dr. Obadiah Moyo, denied the allegations of privatisation saying his institution was a public hospital offering services at par with those offered by the private institutions at affordable fees. Dr Moyo said to buttress the fact that Chitungwiza Central Hospital was a public institution; they were still charging consultation fees as prescribed by Government of $10 for adults and free services to under-fives, senior citizens, socially disadvantaged and for maternity services… (The Herald, February 11, 2015)

Although SGOs deny charging fees, such as the Hospital Chief Executive in this Herald quote (February 11, 2015) or in situations where there are signposts on charging penalties (see Picture 5:1), there appears to exist a system of buyers and sellers.

Photo 5.1: Signpost on no-user-fees

Reflecting on the media report (Herald, February 11, 2015 above), the health delivery system seems to convert health service providers, such as the hospital chief executive
officer, into employees motivated to generate profit. Such economic dynamics become critical, not just for understanding the framing of the value of PLWHA, but also for their impact on life or death, and for insights on the calculative rationalities on which health policy decision-makers depend.

In the context of poverty, where more than 70% Zimbabweans are poor (see Section 2.5.4), a US$10 consultation fee mentioned by media reports seems too wayward. I contend here that it appears ‘too-wayward’ because it can exclude the PLWHA who cannot afford the consultation fees, despite ARVs themselves being provided for free. Thus, the individuals who belong to poorer social groups may have trouble in accessing the HIV/AIDS services they need badly. For instance, the CSO and Macro (2007) argued that financial barriers to accessing health services affect 75% of women in the lowest income quintile compared to only 35% in the highest income quintile in Zimbabwe. Children belonging to the highest wealth quintile have a lower chance of stunting (shorter height for age) and wasting (low weight for height) than those in the lower wealth quintiles (ZIMSTAT 2009, ZimSTAT and ICF 2012). Thus, children born to poorer women living with HIV in Zimbabwe are likely to be permanently disadvantaged (UN 1995) and less likely to have birth certificates and likely to die before their 5th birthday as reported by Munjanja 2007, ZimVAC 2011, ZimSTAT and ICF 2012. These accounts submit a view that costs may have led to many premature deaths, especially in the first 20 years of the epidemic.

5.4 Conclusion
Overall, this chapter has discussed the ways in which health policy decision-makers frame the value of human life in two ways: first, as a rational and thoughtful process (episteme) and, second, as a calculative rationality (techne). The specific ways in these two broad ways overlap and tend to be piecemeal and reactionary. Moreover, the ways of the framing of value appear to be representative of the multiple approaches employed at the policy level in valuing the trade-offs of losing or saving a human life. Drawing from the episteme way of framing the value, it appears that the GoZ, through its attendant health ministry SGOs, tends to value PLWHA as equal, legal and political citizens who can claim the law’s protection. This narrative suggests that PLWHA, like other citizens without HIV, have social rights; they are protected by the law and they can, arguably, access HIV treatment. Similarly, the results also suggest that PLWHA can federate and organise to claim resources for HIV. Here, citizenship of PLWHA can merely be a
collection of rights and obligations as in the juridical definition of citizenship, but it appears also to represent both the legal and social relationship between individual PLWHA, within a community and their relationship with others and the government, as competent members of society.

Drawing from the techne framing, this chapter has shown that SGOs in health policy appear to frame PLWHA based on a ‘shopping list’ approach, presented as a method guided by how cheap or expensive an intervention is. Disability adjusted life years (DALYs), and results-based rationalities, all intermeshed within an economised health care system tend to give a sense of framing PLWHA as clients. In this sense, PLWHA are subject to the dictates of market forces of consumerism and are viewed as paying customers who gain access to HIV/AIDS services through monetary payments or other valuable considerations, such as government budget allocations that introduce a degree of rationing. This intersects with other characteristics of PLWHA. Those with lower purchasing power struggle to access life-saving antiretroviral drugs due to cost implications. Thus, individual wealth can confer value on the lives of the wealthy.

Thus, the framing of PLWHA by SGOs as both citizens and clients tends to be patchy because the SGOs make decisions fragmentarily, influenced by the prevailing circumstances and context in which these choices are made. These SGOs who drive the intricate design, implementation and verification of HIV/AIDS policy choices appear to exert an influence the capacity of PLWHA to access health care and life choices they make or the life and death outcome for PLWHA. The client-framing of value seems to suggest that the citizen perspective is nothing more than a window-dressing framing of value – meant to disguise the actual ‘conduct of government’ and its influence on the ‘conduct of the conduct’. Additionally, the next chapter shall examine, the ways non-PLWHA, who are the men, women and youths not living with HIV in the community, frame the value of PLWHA.
6 FRAMING THE VALUE OF HUMAN LIFE: HOW DOES SOCIETY FRAME THE VALUE OF PEOPLE LIVING WITH HIV AND AIDS?

6.1 Introduction

The ways by which senior government officials (SGOs) in health policy frame the value of PLWHA was the subject of the previous chapter. While the ways SGOs frame the value of PLWHA as citizens and clients points to new frontiers of knowledge in understanding valuation of human life in health policy, it might be naïve to draw generalisations from a single category of participants. Considering society is heterogeneous, views from those who are not senior decision-makers, the men and women who interact and live with PLWHA, could broaden our knowledge and understanding of how society frames the value of PLWHA. This chapter responds to the second research question ‘In what ways is the value of PLWHA framed by people not living with HIV (non-PLWHA)?’ Answering this question is complex, particularly considering that non-PLWHA can be sub-divided into several categories, such as women, youth, children, development organisations, community HIV/AIDS service organisations, faith-based organisations, people living with disabilities, gay men and lesbians, and commercial sex workers. As already discussed in Section 4.4.5.1, this study, however, did not place non-PLWHA into categories, as that was beyond the thrust of this study. The chapter brings together findings from focus group discussions (FGDs) with non-PLWHA.

This chapter is organised into two main sections. Firstly, the chapter focuses on the valuation of PLWHA as a formation of identities – governing others, discussing, as already explored in Sections 3.4.3 and 4.2.3, the forms of persons or identities shaped by actions and vocabularies of non-PLWHA (discursive framings). Finally, the conclusion summarises emerging observations and findings and their implications on the ways in which non-PLWHA value PLWHA.

6.2 Valuation of PLWHA as identity formation – governing others

Most non-PLWHA participants in FGD-GorA, FGD-ChA, FGD-GorB and FGD-ChB framed the value of PLWHA using such terms as Marights (human rights) and Mitemo (laws), which all point to the human rights and policy framework that SGOs used to frame PLWHA. The accounts and arguments used by non-PLWHA for framing PLWHA as equal and legal citizens were very much similar to the ways in which SGOs framed PLWHA as citizens, discussed in Section 5.2. But not all PLWHA are viewed as equal,
legal citizens who could demand the law’s protection. PLWHA, and especially homosexuals, sex workers and ex-prisoners living with HIV/AIDS, are viewed as deserving HIV/AIDS drawing from moral perceptions in normative ethics. Religion emerges as a double-edged discourse, operating between the contradictory axis of love versus condemnatory judgement. This section presents narratives of the interfaces between PLWHA and how they are viewed and thus how their value is framed in the communities where they live.

6.2.1 PLWHA are equal, legal and political citizens protected by the law

In focus group discussions held in both Chitungwiza and Goromonzi with non-PLWHA, there was a consensus that PLWHA enjoyed their rights to access health care, but faced challenges of access to health services in the same fashion as did other citizens without HIV. Also, PLWHA are viewed as a social group that over the years led local authorities and communities towards an effective HIV prevention strategy, fought for and eventually won access to free ARVs in public health facilities, and demanded equality, dignity and value. These notions were especially evident in FGD-ChA when a participant said;

“We can’t be talking about PWAs [people with AIDS] as if vakanyorwa pamhanza kuti vane AIDS [labelled on their foreheads that they have AIDS]. In fact, you can’t tell if one has it or not [HIV]. They are treated in the same way, if they face challenges, it’s not because they have AIDS, it’s because those are the challenges that everyone else faces in this Country. Everyone in this room has the right to health as our new constitution says, this includes the PWAs. It’s simple. PWAs have done a lot, they have come together in their different support groups to fight for their rights, and made all of us see them differently by changing how we thought about them. They are our brothers, sisters, children, mum and dads. They are us. You see the more we talk about them as if they are different, the more different they become. So they are just people in Zimbabwe, struggling to survive like all of us. / Even us here, we are representing the wider community without HIV, but how do we surely know that we all do not have it here (FGD-ChA)

The participant is arguing that PLWHA have been, and remain, important agents for the social and legal transitions necessary for effective HIV responses. Besides, PLWHA are supported by the law and have the necessary community solidarity and are thus no longer viewed as threats but as members of the family unit and the wider community. This narrative is significant in framing PLWHA as that social group that can attain a sense of community identity despite their chronic conditions. The participant also seems to suggest that a deliberate talk about PLWHA as a select group can further ‘other’ them as different and perpetuate notions of otherness and stigma associated with the condition. The Constitution of Zimbabwe remains the major reference point for the ‘citizen’ element of PLWHA. The participant uses the constitution to show a binding obligation between the GoZ and its people, PLWHA included. Further emphasis on the wider health struggles denotes that while PLWHA face access challenges, it is the same set of problems
encountered by the broader community in an attempt to gain access to medication that can prolong life. Placing emphasis on the PLWHA support groups can explain the notions of political participation of PLWHA as equal members of society who can form small groups to demand justice, fairness and, especially, the same treatment. Taken together, the elements in this quote speak volumes on membership and identity, political participation and legal aspects of citizenship highlighted by SGOs (see Chapter Five).

In the same FGD, a youth representative also added,

I think PLWHA are favoured concerning health service provision because all the big donors always put their money of the HIV/AIDS services. They [donors] forget that we have other equally important significant problems such as lack of water and that a lot of children are dying of diarrheal and Kwashi (Kwashiorkor – protein energy malnutrition). They [PLWHA] have free testing, free ARVs and most NGO based clinics including mobile clinics go around the community teaching people on prevention and treatment. The newspapers and radios including TV all talk about supporting them. So they are good. They aren’t treated any differently – in fact; they have more at their disposal these days (FGD-ChA)

The representative of youth suggests that access to HIV treatment, support and care, including free and voluntary counselling and HIV testing, affordable opportunistic infections treatments and nutrition education is readily available to PLWHA. Other non-government entities, such as the NGOs who use mobile clinics as referred to by the participant, also support PLWHA by providing HIV services at a community level. Also, the use of media, including anti-stigma campaigns, entertainment designed to educate the community about HIV, and integration of friendly messages into TV and radio shows was cited as a critical element advancing the integration of PLWHA as equal, legal entities of society.

At an FGD in Goromonzi, participants flagged the presence of a dedicated policy implementation strategy for PLWHA, as one participant observed ‘the ZINASP is just for them [PLWHA], showing the level of commitment that we all have to have our brothers and sisters seen in the same way we see each other here. A few years ago, when I was formally employed, I paid the AIDS levy because we know and understand the importance of saving our kith and kin’. (FGD-GorB). The inclusion of HIV/AIDS priorities in national responses as represented by the Zimbabwe National HIV/AIDS Strategy (ZINASP) shows the likelihood of costing the programmes with an allocated budget and possibly having attributed indicators for monitoring the progress of implementation.
Although these narratives bring forward a sense of cooperation between different players to advance the needs of PLWHA, a sense of identity and belonging for PLWHA, and support of their political participation, as equal and legal citizens, there were contending narratives. Those who contended argued that the involvement of PLWHA on big boards, such as the Global Fund Country Coordinating Mechanisms, was highly tokenistic. On one hand, the involvement of PLWHA in Country Coordinating Mechanisms was seen to have increased the diversity of participants and as such, improving the relevancy of the Global Fund programmes in Zimbabwe. On the other hand, participants felt that PLWHA did not play a role in the creation of the Country Coordinating Mechanisms and are not consulted when their representatives are selected. Although emails are circulated through the National AIDS Council to reach the HIV communities for participation in the Country Coordinating Mechanisms, participants argued that officials in the NGOs working in Harare, with closer proximity to the Ministry of Health offices where the meetings are held, fill up those positions at the expense of PLWHA who are poorer and further away. The participants reported that most PLWHA did not know about the Country Coordinating Mechanisms and are excluded, and thus fail to communicate further to the wider HIV constituents. A representative of the District AIDS Action Committees (DAAC) in Goromonzi highlighted that where PLWHA are represented, they are often not treated as equal collaborators, who should in principle enjoy full rights to participation, and involvement in decision making, as do other members. This suggests a minimal influence on decisions and resultant outcomes. For example, the participant argued,

we met last month in Harare, the PWA rep [PLWHA representative] did not speak because he obviously could not talk in English as confidently and there we were all speaking in English, excluding them just by the language we use in important meetings such as these. This is also what happens when we ask them to review technical proposals; they can’t be fully involved because they won’t know where the writing is coming from and going (FGD-GorA)

In his statement, the participant shows that, of the PLWHA who get to participate in the Country Coordinating Mechanisms, very few knew or understood criteria for funding or rejecting proposals. PLWHA may be afraid to speak, not only because of what the participant highlighted (language), but also for fear that their expressions could jeopardise relationships with funders; inadequate preparation for meetings due to lack of in-depth knowledge on the scope of what they are expected to do and say to contribute effectively. Besides, participants shared the notion that the role of PLWHA was simply to rubber stamp the interests of meeting conveners.
Overall, PLWHA are viewed as citizens in the manner in which non-PLWHA are perceived in Zimbabwean society. Although this view corresponds to the views of SGOs who frame PLWHA as equal legal citizens, non-PLWHA argue that the political participation of PLWHA is largely tokenistic.

6.2.2 [De]valued bodies and expendable populations: Religion as a double-edged discourse of love versus condemnatory judgement

Religion provided, and still continues to operate, as a mechanism through which PLWHA obtain hope, emotional and financial care in the context of Zimbabwe’s HIV epidemic. The population trusts churches in Zimbabwe, and they have large memberships, and well-developed communications provisions, hence the ability to disseminate HIV/AIDS information as well as care for those PLWHA in need. Health service delivery is organized through Roman Catholic and mainline Protestant churches or through the Zimbabwe Association of Church-related Hospitals (ZACH). ZACH, is constituted by heads of Christian denominations and it works with the Zimbabwe health ministry and the European Commission to provide medical services in hospitals and clinics countrywide (FGD-GorA). But the apostolic sect is the most popular religious group in Zimbabwe (42% women and 32% Men), followed by the Pentecostal (25% women and 18% men). Overall, women are more likely than men to belong to a church group with approximately 5% and 17% of women and men respectively not belonging to any church group (ZIMSTAT and ICF 2015). see Table 6.1 below.

Table 6.1: Religious characteristics of the Zimbabwean population by sex

<table>
<thead>
<tr>
<th>Religion</th>
<th>Women</th>
<th>Men</th>
</tr>
</thead>
<tbody>
<tr>
<td>Traditional</td>
<td>0.6</td>
<td>2.6</td>
</tr>
<tr>
<td>Roman Catholic</td>
<td>6.7</td>
<td>8.0</td>
</tr>
<tr>
<td>Protestant</td>
<td>15.7</td>
<td>15.4</td>
</tr>
<tr>
<td>Pentecostal</td>
<td>25.2</td>
<td>17.6</td>
</tr>
<tr>
<td>Apostolic sect</td>
<td>41.8</td>
<td>32.1</td>
</tr>
<tr>
<td>Other Christian</td>
<td>4.6</td>
<td>6.1</td>
</tr>
<tr>
<td>Muslim</td>
<td>0.4</td>
<td>0.7</td>
</tr>
<tr>
<td>None</td>
<td>4.9</td>
<td>17.4</td>
</tr>
<tr>
<td>Other</td>
<td>0.1</td>
<td>0.1</td>
</tr>
</tbody>
</table>

Source. ZIMSTAT and ICF (2015)

Unlike other countries in Southern Africa where Pentecostalism is the main religious following, Zimbabwe is unique in that the Apostolic sect claims almost half of the Zimbabwean population (see Amanze 1998, Mpofu et al. 2014, ZIMSTAT and ICF
2015). For instance, in Botswana, bordering Zimbabwe, an estimated 73% of faith-based organisations are Pentecostal, constituting the majority faith community (Mpofu et al. 2014). The discussions with non-PLWHA, especially in Goromonzi, highlighted the role that the Apostolic sect plays in shaping societal expectations and morality between and within communities. Besides the Apostolic church, other sects such as the Roman Catholic, the African Traditional Religion, Protestant and Pentecostal churches also play a fundamental role in framing the value of PLWHA. Although, data in Table 6.1, gives the impression that the religious affiliations are watertight categories, evidence from thus study as shall become clearer in Section 6.2.2.1 below and Chapter Seven, many Zimbabweans adhere to a Christian denomination but still incorporate many “traditional” religious practices and beliefs in their daily lives.

6.2.2.1 The Zimbabwe Apostolic Church: Mapostori, Madzibaba ne Madzimai veMasowe

*Masowe e Madzibaba ne Madzimai* (the wilderness of men and women Apostolicism) was founded by a self-proclaimed African John the Baptist, Johane Masowe in the *Gandanzara* village of *Makoni* district of the Shona people in the 1930s (FGD-GorB). The *Masowe* sect is purist and widely known for its dismissal of any westernised Christian ideologies of God and scientific medication. Congregating on ‘*Zuva rakayereswa*’ [the holy day of God – the day of healing], a Friday, the *Masowe echishanu* (fifth day apostolic) identify themselves as Christians who do not read the Bible. They argue the Bible as flawed and ‘*rakanyorwa nevarungu vakauraya mwana Yesu*’ [written by white men who killed the son of God] (FGD-GorB). They claim to receive the anointed wisdom directly from the Holy Spirit. In this insightful and sensitive historical ethnography of *Masowe*, such rejection of biblical scriptures appears to speak to longstanding tensions between Christianity over mediation and authority. Although the Bible in itself has, and remains, the route through which Christians worldwide recognise God’s word, the *Masowe* Apostolic perceive biblical scriptures as unnecessary and a dangerous mediator. ‘*Bhaibheri nderevemaSinagogi, vanopemberda kufa kwayeso, vachishoropodza rudzi rwedu, mwari anemufanamidzo wavo, zvino ko rudzi rwedu rwungasvikasei kuna Yesu*’ [the Bible is for those with synagogues [buildings], those who celebrate the murder of Jesus, they represent our Saviour in their images and force us to believe that he is a saviour for all of us, no, we get messages directly from God himself and he does not look like them [white people]]. For the *Masowe* following, the materiality of the biblical scriptures
marks complicity to the murder of Yesu [Jesus] and creates a barrier between them and the divine which can prohibit the realisation of pure, unadulterated faith (FGD-GorB).

This is significant because Masowe creates new norms from what the world already understands about Christianity, framing a unique narrative on the value of PLWHA. For instance, one participant at an FGD in Goromonzi remarked,

Tinavo vanhu vane dande irori rechirwere, isu tinovarangaridza kuti urwere hweHIV hwuriko, uye mazuva ano hwava kutoda ma ARVs, asi chakakosha ndekhekuti munhu azive kuti chamupa urwere mweya yetsvina yemadzinza ekwaakaberekerwa. Mweya iyoyo nidiyo inomuteera ichisundira kuchihure, kuhungochani kana kupiwa kana murume anorwara kare, iwe wotapurirana nazvowo. Mweya iyoyo nidiyo yatinoda kutandira kure munhu asati avhiringwa. Munhu akapomba ngazive kureura paMasowe, wakasareura mudzimu unoera unofuratira ndipo pakuwira mugomba ka uko. Gehena unoriona uripano pasi, vasina kuroorwa ngavasaita bonde kusvika wapinda mumba zvakanaka. Chipfambi, hungochani kana mamwe mabasa erima, mweya yevakafa vanenge vachtivaga kwekupotera (FGD GorB)

Loosely translated as,

We do have people suffering from this horrible infection [HIV]. We remind them HIV is there and these days it needs ARVs, but what is important is that they must know that the disease came as a result of evil clan spirits and demons from where one was born that linger and loiter on earth trying to find a soul to occupy. Such spirits haunt us and lead you straight into prostitution, homosexuality or end up getting a wife or a husband who is already infected and one ends up infecting self. Such are the spirits that we deal with, we exorcise and chase them away preferably before a person gets into misfortune. People should learn to confess in front of the congregation so that God can forgive them. People go to hell while they are still breathing, the unmarried should abstain from sex until marriage. Prostitution, homosexuality or other works of darkness are works of dead spirits looking for sanctuary (FGD-GorB)

In this quote, the participant shows how the church, and the Masowe sect in particular, operates as epistemic or knowledge-generating, as well as validating social environments. The Church transmits to its following morally encoded norms about what constitutes valid knowledge and how that knowledge should be utilised. The prioritisation of faith-informed knowledge over secular ways of knowing brings a sense of protection on PLWHA, who may be desperate for transcendental deliverance on the hope that their HIV infection may go away. As the participant highlights, the Masowe doctrine, therefore, communicates to followers about the obligation to adhere to expectations and behaviours that are consistent with core values of the church. The 2015 Demographic and Health Survey reports that knowledge of HIV prevention methods is generally widespread in Zimbabwe, with 84% and 88% of women and men respectively knowing that correct and consistent condom use can prevent HIV infection (ZIMSTAT and ICF 2015). Similarly, 92% of women and 94% men recognise that limiting sexual intercourse to one uninfected partner can significantly reduce the chances of getting HIV (ZIMSTAT and ICF 2015).

But, as observed in the participant’s quote, churches tend to emphasise information that reinforces faith teachings, and condemn strategies that contradict established Masowe
teachings. This could suggest that those who are living with HIV within the church may be viewed as objectors of church doctrines, or ‘living hell, while still breathing’ (FGD-GorB), a punishment from God for sins committed by the PLWHA.

Churches are not the only source of HIV information for the Zimbabwean population. Both primary and secondary schools have also incorporated a curriculum for HIV education, but misconceptions about HIV transmission are still common. For instance, the 16% of women and men age 15-49 have in 2015 reported that HIV is transmissible through mosquito bites. Similarly, 7% report that a person can become infected by sharing food with a person who has HIV, and 5% firmly believe that HIV is transmissible through supernatural means (ZIMSTAT and ICF 2015). Thus, if faith organisations, such as the Masowe, overemphasise abstinence-only messages and confessions of sins that led to HIV infections in front of a big church gathering, they appear to encourage inadvertently a disconnect between what is publicly said and the actual private behaviours of both non-PLWHA and PLWHA. On the other hand, in professing that God is compassionate and forgiving once one has confessed, the church teachings may equally be read as allowing for sexual permissiveness because God will forgive once a confession is made. The ways, in which PLWHA integrate messages from possibly conflicting multiple sources may be a factor of both personal or social arrangements, including but certainly not limited to their religiosity. But, this has implications for the ways in which PLWHA are valued within the church. On one hand, they are valued as people needed by God, who after confessing they are granted their normal lives. On the other hand, they are condemned for not observing the religious teachings from the church.

6.2.2.2 The church promotes both good and evil.

In Chitungwiza, participants at an FGD-ChB argued that the Methodist church ‘provided food, clothes and money support for families whose member(s) lived with HIV with food, clothes and money’ (FGD-ChB). Another participant at the same meeting corroborated, stating that senior members of the Church from Pastor Makandiwa’s Pentecostal church ‘visit families to support with prayer and food’ (FGD-ChB). ‘We also make sure that we invite a volunteer nurse from the church to provide support for those who should start, know someone who should and those who are already on treatment’ (FGD-ChB). From these accounts, religion appears to drive some to commit their lives to helping the poor and the needy. But, participants were also unforgiving about those who ‘do not come to
church frequently’, and who practised acts of ‘darkness se mahure ne ngochani’ [such as gays, lesbians and sex workers] (FGD-ChB). Participants reiterated that it was important for PLWHA and their families to ‘know God and receive salvation’ as this was believed to rationalise the actions of the dedicated members of the church, who create time to help PLWHA when in need.

We also employ them [PLWHA], because we understand they go through difficult times in finding employment, some of them work as ushers at our church, I’m the leader of the Ushering department and I always ask the women if they remembered to take mapiritsi [pills-ARVs], we pray and ask the Lord to guide us, together. This is serious because I will be working with ill people, it’s not a joke, they need to know God and receive salvation. For me those who think it’s a joke or believe whatever else they believe, or who continue to do works of darkness such as witchcraft, multiple sex partners, kubika mapoto [cohabitation] homosexuality, prostitution or Satanism, I simply report those I suspect to the Pastor’s wife and they can be removed from ushering, there are so many who need the job (FGD-ChB)

From these accounts, while the church appears to value PLWHA by praying for them, creating employment opportunities, and giving emotional support from dedicated members of the church, religion also drives the same dedicated members of the church to eliminate heretics. Thus religion has the aptitude to generate unselfish love, personal commitment and passion to some people, and vicious, raw hatred in others for PLWHA. Religion, as expressed by the participant in FGD-ChB, can motivate people to hate homosexuals, sex workers, or people from other faiths, such as the African Traditional religion where witchcraft is believed to be anchored. This can escalate into actions of exclusion and othering of the very same people the church purports to love and care for. Besides, the tone of speech that participants used as they spoke firmly on morality and the faith revealed undertones of an exclusory language which, among other aspects, represents violence.

Such representation of violence through undertones of speech may represent a view of a vengeful God who punishes sins, and thus suggests less acceptance of PLWHA, who may have secular-oriented views of HIV support and care. In this regard, the influences of church ideology on the ways in which non-PLWHA frame the value of PLWHA is significant as it frames PLWHA in two contradictory ways. On one hand, as loved people of God, and the other, as expendable populations, who should be left to the devil’s delight upon failing to adhere to the church’s doctrines. Thus, the church operates as a knowledge social environment which implicitly essentialises faith-informed framing of the value of PLWHA.
6.2.2.3 Governing the devalued bodies

In the community, and at home, gay people who struggle with homosexuality attempt to keep their sexuality a secret. Lesbians, gay men, bisexuals and transgendered people (LGBT), especially those living with HIV, experience societal hostility, discrimination and stigma once the homophobic others know of their homosexuality and their HIV status; as explicitly said by a participant at an FGD. ‘If we see them here, we will hand them over to the police as VaMugabe said [Robert Mugabe5]’ (FGD – GorA).

The FGD participant above appears to suggest that senior leadership in government supports the discrimination of homosexual people living with or without HIV and that the violation of the rights of PLWHA emanates from the highest level of government. Media reports also suggest that the discrimination against homosexual PLWHA, including their denial to life-saving health care services, emanates from national leadership. Mugabe’s first public condemnation of gay people was during the time Zimbabwe had the highest prevalence of HIV infection in the world, averaging (27%) (Dunton and Palmberg 1996, World Bank 2015). Mugabe waged a violent campaign against homosexuals, and his utterances became ‘policy’, which shaped how homosexuals, especially those living with HIV, were viewed and respected in society. Homosexuals are devalued, degraded and humiliated. Mugabe’s speech against homosexuals is repeated by law enforcement agents, government departments and his enthusiasts;

...I find it extremely outrageous and repugnant to my human conscience that such immoral and repulsive organisations, like those of homosexuals who offend both against the law of the nature and the morals of religious beliefs by our society, should have any advocates in our midst and even elsewhere in the world. If we accept homosexuality as a right as is being argued by the Association of sodomists and sexual perverts, what moral fibre shall our society ever have to deny organised drug addicts, or even those given to bestiality, the rights they might claim and allege they possess under the rubric of individual freedom and human rights… (Robert Mugabe, at the Zimbabwe International Bookfair, 1995)

Mugabe did not see any ‘value’ in homosexual humans. He did not call them ‘humans’, he called them ‘sodomists’, ‘perverts’ who were worse than ‘dogs, pigs and insects’. ‘What an abomination...immoral and repulsive... lower than pigs and dogs... animals in the jungle are better than these people because at least they know that this is a man or a woman... I don’t believe they [homosexuals] have any rights at all’, Mugabe told reporters after presenting his 1995 ‘Book Fair’ speech in Harare. Mugabe, here, authorised the

---

5 At the time of the study, Robert Mugabe was the president of Zimbabwe. Mugabe had been president of Zimbabwe since 1987 and before then, he served as the country’s head of Government in the Prime Minister’s office since Zimbabwe’s independence from British Colonial rule in 1980.
stripping of rights of homosexuals in Zimbabwe. His statement suggests that homosexuals can neither vote nor participate as citizens and ‘it was ok’ to allow them to die or to kill them, because they did not have rights, and they were not ‘human’. ‘If you see people presenting themselves as lesbians and gays, arrest them and hand them over to the police’ (Mugabe in 1995 at the Book Fair). Mugabe’s actions and attitudes towards homosexuals suggest that, according to him, human rights have limits, there are people in society who have more rights than others, who have more value than others, and those without equal value should be left to their own devices. These accounts from the highest level of leadership have had a negative impact on gay people living with HIV as media and health institutions seem to repeat these statements and propagate the violation of the rights of gay people living with HIV. The media propagates the ‘othering’ discourse through newspapers, radio and/or television by publishing and retelling hostile comments about lesbians, gay men, bisexual and transgendered people (LGBT) made by the leadership.

6.2.2.4 Lack of ‘hunhu’ [being human] - Valuelessness

While the SGOs in health policy tend to view PLWHA as citizens, as discussed in Section 5.2, it appears that some non-PLWHA do not view all life as containing the inherent value of life. The laws, human rights and policy provisions for PLWHA seem just as provisions of laws and rights that fail to provide the restitution needed by PLWHA in practice. Due to their same-sex sexual orientation, homosexuals fail to demonstrate the qualities of Hunhu and are thus seen as quasi-humans, undeserving of HIV/AIDS services. In practice, the enforcement of equity and human rights principles contained in AIDS laws and policies produce quasi-citizens who can not ‘participate’ and ‘identify’ as an equal, legal citizen. The nature of this reality has contributed to a climate where individual LGBT people living with HIV/AIDS have been subjected to family ostracism, and HIV care discrimination, like in Tino and Tatenda’s cases (see Boxes 7.1 and 7.2 in Chapter Seven). More striking was the statement shared by a senior authority in the district administration team at a Rural District council meeting in Goromonzi, who said,

…we have more decent problems to deal with, to provide ARVs to those who need them not Ngochani. Munhu wepi anoisa chinhu chake mumwena wakazara cholera ne majuru woti handirumwi? Unenge uchiziva, saka vanoda kutineterei? Tiribhizy’’ [what human, in their rightful mind, would take his thing [penis] and put it in the hole full of Cholera and anthill termites and expect not to smell or get bitten? They know what they seek, so why do they want to bother us? We are busy] … (district meeting - participant observation).

When the local authority shared her sentiments, her voice was tinged with disapproval, as well as something else – a haughtiness, as if she was questioning why I could not
reason with her. Her statement suggests that homosexuals, especially gay men, did not
deserve ARVs. They deserved to die. I refer to gay men because she used the term *chinhu*,
(a thing, a penis) that would penetrate ‘something’ from which the *chinhu* gets infested –
gets bitten by *Majuru* (termites).

She viewed same-sex sexual conduct as ‘unbecoming’ behaviour and, therefore, as
unacceptable. Here, I use the language ‘unbecoming’ and ‘unacceptable’ because of the
terms the local authority participant used – *cholera* and *Majuru* [anthill termites]. These
terms suggest that homosexuals’ actions are viewed as being as ‘filthy’ as the bacterium
that causes cholera, the *vibrio cholera*, which is found in human faecal matter (Pierce
1973). In the cholera idiom, the participant could have been pointing to the anal sex that
gay men may experience, suggesting that, in her view as local government decision-
maker, gay men deserved neither respect nor life because they [gay men] lack value and
respect. Also, *Majuru*, the termites, are insects that are known to put up a good fight using
their big, sharp mandibles made especially for biting. While *Majuru* are eaten as a
delicacy in some parts of Zimbabwe, they are commonly viewed as notoriously
destructive insects. The use of the term *Majuru* in her statement reveals the mentality of
local decision-makers who view homosexuals as irresponsible people, who put
themselves at the risk of HIV infection knowingly, and, thus, are undeserving of
sympathies from society, including receiving ARVs from the government. She also seems
to speculate that gay men engage in unprotected sex (without a condom) because their
attraction lies in the forbidden and the risky. A female participant at an FGD-ChB agreed
with the claims made by the local authority member. The participant associates anal sex
with shame, pain and danger. ‘*Won't a person be in pain [anal sex]? kubooka kwese uku
wozontsa futi ne maOI* [hollowed all the way up, and they want to cause trouble with
OIs (opportunistic infections)]?’ From these accounts, anal sex is associated with HIV
and opportunistic infections, and as such, there are expectations that it is something one
should avoid.

These accounts show that homophobic prejudice is manifest among Zimbabwean leaders.
It is also evident among non-PLWHA.

6.2.2.5 *Resisting identities of expendable people*

There were some participants who disagreed with homophobic views imposed by
leadership and their institutions on homosexuals. At the first national all stakeholders’
half-day meeting on Social Determinants of Health, in February 2014 in Harare, a WHO country representative for Zimbabwe said, ‘Health is influenced by the social and economic conditions ...These... include income and its distribution, early childhood... education..., food security, gender and housing including access to safe water and sanitation, and social safety nets...shaped by the distribution of money, power and resources at global, national and local levels’ (MoHCC 2014). In these remarks, while the WHO official was explicit about other conditions such as income, wealth and gender, the issue of sexuality (particularly homosexuality) was not spelt out as a determinant of poor health or HIV/AIDS. However, the WHO official’s statement might have also inferred that the issues of sexuality are embraced in his statement, given that the statement itself was not exhaustive of all the social determinants of health. Similarly, at an FGD-ChB, a participant said,

…this issue is very sensitive to government and offices that be. But we have continued to talk about it from a public health perspective, and there is a green light. The Global Fund is also breathing fire on the same issue. There is an international condemnation of how we treat them [LGBT] here. We will not be all noisy about it as yet. We will start with size estimations, and then other behavioural empirical studies. The work is in the pipeline; we may start next year but one [2016]... (FGD-ChB)

Providing possible timeframes on the likelihood of beginning implementation of work to address HIV/AIDS issues among homosexuals in Zimbabwe and referring to this possibility as a ‘green light’ suggests the existence of a hidden world of non-complicity outside the complicity demanded by societal norms.

6.2.3 Degraded and demeaned: Labelling of Opportunistic Infection clinics
In both Goromonzi and Chitungwiza, problems with infrastructure set-up were identified as sources of conflict between health workers and their clients. In Chitungwiza, FGD-ChA argued that health facilities have special sectioned zones earmarked for PLWHA, including opportunistic infection (OI) clinics and private treatment literacy and counselling spaces. However, FGD-ChA argued that PLWHA did not like to be separated from the rest of the patients, and held health workers responsible for these deficiencies.

they don’t understand that we didn’t build these hospitals. We are not Ministry of Public Works or mashefu [the bosses] who decide that we want an OI here [OI Clinic], I’m just an employee, I have my own problems, and I’m just coming to work to do my job. But you’ll hear someone calling you names in the community as if I’m responsible (FGD-ChA)

This quote signals intent by health workers to distance themselves from demands that may appear administrative. It may also suggest that health workers may subconsciously treat PLWHA differently as a result of the perceived demands from PLWHA, which health workers may not be able to address. FGD-ChB reported that health workers often
presented themselves as experts, knowledgeable and, therefore, claiming more power over PLWHA. For instance, FGD-ChB reported that while PLWHA appreciate and know that HIV adherence counselling is supposed to be carried out in private rooms, health workers in Chitungwiza often conducted the adherence sessions in groups. The counselling sessions, which are supposed to be held in private, are sometimes held outside the hospital under a tree close to the mortuary, in spaces where other people who may not be part of the sessions can identify PLWHA. This often brings people who are not treatment-ready into difficult circumstances that they may not be able to deal with. In addition, such situations were reported to likely reduce the probability of PLWHA repeatedly returning to these sessions, thus, treatment readiness is gravely compromised (FGD-ChB). The FGD-ChB and FGD-GorA showed that a shift towards a balance of power between service providers and clients was more favourable by allowing PLWHA to participate in some hospital meetings. FGD-ChA and GorA participants argued that the involvement of PLWHA could enable providers to feel gradually less threatened by their increased involvement, who, in turn, grow in self-confidence to analyse and articulate their needs and entitlements.

When asked if there had ever been major disagreements about how to manage resources fairly at the clinic level in communities and if everyone agreed on the means to do this, a nurse in charge participating in an FGD in Chitungwiza (FGD-ChA) said,

…there’re always disagreements. One of the disagreements is whether we need to label specialised HIV clinics or not. Some say “why is that we do not label diarrhoea, diabetes, etc. on doors and why do we label OI clinics?” I mean, it makes sense to hear HIV positive people say that, because it can reinforce stigma at a time we want HIV to be viewed as just another chronic infection. But at the same time, that’s how we can earmark resources for those facilities especially when donors come and want to check if “that machine” they funded is there in its OI clinic. So who should I listen to? I will get the resources first so that the person with HIV can be treated… (FGD-ChA)

Since health workers were aware that the choices they made regarding policies, such as specialised and earmarked HIV/AIDS clinics, had the potential to reinforce stigma, it appears here that PLWHA are often given a ‘deaf ear’. Also, the quote from the FGD-ChA participant may suggest that officials in government tend to listen to donors rather than the people that they purport to serve. On the same note, a participant in FGD-GorA, representing one of the NGOs, argued that OI clinics only serve to strengthen exclusion, by making everyone view PLWHA as the ‘other’, a process instigated at the policy level. Specifically, the participant said,

…why OI clinics? It’s unnecessary and demeaning to label them OI. Kudhigredhana [degrading], even here Kumusha [rural areas] at a small health centre like this one [pointing at the clinic, see picture 6:1]. PLWHA are told to come on specific days and on those days they are told, through a
hailer that vemapiritsi varwere huyai ku OI [Those on pills, the ill, come to the OI clinic] Why is that? It’s unfair. Moreover, why a loud speaker or why shout? This is policy exclusion senge mu Rhodesia [like in Rhodesia]…’ FGD-GorA

Photo 6.1: A rural health centre in Goromonzi District

In Chitungwiza, media reports also corroborate;

…thousands of patients are forced to wake up early in the morning to congregate at the many distribution centres, only to be served late in the afternoon… Most of those falling victim are bedridden AIDS patients who are no longer able to visit health care centres to collect their supply… My husband has vowed that he would never set foot at an OI clinic again. Citing the lack of privacy and congestion at the place [Chitungwiza Central Hospital] … The rudeness displayed by some nurses, the fact that one has to wait in a shed waiting for one’s file to be called out, and the late opening times of the pharmacy – all combined – made him lose interest. He, therefore, buys the drugs from a man in our street who has connections…’ (Interview with woman living with HIV in Chitungwiza; The Daily News, Zimbabwe March 4th, 2012)

Some participants disagreed on the dates for ARV collection, arguing that it was important for PLWHA to come on the same specific dates to allow for coordination, monitoring and for health workers to manage drug stocks. Others argued that the specific

---

6 Rhodesia was an unrecognised de facto successor country to the former British colony of Southern Rhodesia from 1965 to 1979. It was located in the region now occupied by Zimbabwe. Zimbabwe gained its independence in 1980.
days would allow PLWHA to remind each other through their networks to go and fetch their medicines. Participants who concurred with those not in favour of the ARV collection dates challenged the marked OI clinics as choices made by policy-makers to discriminate against PLWHA; a situation likened to segregationist policies seen in Rhodesia. Also, some argued that the discriminatory policies are made to please the donors at the expense of PLWHA, or as a means to create pilferage and corruption in the system to sell ARVs using the back door. In the same vein, in 2012, The Daily News interviewed Chitungwiza ARV street dealers who revealed that the pilferage was facilitated through government institutions: ‘One street dealer in the drugs, who preferred anonymity, was clear on his supply source – “I get my supply from the hospital guys. I do not manufacture them in my back yard. Every month I get a consignment, and I am saving many lives in the process.”’ (The Daily News, Zimbabwe, March 4th, 2012). These accounts suggest that health workers tend to prioritise themselves as they too have to survive in the context of scarcity – by selling ARVs, for example. Also, PLWHA’s voices to claim their ARVs or when demanding a safer private space for counselling were not considered, suggesting powerlessness as if to say they were invisible.

6.2.4 Undervalued, underpaid and frustrated
Lack of time, huge workloads and poor communication skills were raised as the reasons why health workers tend to be ‘rude’ to PLWHA. In the FGDs in both study sites, long waiting times were identified as the primary complaint often raised by PLWHA (see section 7.3.3), and that it often led to conflict between the health service provider and PLWHA. Nurses who participated at the FGDs (FGD-GorA and FGD-ChA) highlighted that the shortages of medicines were in part a national demand by patients to be treated with medicines, and especially the worried-well patients who did not need medicine for other ailments but just their ARVs. However, a representative of women in the community at an FGD held in Chitungwiza (FGD-ChA) pointed out that there were cases where the in-demand lifesaving ARVs were left to expire at the Chitungwiza hospital. She argued that whatever the justification that the hospital gave, it was morally wrong and unacceptable to let ARVs expire. The [Zimbabwe] Daily News, in 2012, investigated the case of expired medications and noted,

...Zimbabwe’s Ministry of Health and Child Welfare is letting crucial HIV/AIDS drugs expire in government hospital pharmacies as thousands of desperate patients battle to access the life-prolonging drugs. An investigation on the anti-retroviral (ARV) drugs distribution network in Harare and Chitungwiza has established that many people living with HIV/AIDS were resorting to getting drugs on the black market, while tonnes of drugs are expiring in government
An analysis of this story could reveal the pressing economic circumstances that force health workers to devalue the lives of PLWHA in order to survive. It could also suggest that PLWHA, unlike other patients without HIV, are easier to rob of their lives. Participants highlighted that sometimes HIV patient queues can be long, and nurses, who are often few in number, can become irritable, a situation that in itself can contribute to nurse job dissatisfaction. Low pay was reported as the primary element that caused nurses’ dissatisfaction with their work and resulted in the lack of value attached to nursing – implicit in the low salaries. Participants argued that, because nurses are bitter and angry and ‘feel provoked, they (nurses) employ implicit rationing tactics, especially on ‘time rationing’, working as and when they want, especially in rural areas – at the expense of the patients needing care, including PLWHA.

In the FGD-ChB held in Chitungwiza, access to CD4 counting machines was reported to be the element that the government was neglecting. Participants reported that PLWHA struggled because ‘they can’t afford medical aid [health insurance] and the $30 for consultation fees at private clinics and private doctor surgeries are too much’ (FGD-ChB). Chitungwiza Central Hospital was reported as the only ART initiation site in the whole of Chitungwiza. This led to congestion, long waiting hours and huge workloads for health workers at the hospital. The huge workloads often resulted in sour relationships between health workers and PLWHA, condescending behaviour towards PLWHA and inadequate counselling provided to PLWHA. Nurses reported that CD4 count machines, liver function testing machines, and full blood count machines were in short supply (FGD-ChB, FGD-GorA). The costs of purchasing the fluorescent activated cells (FACS) machines (for the CD4 count) and a shortage of trained persons necessary to maintain the equipment was another factor identified in hindering access to HIV treatment care (FGD-GorA, FGD-GorB).

These narratives are opposed to the notions of rights pinned on equality in access to health services. Where resources are scarce, the notions of ‘health comes with responsibilities’ are pushed forward for PLWHA to take the responsibility of shouldering the burden of costs to cover the resource gap. For instance, in an FGD in Chitungwiza one participant
raged, ‘the ministry of health through the clinics and ourselves here work with disabled people, street kids and HIV positive people. We tell all of them that health is your right and responsibility, that actually, is our motto. Yes, you’ve your rights and panemutemo (there are policies and laws) but you and members of the community also have responsibilities, period!’ (FGD-ChA). These narratives seem to connect human rights with responsibilities where all citizens are entitled, regardless of their HIV status.

6.3 Conclusion

This chapter has examined the ways of framing the value of PLWHA by non-PLWHA. Non-PLWHA are men and women not living with HIV in the study sites. As discussed in Section 4.4.5, these were purposively selected from mapping of residents in the study sites; see the list in Appendix 7.

The accounts of PLWHA membership political participation and legal identity of PLWHA corroborate with notions of citizenship affirmed by SGOs about PLWHA (see Chapter Five). Although non-PLWHA agreed with SGOs in this regard, they also differed by arguing that the participation of PLWHA is highly tokenistic and works to serve the interests of the organisers of participation forums, as well big development organisations such as the Community Coordination Mechanisms in the Global fund for AIDS, TB and Malaria. Religious accounts, especially among Masowe eChishanu and Pentecostal churches, give a sense of love and care for PLWHA, but also condemn and frame homosexuals and sex workers PLWHA as devalued bodies, worthless, degraded and undervalued people. Taken together, these descriptive themes tend to suggest that while PLWHA are broadly framed as citizens, some sub-groups of PLWHA are framed as ‘Expendable Populations’. The cold discursive space of language emerges as a site of violence and desolation that is negotiated by other social factors, including religion, hunger and unemployment, and poorly remunerated, frustrated health workers. The accounts in this chapter explore the dynamics of the struggle for health care by PLWHA in the communities in which they live. Particular attention is placed to the forms and tensions of vocabularies, identities and power struggles among PLWHA, religious groups, health institutions and society in which PLWHA reside. The emphasis is placed on these elements, as PLWHA seem to remain in a continuous struggle with organisations and the discursive space to extend their ‘value’ as ‘citizens’. Also, in a discursive space, PLWHA, particularly the homosexuals, are subjected by law, policy and morality, to redefinition and renegotiation of hunhu [being human, personhood]. Hunhu frames the
cultural limits of a working conception of value. In other words, homosexuals living with HIV are not equal, ‘legal’ citizens and thus cannot demand or claim their rights to life, health or fair treatment as other citizens would do, because they [homosexuals] do not fit in the munhu [person] category as they lack hunhu and value. The munhu and hunhu – personhood – of homosexuals living with HIV comes out as a fiercely argued territory of people with little, if any, value in Zimbabwe.

Not only does the valuation of PLWHA as formation of an ‘expendable population’ identity reveal the exclusion of precisely those who are making demands for inclusion through the rights to life and health claims, but it also amplifies the struggles by PLWHA for fair treatment from institutions of health. Nonetheless, there is a great deal of common ground between health workers and PLWHA because, at the end of it all, both feel ‘undervalued, frustrated and mad’.

In this chapter, writing the accounts of how non-PLWHA frame the value of PLWHA was a relentless struggle, particularly on how to maintain appropriateness without seeming ‘prissy’. Prissiness runs the risk of introducing the ‘vulgar’, which may be contested by ethicists because evidence can be construed as ‘offensive’. However, the very mention of some subjects around the framing of the value of PLWHA prompts either ‘dislike’ itself or ‘offensive’ terms. Ethics, morals, offence and disgust can share significant points of contact with emotions around the subject of HIV/AIDS.
7 THE FRAMING OF THE VALUE OF HUMAN LIFE: HOW DO PEOPLE LIVING WITH HIV FRAME THEIR OWN VALUE?

7.1 Introduction

The way senior government officials (SGOs) and non-PLHWA frame the value of PLWHA has been explored in Chapters Five and Six respectively. In particular, these two groups frame the value of PLWHA as citizens, statistical representations, clients and expendable populations. However, incorporating the perspectives from PLWHA on how they value themselves might provide a complete picture on how the value of PLHWA is framed across Zimbabwean society. This chapter explores the perspectives of the PLWHA by addressing the third research question: ‘how do PLWHA frame their value of life?’ Although PLWHA tend to view themselves as defeated bodies with no sense of hope for their VoHL, as expressed by such terms as ‘tinovanyangadza’, ‘tinovasembura’, ‘tinovasemesa’ [disgust] and ‘vachirikungofa sembwa’ [they are still dying like dogs] – see Table 7.5 – they also view themselves as ‘resiliencers’ who have conquered HIV/AIDS. The themes emerging from the majority of interviews with PLHWA highlighted themes of ‘kushingirira’ [perseverance], ‘kukunda’ [victory], ‘kutsvagatsvaga’ [improvise or cope]. The framings of PLHWA who have sex with the same sex point to many forms of labelling: kufa sembwa [die like dogs], kusemesa [disgust], varwere [the ill, the sick, and the mentally disturbed], makuva [graves]. These forms of labelling are not simply as aversive expressions; they are complex and, at times, paradoxical. But the three themes of self-value, that is, victors, improvisers and perseverers, as this chapter demonstrates, not only overlap in meaning and in how they were used by participants to frame value, but they also have subtle though crucial differences. It might be worth highlighting that the three themes did not carry the undertones of confidence, extraordinary capabilities or success synonymous with victory, coping or perseverance. Instead, they carried hints of acceptance, hope, will-to-live, and independence of the PLWHA in their everyday lives.

The chapter is organised into three main sections. Firstly, to understand the background characteristics of the PLWHA interviewees, the first section reports the demographic highlights of the PLWHA participants interviewed. The second section highlights the narratives of both suffering and perseverance, which stress the importance of understanding the trajectory of labelling and expendability as it also stresses narratives of survival, and in many ways provides testimony to the tenacity of PLWHA and how they
value their lives. PLWHA, particularly those on antiretroviral treatment (ART), on the one hand struggle to adhere to ART as the conditions set by clinicians are difficult. While, on the other hand, failure to adhere to prescriptions can lead to drug resistance. These experiences of PLHWA have, to greater or lesser extents, been normalised into everyday struggles as they make ends meet to keep the virus at bay and maintain the benefits of treatment. The PLWHA not yet on ART must also demonstrate readiness to take on the responsibility of a lifetime’s medication by completing diagnostic tests, which are considered expensive. What is common in these accounts is how the ‘will-to-live’ and the purpose for perseverance seem to be driven by ‘children’ as something for which to live for. Narratives on ‘improvising’ equate being poor as a disease in its ‘own right’, where one struggles with two lifetime diseases, i.e. HIV and poverty. While PLWHA gave experiential accounts of improvising, the ability to do so appears to be compromised by the presence of these two diseases. The ‘diseases’ can work together as constant reminders of not only of the nearness of death but also of a ‘loss of dignity’. The main highlights show that while the shame, labelling and humiliation remain powerful constant reminders of a difficult life, PLWHA expressed the joy of the conquest of being alive. Although there were undertones of a loss of hope in the face of exclusion, humiliation and abject poverty, there are PLWHA who stated how they conquered the disease by staying alive. Despite the victory, the narratives highlight how PLWHA, who stand out, continue to be subject to varying combinations of delight at their misfortune, gossip, belittling, or outright hatred. These accounts, all tied to conservative sexual morality, play a role in shaping social respectability. Finally, the last section provides the conclusion, drawing the findings of this chapter together.

7.2 Demographic profiles of PLWHA interview participants

As already discussed in Chapter Four, the face-to-face semi-structured interviews with 111 PLWHA in Goromonzi (56) and Chitungwiza (55) ranged from 20 to 60 minutes in length. Most participants engaged in the process and gave lengthy responses to the open-ended guiding interview questions. G08’s interview was the shortest, lasting only 20 minutes. Although she answered all the questions, the curtailed responses did not add the same level of depth as other participants’ responses. The participants were all aged 18 or over and had a medically confirmed HIV seropositive status. See the detailed matrix of all 111 interview participants in Appendix 10.
a. **Age of SSI participants**
The highest percentage of respondents was in the 35–39 age group. Those above the age of 60 constituted just 1%. About 65% of respondents were females. See Table 7.1.

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>18–19</td>
<td>4</td>
<td>1</td>
<td>5</td>
<td>4.5</td>
</tr>
<tr>
<td>20–24</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td>4.5</td>
</tr>
<tr>
<td>25–29</td>
<td>4</td>
<td>4</td>
<td>8</td>
<td>7.2</td>
</tr>
<tr>
<td>30–34</td>
<td>4</td>
<td>9</td>
<td>13</td>
<td>11.7</td>
</tr>
<tr>
<td>35–39</td>
<td>6</td>
<td>18</td>
<td>24</td>
<td>21.6</td>
</tr>
<tr>
<td>40–44</td>
<td>3</td>
<td>14</td>
<td>17</td>
<td>15.3</td>
</tr>
<tr>
<td>45–49</td>
<td>10</td>
<td>11</td>
<td>21</td>
<td>18.9</td>
</tr>
<tr>
<td>50–54</td>
<td>5</td>
<td>7</td>
<td>12</td>
<td>10.8</td>
</tr>
<tr>
<td>55–59</td>
<td>1</td>
<td>4</td>
<td>5</td>
<td>4.5</td>
</tr>
<tr>
<td>60+</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0.9</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>39</td>
<td>72</td>
<td>111</td>
<td>100.0</td>
</tr>
</tbody>
</table>

b. **Educational attainment**
The majority of respondents had attained secondary education. Among them, one had a Master of Science in Business Administration (C007), and another was a doctoral student at a university who continued to work at a professional job in Harare while going to school (C043). Less than 10% of the participants had no schooling completed (see Table 7.2).

<table>
<thead>
<tr>
<th>Education</th>
<th>Sex</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>The level of education</td>
<td>Male</td>
<td>Female</td>
<td>Total</td>
<td>Percent</td>
</tr>
<tr>
<td>No schooling completed</td>
<td>4</td>
<td>3</td>
<td>7</td>
<td>6.4</td>
</tr>
<tr>
<td>Primary</td>
<td>8</td>
<td>19</td>
<td>27</td>
<td>24.5</td>
</tr>
<tr>
<td>Secondary</td>
<td>2</td>
<td>48</td>
<td>72</td>
<td>65.5</td>
</tr>
<tr>
<td>Higher</td>
<td>2</td>
<td>2</td>
<td>4</td>
<td>3.6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>38</td>
<td>72</td>
<td>110</td>
<td>100.0</td>
</tr>
</tbody>
</table>

*The crosstabs only included valid (non-missing data) in this table*

c. **Religion by sex**
About 85% of respondents were Christians by religion, while Muslims made up about 1%. About 5% of the participants were of the African traditional religion. The African Apostolic sect and the Pentecostal Christians were the main dominant Christian groups, each with about 21% of the participants (see Table 7.3).
Table 7.3: Religion by sex

<table>
<thead>
<tr>
<th>Religion</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Traditional</td>
<td>4</td>
<td>1</td>
<td>5</td>
<td>4.5</td>
</tr>
<tr>
<td>Roman Catholic</td>
<td>7</td>
<td>12</td>
<td>19</td>
<td>17.1</td>
</tr>
<tr>
<td>Protestant</td>
<td>2</td>
<td>9</td>
<td>11</td>
<td>9.9</td>
</tr>
<tr>
<td>Pentecostal</td>
<td>8</td>
<td>15</td>
<td>23</td>
<td>20.7</td>
</tr>
<tr>
<td>Apostolic Sect</td>
<td>7</td>
<td>16</td>
<td>23</td>
<td>20.7</td>
</tr>
<tr>
<td>Other Christian</td>
<td>4</td>
<td>11</td>
<td>15</td>
<td>13.5</td>
</tr>
<tr>
<td>Muslim</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0.9</td>
</tr>
<tr>
<td>None</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>3.6</td>
</tr>
<tr>
<td>Other Specify</td>
<td>4</td>
<td>6</td>
<td>10</td>
<td>9.0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>39</td>
<td>72</td>
<td>111</td>
<td>100.0</td>
</tr>
</tbody>
</table>

d. Marital status by sex

Those who are married accounted for about 46%, followed by widows who are not in a relationship. Only 5% of men were widowed and not in a relationship, compared to 36% of women also widowed but not in a relationship. Less than 2% of all participants were separated and in a relationship (see Table 7.4).

Table 7.4: Marital status by sex

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single never married not in relationship</td>
<td>6</td>
<td>3</td>
<td>9</td>
<td>8.2</td>
</tr>
<tr>
<td>Single never married in a relationship</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>1.8</td>
</tr>
<tr>
<td>Married or domestic partnership</td>
<td>22</td>
<td>27</td>
<td>49</td>
<td>44.5</td>
</tr>
<tr>
<td>Widowed not in a relationship</td>
<td>2</td>
<td>26</td>
<td>28</td>
<td>25.5</td>
</tr>
<tr>
<td>Widowed in a relationship</td>
<td>2</td>
<td>8</td>
<td>10</td>
<td>9.1</td>
</tr>
<tr>
<td>Divorced not in a relationship</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>2.7</td>
</tr>
<tr>
<td>Divorced in a relationship</td>
<td>1</td>
<td>3</td>
<td>4</td>
<td>3.6</td>
</tr>
<tr>
<td>Separated not in a relationship</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>2.7</td>
</tr>
<tr>
<td>Separated in a relationship</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>1.8</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>38</td>
<td>72</td>
<td>110</td>
<td>100.0</td>
</tr>
</tbody>
</table>

The crosstabs only included valid (non-missing data) in this table.

e. Antiretroviral therapy source and status

About a quarter (25%) of the participants was not getting the lifesaving ART. Three-quarters of respondents who accessed ART obtained ARVs free from the local health facilities (see Figure 7.1).
Source. Semi structured interviews with PLWHA

\section*{Employment status}

The majority of participants (40\%) were self-employed while almost a quarter were out of work and looking for work. Only five participants were employed for wages. The 6\% (7 people) in the ‘other’ category included commuter bus conductors (\textit{Hwindi/Touts}), seasonal farm workers (\textit{maricho}) and on-request workers (building, cleaning, organising political party meetings) (see Figure 7.2).

\begin{figure}
\centering
\includegraphics[width=\textwidth]{figure7.2}
\caption{Employment status of PLWHA interview participants}
\end{figure}

Source. Semi structured interviews with PLWHA
7.3 Ethical government of the self

As explored in Section 3.4.3 and then Section 4.2.3, ethical government of the self explores the ways in which non-PLWHA and PLWHA govern their everyday lives (their bodies, social, souls, spirit), how they do it and why they do it, and how they interpret the identities of themselves and of others that emerge as a result of what they do as they interact with PLWHA and as PLWHA live with HIV. The sections that follow present accounts of PLWHA as they live with non-PLWHA, and how they see non-PLWHA valuing them. The sections also present narratives of how PLWHA value themselves. From interviews, the terms such as ‘tinovanyangadza’, ‘tinovasembura’, ‘tinovasemesa’ [disgust] and ‘vachirikungofa sembwa’ [they are still dying like dogs] were used by PLWHA to express how non-PLWHA framed PLWHA, and gays and lesbian in particular. But also ‘Tinoshingirira’, ‘Vanotsvagatsvaga’, ‘Takunda’ for perseverers, improvisers and victors respectively revolved around the ethical conduct of the self. Taken together, although notions of disgust give a sense of expendability and loss of hope, the expressions of perseverance or perseverers give a sense of an identity to PLWHA and as means of valuing-up the self. The expressions are explored below.

7.3.1 Devalued bodies: Homosexual PLWHA as expendable people

Tino’s story highlights his struggle as a homosexual inmate and as a homosexual living with HIV. See Box 7.1 Box 0:1:below and refer to Box 0.1 in Appendix 13, for a full excerpt on Tino’s case.

<table>
<thead>
<tr>
<th>Box 7.1: Tino’s Case – Goromonzi (LHIG078)</th>
</tr>
</thead>
</table>
| At the prison, Tino and his inmates would be restricted to their putrid cells between ‘3 late afternoon and 7 the next day in the morning everyday including when those jail guards are eating from morning, like at around 11 to around one in the afternoon. We did not have beds, so we slept ‘pamasaga’ [mats from remains of used cotton bags]. We hardly had soap, we skipped baths, some coughed a lot and spit phlegm in the same room we lived and slept, our blankets were lice infested, and some had pus oozing from their wounds. Some had HIV, we were not given condoms, and some died in the cells. We hardly had nurses come to see us. When I started coughing, my partner [homosexual partner] was also coughing. We both knew that we had TB; we just did not talk about it because it was not abnormal in the cells. In fact, before Kidza [not real name], mushakabvu [deceased] died; he endured painful, raw prickling sores of herpes for months. It was unbearable. Most of the inmates were ill, and some could not control ‘tsvin dzekuzasi, dzaingobuda, unenge worwara [dirt (faeces), pus, STI discharges] coming out from down there, you [one] would be ill’. So, when I finally came back, I was tested and was HIV positive, I was not surprised. But how they treated me at the clinic there, I should have died in prison, its worse out here’.

His face began to fall, almost as if ashamed; he lowered it slowly, his chest caved inwards exposing his sharp shoulders, which crawled into one another. His pale left palm pulled to his face, and then the right clasped the left supporting his face, and he began to sob. Deep, irrepressible, hurting sobs. He wept, ‘I am as good as dead here, I wait for death each day, they all do, everyone appears to have authorised it. You just can’t be homosexual and HIV positive in this country, they all reject you’. |
Tino (LHIG078) was putrefying even before death, in his home, not too far from the clinic – about 5 km. It appears that a dying such as his was ‘okay-ed’ and authorised while he was both in and out of prison, and at home. It seems that both the prison and home as institutions can make dying easier and death for ‘certain people’ allowable. I employ the expression ‘certain people’ to highlight that not all PLWHA go through prolonged pain, agony and exclusion like Tino’s pain, even if they had been incarcerated before.

Beyond the poor service delivery in the prisons, which in itself could suggest valuing inmates as worthless, expendable people by service providers, Tino also exposes how the criminalisation of homosexuality in Zimbabwe degrades the ‘value’ of homosexual PLWHA. The anti-homosexuality laws in Zimbabwe increase the chances of HIV infection and legitimate violence against people who practise same-sex conduct.

7.3.1.1 Governing the devalued bodies

Zimbabwe laws and leadership have promoted social discrimination and criminalisation of homosexuals, and this has consequences in the way they are treated in institutions such as prisons and hospitals. One such law is the anti-sodomy law articulated in ‘Section 73’ of the Criminal Law (Codification and Reform) Act (2006) that makes the act of same-sex conduct between males a felony, punishable by incarceration. Section 73 (1) of the anti-sodomy law states that ‘any man who, with the consent of another man, knowingly performs with that other person anal sexual intercourse, or any act involving … contact other than anal sex..., shall be guilty of sodomy and liable to a fine … or imprisonment’ (GoZ 2006a). Tino’s sexual conduct as a homosexual man was in contravention of the laws and mores of his time. Zimbabwe’s constitution, Section 78 (3), explicitly states that ‘persons of the same sex are prohibited from marrying each other’ (GoZ 2013a). Same-sex conduct and homosexual marriage are presumably linked. The condemnation of same-sex sexual conduct can explain why Tino, like other (not all) homosexuals interviewed in this study, was not married to a same-sex partner. He said that:

…at Chikurubi, they [Heterosexual inmates] used to brag that they were not homosexuals and said that they only had sex with other men simply to satisfy their physical needs and sexual desires. Some heterosexuals raped homosexual men and the jail guards knew but did nothing. But in a short time you would find the same men [heterosexual] not saying anything mean about homosexuality, it’s a natural thing, many things can spark that biological thing in you that determines if you are homosexual or not. It’s a combination of factors, but the biology part is definitely there. God knows it’s true. (Tino LHIG078)
Tino’s statement reveals that ‘gay inmates’ appear to be construed as people with little value and as easy ‘prey’ for casual sex and/or rape by ‘heterosexual men’ wanting to satisfy their sexual thirsts. Tino’s account could suggest that prisons, as institutions, ‘authorise’ or legitimate such torture on gay men by turning a blind eye to violence against homosexual people, and they use anti-sodomy laws to justify their actions. It appears that the penalties, therefore, of dealing with homosexuality openly in a prison setting can be difficult if not dangerous as they inadvertently lead to HIV infection.

7.3.1.2 Institutionalisation of governmentality in public health care

Hospitals and clinics also contribute to public prejudices against LGBT people by denying them the services they need and humiliating them. Tatenda (LHIC025), a 27-year-old ‘masculine’ lesbian, who identified herself as a transgender man, interviewed in Chitungwiza, explained how she and her partner were refused voluntary counselling and testing (VCT) in Harare by a terrified nurse. Her partner, Memory, was 29 years old at the time of the research. Memory had a six-year-old child from a previous marriage of three years. Tatenda and Memory had known each other for two months before the interview. Tatenda’s story is captured in Box 7.2.

Box 7.2: Tatenda’s case – Chitungwiza (LHIC025)

In February, my girlfriend and I [lesbian couple] went to the New Start Centre7, to get an HIV test. Once we’d experienced that freedom; that power, that pleasure under our skins inside our bellies, you see, we knew how it felt to share our intimate sexual chemistry moments, we knew how these [she pressed her chest] things feel like, we wanted to experience that sexual chemistry while it lasted. We wanted it [sexual chemistry] fast. We craved it when we shared a bed, and our bodies demanded it. We agreed that we would get an HIV test to be on the safe side. So when we got there, we got in the first room where they asked each of us to pay $1 for the service. We were also asked to register first, by writing our ‘fake names’, sex and age. We did that. We were then sent to the second room to wait for our names to be called out for the next steps. We were nervous. We held hands and pretended to be strong. We kept ourselves busy by chatting away, but my heart was pumping fast.

I don’t know which one of us was more nervous, but I know I was scared about both our results. My partner is bisexual and her chances of having contracted HIV I thought were higher than mine. But I also thought that my previous girlfriend was bisexual, and she was not exactly the most trustworthy woman. Then our ‘fake names’ were called out, and we went to the third room where we waited for our turn. We watched television, but my mind was on the ‘what if I was HIV positive’ question. I was afraid of being rejected; I feared AIDS and death the most. I’m sure my face told a tale of a plain unvarnished story of fear and vulnerability; I did not want to imagine the burden of taking a cocktail of pills all my life. Then in no time, it was our turn.

7 New Start centres in Zimbabwe began in 1999 as a franchise of voluntary HIV testing and counselling. They seek to support the health ministry to counsel and test people for HIV.
We worked our way down the steps to the 4th room where we met our HIV counsellor. She asked us to confirm whom we were, using the ‘fake name’ codes we’d provided and referred to me as the man and my partner as the woman. That’s the information we’d offered in the registration files, and indeed, I look like a male. She began to ask some questions which, were unmistakably designed for heterosexual partners. We found the questions to be insufficient, and seemingly (as judged by my girlfriend) neither necessary nor useful. So we told her that we were both female, and we were sexual partners. Her eyes snapped wide open in alarm, lips parted, visibly shocked and she swallowed saliva hard, putting a hand on her stomach and asked if it was a joke and asked again. She couldn’t continue with the service because it was against her moral conscience. She felt that she was ‘sinning’ before her God and that it was against the law and so by helping us she was extending complicity in criminal activity of sodomy. She said:

‘I can’t imagine beautiful young women like you doing disgusting, unhuman things like that! Hazvina Umwari [ungodly], if I let you go, it means I’m encouraging it [homosexuality] and breaking the law. What is left of you? You have lost all your dignity and respect hamuna kana chiremera [You have no value] why do you even want to get an HIV test imi musina hunhu, kana usina hunhu tingakuti uri munhu?’ [Why do you even want to get an HIV test when you have no ‘hunhu’, if you don’t have ‘hunhu’ do you think we can call you human?] ‘We only test vanhu nekuti vane hunhu pano, mungamupone mujeri imi?’ [We only test ‘vanhu nekuti vane unhu’ (no direct translation here, do you think you can survive jail?).’

Our attempts to talk about our rights were futile. She was angry, offended, and she picked up the phone to call the security guard. We knew we had to leave and run. We just held hands; we were lurching from outrage to anger to regret to outrage at the violence, and back again in microseconds. We were angry and terrified. We ran downstairs, running for our lives.

The anti-homosexuality sentiments expressed by the nurse in Tatenda’s story resonate with narratives shared by other homosexuals living with HIV that I interviewed. ‘Ungodliness’, ‘disgust’, ‘lack of hunhu’, deviation from normality were frequently stated by the homosexual interviewees living with HIV (C028, G057, G072, C053, C025 – see Appendix 10), as expressions that are used to label them and to legitimate violence against them. This violence, according to C028 and G072, is often perpetrated by the institutions of government, including clinics and by individuals in society. The terms suggest undertones that condemn same-sex sexual conduct by devaluing the life of homosexuals living with HIV/AIDS. Such treatment of LGBT PLWHA appear to inflame homophobia in the communities and exacerbate self-hatred, self-stigma, closetedness and authorises a kind of slow, painful and lonely death, as suggested by (C027).

‘The word [Ngochani ] rinomakisa [is derogatory] plus rinonyadzisa [and it’s embarrassing] ende rinoshoresa [and it’s shameful], it's just not supposed to be used especially by nurses’ (CO25, see Appendix 6 and 10). The term Ngochani is used in Zimbabwe to refer to homosexuals. It carried connotations of shame, embarrassment and it is also derogatory. The term evokes shame, self-hate, anger and perpetuates closetedness and denial, and may lead to HIV infection as contained in Tatenda’s case (Box 7.2). Both Tatenda and her girlfriend left the New Start Centre without the HIV test they sought, suggesting that health care services turn away potential users of HIV/AIDS
care services because of homophobia. Tatenda managed to get an HIV test at another facility in Chitungwiza by presenting herself as a ‘man’, and she tested HIV-positive, but her girlfriend was HIV negative. Had Tatenda not bothered to seek HIV testing elsewhere, it is reasonable to suspect that the chances of transmitting HIV infection to an uninfected partner were present. This silent, or rather less-discussed, HIV infection route between bisexual women and their partners in Zimbabwe seems dangerous. Also, the lack of active engagement on the issues at policy level suggests a low value attached to the lives of homosexuals living with HIV/AIDS in Zimbabwe.

There is fear among lesbians (C003, C025), bisexuals (C027, G058) and gay men (C045, G072, LHIG078) of being labelled ‘Ngochani’. ‘My girlfriend lived a double life for three years, the consequences of living in a violent home with someone you don’t even love are better than being called a lesbian here. It's even worse for her because she once got punished in high school on accounts of lesbianism’ (C025). Homosexuality in Zimbabwe seems to suggest that women (and men) date, marry and have children in heterosexual relationships whilst concomitantly having sex with one or more same-sex partners: ‘that’s why I split with my last girlfriend. She had had two different men before and on the third one, I felt so disrespected and I called off!’ (C003). Women succumb to pressure to marry, raise families to establish belonging (an aspect of citizenship), and respect (an aspect of value). Being poorly informed about HIV/AIDS, while having both heterosexual and homosexual sex, combined with fear to seek HIV/AIDS services because of the stigma of both HIV and homosexuality, all seem to contribute to a low human life value of homosexuals living with HIV in Zimbabwe.

7.3.1.3 Lack of ‘hunhu’ (being human) - Valuelessness
The phrase ‘vanhu nekuti vane hunhu’, expressed by C009, C014, C022, G074, G085 and G091 (see Appendix 10) and the nurse in Tatenda’s case (see LHIC025 in Box 7.2 above) lacks a direct English translation that can express its rich and complex construction. Vanhu simply means ‘people’. Nekuti means ‘because’, thus the phrase becomes ‘they are people because they have hunhu’, suggesting that people are only people insofar as they have Hunhu. The way in which Hunhu was expressed by the nurse in Tatenda’s case reflects a deep-rooted tradition of thought and behaviour in Zimbabwean culture based on the philosophy of hunhu – being human. The term connects people to a collective sense of a shared Humwari or the ancestors or godliness (Mwari), as the nurse implied. Hunhu is an acceptable, moral way of life which embraces heteronormativity.
Godliness, kinships, family, behaviour and relationships – the base of the talk by the nurse in Tatenda, COO3, G098 and GO72. It is likely that health workers, such as the nurse from the New Start Centre, view ‘Hunhu’ as the capacity to show one’s value, dignity, harmony and humanity as ways of being. Here, homosexual PLWHA are construed as people who devalue themselves by robbing the philosophy of Hunhu. The practice of homosexuality appears to threaten normality (heteronormativity) and invokes violence against gay men and lesbians, including their rejection from services, thus denying them the necessary HIV/AIDS services. It is likely that expressing oneself as a homosexual in Zimbabwe is seen as provocative and lacking the enculturation of Hunhu, which determines one’s value, a symbol of African identity.

7.3.2 Disgust and worthlessness [Kusemesa ne Kufa sembwa]
The expressions ‘tinovanyangadza’, ‘tinovasembura’, ‘tinovasemesa’, ‘tinovabhowa’, ‘tinovanetsa’, were frequently raised by PLWHA to express how they thought and felt people in the community, including health workers, treated them. These Shona terms have no exact English equivalents but can be construed to mean ‘dislike and/or disgust’ collectively and individually, as highlighted by a 45-year-old woman in Chitungwiza (C050): ‘There isn’t much they [people in the community] can do because people have been educated about HIV a lot, but the truth is, I really feel kuti tinovasemesa [that we “disgust” them]’. A 29-year-old mother from Goromonzi said, …Most pretend to smile when I’m there, but I know how they feel about me, recently Mai Dylan [her friend] told me about the stories that my best friend used to say behind my back, people are hypocrites, they smile at you, when in the actual sense. “Tinovashoresa”. [We bring shame on them] … (G067)

While most participants varied in the ways they articulated these expressions, the messages were generally similar. However, there were some who argued that there were people in the community who understood the suffering of PLWHA as a shared struggle, but who could not do much to change perceptions of kusemesa among individuals in the community. In their simplest sense, the expressions articulating kusemesa may be used to refer to something offensive to the taste, to sight or to associate. It is curious how readily this emotion is motivated by anything uncommon in the appearance, stench or nature of our behaviour, the food we eat or what is excreted out of our bodies. In an interview with a 31-year-old sex worker (G077) entrepreneur, the expression of disgust was conveyed using the motivation of a possible offensive odour (see Box 7.3).
Box 7.3: Sex worker’s case – Goromonzi (G077)

At Mverechena growth point, G077 grilled meat on an open fire. She did this mostly for rich men who travelled from Harare to drink beer and who spent time with their friends away from the madding crowds of the busy city. G077 also exchanged sex for money when she got clients. She mostly liked the wealthier men from Harare because ‘they give me more than three dollars, on a good day ‘mhene’ yangu [my rich client] can give me ten dollars,’ she said. ‘Sometimes I tell them that I’m HIV positive, but sometimes I don’t especially if someone wants to use a condom. If they insist that they don’t wish to use a condom, I tell them I’m on ARVs, and things often change immediately as if I smell of the stench of death. Then, there is sudden uncooperativeness, he may start to act as if “uriKumusemesa” [you disgust him] and his tone of voice changes, that little respect there is, flies out through the window and you know you will definitely be treated like a “dog”.’

From these accounts, it could be that the feeling of *Kusemesa* follows from the association in our minds between the sight of a ‘thing’ that can get in contact with one’s body and the idea of consuming it or making bodily contact with it. Thus, it might be that it made it easier for the voices expressed in G077’s case and in the accounts of G107, G073 and C012 to link *Kusemesa, Kushoresa* as readily with HIV/AIDS. It appears that the association of *kusemesa* with HIV could have had a connection with sexual intercourse and the exchange of human fluids, sweat and saliva. In many forms, *Kusemesa, kushoresa, kusembura, kubhowa*, are complex expressions. They carry an insistent feature of the lurid and the sensational, informed as these are by sex and the defilement of norms. The terms impose themselves on the one feeling the *kusemeswa*, motivating them to assign PLWHA a lower status in the relevant social rankings, as highlighted by one participant in an FGDPWA-GorB:

> I sometimes get ‘zvidzimu’ [cold sores] especially when I’m on menstruation, and people think that I become highly infectious and spread Zvidzimu, and my in-laws tell me to stop cooking, I do not do the dishes, I do nothing. A scowl always falls across their faces whenever I try to touch food or clean the house. Their faces show anger, as though to say, I don’t like you and unondisembura [as if you disgust them] … (FGDPWA-GorB)

The statement not only speaks of the contempt expressed by those not living with HIV (non-PLWA) at the household level, but also unhappiness as suggested by the looks of condescending ridicule on the faces of relatives and family. The term *zvidzimu* is a Shona term for cold sores or herpes of the lip. Cold sores are mouth and lip blisters caused by a herpes simplex virus passed through skin-to-skin contact and usually appear in people with compromised immune systems (NHS 2015). In Shona, *Zvidzimu* is plural for *Cold sores also called herpes of the lip are small, fluid-filled blisters that develop around the lips or inside the mouth. Cold sores are caused by herpes simplex virus. The infection is passed on through skin-to-skin contact such as kissing and usually clears up without treatment within 7 to 14 days. They can recur. (NHS 2015)*

---

8 Cold sores also called herpes of the lip are small, fluid-filled blisters that develop around the lips or inside the mouth. Cold sores are caused by herpes simplex virus. The infection is passed on through skin-to-skin contact such as kissing and usually clears up without treatment within 7 to 14 days. They can recur. (NHS 2015)
Chidzimu. Chidzimu is a lip ulcer believed to appear mysteriously on the lips of its victim overnight, and is associated with illness that occurs while one is asleep, brought by Mhondoro [clan spirits] or Vadzimu [family spirits]. The name is commonly associated with Vadzimu hence its name Chidzimu. The latter uses the Shona class noun *chi*, which is often associated with the despised and the ridiculed. Thus, Chidzimu may refer to bad family tutelary spirits of the founders of the family clan who may bring disease. Like one from whom people hide their faces, the one whom the cold sores have seized is despised and assigned a lower rank. The quote below highlights this;

…they forget that anyone can get Zvidzimu, it’s even worse for me because sometimes I’m stressed and like I said I’d be on my Menses [menstruation] but they believe that Vadzimu forget you when you get chirwarausiku [night illness - another term for cold sores]. So who could ever like you if forgotten by your own ancestors? Unofa sembwa uchisemesa [you will be sickening by the time they leave you to die like dog] … (FGDPWA-GorB)

The expression *Kufa sembwa* expressed by the FGD participant was also expressed in semi-structured interviews with participants who associated the phrase with *kusemesa* [disgust], *kubhowa* [boring] and *kusembura* [disgust]. G080, a teacher in Goromonzi, said,

…the sad thing is, despite all the education around HIV, the reality here is that people are still afraid of death and still associate HIV with death. The reason is that even if we now have the ARVs, there is no difference because most of us struggle to keep our families alive nenyaya yenzara [because of hunger]. To take these pills [ARVs], I need to eat. My wife needs ARVs with food, children need school fees. So you can imagine if a person like me who is working is struggling like this – look I have nothing to my name. I earn less than 500 dollars [US$], which doesn’t come sometimes. How about those who are not employed? They die anyway irrespective of whether they are on ARVs or not. Most will stop the treatment and stick to faith healers and use holy water because these pills (ARVs) are painful (to take on an empty stomach). So, PWAs (People with AIDS) still die like dogs here in the reserves (rural areas), no one gives a hoot (no one cares), to them we are already dead, to them we are disgusting and sickening… (G080)

At the core of this statement is a subtle distinction of emotions that cannot be confused. There is the difference between the feeling of a ‘sickening dead body’ and ‘fear of death’. A ‘sickening dead body’ can be associated with strong, pungent, nauseating and repulsive odour. The moment a human body dies, it is likely to start decomposing unless frozen. In this case, the corpse is possibly decaying and may make any living human reel back upon encountering it. Thus for living PLWHA to be equated to a ‘sickening dead body’ suggests a rank much lower than any living person. ‘Fear of death’ in everyday language can be understood as being afraid of one’s mortality. The way in which the teacher employed these two expressions ‘fear of death’ and a ‘sickening dead body’ in the quote shows that the two are frequently co-experienced. Thus the acceptance of the association of fear and sickening – *kusemesa*. It appears that people are generally afraid of PLWHA,
whose value in these accounts is associated with fear and, perhaps, ‘infectious’ bodies. It seems that the unadulterated experience of fear of death is more likely than a distinct feeling of intense nausea out of a ‘sickening dead body’. Just being afraid of death can be associated with disease and conditions other than HIV/AIDS. But a sickening feeling motivated by HIV can suggest that non-PLWHA have the burden of cleaning and sanitising. This phenomenon, as described by a participant in the FGDPWA-GorB (above), appears to be more problematic labour than mere flight, perhaps the reason the woman participant would not be allowed to cook or touch utensils because of cold sores. It could also explain why the teacher said, ‘...so, PWAs [People with AIDS] still die like dogs here in the reserves [rural areas], no one gives a hoot [no one cares], to them we are already dead. Moreover, sickening’. The labour of purifying oneself appears to be that one that takes more time, always lingering and motivating stigma and creating a rank of expendable people.

Furthermore, participants highlight *kufa sembwa* [dying like a dog], a Shona phrase with connotations of little dignity and lack of worth. When a human is equated to a dog in Shona culture, they are understood to be immoral, having no value, having lost all dignity, and being seen as worthless and deserving no respect. The FGDs showed that such demeaning connotations of *humbwa* [dog like] often have powerful psychological influences over PLWHA, making them vulnerable to guilt, depression and self-imposed isolation (self-stigma). Exaggerated kindness in the community, often seen from neighbours, church colleagues, work colleagues and from friends, was reported as a cause of distress also equated to *kubatwa sembwa* [treated like a dog, worthless] (G084, C037, C040). The treatment is equated with this because of the connotations of false kindness. Further, this was also seen as one of the reasons associated with non-disclosure and difficulty in seeking treatment (CO40), care and support reinforcing stigma and discrimination (C010). Such labels and fear are perpetuated when communities often only recognise PLWHA when they are in the symptomatic stages of AIDS, and denial and silence buttress the stigmatisation of these already vulnerable individuals.

Similarly, PLWHA identified several constructs that symbolised how society framed their (PLWHA) worthlessness, shown in Table 7.5. Contrary to symbolic constructs that give a sense of defeat and hopelessness, PLWHA also gave alternative constructs of victory and counter-conduct (resilience), developed further in Section 7.3.6 on Table 7.6.
Table 7.5: Symbolic constructs of value of PLWHA- Defeat and hopelessness

<table>
<thead>
<tr>
<th>Symbolic construct</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost/expense</td>
<td>• ‘My life is like a huge expense to everyone around me including the government. The value of my life depends on how much money I have. Money talks’ C007</td>
</tr>
</tbody>
</table>
| Dog                | • ‘My life feels like that of a dog, we are never involved in big meetings in this area. We are only called when there is a meeting with NGOs when they are taking pictures to show to their donors. If its issues to do with development for this area [Arcturus], it is only the big bosses in big cars that go. We have double trouble of not having money and being left out in things that can give us money. That’s what you would do to your dog isn’t it, leave it and only look for it when you are in trouble.’ FGDPWA-GorA  
• ‘Imbwa hadzina basa radzjonyatsakugona [Dogs have no substantial utility value]’ FGDPWA-ChA  
• ‘Imbwa hadzina chiremerera [Dogs have no value]’ FGDPWA-ChA  
• ‘Imbwa hadziremekedzwe [Dogs are not respected]’ FGDPWA-GorA |
| Dirt               | • ‘I just feel I don’t belong on this earth, I feel like my life is like marara [dirt].’ G069  
• ‘People treat us like dirt, sometimes it rubs off and you begin to feel like dirt.’ G107 |
| Dry fallen leaf    | • ‘I feel worthless, like we are dry fallen leaves blown by the wind and formed small piles in forsaken old buildings’ FGDPWA-ChB |
| Birds without nests| • ‘No hugs, no warm homes, no pillows to cry on for birds without nests just the way we are treated by the government. How can they give us ARVs with no food?’ G077 |
| Useless people with no utility value | • ‘We have already looked down upon ourselves. Most of us here are ashamed of themselves and we discriminate ourselves first. We hate ourselves. It’s difficult to give yourself any value when you wish you were dead, most of us here are as good as dead.’ FGDPWA-GorB |

Source. SSI interviews

The participants in both the FGDs and in interviews could be suggesting that given that PLWHA equate themselves to ‘living dead’, ‘dirt’, ‘costs’, ‘dry fallen leaf’, ‘useless’, non-PLWHA may not want to touch them or grapple with them. Almost 30 years of HIV in Zimbabwe have passed, and PLWHA still grapple with stigma; they are left to their own devices – a phenomenon of having nothing (little or no income and food) and no one (as non-PLWHA want to disassociate themselves from those that may contaminate them). This quality of having nothing and having no one, described by participants as kufa sembwa, relates to the quality of something that could be dreadful. The dreadfulness can suggest devalued PLWHA, who are seen as expendable. The terms of ‘disgust’ and those equating PLWHA as dogs, invites understanding into the unmentionables that tend to undercut certain pretences that society likes to maintain about human value and its relationship with HIV, sex, sexuality and what is considered ‘immoral’. These terms showing ‘dislike’ ‘disgust’ and ‘contempt’ appear to motivate and sustain the low rankings of PLWHA, and actions deemed ‘sickening’ and contemptible. They also invoke a sense of expendability, uselessness, unimportance – or rather, expendable framing.
7.3.3 Undervalued, poor and feeling mad

Although ARVs are provided at no cost at government clinics and hospitals. PLWHA participants at an FGD in Goromonzi (FGDPWA-GorB) did not agree with the notion that ARVs were free products. One participant said;

…free? What free? Ha! Every month the local clinic here demands that we pay a dollar and we ask what that dollar is for, we never get an answer. I struggle to get a dollar rekuchigayo [for the grinding mill] so where will I ever get a dollar? Without that dollar you don’t get your [ARV] pills. Because of a dollar, one dollar! Hurumende [the government] tells us that mapirisit [ARVs] are free, but free doesn’t exist here. I think we’re being forced to pay the one dollar so that the nurses can get paid, though they say it’s for security of mapirisit [ARVs]… (FGDPWA-GorB)

Another participant, from FGDPWA-ChB, also disagreed that ARVs were free, arguing that ‘free’ is a subjective term;

It’s not just the HIV that should be treated, sometimes I have period [menstrual] pain, like any other person and I need to get to the hospital. My conditions can be worse because ndiri mu PWA, [I’m a PWA-Person with AIDS]. When I get there, they need 5 dollars for card fees. Then they [nurse or doctor] gives me a prescription to buy medicines. So, in this case, I will buy the medicines for my pain or whatever disease, so it’s not free. If you don’t have money, you just don’t go to the hospital because of your stupid cough, which can get worse and make your HIV condition worse… (FGDPWA-ChB)

Similarly, an interview with C056, a 32-year-old teacher from Chitungwiza, highlighted that out-of-pocket costs can sometimes be higher than the costs of ARVs in local pharmacies, as outlined in an excerpt from his interview. See Box 7.4.

### Box 7.4: Out-of-pocket costs (C056)

I get my ARVs from Chitungwiza Hospital, ndogara ku A [Seke, Unit A], I will describe a typical ARV collection day for me. I wake up in the morning and eat. We have to eat for those medicines to work, you see and we need good food. So most of my money really goes to food. Moreover, we need to eat frequently, so for my breakfast, let’s put it at US$3. Then I get a Kombi [commuter bus] and pay. So to and from the hospital, that’s a dollar [US$1]. I get there, I wait and wait, and that’s also money, that’s a dollar [US$1]. Sometimes you can wait for almost 5 hours depending on many things happening at the hospital there, so the cost of waiting can be high depending on the job that you do. But for a lowly paid teacher like me, that’s a dollar. Then, because I have been made to wait, I will need food. So for me, I will buy Sadza ne nyama ne maveg [thick porridge with meat and vegetables] and that’s US$5. When I finally get to my turn to be attended, they charge me US$10 for consultation. Then we go for treatment literacy classes, if you need them and go back home, so you see now, how much is that in total? [We calculated the total], yes, it’s 20 dollars. If you have to go for more tests you will need about US$50 for the diagnostic tests. How much are ARVs at the pharmacy? 15–17 dollars, so what’s easier? Or what is the ministry of health telling us? Yatove Mbare Musika [government is like the Mbare Market].

C056 equated the health system to *Mbare Marketplace*. *Mbare Market*, referred to as the *Mbare Musika*, is Zimbabwe’s largest farm produce market located in the neighbourhood of Mbare in Zimbabwe’s capital city, Harare. The name *Mbare Musika* is locally understood as synonymous with trade or a market place, were buying and selling is all day and night. CO56’s narrative here locates the economic role of the Zimbabwean government as largely confined to facilitating domestic market performance.
Also, PLWHA in FGDs reported that health workers give treatment recommendations without understanding how realistic they are for PLWHA to follow them, and what the barriers are to adhering to HIV treatment. In an interview discussing his life history, Bernard asked if I could join him at the clinic on the next morning to finish the interview. The day he suggested was the day he collected his ARVs from the local clinic in Goromonzi District. He asked if I could be there as early as 6.00 am. What was striking about the interview with Bernard (LHIG075) was not the interview itself but what he had wanted me to see (see full story from LHI extracts in Appendix 13 and extract in Box 7.5 below).

**Box 7.5: Excerpt - Bernard’s story – Goromonzi (LHIG075)**

At 9.00hrs, I could see the nurse walking nonchalantly from her house a few hundred meters from the clinic. On one hand she was holding some keys, on the other, she was biting a Mango. As she approached the clinic door, she threw the mango seed into a bin that was lying next to the clinic door. There were buzzes as people greeted her ‘good morning’ in different Shona accents: ‘Mangwanani Sister’, others ‘mamuka here? Ko makadii henyu sister’. I thought some were greeting her so that they could get noticed, perhaps in a way to buy good treatment from the nurse when it was their turn to get service. After about 20 minutes in her treatment room, it was almost 10:35 am, she officially opened the clinic. I had hoped that another health worker would come, but on this occasion, she worked alone. ‘Vemapiritsi endai kuseri uko, wese anonoka you will be served kuma4, chop chop tione handina time [Those on pills, go behind the wall there, whoever was late will be served later around 4, chop chop, I don’t have time]. Make sure if I call your name you come and get your green file, [the green file contained the patients’ personal information and record on ARV history]’. When Bernard’s name was called, his wife crept and sped to get his file, and the nurse retorted, ‘Are you also Bernard? Did I not call Bernard? Did you not pick up your file a few minutes back? She tried to tell the nurse that Bernard could not walk easily because he had a deep wound on his leg, but she was not given a chance to speak. The nurse was unforgiving. At that moment, I felt the urge to go and tell the nurse to stop, but if I did, I would deny myself the opportunity to learn more and see what would happen next. So I kept watching and listening like others, as I sat helplessly next to Bernard. Bernard narrated how such situations had become a norm and that if I stayed longer I would see more. Bernard finally got his ARVs at 1215hrs, but the queue was still long. The nurse looked tired as she locked her treatment room and resigned for lunch at 1357hrs, ‘I’m off to lunch, I’m not paid for working overtime’.

From Bernard’s story there were clear power differentials between the nurse and PLWHA, who appeared to have become her subjects. The way PLWHA greeted the nurse told a story of those who valued-up the nurse because they sought a service from her that could mean life or death. It also suggested the power of the nurse to value-down PLWHA because she had the means to ill-treat someone or deny service. The lack of urgency in the way the nurse did her work, including opening the premises late, talking down to clients and announcing publicly that she was not paid overtime could suggest that she did not care for PLWHA because she was not being cared for by her employer. Poor salaries appeared to provoke emotions of bitterness, which tended to be shifted onto PLWHA. In Chitungwiza FGDPWA-ChB highlighted that they were often made to wait for long hours
while nurses ‘conducted their business of selling second-hand clothes or blankets to other patients or between themselves’.

Also, the $35 cost of CD4 count (user fees) was reported to be too exorbitant and unaffordable, given that communities struggled to pay the $5–$10 initial costs before the cost hikes. Participants noted that the costs associated with access to ARVs and CD4 counting machines were too high. FGDPWA-ChB participants broke the costs down as follows in Box 7.6

**Box 7.6: Costs of getting ‘free’ ARVs from Chitungwiza Central Hospital**

- The transport costs needed to reach the hospital and back (from C junction one) would be about US$2 for a round trip to the Chitungwiza Central Hospital.
- The card fees at the hospital (one needs to pay US$35 for a CD4 count and other diagnostic tests).
- Other diagnostic tests – the PLWHA may be asked to come back for further tests such as the liver function test – or when the broken machine has been repaired, increasing the transport costs.
- The long waiting times (opportunity costs – it’s likely that one would spend the time in an income generating project such as selling tomatoes by the road side where they are likely to make about $5–$30 a day, depending on quality of the produce, rather than waiting for a CD4 count or counselling at the hospital).
- Food costs (due to the long waiting times, the client is likely to buy food while waiting. For local Sadza and a ‘cool drink’ one may need an average of US$3 to US$5).

PLWHA blamed the government for failing to allocate adequate resources to hire and remunerate health workers and to purchase the needed equipment – and its maintenance. In interview G110, a 28-year-old teacher argued that the resources allocated to health were inadequate, and the government was not accountable to the people. He said, ‘the ministry of health gets money to pay salaries not to cater for PLWHA; the actual money for PLWHA comes from the global fund and other big donors. I watched on the news. The government does not tell us what’s going on. Maybe they buy those cars with AIDS money’. The connotations in G110 suggest that poor accountability in government to the public on HIV/AIDS funds led to suspicion and distrust from the public.

The costs involved to access the otherwise ‘free’ ARVs was reported to result in faltering in ART and PLWHA, such as G059, G097, G076, G082 and C009, who resorted to indigenous medical practitioners and ‘Mapostori’ [African Masowe apostolic faith healers], whom they understand and trust, and from whom they receive sympathy and emotional support. The discussion in FGDPWA-ChA showed that there is a tragedy especially associated with when PLWHA develop resistance to the first-line drugs. As a result, they may develop complications which traditional healers and prophets may not be able to deal with effectively. Unbearable costs of HIV services have also hindered
access and, in some cases, resulted in premature deaths, as was noted by G108, a 46-year-old who lost a husband to AIDS in 1994 as a result of pneumocystis pneumonia⁹, an opportunistic infection, treatable in Zimbabwe (MoHCW 2006) (see Appendix 10).

In addition, an excerpt (Box 7.7) from LHIG111 on Nyovorwai’s life history, born in 1964 and with three children, who also lost all her brothers to AIDS in the 1990s, corroborates;

**Box 7.7: Lost all brothers to AIDS and cost impeded access to health care (LHIG111)**

We watched death each day; it felt like Ngozi [avenging spirit] lurked around our homesteads, as it hovered over our heads, reaching out for us every day. As each of my five brothers passed on, one each year, I feared it would soon be my turn. In the nearby homesteads and villages around us, it was the same story. Zvuru zvinemakuvu zvepamusha [homestead graveyard anthills] are full of people who didn’t live their lives to the end. People died; you could hear cries, both day and night, we slept out of our homes attending funerals most nights. We’d do that because you wouldn’t know when it was your turn. At night, it was typically common to see a single paraffin lamp on the shelf throwing a glow-worm light over a round hut full of elders guarding and watching the dead body until after its burial. Taitamba jiti kunje [we used to dance to the traditional Jiti dance as if the whole thing was a joke]. In the 90s, the funeral ceremonies shortened from a standard five-day period to half a day. On a daily basis, they dug graves, covered them with earth and as soon as the ditches filled up, they dug more. Freshly dug graves marked the landscape, as the village’s prime youth died one after the other from AIDS. So many died prematurely, we got poorer and poorer and the hospital costs rose higher and higher, it was expensive. We could not afford it. I’m lucky that I’m still alive; maybe God spared me so that I could look after my children and my brothers’ children. At least they are grown up now and they help me to get the HIV medicine.

Consistent across these narratives is how the rights of PLWHA tend to be reducible to demands for equality where all laws are applied fairly and consistently. Yet in reality interpretations of the ‘laws’ might be hard to reconcile with cost of care and access barriers. For instance, as one participant living with HIV for an FGD in Chitungwiza said,

they say we are protected nemitemo asi [by the law but] that’s all nonsense nekuti haitione mitemo yacho kuno [because the law is invisible in communities], it stays up there in their offices and their meetings, that’s it. The law says I should be assisted to get treatment; I go to the clinic they say if you want treatment unofanira kubhadhara [you have a responsibility to pay the consultation fee]. Where is the law?’ (FGDPWA-ChB)

Here, the *mitemo* (laws) (see 2.2.1-5.2.3) that protect the rights of PLWHA seem to be reducible to political rhetoric instead of concrete provisions to value life, as the GoZ

---

⁹ Pneumocystis pneumonia is an opportunistic infection that usually attacks the bodies of mainly people infected with the HIV virus when their CD4 cells (cells that fight infection) are significantly lowered to below 200 from a normal range of between 500–1200cells/mm³ for adults. This type of pneumonia was common in Zimbabwe before the advent of ARVs, thus more common in the 1990s. It is life-threatening and occurred in more than 80% of PLWHA. It can also attack healthy individuals, but it can be managed and treated easily with a course of high dose cotrimoxazole (MoHCW 2006).
strives to shift its responsibilities. Also, the notion of legal citizens who are protected by *mitemo* (the law) seems difficult to reconcile with notions of responsibility, which tend to shift the obligation of government to PLWHA to ensure the fulfilment of the right to health.

7.3.4  ‘Tinoshingirira’ [perseverers]: Refusing to die – we will not brittle in the face of adversity

A 23-year-old Zimbabwean female diagnosed with HIV in 1996 could expect to die from AIDS in less than five years, and most certainly before reaching 30. At the time of this research, a 23-year-old female diagnosed with HIV in Zimbabwe had the chances of a healthy life. The 23-year-old would possibly never experience the wrath of full-blown AIDS, may have a family and may give birth to an HIV-negative child if they could adhere to their medicines. In the early years of HIV, the virus found a way into the lives of many, infecting and affecting families. ‘We all have our HIV stories, don’t we? Affected or infected we have a story to tell about “kurohwa nematsotsi” [to be beaten by thieves/gangsters/thugs] and its effects,’ C035 had said in Chitungwiza. The employment of the term matsotsi to refer to HIV was not uncommon. In its usage, Matsotsi, a Shona term, means ‘thief, crook, gangster or thug’ and is usually associated with ‘cunningness and violence’. Shona is the most widely spoken Bantu native language in both Goromonzi and Chitungwiza. The usage of the term ‘matsotsi’ in ‘Chibhende’ [colloquial] reveals how HIV is understood and accommodated. The word ‘Chibhende’ is derived from the English term ‘bend’, and is often presented as colloquial or street language which is ‘bent’. This brief statement could be much extended, but it contains the essence of ‘bend’ or to ‘twist’. The aim is to ‘bend’ words so that the meaning is used to refer to things obliquely. The expression ‘kurohwa nematsotsi’ as a reference to HIV sends a message of indirectly speaking about HIV to comfortably express something about a disease that is often associated with poor morals. The expression also gives an idea of how HIV is understood – as a thief that robs lives and misleads people. HIV is seen as violent, villainous and criminal, suggesting that the epidemic derailed Zimbabweans in the prime of their lives – physically, emotionally and socially – in a violent manner, similarly to how ‘gangsters and thugs’ can derail lives.

Narrating her life history, Nyovorwai (LHIG111) (see Box 7.7) had also explained in detail the deaths of all her siblings in the 1990s and early 2000s: ‘They died, one after the other, yaive smoko [it was smoking]’ (Nyovorwai, LHIG111). The expression *smoko,*
which means ‘smoke’, is coined from Boys Dzesmoke, a nickname given to a Zimbabwean musical band called Chazezesa Express, which was led by the late lead vocalist System Tazvida. The band gained national prominence and popularity in the 1990s at the height of the HIV epidemic, and the Chibhende in their music became the de facto lingua franca of the time. Others shared the manner in which Nyovorwai used the expression ‘yaive smoko’ (it was smoking). C051 said, ‘Ismoko’ (it smokes); C032, ‘Pane Smoko’ (there is smoke); G089 ‘Chakatsva’ (it’s burnt) and G090 ‘Husiku’ (it is night). All these expressions of smoke, something burnt and night implies a serious dilemma or difficulty. When used by System Tazvida and the Chazezesa Express, ‘Boys Dzesmoko’ meant how they made people dance and push a wall of thick gray smoke and dust into the crowd. The band implied their great entertaining ability. However, when PLWHA use the term Smoko they appear to index the difficulties of survival.

C008, a 43-year-old man, attributed his survival, which from the 1990s to the 2000s was quite remarkable, to luck. C008 pointed out that most Zimbabweans who had been infected by the virus had perished, and those that remained represented a small portion of the ‘lucky’ and ‘vashingi’ [perseverers].

…It’s 2014 now, almost 20 years after my HIV diagnosis, we are here, we survived the battles of war [HIV], we were lucky, we are battle-scarred but stronger. If we survived it when it was called “shuramatongo” [that which threatens the extinction of humans] and lived with it [HIV] when ARVs were just a dream, then we can do it again, tirivashingi tinoshingirira [we are survivors we persevere]… (C008)

C008 expressed these words as he described what he valued the most in his life. He highlighted the panicked reactions of Zimbabweans when it was revealed that the former ceremonial President of Zimbabwe Canaan Banana was homosexual. C008 said,

…When Banana died, he wasn’t buried kuHeroes [national heroes’ acre] as other comrades [liberation-struggle nationalist leaders] because of hungochani [homosexuality]. In fact, what made his story horrifying was how his partner Jefta Dube [sexual partner] who had murdered someone and who had involved with Stan Mudenge10 brought up issues of being infected with HIV. So people could not separate if Jefta had gotten it [HIV] from Stan and if he [Jefta] had occasional sex with Canaan and gave it to him [Canaan] we don’t know but the fact that there was HIV there, then the whole story became horrid. The comrade was not buried at the hero’s acre, Banana of all people, Haa-ti mmm nca nca [sounds to show disapproval] … (C008)

---

10 Stan Mudenge was an academic who focused on pre-colonial Zimbabwean history. He had served as a foreign minister of Zimbabwe for ten years since 1995 and was appointed as Minister of Higher and Tertiary Education in 2005, a post he held until his death.
Had people known that the former ceremonial president of Zimbabwe was homosexual and that there were possibilities of HIV infection, would they have accepted Banana for seven years in the presidential seat? At the time of his conviction in 1999, homophobia and AIDS phobia in Zimbabwe were very visible as most people died before the advent of HIV medicines (NAC 2014). Society viewed, and still views, PLWHA as vessels of a deadly disease: ‘then they said we were in the departure lounge, just waiting to go, now they still say the same thing in a different language, like Mutswi [a deep crack on the wall of a building] meaning that we are dead people’, C001, a former nurse stated. Similarly, C052, also a former nurse in Chitungwiza, highlighted,

…I hid my HIV status from my family and children, that’s when I quit my job. I didn’t want anyone to know. That’s when Lucy [friend] who was a nurse aid and I started the home visits programme. We provided prayer, initiated Mikando [credit clubs], Moringa clubs [herb clubs], bhora [sports] tichigamhana [we provided these as safety nets for each other] until today. I only told my family in 2006 after I had started on ARVs, it was a long road and here I am… (C052)

Like other PLWHA participants, C052 remained silent about her HIV status for fear of being found out to be HIV-positive and to be labelled ‘waiting in the departure lounge’.

…my life has been one of trial and error, trying whatever that came my way to survive. My story is of will-power and the mercy of God. God is great, I tell you. I don’t know how much of the African Potato and Moringa leaves I consumed every day for several years before the ARVs. I don’t know if the herbs worked, but I’m alive. A traditional healer’s Rufandichimuka [herb] is the best; he mixes with Zimbani [herb] and Mugamutiri [gumtree herb] for the best concoctions for the chest, colds and fever. I also go to church; I am a Methodist and back then, people from the church came to do prayers at my homestead, but I did not tell them I had HIV. I did everything to stay alive. I couldn’t stand the thought of leaving my two children on their own; I refused to die. My wife had died when my little one was just 7 months (G065)

G065 remained healthy by combining makwati [traditional herbs] and spiritual treatment in the absence of any effective antiretroviral treatments. G065 must have tapped into his will-to-live to believe that the therapies that he administered to his weakening body made him stay alive. Despite having started the ARV treatment, G065, like C052, continued with the herbal and spiritual therapies. The herbal therapies were believed to boost the efficiency of the ARVs but also manage the damaging effects of some of the ARV medicines on the body, as argued by C036. In the absence of food, ARVs can damage the body. However, LHIC013 reported that combining alternative therapies such as Christian healing with traditional African spiritual healing and herbal therapy is done to help PLWHA cope with the toxic effects of ARVs: ‘I use Mutsine and Gavakava [types of herbs] because they make the ARVs less damaging in the tummy, especially when you have little food to eat. You know the ARVs need food, but food is money, and there is no money, so to make it manageable Gavakava can neutralise things [toxicity] plus it can heal other things in the tummy’ (LHIC013). G098 and G082 in Goromonzi and C056,
C036 and LHIC013 in Chitungwiza, all women, used muremberembe, tsangamidzi, Muriranyenze and gavakava as immune system boosters alongside their ARVs. ‘I drink muremberembe to manage diarrhoea nedzimwewo sicki dzinogona kungonyuka [and other STIs that may attack my body]’ (C056). C036, a former sex worker in Chitungwiza, identified Muriranyenze as makwati that she had used for over eleven years and swore by it: ‘I use Muriranyenze for many things; I swear this has kept me alive, and I have made sure that I get it over these years. Makwati acho anobatsira kusunungura mudumbu, mashizha acho anosuka mudumbu midzi yacho inobatsirawo kuti unzwe kuda kana kugeza tsvina dzemaSTI [I use the bark extract to relieve constipation, the leaves as natural purgative remedy and the roots as an aphrodisiac and also for the management of diarrhoea and STIs].’

While others had to do all sorts, including cross-border trading (LHIC013, G100), selling second-hand clothes – ‘mabhero’ [bales of clothes] – from Mozambique (G100), formal employment (if lucky) to ensure that they lived (G077, C041, G093, G110, C007), most struggled to make ends meet. In a life history interview with Mai Shingi, she detailed how she managed to get a constant supply of Moringa, Gavakava and Mowa [herbs]. She highlighted her struggles raising two children alone, unemployed and living with HIV in the city (see Mai Shingi’s case in Box 7.8 below and refer to Appendix 13, for Mai Shingi’s full life history excerpt. The interview with Mai Shingi was held at her home).

**Box 7.8: Excerpt - Mai Shingi’s case (LHIC013)**

In 1995, Baba Shingi fell ill, very ill, and in 1998 he died, and on his death certificate they said it was TB. That’s when it all started haaa iwe! [you!]. First, I also had TB, in the same year that he died, but luckily, I was treated and recovered well. I thank the ancestors. I was tested for HIV and yes, he had given it to me because of his prostitution. We were evicted from the Kembe in 1999 and I could not contain going back to the rural areas. I began the project yemagardern Kuma sewage, kuseri kwemba nemuzasi memajuraworo [urban small-scale local gardens close to the sewage area, my backyard, and roadside verges along the durawalls]. I was now living kuSeke, Unit C here in Chitown [Chitungwiza]. I had to send my girls to school, I had to pay rent, I needed to get my herbs, go to the clinic, and I needed food, many things. I refused to die. I fell sick, many times and I think I died countless times, but I refused to die. I said Vadzimu [ancestral family spirits] help me. Mwari [God] help me. I sent those two girls to boarding school selling the verges. I was also selling Moringa, Gavakava, Mowa and other herbs to others who had HIV. Many HIV positive friends that I met when I was selling the herbs and Verges died. New ones came, and newer ones still come today. In 2007, I started taking my ARVs. Shingi was finishing her degree kuUZ [University of Zimbabwe] and Tari followed the footsteps of her sister (she broke into a smile then into an irresistible, girlish victorious laugh), these hands worked. Things were getting difficult, and I had just started mapiritsi [the ARV pills]. The nurses told me that I must drink the pills at the same times every day with food without mistakes. Like, it’s supposed to be close to perfect to avoid the virus getting cleverer [developing drug resistance]. The pills made me exhausted. I needed more food than before. It meant that I needed to ensure that I ate well and kept my herbs to maintain the benefits of treatment. They changed my combination many times [ARV drug
Like other PLWHA taking ARVs, Mai Shingi (LHIC013) had to ensure that she became the responsible person that the nurse had advised so that she could benefit from the treatment. To do so, the responsible person living with HIV had to take individual responsibility for their own health through a healthy diet and responsible lifestyle. It would appear that the nurses governed the lives of PLWHA by ensuring that she took the ARVs, consistently and correctly, every day. As the patient taking ARV, Mai Shingi, had to train herself by establishing adaptive, coping and transformative mechanisms that allow the functioning of the ARV. In addition, it seems that Mai Shingi was already responsible prior to taking ARVs. She was on a self-prescribed herbal therapy over the years and had to find means to earn an income not only to raise her family but also to access health care facilities.

Others who also had this will-to-live and who equally persevered failed to live a little longer because their bodies were already too damaged to make effective use of the alternative combination therapies in the absence of ARVs (such as Nyovorwai’s [LHIG111] siblings who all succumbed to AIDS). In the midst of these circumstances, there are PLWHA who, despite the odds and despite the fact that they were infected prior to 2004 when the first ART programme was introduced in Zimbabwe, have managed to survive (such as C007 and C050). The ARVs were only introduced in Zimbabwe in April 2004 by the National AIDS Council (NAC), and fewer than 5% of PLWHA had access to ART before 2006 (NAC 2011). There are also those, who despite the hardships of hunger (G077, G092), lack of money (G065, G098, C008, C014, C032), stigma (G073, 11)

11 Zidolam is a single tablet used in the treatment of HIV. It is a combination of Zidovudine, Lamivudine and Nevirapine ARV drugs. It reduces pill burden.

12 Zidolam a combination antiretroviral therapy may cause changes in body shape due to changes in fat distribution. These may, among other effects, include loss of fat from legs, arms and face, increased fat in the abdomen (belly) and other internal organs, breast enlargement and fatty lumps on the back of the neck (“buffalo hump”) (Zidolam tablets, package leaflet: information for the user). The causes and long-term health effects of these conditions were unknown at the time of the research.
G107, C028) and loneliness (C044, G099, C007, G098), still manage to take the pills, despite the known toxicities, and live. Many of these prepared for their deaths every day, but they did not die.

7.3.5 ‘Vanovagatsvaga’ [improvisers]: When adversity builds and reveals character

Narratives on ‘improvising’ equate being poor as a disease in its ‘own right’, where one struggles with two lifetime diseases, i.e. HIV and poverty. While PLWHA gave experiential accounts of improvising, the ability to do so appears to be compromised by the presence of these two diseases. The diseases can work together as constant reminders of not only of the nearness of death but also of the loss of dignity.

The life perspectives of PLWHA in their battle against the HIV/AIDS epidemic in the face of high unemployment (C008, C014, C032, C053, G065, G098) and hunger (G092, G077, G071) through improvisation were extraordinary. At the time of the research, Zimbabwe was considered the poorest country in the world, with more than 75% of its population experiencing poverty and a 95% formal unemployment rate (UNDP 2015). The behaviours and coping strategies demonstrated in times of hardship and stigma may be demonstrative of a self-worth, self-proclaimed intrinsic value among those living and surviving with HIV/AIDS.

Drawing upon the data from SSI, PLWHA attributed their survival to luck (C008), the mercy of the Midzimu (ancestral family spirits), forgiveness from Mhondoro (ancestral clan spirits) (see C052, LHIC013), sympathy from Mwari (God) (GO97, G088, C022, G090) and/or pharmacovigilance of biomedicine – the ARVs. However, the term ‘Kutsvagatsvaga’, loosely translated as ‘finding means and ways where there is scarcity or improvising’, was also frequently mentioned. However, there are overlaps between the perspectives of kushingirira (perseverance) (Section 7.3.4) and Kutsvagatsvaga (improvisation); the nuances of survival stand out in the latter. The latter brings out the quality that makes some PLWHA able to survive stigma and catastrophes, and some PLWHA, perhaps equally just as brave, able and strong, fail. Some people survive adversities; others do not. The narratives are telling of a struggle to protect an intrinsic human life value as that which can propel life.
As part of our ongoing conversation, I asked the SSI participants to describe how they make meaning of the construct of value (Hukoshi, Huremu, Hundefu, Mwero, Udzamu; refer to Section 1.4.2). They described value in relation to their own personal challenges managing HIV. This included the strains, anxieties and stress of living with HIV (See Section 7.3.1- 7.3.3), and the improvisation as the main mechanism enacted to deal with HIV over the course of their lives. Despite having acquired secondary education (66%) (see Table 7.2), most participants were not formally employed (5%) but self-employed (42%) (see Figure 7.2). G086, a 46-year-old father of two, and the only surviving child of his old mother, describes how the need for income increased over the years as the demand for regular check-ups, trips to the health facility and food increased, despite having access to secondary education. G086 said,

...I wasn’t just looking after my two children, but also the children of my two late brothers plus my mother to make us ten, including myself. These children only have me as their father and mother, so they all look up to me. Despite my high school qualification, there are no jobs here so, I had no choice asi Kutotsvagatsvaga [I had to think of improvising to survive]. That’s when I started zvemaBhero, tichimapinzisa neScania zviya zvima goneyet – straight from Mozambique [Bales of second-hand clothes smuggled into Zimbabwe through Scania long-haulage trucks straight from Mozambique]. I accepted money, maize, beans, peanuts, anything because I understood that some did not have money but had other things I also wanted… (G086)

The selling of second-hand clothes not only enhanced G086’s livelihood, but also worked as a way of mitigating the effects of HIV. Where unemployment was high, improvisation through self-employment was quite common. This understanding of value as ‘kutsvagatsvaga’ (improvisation) through income generating projects is also very evident in Takesure LHIC008’s (male) and Clara LHIC011’s (female) lives, both 19-year-old teenagers in Chitungwiza, born with HIV and orphaned before the age of 15.

Takesure’s story of improvisation is perhaps not as severe as what he experienced in his childhood, but as physically and emotionally painful. ‘For me, lately, it’s been recurrent painful and frequent urination. The pain is sometimes very severe that it feels like the veins in my bladder are burning. The feeling is defeating, depressing and many times I lost the will-to-live.’ Tears of remembered pain and despair streamed from his eyes and sobs stopped his breath. His tears were painful to witness. Despite the pain, he managed a sarcastic grin and said,

...I get the cents to survive because ndinotsvatsvaga mwana wamai [I improvise, my mother’s child]. I lived in town [Harare, as a street kid] along Tongogara and Mazowe Street. I used to sleep at five avenue’s shopping centre, cleaning people’s cars. I would get a dollar on a good day, sometimes more. But, you know when the going got tough we hit them [car windows] and got
Hanabusua and Tagami (1999) describe the condition that put Takesure to despair as an adverse effect of ARVs – renal atrophy. Renal atrophy is associated with long-term treatment of HIV with ARVs – what Takesure described as his kidneys ‘working hard since I was born’. Hanabusua and Tagami (1999) argue that the symptoms of renal atrophy are similar to a urinary tract infection, which include painful and frequent urination, as were those that Takesure highlighted. The damage is likely to cause the chronic loss of the kidney’s function and can result in the shrinkage of the kidney, which Takesure highlighted with ‘my kidneys are now smaller’. Takesure’s (LHIC008) account shows that in some cases, the improvisation mechanisms were not viable, and were perilous and unsustainable.

Moreover, some existences, like Takesure’s, living on the streets, surviving on pilfering and immersing themselves in a world of substance use to escape reality, are telling of the death-defying experiences in the face of extreme poverty. However, the ability to refrain from addiction also demonstrates the strength to cope with and adapt to the new demands of the disease. See Takesure’s laundry basket, at Chikwanha Shopping Centre, in Picture 7.1.

Others, such as Clara (LHIC011), also understood their management of HIV and, more importantly, their survival despite HIV as illustrative of their value of life. Clara, a teenager who struggled to finish Grade 7 at primary school because of illness, only knew a life with HIV. Clara had asked that I come to interview her at her home, an orphanage; in Box 7.9 is an excerpt from her story.

---

13 ZED is an illicit brew. The brew can cause a sudden death, it is thought to originate from Mozambique (NehandaRadio, June 7 2013)
14 Bronco short for Broncleer is a prescription cough medicine used to treat bronchitis. The medicine is often abused and taken with alcohol, to achieve a sensational high (Herald June 9, 2014)
Box 7.9: Clara’s case – Chitungwiza (LHIC011)

‘I’m happy here, this is my home, and I also work at the salon. People come to my salon. Well, it’s not really mine; I rent a chair for US$40 a month including water and ZESA [electricity]. I do all hair plafting, it’s US$3 for cornrows, straight-lines, zig-zags and $10 to put a weave if you bring your own Brazilian hair. Box braids are $12, I still need to learn to do nails [manicure and pedicure], and eyelashes [fake eyelashes]. Chipo can teach me [her friend] but she needs $50 for the training. In a good month, especially December last year [2013] I made $150, that’s how I bought this cell phone. It has an app [WhatsApp], and I can get on Facebook. I also sell ma-freezits [small frozen plastics filled with coloured soft drink] it’s 1 rand each [about US10c]. So, I’m ok now. I can manage to go to the hospital, get my supply [ARVs], and buy some fruits. We are told to eat healthy and fruits are very good especially mawuyu [Baobab fruit] and oranges. Before my mother died, she always told me I had a heart problem and told me to tell anyone who asked about my health that my ‘heart was weak’. Come I show you her picture. (With a wide smile, she beckoned me toward her with a slight movement of her hand. In her room was nothing more than her little belongings heaped in a corner. Clara was left there by a community home-based care giver five years before the interview, when she was only 14 years. At the home, the caregivers called her ‘Shura’. The term ‘Shura’ is a homonym. It can mean a miracle, a survivor, a flatulence or a curse. I asked her why they called her ‘Shura’ and she said, ‘because I have HIV. When they say Shura, they always laugh. When I ask them why they laugh, they say I am a miracle survivor. But I suspect they mean that “ndinotonzi chimusiri” [I am literally called a “flatulence”].’ She explained how incessant bloating and gas produced massive flatulence sounds from her stomach. Below is Clara’s Salon.)
The term ‘Shura’ or ‘Kusura’, which appeared to have been used to refer to Clara, is considered a common profanity with an often humorous but mocking undertone. ‘Shura’ in this context may convey the sense that Clara was unduly annoying, and the term intended to insult her, however sarcastically. The term was used to refer to Clara’s struggles with HIV and opportunistic infections, which the carers considered negative features of Clara. The term was used with undercurrent intentions of being offensive. In this sense, the term is vulgar, disrespectful and suggests valuing down someone’s life value. The usage of the phrase resonates with the Western usage of the phrase ‘not worth a fart’, which in a Western context could imply a subject being worthless.

For Clara, the salon was a way of earning an income. It was also a way of spending time away from the labelling and stigma. This labelling often goes unchallenged. Most people at the home had nicknames. While Clara was aware of such labelling and othering she was ‘happy to ignore them’ given that ‘I [Clara] have a home, and when I die, I have people who can bury me as a person, not as a dog’. Clara was condemned in advance as the other, a ‘shura’, a worthless human. Unlike Takesure’s problem, which was in part medical, Clara’s predicament is social. The ‘everyday’ experiences of such people as Clara are produced and reproduced by society’s institutions.
A home-based care giver, Mai Linda, at an FGD in Chitungwiza, had highlighted that ‘if we want to be “all lovey-dovey” [caring] about every HIV case, vanodyiwa nembwa nemakunguwo [they would be eaten by dogs and vultures] in government institutions. Most of them are always ill even if they are on ARVs, they can’t work so they don’t contribute anything, but at their own homes or at orphanages they can improvise and earn a living’. Mai Linda’s statement could have referred to how government institutions, such as clinics and mental hospitals, including the family, were breeding grounds of misery. It may also suggest that, in communities, PLWHA are known and acknowledged as improvisers, as survivors and as resilient people, and that communities recognise this capacity. It could also have touched on how society was shaped by market logic (economisation of health care, refer to Section 5.3), where non-paying consumers are viewed as undeserving of service, and as such are regarded less useful, worthless or contributors of nothing.

Clara’s statement ‘When I die, I have people who can bury me as a person not as a dog’ expresses a paradox. On one hand, Clara is regarded as a worthless, non-paying consumer, a ‘Shura’ and perhaps a person with nothing and worth nothing. And on the other, she appears to gain the status of a ‘a person’ upon her death. Did she mean that in her current state, she was not considered ‘human enough’ but upon her death, she would be considered so? And that, in her now, she was a ‘Shura’, and upon her death she would acquire a person status? Despite her strength, will-to-live, and ability to improvise, the reality that Clara could have known that she was not considered human enough in the now is not only disturbing and unsettling, but also goes against all narratives on the right to life, the right to health and all aspects of citizenship (legal rights, participation and identity; refer to Section 5.2).

7.3.6 ‘Takunda’ [victors]: There wasn’t anything left for us but to fight with our backs to the wall until the win

Drawing on the responses to the question: ‘based on your experiences living with HIV, what would you equate your life to?’, PLWHA equate their lives to something that is of priceless value. They view their lives as that which must be protected by law and defended, even at the risk of death. Responses to this question also show that PLWHA see themselves as victors, who argue that the stories of their lives mark the difference between deserving life and being worthy of it. Almost invariably, the clearest statements
about victory and conquest came from PLWHA at the end of the interviews and FGDs. For me, it was not only the responses to the question that were important to note, but also the body expressions as people gave accounts of their victories as part of participant observation method.

there was a time I believed that I was what people said I was. Mad. I almost believed I was mad, you know, a crazy person and that I had lost my mind because people said I was mad. It rubs off from the way people think about us. We start thinking of ourselves that way too. But now, it’s a different story. These ARVs brought back chiremu chedu [our dignity], my life is like ‘water’, it’s deep, it’s calm, it’s violent, it’s life, its death it’s everything I want now. But the torture in those years taught me to fight. No one can say nonsense about me or other “maliving” [People living with HIV and/or AIDS]. No NGO comes to work here [Chitungwiza] without my involvement. We are the stakeholders; we call the shots. We can make it or break it [NGOs]. If we say they can’t work here, they wont. Because some of these NGOs come here and flash their cars in front of us reminding us of life that we will never have. Some actually help us, but some don’t. Those that don’t, we make sure they leave (FGDPWA-GorB)

For this FGD participant, victory was the ability to finally be able to speak and be listened to despite having been labelled ‘mad’ before the advent of HIV treatment. The FGD participant speaks of a time when there was nothing left to take hold of except prejudice of PLWHA. However, the participant also mentions the fighting spirit which appears to have increased survival, extroversion, anger, and perhaps adjustment. The statement also suggests that PLWHA enjoy the position of power which they now occupy, a phenomenon that could be understood as victory. Equating one’s life to ‘water’ was an unexpected, but pleasant finding. The participant described water as life and death, calm and violent, as was his life and its ‘ups and downs’. Water, however, be it still, flowing, deep, fierce, as Slattery (2006) believes, dramatises the world; in its depths and its behaviour are all the symbols, hardships and joys of human life.

Using symbolic expressions, the NGO worker in Goromonzi (G108) also equated her life to ‘Muuyu’, the baobab tree. In Box 7.10 is G108’s expression about her value of life.

<table>
<thead>
<tr>
<th>Box 7.10: Symbolic expressions: Baobab tree (G108)</th>
</tr>
</thead>
<tbody>
<tr>
<td>For me, living and working with people with HIV, I can tell you that we have conquered. If I had the Obamas’ [US$ - money], I would organise a big party for PWAs so that we just celebrate life. Because while we know that the trips to get our ARVs can be daunting; the nurses are rude; drugs are poisonous and that the government forgets us, those without HIV are disgusted by us – I know that we are prouder than ever. When we started the support group here, we were very few, just 4 then we got to 46 in the early 2000s and now we are 15 because many died. In the 2000s people died but that’s when we knew we need the support groups even more. We organised mikando, ma round (social security and safety nets) doing the savings methodology. Every month each one of us would contribute something, clothes, soap, and money, anything. Most women volunteered to help with work at funerals or even at home providing home-based care for our friends that lost the battle. We approached DAC [District AIDS Coordinator]; we spearheaded the formation of the DAAC [District AIDS Action Committees], and that’s how we connected with NGOs in this area. We started those nutritional gardens [pointing – see photo 7:2] we all take turns to water them and every family gets a bundle every Friday. We were looking for help because it could have been me, you know. Through DAACs, we also helped the headman with the identification of HIV orphans to benefit from the Zunde Ramambo [Chief’s harvest]. I know two children had orphaned before they were five who benefited from that project when it was still viable.</td>
</tr>
</tbody>
</table>
Box 7.10: Symbolic expressions: Baobab tree (G108)
Now it doesn’t work; there is much favouritism, so we no longer ask for help. Now we do sports projects between our Wards. Next month we [Mwanza ward] will play Arcturus, and we get support from a few NGOs. We fought, and we won. We remained focused, and we grew stronger by day, taita seMuuyu [we were like a baobab tree]. There wasn’t anything left for us but to fight with our backs to the wall until the win. I now work for an NGO, and I know almost all the people living with HIV in this ward. I make sure they benefit. It’s about respect mingled with some hope.

Photo 7.2: Nutritional gardens for PLWHA by PLWHA – the project spearheaded by G108 – Goromonzi, Mwanza Ward

Source. Field notes

G108 nestled her victory in terms of her history living with HIV in her community, but not on her own health. Rather, she understood it in relation to the ongoing lives of the many who were part of her HIV/AIDS support group who had survived. In her view, government projects such as the District AIDS Action Committees (DAACs), led by the National AIDS Council (NAC) and the chief-led local government programmes such as the Zunde Ramambo [Chief’s granary], played a huge role in mitigating the impacts of HIV. The former is composed of PLWHA and coordinates rural district level HIV/AIDS programmes while, the latter is a food and social security programme to help orphans living with HIV. To her, the contributions through government policy initiatives were part of her story to victory with HIV. She also hints to the corrupt nature of local government
projects, which her account identifies as ‘favouritism’ hinting ‘corruption’ and thus no longer useful. G108 also quickly listed the problems she and others living with HIV still face, including the long distance to the nearest ARV initiating clinic, poor interactions with health workers, drug toxicities, neglect by government and stigma. However, in this long list of problems she still managed to celebrate the disease, ‘hoping to host a party’ (G108). This could be demonstrative of resilience, which in itself can be celebrated as victory.

The reference to the baobab tree was another serendipitous finding. G108 equated the value of her life to the baobab tree (see Photo 7.3).

![Photo 7.3: Muuyu tree was taken along the road between Chipinda Pools Camp and a turn-off to Masasanya Dam, Gonarezhou National Park. Zimbabwe](image)

Source. Photograph by Bart Wursten.

The baobab tree, referred to as ‘Muuyu’, is a common tree in Zimbabwe. The Muuyu tree, known to be one of the most resilient trees on earth and growing to about 20 metres high, is known to survive longer than 3,000 years and more than 40 people can be sheltered in one trunk (Wursten et al. 2015). These characteristics appear to resonate with G108’s description of her life, as one who has lived longer with HIV, who has taken care of others and continues to prosper despite formidable challenges. In addition, the Muuyu tree, when bare of leaves, looks like one that is planted upside-down. These characteristics could
suggest that G108 believes that others in the community view her as a person whose life is upside down. It could also refer to the actual problems that G108 listed, which may make her life appear to be upside down like a baobab tree bare of leaves.

The *Muuyu* tree is known to be difficult to destroy; it can be burnt, or stripped of its trunk, but it will just form new bark and carry on growing. Similarly, G108 might have suggested similar attributes in her statement. Despite the stigma, physical and emotional pain that PLWHA have gone through, some have survived in the way the *Muuyu* refuses to die. PLWHA have revived hope and regenerated strength to move on, in the same way *Muuyu* regenerates bark and carries on growing when cut. Writing in *Flora in Zimbabwe*, Wursten and colleagues (2015) highlight that a *Muuyu* tree can establish an independent ecosystem, as it supports animals, humans and birds. Similarly, G108 makes mention of the way she supported orphans, organised home-based caregiving, income-generating projects and supported others who lived with, and those who succumbed to, HIV. The symbolic use of a *Muuyu* tree is demonstrative of resilience and conquest, which G108 celebrates and wishes to celebrate with others living with HIV, at a party.

Victory is portrayed as something that is achieved through celebrating the collective resilience of PLWHA as a group. G108 expressed, ‘*My life is not useful if it’s just mine. I live for others with HIV because they were there for me when I was lost. If it wasn’t for my relatives, and for the support group at church I would have committed suicide.*’ C030 expressed a similar sentiment about giving back to those who made her survive in difficult times: ‘*I have a women session that I lead kuMasowe [African Apostolic Church] every Friday at sundown to talk about how to survive with HIV. I do this session with young and old women and more and more are coming. I know that many of them have it [HIV], but our rule is not to ask if one has it or not because some won’t come. This is what I call kukunda [Victory]. Satan has no door.*’ Sharing similar sentiments in collective struggles, participants in FGDPWA-GorA argued that their ability to organise and discuss issues of priority concern for inclusion in local planning was a win.

We raise our issues with NGOs working in this area, and sometimes we see action in our favour; that’s a win. We have asked the Chief that no NGO should come and work in this community without registering with the DA [District Administrator], Mambo [Chief] naSabhuku [and the Headman]. We are consulted when the NGOs come. That’s how we managed to organise ourselves meaningfully during the constitution making process as PWAs. We demanded the inclusion of the
right to health in the new constitution. We coordinated with all the ZNNP\(^{15}\), ZAN\(^{16}\), WASN\(^{17}\) and CWGH\(^{18}\) members across the country to make this work. Thanks to NGOs who supported us now, we have the right to health in the constitution (FGDPWA-GorA).

Many participants expressed victory in relation to their experiences. While most spoke of winning, others also spoke of hopelessness (refer to Section 7.3.2 in Table 7.5). In both cases, symbolic expressions were used. Table 7.6 summarises the expressions of victory from PLWHA participants in interviews and FGDs.

**Table 7.6: Symbolic constructs of value of PLWHA - Victory**

<table>
<thead>
<tr>
<th>Value</th>
<th>Meaning/Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baobab tree</td>
<td>• Resilient, accommodative, unbreakable in the face of adversity (G108)</td>
</tr>
<tr>
<td>Gumtree</td>
<td>• ‘The gumtree is tall, strong, doesn’t dry or show any mood, works very hard like us’ (FGDPWA-GorA)</td>
</tr>
<tr>
<td></td>
<td>• ‘The gum tree is strong; it is very important to me like my life; I use it for medicinal purposes. The wood from the gumtree burns very well for the fire the tree is ever happy, just like me, that’s how I see “hudzamu weupenyu hwangu” [Value of my life]’ (G099)</td>
</tr>
<tr>
<td></td>
<td>• ‘The gumtree doesn’t wilt even when there is a drought. The tree deserves respect just like me’ (C021)</td>
</tr>
<tr>
<td>Tree</td>
<td>• ‘You can cut a tree but it will shoot back in all that pain, perseverance in the middle of pain. That is what I call Chido [will-to-live], not deserving but worth it. Just like my life. In the middle of pain, I rose again’ (G057)</td>
</tr>
<tr>
<td></td>
<td>• ‘Even when you burn the trees they will grow again, we have survived and we are happy to be alive. Like trees’ (FGDPWA-ChA)</td>
</tr>
<tr>
<td>Soil</td>
<td>• ‘Tese tirivana vevhu pano [We are all children of the soil], we came from the soil and we will end in the soil. The soil gives life and takes back. The soil is the father of everything including the food we eat and so is my life. My family depends on me. If I die they all die, I am very important not just to myself, but to my family. The country also needs us’ (FGDPWA-GorB)</td>
</tr>
<tr>
<td>Water</td>
<td>• ‘Water is a sign of life, without it we all die. If I die, I will die with many, that’s the problem. My children will starve and the country will lose if I die. Who is going to sell the tomatoes on the corner? Someone will not eat the day I am gone you see. So my life is like water. Very important’ (G083)</td>
</tr>
<tr>
<td></td>
<td>• ‘Water is important whether you want to agree or not. It has to be there. Just like all of us here [PLWHA]. Our lives are important whether we agree or not. We need them.’ (FGDPWA-GorB)</td>
</tr>
<tr>
<td>Shining star</td>
<td>• ‘We are strong people and we bring hope to people’s lives. All those people who cry with other small diseases learn from us. They think, well, what about those people with HIV? The moment they do that; they gain some hope. We are important. Our lives deserve respect because we are shining lights to many people’ (FGDPWA-ChA)</td>
</tr>
<tr>
<td></td>
<td>• ‘My life is like the Shining beacon, a star that’s always looking ahead and doing great things’ (C023)</td>
</tr>
</tbody>
</table>

---

\(^{15}\) Zimbabwe National Association of People Living with HIV and AIDS

\(^{16}\) Zimbabwe AIDS Network

\(^{17}\) Women and AIDS Support Network

\(^{18}\) Community Working Group on Health
<table>
<thead>
<tr>
<th>Value</th>
<th>Meaning/Quote</th>
</tr>
</thead>
</table>
| Reserve bank/big | • ‘Our stories when you [the researcher] have written them there in the UK [United Kingdom] will live forever as nyaya dzemagamba [stories of heroes], like the reserve bank, with power and strength. Our lives will attract more respect that we are given now when people have learnt about us’ (FGDPWA-ChB)  
• ‘Only God who can destroy a strong house not any human being can do the same. God fearfully made me, as a big building and nothing can tear me down. Nothing equals my life. My life is bigger than these giant clinics’ (LHIG075 [Bernard]) |
| Rugare (Kyle)    | • ‘Kyle is ever green – very important and strong’ (G085)                                                                                     |
| Citizen          | • ‘I have rights like anyone else and I want my rights to be protected by the government because my life is very important’ (G110)             |
| The ARV          | • ‘The ARV has value. So does my life. Because no one who is positive can exist without the ARV’ (C002)                                      |
| Virgin           | • ‘I value myself just like a virgin; virgins are clean from the poison of sex, which brings this disease. But after a long struggle I feel pure, good and closer to cleanliness, like a virgin’ (C056) |
| Diamond          | • ‘I am Unbreakable, and ever strong, my life is like a diamond and I feel like Mohamed Ali in the ring [boxing ring]’ (C033)                   |

Source. SSI field notes

These ideas evoke a very grand and multifaceted conception of victory. PLWHA understand their victory in terms of not only their physical lives but also their emotions and their social engagement and cohesion. What is common to all these accounts is that PLWHA all kept moving forward – the will-to-live, despite the grimmest prospects, is the most illustrative aspect of what they coin as victory. Victory is first demonstrated in the steps PLWHA take to manage the disease. It is further illustrated in the fortitude of spirit that is evidenced, despite the reality of the nearness of death, hunger, being alone and stigma. Tellingly, and after managing many moments of despair, the next steps taken by PLWHA as they regain their strength are moments of victory.

7.4 Conclusion

This chapter has presented and analysed the ways in which PLWHA frame their own value. The narratives of homosexual PLWHA in the chapter produce several leads. They point to the importance of the interactions between health workers and PLWHA to understand framing the value of PLWHA. Also, the interactions between health workers and non-PLWHA with PLWHA reveal a cold discursive space – of language as a site of desolation. The discursive space is negotiated by other social factors, including stigma, hunger, unemployment, and poorly remunerated, frustrated health workers. Bringing together the emerging threads in this chapter, the expressions that confirm others as belonging to a lower or higher value are manifest. These are sentiments that constitute PLWHA’s experience of being lower, de-valued, or equalled, presented as existing in a
rough economy where the poorer struggle for survival. But, drawing from observations and the narratives of the life experiences of the few highlighted, this chapter also reflects the realities of PLWHA, who have refused to die, despite being viewed as those waiting on death ‘in the departure lounge’. These accounts represent perseverance, the hybridisation of healing, strength, and resilience of PLHWA in the face of an overwhelming and draining virus. All combined, these factors are telling of the way PLWHA frame their value of life.

In short, the lived experiences of PLWHA emerge from the ethical government of the self (see Sections 3.6.3 and 4.2.3), highlighting self governance. The chapter discussed the stories of hopelessness as well as perseverance, improvisation, power and, above all, resilience. These are characteristics of agency that are often attributed to and reserved for people who are not infected with or affected by HIV/AIDS because they are thought to be stronger. The attributes of power, will-to-live and strength are much more evident in the manner in which seropositive people have managed their lives and how they view their lives as worth living. The chapter is more than simply descriptive and anecdotal. It provided an empirical analysis of coping strategies and systems for surviving. Underlying the delineation of these life experiences of ‘perseverers’, ‘improvisers’ and ‘victors’ is the notion that health policy SGOs, who provide health services and care, can learn from the experiences of poor sex workers, or homosexual men and women living with HIV. From their experiences, and the manner in which PLWHA have managed their lives, one can glean a better understanding of ‘priceless’ human value, where, if at all equated to anything, ‘water’ and the likes of ‘baobab trees’ might provide closer analogies of human life value. What becomes clear in the stories of the PLWHA with whom I spoke is that these people are all true ‘resiliencers’, because it is apparent that PLWHA have created lives and continue to live in ways from which we all can learn. Therefore, from a development and health policy management standpoint, this is perhaps the period to reflect on the deleterious conditions which PLWHA have experienced over the last three decades. A reflection on the legacy of individuals living with HIV and populations to protect their value of life can serve as a model of resilience for future generations of PLWHA. Such knowledge, as shall become clear in the next chapter, is critical not only to inform policy and programmatic initiatives that are PLWHA-centered, but also to assist those living with other demanding and chronic diseases.
8 UNPACKING THE VALUATION OF HUMAN LIFE: ARE PLWHA VALUED OR NOT?

8.1 Introduction

Discussion in this chapter builds insights in the analysis of various ways of framing the value of PLWHA (Chapters Five, Six and Seven). Specifically, the chapter answers the research question ‘What are the implications of valuing PLWHA for their lives or, conversely, their deaths?’ As highlighted in Chapter One, *hukoshi* (importance), *hunhu* (personhood), *mutengo* (costs), *rukudzo, chiremera* (respect, worth, dignity) are terms used by the Shona-speaking people to express the distinctive nuances and normative meanings of value. Engaging a governmentality approach and especially the analytics of government to investigate the ways in which this multi-attributed term, value of PLWHA, is framed, was quite informative as these analytics of government form the major means of forming identities (framing value) by governing others and ourselves (refer to Section 3.4). As articulated in Chapters Three and Four, an underlying premise for the consideration of analytics of government was that valuation of human life (VoHL) is understood from three perspectives – human rights, health economics and the moral viewpoints. These perspectives all correspond to the analytics of government (episteme, techne and ethical government of the self, refer to Section 4.2). Chapter Five discussed the ways in which senior government officials (SGOs) in health policy frame the value of PLWHA, while Chapters Six and Seven discussed the ways of framing the value of PLWHA by non-PLWHA and PLWHA respectively. Table 8.1 summarises the emerging themes through which the value of PLWHA is framed.

This chapter is divided into four sections. The first discusses valuation of PLWHA as a rational and thoughtful activity (episteme) and focuses on ‘citizenship’, exploring the implications for life or death of PLWHA. The second section discusses the techne dimension of government, focusing on the calculative rationalities of government that frame the value of PLWHA from a ‘client’ and ‘statistical’ perspective and the implications for life or death of PLWHA. The third section discusses valuation of PLWHA as an ethical government of the self, focusing on framing the value of PLWHA as ‘expendable populations’ and as ‘resiliencers’, and the implications for their life or death. The fourth section is the chapter’s conclusion.
### Table 8.1: Results summary

<table>
<thead>
<tr>
<th>Research question</th>
<th>Emerging ways of framing the value of PLWHA</th>
<th>Descriptive themes of framing the value of PLWHA</th>
<th>Data source</th>
<th>Chapter focus</th>
</tr>
</thead>
<tbody>
<tr>
<td>In what ways do senior government officials in health policy frame the value of PLWHA in Zimbabwe?</td>
<td>Citizens</td>
<td>Equal, legal and political citizens who can enjoy their human rights can seek the protection of the law &lt;br&gt; Citizens – who can federate and can claim their entitlements to extend their rights</td>
<td>Senior government officials (SGOs in health policy) document analysis</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Clients</td>
<td>Paying customers – who should pay for services to access HIV services</td>
<td>Non-PLWA – people not living with HIV in the study sites, participant observation</td>
<td>6 and 7</td>
</tr>
<tr>
<td></td>
<td>Statistical representations</td>
<td>Statistics – reflect trends of mortality, morbidity, availability of HIV resources - can visibilise the needs of PLWHA, but homosexuals and sex worker data is invisibilised, any visibilisation of such social groups works to abnormalise them</td>
<td></td>
<td></td>
</tr>
<tr>
<td>In what ways do PLWHA frame their value of life?</td>
<td>Resiliencers</td>
<td>‘Vashingi’ [perseverers]: who refuse to die – we will not brittle in the face of adversity &lt;br&gt; ‘Vatsvagi-ts vagi’ [improvisers]: Adversity can build and reveal character &lt;br&gt; ‘Takunda’ [victors]: being alive despite the difficult circumstances in the struggle for survival while living with HIV and AIDS. ‘There wasn’t anything left for us but to fight with our backs to the wall until the win’ (Section 7.3.6)</td>
<td>PLWHA Participant observation</td>
<td>7</td>
</tr>
</tbody>
</table>

### 8.2 Episteme of government: Implications for life and death

Investigating the ways in which SGOs and non-PLWA frame the value of PLWHA revealed that PLWHA are framed as citizens because they can access *Kodzero* (rights), enjoy protection of *Mitemo* (laws and policies) and *kubatana* (can organise into small groups for participation). Taken together, these elements are consistent with the framing of VoHL from a human rights framework (see Section 3.2.1) and especially the contributions by the UN (1945, 1948), the works of Riga (1981), Henry and Merrills (1993) and Alberti and Emmons (2001), all asserting that everyone has entitlements to a dignified life through the protection of human rights law. The interpretations of rights and policies in Sections 5.2.1–5.2.4 and Section 6.2.1 reveal elements of ‘citizenship’ of PLWHA brought together through a rational, thoughtful process of know-how (episteme). This is consistent with Foucault (1991, p. 93), who sees government as always directed
toward a ‘series of specific finalities’, such as human rights, citizenship and ideals for equality, including their sources of knowledge (experts). Faulks (1998) provides a framework for understanding citizenship by reference to three main criteria;

‘Legal [aspect]...the rights and duties of citizens; philosophical [aspect]... normative questions such as which model of citizenship can best deliver a just society… socio-political [aspects]… status denoting membership...involves a set of social practices’ (Faulks 1998, p. 2)

While the separation of these aspects of citizenship (legal, philosophical and socio-political) is vague, and a detailed delineation remains elusive if not impossible, they inform most perspectives of modern citizenship emerging from the literature (Oliver and Heater 1994, Dwyer 2000) as this study corroborates (refer to Sections 5.2.1–5.2.3 and 6.2.1). But, this study has revealed that, although most SGOs (EI:1, EI:2, EI:7, EI:4, EI:8, EI:9, EI:3; EI:6 and EI:8) and some non-PLWHA tend to frame PLWHA from this citizenship perspective, not all agreed to such valuation. The SGOs who opposed this valuation (EI:1, EI:4 and media reports) contended that the ‘citizenship’ framing was a mere political ‘game’ which has failed to translate into tangible benefits, arguing that ‘expert power’ was the source of health inequality or premature deaths. This finding is not new; Dean (2010) argues along the same lines, noting that the role of experts is to provide a practical rationality for saving lives or letting deaths happen. Thus life or death relies on the expertise and know-how of service providers.

But, contributions from Riga (1981), Foucault (1991), Henry and Merrills (1993) Alberti and Emmons (2001) and Dean (2010) have largely been theoretical arguments. This study has provided an empirical perspective, showing how episteme – represented through rights, policies and their experts – is a means for governing populations. Not only that, but also that governing through rights is a means used by SGOs to frame the VoHL. This study reveals that the framing of PLWHA as citizens is a governing mechanism that enables SGOs as experts to govern PLWHA, and also enables PLWHA to accept being governed through rights. These SGOs influence the mundane, everyday practices of PLWHA through actions that are normalised in HIV/AIDS decision-making, carrying life and death consequences. The following section discusses the findings.

8.2.1 PLWHA as citizens

Kodzero (rights) and Mitemo (laws) frame PLWHA as citizens whose lives and dignity must be respected, protected and fulfilled at every stage of their lives and in every
condition. SGOs, as do non-PLWHA, assert the importance of the rights to life and health, enshrined in Zimbabwe’s constitution (see Sections 5.2.2 and Table 5.1), as fundamental principles that guide the respect for human life and greater commitment to justice and fairness. *Kodzero* for PLWHA are presented as governmental obligations towards PLWHA, because these obligations are relevant to the planning, design, execution and monitoring of HIV/AIDS policies, laws, and programmes (policies) (refer to Section 5.2.1). Based on these obligations, the GoZ can be understood as constitutionally and legally responsible for instituting policies and programmes that uphold the right to health and reduce the impact of HIV/AIDS. However the respect (as argued by EI:7; EI:4, EI:8 in Sections 5.2.1), protection (EI:2) and fulfillment (EI:7) of the right to health is necessary, not only because it provides a binding legal obligation of the GoZ, but also because it is critical to an effective HIV/AIDS response. The human rights framing of the value of PLWHA involves the SGOs and non-PLWHA looking not only at the technical and operational aspects of HIV interventions but also at the socio-economic, political, religious and cultural factors that surround them (refer to Section 5.2.1 and 6.2.1). Individually and collectively, these factors may influence the extent to which PLWHA can access HIV services. Consistent with Cohen (1999) and Carens (2000), a citizen is a legal person who is free to act insofar as the law dictates, and has the right to demand the protection of the law. In this view, it appears that SGOs conceive PLWHA as individual persons who on one hand can enjoy the protection of the law from discrimination and, on the other hand, are protected by the state through constitutional rights. This formal dimension can be traced back to the assumption that human life has an intrinsic value, an inherent worth, and is grounded in the human rights literature. Refer to Section 3.2.1 and see UN (1945), Rice and Cooper (1967), Riga (1981), Henry and Merrill (1993) Alberti and Emmons (2001) and Feldman (2002).

This perspective on *Kodzero* and *Mitemo* is thus important because of what it says about the rights and policies in value framing – that rights and policies of PLWHA are technologies of governmentality, meaning that the rights can govern and that PLWHA accept that way of being governed. Furthermore, it appears that PLWHA do it with a (false) sense of being governed ‘less’ because they can federate (*Kubatana*) (refer to Sections 5.2.3) into groups that can liberate them as free political entities who can participate and force the government to account on any rights violations. Here, PLWHA do it without knowing how governmentality operates. This is significant as it makes
PLWHA govern themselves, becoming (lay) experts in their own right (see governmentality of the self, Section 8.4 below).

Furthermore, this governmentality of rights model is executed by experts (Section 5.2.4), who employ health statistics and surveillance as management tools (see Section 5.3.3). This aspect is discussed further in Section 8.3.1 below.

8.2.2 Implications for life or death of PLWHA

8.2.2.1 Expert communities ‘make live and let die’

Governmentality of Kodzero, MitemoneKubatana (rights, policy, and legal framework) signals how the HIV/AIDS rights, policy, and legal framework operates as a regulatory and normalising regime (refer to Section 3.3). It is also telling of the implications this has for the life or death of PLWHA. Kodzero, MitemoneKubatana are techniques of governing because: first, we are alerted to the experts (SGOs) who frame and operationalise the rights and policies for PLWHA. We can, therefore, question: who are the experts who govern life and death of PLWHA? But the identities of the SGOs is not the issue because they are known and I managed to interview them, so it is not necessarily about transparency here. Rather, it is one of disentangling the intricate networks of SGOs that conceal workings of power under the umbrella of policy experts. The issue is also one of the nature of these policy experts. The SGO network interviewed was made up of six medical staff (doctors and nurses) and two economists (See Appendix 4), who provided mainly medical and economics data on HIV/AIDS. These represented the main decision-makers in the MoHCC. But gleaning the data in this study, it appears that the bias towards medical expertise in the MoHCC is uneven, as HIV/AIDS issues go beyond medical issues to include policy, food and nutrition security, development, legal, sexuality and demographic issues (see Chapter Two). This signifies the need to invest in skills from other disciplines, such as development and sexuality, in order to have a fairly balanced team in HIV policy management.

Second, governmentality of Kodzero, MitemoneKubatana raises questions of expert (SGOs) responsibility – who carries responsibility? Can SGOs take responsibility for their actions in the management of conduct (of PLWHA)? What if these experts refuse to take responsibility for their rule? Kennedy (2005) argues that they often deny responsibility by claiming that they interpret data and advise accordingly but certainly do not rule. Kennedy (2005), by contrast, views experts (SGOs in this case) as rulers who...
deny their role to rule in governing people. This is significant, because, in the
governmentality of Kodzero, Mitemo neKubatana, SGOs as experts work in many
departments in the MoHCC (refer to Section 4.4.3 and Appendix 15), as well as other
sector ministries, including in Finance, Education, and Social Welfare, along with with
many partners. They form an interlocking network of experts who influence mundane
everyday practices (valuation) through actions that are normalised and presented as
methods of HIV/AIDS decision-making and governance. Thus SGOs wield power to
decide who should be saved and who should not, and the numbers of those who should
be saved, including such aspects as for how long one could be retained on HIV treatment,
based on the decisions made in rationing of scarce HIV/AIDS resources. They make ‘live
and let die’.

But there are contradictions within this discourse of governing through rights. On one
hand, governmentality of rights reveals a process where PLWHA are governed through a
discourse that claims to emancipate them (valuing-up) through their various ways of
federating, and thus being governed less. On the other hand, despite being viewed as
equal, legal citizens who can federate and be governed less, the governance of PLWHA
has been ingrained more deeply into everyday practices of PLWHA. This has made it
easier for SGOs to make PLWHA live or die. Such governance by SGOs of ‘make live
and let die’ is less obvious because it manifests itself in forms that do not depict the
presence of authority (but networks of experts). Also, it is more entrenched because it is
within everyday operational practices of expert networks, such as the District AIDS
Action Committees (DAACs), and it is within activities of the Chiefs. A good example is
the ‘Doro re Matare evarwere’ ceremony practiced by PLWHA and led by a traditional
healer, but coordinated under the influence of powerful chiefs, Masvikiro ne Midzimu
(spirit mediums), to seek help from Madzitateguru (Spirit mediums) (refer to Section
5.2.3). While this can facilitate a sense of belonging for PLWHA to their own community
by strengthening social cohesion, where they feel valued, it is also governmentality
systematically ingrained in cultural and traditional conduct that it seems PLWHA are
governed less. Carens (2000, p. 166) describes such federating as a means towards
psychological citizenship that brings about a particular community's collective identity
through the integration of PLWHA. But, such integration does not seem to guarantee the
expression of equal legal citizenship of PLWHA because it is only the PLWHA who can
characterise their own attachment to the wider political community. Even more, PLWHA
struggle to enjoy their right to health, human dignity and right to life due to the lack of,
among others, lifesaving ARVs, diagnostic testing equipment (Chapter Five), poor health worker–PLHWA communication (Chapter Six) or inadequate protection from violence and stigma (Chapters Six and Seven). These ‘lacks’ on the part of government potentially activate the tension between provisions of human rights policies on HIV and the concept of citizenship. Overall, SGOs in health policy have a role to make live by way of instituting HIV/AIDS programmes that ensure enjoyments of the rights of PLWHA, and/or to let die, by denying the same rights to social groups such as homosexuals who may also be living with HIV/AIDS (as in Tino or Tatenda’s cases; see Appendices 6 and 13).

8.2.3 Allowable deaths

Based on the analysis of the study’s findings, I conclude that not all lives of PLWHA matter in Zimbabwe, and not all lives have value. One underlying conclusion drawn from the study’s findings is that the legal protection of human life is not, for example, subject to acceptable moral behaviour of PLWHA because the Government of Zimbabwe (GoZ) constitution guarantees it for all (see Sections: 2.5.2; 5.2 and 6.2.1). It follows that the right to, and value of, life cannot be forfeited by an individual whatever immoral or sinful crimes he or she commits. Thus, from a human rights perspective, the right to life reminds us that there is an inherent value in all life, and the right to health infers that there are positive steps that the government should be prepared to take in ensuring the protection of the right to life of PLWHA. But, as the study shows, if the enjoyment of the rights to life and health for PLWHA is conditional, then not all human life is considered by experts to have an inherent value. It also follows that if PLWHA in general, and sex workers, LGBT and prisoners living with HIV in particular, are on the extreme end of those less protected by the rights to life and health, then these groups could be considered as ‘moving graves’ or ‘sitting in the departure lounge’ or ‘waiting for death’ (those that bring little value to society; see Section 7.3.1–7.3.3). Similarly, in the light of these findings, if the VoHL can be removed as a punishment for prostitution, homosexuality, sex work or past crimes, to deter future immorality by other individuals then the lives of those groups is of less value as compared with the morally upright groups. In short, and coupled with a short life expectancy, scarcity of ART for HIV or homosexuality somewhat create progressive conditions for allowing preventable deaths – even if rights are given.

Furthermore, while the valuation of human life is not an explicit process in health policy, this study reveals that the rationing decisions of the available HIV/AIDS resources
implicitly value and valorise the human life. By their nature, enforcing the rights to life and health involves rationing of finite resources. The GoZ has constitutionally accepted that the limitations upon the reach of the right to health obligations may stem from the reality of finite public resources and, as such, the GoZ operationalises the rights in light of the available resources. Despite the provision of the right to life and health in the constitution, the GoZ, through its decision-makers (in policy and health care provision), leave out other social groups living with HIV from HIV treatment, support and care. But it is not only the SGOs in the health ministry, but also those from the Ministry of Finance as they have a critical role in allocating the national envelope. While the health ministry SGOs ration an already determined share of the national budget, the Ministry of Finance makes decisions around who gets what among sector ministries. Simply, they can decide who deserves more attention and who does not. The key issue in allowing death is not whether the right to life and its inherent value of human life is applicable – because it will always be applicable (see UN 1948 and Section 3.2.1) – but rather what choices decision-makers and health care providers, including in the Ministry of Finance, make to preserve the lives of PLWHA. As the findings of this study suggest, rights have very little to do with preservation of the VoHL.

Nonetheless, while there could be some value in the actions or omissions of what the decision-maker in policy or the health care provider at a hospital does, it is not helpful in the HIV/AIDS health care context, where all (non)actions are manifestations of decisions made under a duty of care. In determining what value the PLWHA are accorded in order to preserve their lives, the other broader economic factors come into focus. Critically, the willingness of the GoZ or of the ability of PLWHA to pay, must be put into account. In the case of finite HIV resources, the findings show that this willingness and ability to pay (WTP/ATP) approach suggests that HIV resources should be distributed to those who value the resources most (pay the most for it). Although the GoZ has set up the AIDS levy (see Section 2.5.2), which signals the willingness to pay, to enable PLWHA to obtain lifesaving treatment, the findings reveal that there is always an excuse of limited resources to transfer the burden of HIV treatment on donors and individuals (see Figure 5.3 and Table 5.2). Making the situation worse is that most PLWHA are predominantly poor (given that over 75% of Zimbabweans are considered poor) and are not able to pay for their own HIV treatment (see Chapter Seven). Thus, the value of PLWHA appears cheap and their deaths can be imminent because they cannot pay for their services, despite having rights.
Taking these points together, this study contends that while there are PLWHA who die because of natural causes of death, some PLWHA also die prematurely because of the nature of (non)actions by decision-makers in health care. Simply, they are allowed to die.

8.3 Techne of government: Implications for life and death
Techne of government, as outlined in Section 3.6.2 and further developed in Section 4.2.2, describes the calculative rationalities used by the government to govern its population (Dean 2010). These point to technologies, surveillance, calculative means, instruments and statistics that reflect both the history and context ingrained around the governed populations (Foucault 1998). Techne of government provides the basis for the choices of government and the justification of governmental action (e.g. privatisation or economisation of health care) (Marttila 2013). As already highlighted in Section 5.3, the main descriptive themes that emerged from the data included: results and market-based rationalities; cost-effectiveness (shopping list) and disability-adjusted life years. Taken together, these themes could signal a calculation, or as Foucault (1991) put it, the rise of apparatuses of security. These apparatuses of security are statistically calculated or, as set by Dean (2010), they are a calculative rationality, or means of ordering reality into a form that is calculable. Once the calculation is complete (surveillance), the product of calculation is made visible. When describing Panopticism from Jeremy Bentham’s panopticon, Foucault (1991) defines visibility as subjectification that produces homogeneous effects of power (Foucault 1977).

The significance of such calculative rationality on people as statistical products is not new and contributes to the already extant literature on health statistics as a management tool for populations and especially in the works of Foucault (1977) and Rose (1999). Section 2.5 already explores various statistics about PLWHA in Zimbabwe, showing the significance of HIV surveillance, measurement and statistical representation in the overall management of HIV and PLWHA by the GoZ.

But what this study contributes is not just about how the mere presence of statistical products can define public health discourses – about where, how and why resources are rationed – rather, it is the representation of people as statistical products, that plays a fundamental role in framing the VoHL. As this study reveals, statistics are more than numbers or techniques used to govern populations (Foucault 1991, 2004, Dean 2010);
they are a language of framing the VoHL, where statistical outputs play a significant role in shaping how the VoHL is imagined and framed. Statistical representations allow SGOs to make ‘live and/or let die’.

8.3.1 PLWHA as statistical representations and implications for life and death

Similarly, the Zimbabwe health ministry’s primary task of collecting, cleaning, analysing, packaging and disseminating HIV data that is accurate, reliable, complete and timely is achieved by the gathering of statistics. As shown in Section 5.3.3, the HIV/AIDS statistical data comes in the form of maps, annual reports, health profiles, surveys among other (refer to Box 5.4). The National Health profile, the most comprehensive data report of all the data reports in the MoHCC, aims to assimilate comparable data across all of Zimbabwe’s ten provinces. The largely medical statistics collected by the National HMIS feeds into all other reports compiled by other departments in the MoHCC. Among other diseases and conditions, the national health profile presents trends in HIV/AIDS which are communicated through a number of statistical outputs, such as pie charts, histograms, numbers and tables (refer to Section 5.3.3). The results are compared between males and females, districts, provinces and age groups in tabulated form throughout the report. A table in Figure 5.1 in Chapter Five illustrates an example of a trend analysis between 2009 and 2016, showing achievements versus annual targets, titled ‘Coverage of HIV Testing and Counselling Services’. Also, the map in Figure 5.2 in Chapter Five shows the distribution of HIV prevalence across all of Zimbabwe’s provinces, illustrating the provinces that are doing well and those that are not. It shows the provinces with the lowest HIV prevalence and those with almost a quarter of its population infected. The figures thus enable a comparative enquiry and, by consequence, are used to draw conclusions on the overall HIV/AIDS situation within specific areas of investigation.

The health data and advice provided by SGOs as experts who make up the senior expert community of HIV/AIDS policy and programming becomes the dominant discourse describing how human rights are promoted and protected by SGOs in the health ministry. This data and advice in various statistical representations (policy monographs, HIV mortality figures, new HIV infections, profile health reports – refer to Box 5.4 in Section 5.3.3) is released by the health ministry periodically to show progress against HIV/AIDS targets set towards the fulfillment of certain rights of PLWHA. Such targets may include ‘HIV/AIDS-related mortality reduced by 38% by 2015’ (UNAIDS 2014b, p. 7), contained in the national health profiles and/or UN country reports on HIV/AIDS. Through these
statistical products, an analytics of government is formed. A means of governing through surveillance (refer to Section 3.3.2) or Panopticism, as Foucault (2004) puts it, is managed through calculation rationalities that inform PLWHA to want rights protection, and to know their rights and means to fulfil them. Statistics, therefore, create knowledge about the MoHCC and especially about its approaches to fulfilling the right to health, offering examples of good practice.

Interpreting these statistics, which show trends and comparisons on HIV/AIDS, demonstrates how statistics work as a technology of governmentality because they make the SGOs’ discourse on policy management – and specially to ensure equitable access to HIV/AIDS services – visible. Thus, through techne, the SGOs are constructed as promoters of the discourse on justice, fair access to HIV services, and Kodzero (Rights) of PLWHA. They are also seen here as those who protect the law; for instance, they will ensure that data on criminalised social groups, such as sex workers and homosexuals, is invisibilised by not reporting in the routine health surveillance. Reporting of HIV statistics for distinct social groups such as sex workers and MSM is a global recommendation made by the UNAIDS with the WHO in 2000. The UNAIDS recommended that all countries experiencing a generalised (over 1% HIV prevalence) and concentrated (over 5% HIV prevalence) HIV epidemic institutionalise ‘second generation surveillance systems’ (SGSS) (WHO and UNAIDS 2000). South Africa is one such nation that has prioritised routine surveillance of HIV among MSM, lesbians, persons of transgender experience and persons who inject drugs (UCSA 2015). Also, South Africa formalised the routine surveillance through its 2012–2016 HIV/AIDS National Strategic Plan (NSP), recognising the disproportionate burden of HIV among these social groups (SANAC 2012). SGSS monitor both HIV infection and risky behaviours, such as sexual intercourse with one or more infected partners, using the data to monitor and explain changes in levels of HIV infection. Where SGSS have been used, in South Africa for example, they ensure the efficient use of money and expertise, and that data gathered is used. Significant for this study is how reporting of other significant areas of HIV in Zimbabwe is rendered invisible. Although the statistics data compares HIV in relation to wealth quintiles (Demographic and Health Survey), or gender (Gender and Health Survey), or sex (national health profiles), making these areas visible, others, such as comparisons by sexuality, are silent, rendering LGBT populations invisible on the policy agenda. This approach of invisibilisation is perhaps intentional and legitimated by criminalisation laws against LGBT people (refer to Section 2.5.1). It aims to value-
down some categories of PLWHA by invisibilising them and thus making them appear worthless. The bias towards medical data could also suggest the paucity of social surveys, including, for example, linking sex workers or LGBT with HIV, and attitudes from non-PLWHA, hate speech and freedom of association, and implications for HIV treatment, life and death.

Thus, the MoHCC has, similarly, constructed a discourse about ART coverage, using statistics to show gaps in coverage as a means to access funding from the Global Fund to Fight AIDS, Tuberculosis and Malaria, and other development agencies such as PEPFAR and DFID (refer to Box 5.2 in Section 5.3.1). The bargaining methods not only use statistics to gain access to international funding, but also use the human rights language discussed in Section 8.2 above. Specifically, the human rights language notes that the international community has an obligation to help developing nations to curb the HIV epidemic and protect PLWHA’s rights by addressing gaps that exist in HIV responses. These gaps are rendered visible through statistics. By the same token, good practice data and progress statistics are used, moreover, to show progress and good practice in the relevant HIV domains.

Using the statistical data, the SGOs in the MoHCC can therefore decide the group that is most vulnerable and that will become the focus of funding using the so called ‘shopping list’ approach, often represented as cost-effectiveness analysis (CEA) (refer to Section 5.3.1). Similarly, the group identified as vulnerable can then be used as a means to justify further research – focusing on that particular group to ensure control, management or in-depth insight into the behaviours of that group. Using mostly ad hoc surveys, the SGOs construct a discourse through which the most vulnerable PLWHA can be identified, and these can be labelled as ‘key affected populations’.

Similarly, ‘key affected populations’ (KAP) are identified as sex workers, truck drivers, LGBT people and prisoners (refer to Section 2.5.1). Among these KAPs, women and adolescents are identified as experiencing a higher risk of HIV infection (UNAIDS 2015). Labelling of LGBT people, prisoners and sex workers presents them as victims of higher risk of HIV infection. Thus, when the MoHCC, NAC and their partners finally get to the communities of these victims, or rather ‘key affected populations’, to conduct further research, they target these KAPS for research viewing them as the ‘most at risk’, or the less ‘normal’ social group. Through interviews, focus group discussions, questionnaires
and surveys (e.g. in the MIMS, DHS reports), conducted by SGOs or their representatives in direct contact with KAPs, the KAP member automatically becomes involved in governmentality. There is, thus, an inevitable element of government of the self, attached to this notion, when a member of KAP begins to feel different and perhaps abnormal. Here, the ‘KAP’ member is ‘ab-normalised’ as that which we cannot become – they are not the ‘normal’ citizen. This (ab)normalisation is a result of the ‘statistics as governmentality’, or governing through statistics. Here, statistical data first produces the knowledge about PLWHA (not routine), and then disaggregates the knowledge into social groups that are then targeted by SGOs. Moreover, they create a category of ‘key affected populations’ that are viewed as abnormal and thus become devalued citizens. But, becoming more visibilised as KAPs equally prompts more positive outcomes, such as greater public sympathy and funding to help them.

Indeed, it is the leadership’s homophobic public rants (see Section 7.3.1) that are very explicit about the abnormalisation of homosexuals – which attaches stigma to KAPs, further devaluing them. The aspects of homophobia are dealt with in more detail below (Section 8.4). The ways in which LGBT people in general, and especially those living with HIV in particular, are treated by the leadership in Zimbabwe perpetuates a culture of stigma and low value. Within their everyday spaces in the communities they live in, KAPs are treated with suspicion, stigma and sometimes discrimination, as people do not want to be associated with the ‘abnormalised’ citizen. Refer to Tino in Box 7.1 or Tatenda’s case in Box 7.2 for these examples. The behaviour at the community level could explain the accounts of disgust expressed in Sections 7.3.1–7.3.3.

This study suggests that the application of statistics enables translations of HIV infection to inform planning and management of HIV resources in the same manner in which Foucault (2004) outlines how surveillance is used by the state to manage populations. But even Foucault did not connect health surveillance to the VoHL. Several studies of HIV and health surveillance are primarily descriptive, and broadly lay out guidelines for surveillance (Flemming et al. 1999), monitoring HIV trends (Dondera et al 1988, Rehle et al 2004), proposing evaluation designs (Chandrasekaran et al 2008) or laying out weaknesses in routine health information systems (Mastro et al 2010). But, this study extends this scholarship by revealing that HIV surveillance and statistics are governance tools through which SGOs govern by visibilising PLWHA for purposes of valuing their lives regarding resource prioritisation or by increasing chances of them being stigmatised.
As they become visible and known as KAPs. In communities, KAPS are targeted for mockery and abnormality. They are often left to their own devices, to deal with stigma, discrimination and lack of HIV services. They are allowed to die. Here, I argue that calculative rationalities, and especially using statistics or other calculative products such as disability adjusted life years (DALY); a shopping list (CEA); results or market-based methods (refer to Sections 5.3.1–5.3.4), are a set of calculative devices which create knowledge about PLWHA for government action. Statistics as governmentality become a means for ‘valuation’ of human life by defining who should be abnormalised and/or visibilised and thus (de)valued and allowed to die, or live.

8.3.2 PLWHA as clients and implications for life and death

As already shown in Section 5.3.4, there are no guidelines, operating procedures or standards approved by the MoHCC that guide and bind decision-makers to their actions on HIV/AIDS. Thus, despite the talk by SGOs to base their rationing decisions on cost-effectiveness analysis (CEA), CEA is, in effect, not essentially a consideration in decision-making (refer to Section 5.3.1.). The interviews from EI:2, EI:6, EI:7, EI:1 (refer to Box 5.1 and Section 5.3.1.) showed little knowledge of CEA or how it should be used among SGOs. This was despite their rather carefree use of the term cost-effectiveness. The use of such terms by decision-makers casts doubt as to whether they knew what these economic terms meant, and is telling of little care or little value accorded to PLWHA.

Moreover, it is not surprising that the burden of costs of HIV care is left on the shoulders of PLWHA. Zimbabwe’s vast literature on health care reforms points to the effects of the users fees and increased out-of-pocket costs that mimic free market principles aimed to shift health care spending from government to its citizenry (see Chisvo and Munro 1994, and Honogoro and Chandiwana 1994). While the GoZ has a responsibility for user fees policy, still functional there is also a role here for overall reduction in government budget as a consequence of international financial institutions (IFIs), such as the World Bank and the IMF, to hollow out the state by cutting spending in order to increase the role of the private sector and improve efficiency. The result of user fees was tantamount to a shift in government expenditures as the burden of costs was shouldered by clients of health services (refer to Section 5.3.4), along with rapid impoverishment of PLWHA (Basset et al. 1997). This discourse lies at the heart of the market agenda, and thus problematising this construct allows for understanding PLWHA as clients. PLWHA are subjected to user fees, increased out-of-pocket costs, increased diagnostic tests, more deductibles, or
ultimate exclusion from HIV treatment. Thus, on one hand, those who are able to pay (who have fees for services) tend to live longer because they can access better health care. On the other hand, those who are unable to pay are allowed to perish in their poverty, illness and misery. As a consequence, in the 1990s, premature deaths became common (Mlambo 2014; also refer to Box 7.7 for deaths in Nyovorwai’s accounts), around the time user fees were introduced. But, it is not only the MoHCC that is responsible for clienteling PLWHA, as there is a role played by other sector ministries, including in Finance, Education, Social welfare and/or Transport (See Sections 5.3.1 and 4.4.3), who determine the national envelope or the policy environment upon which the SGOs in the health ministry must negotiate. Thus, mono-focus on HIV/AIDS in the MOHCC has the effect of invisibilising the other policy dilemmas that SGOs in the MOHCC face, such as how they balance resources between HIV/AIDS and other health priorities. But also, the focus on development organisations working directly with the MoHCC on HIV/AIDS may also reflect other potential allowable deaths in health programmes receiving less attention but with equally importance, such as diarrhoea or respiratory tract infections. The HIV/AIDS share of morbidity and mortality in Zimbabwe as the leading cause of death (see Sections 2.2–2.5) may in some ways create pathways for allowable deaths in other critical areas, like tuberculosis, as focus and priority is given to HIV. See Table 2.1 for leading causes of death in Zimbabwe between 2000 and 2010. Several studies and works across the globe demonstrate the importance of mainstreaming HIV in other sector ministries, in policy and programmes (see White 2002, Oxfam Canada 2004, SDC 2004, Onipede and Schmitt 2011). But, as Cohen (2006) and Skovdal and others (2011) argue, only when a complex web of expertise and knowledge brought by mainstreaming of HIV succeeds should there be expectations for change in light of the narrow understanding of the epidemic in other sectors outside the health sector. For instance, the national routine HMIS, which should monitor the epidemic and provide timely and quality data on HIV-related information, is donor-driven and remains weak, with little capacity for self-sustenance (Foster 2012). Also, the perennial strain on the national budget suggests that parent ministries of other sectors might focus on their key deliverables at the expense of HIV/AIDS.

Here, valuing PLWHA as clients brings out a practical restraint upon the duty of the GoZ to take active steps to preserve life. Inasmuch as HIV/AIDS care should be provided under constitutional provisions of the right to health care, SGO actions may render some PLWHA less able to access care or, worse still, die from preventable causes because of
these costs. While the death of PLWHA is not the intention of SGOs, governmentality can also work to result in loss of life instead of its preservation. As Foucault (2004) argues, governmentality results in a process by which the state is gradually governmentali
ded. This means that both those who govern and those who are governed act according to the prescriptions of governmentality. In this case, PLWHA are exposed to death because of the inaccessible costs of HIV/AIDS services that are instituted by SGOs applying the technologies of governmentality. But the SGOs do not intend to cause death on the part of PLWHA, despite instituting costs that PLWHA will have to pay, resulting in exclusion (refer to Tino’s case in Appendix 13 or Tatenda’s case in Box 7.2) or even death (refer to Nyovorwai in Box 7.7). It is important to note, as already elaborated in Section 4.4.3.2, that even SGOs may also constitute a category of PLWHA, thus it is not that their intentions aim at harming PLWHA. But when governmentality operates in such subtle ways of rule, the state has been governmentali
ded.

In addition to the absence of clearly defined approaches to rationing scarce health resources in the MoHCC, the lack of both knowledge and expertise (refer to Section 5.1) suggests a gap in the ways of determining the fairness of the decisions made by SGOs to provide an explanation of their reasoning. This is critical, because in the context of scarcity, as already highlight
g in Chapter 3.2.2, rationing is a rational conduct on principles of progressive realisation of social rights, such as the right to health. Therefore, assessing the procedure to judge whether decisions are fair raises questions: if from the SGO perspective, diseases may carry equal weight in their potential to cause death. Thus, it may be that SGOs lack consensus on principles that tell them what is fair, or even when they have general principles but are burdened by reasonable disagreements about how they apply. The absence of such procedures or the presence of a ‘shopping list approach’ in rationing of HIV/AIDS resources in Zimbabwe opens up possibilities for allowable deaths, without any means of monitoring by the citizens who could challenge denial of potentially life-saving ARVs, like for Tino (Chapter Seven), a homosexual man living with HIV. The question is whether the life of the homosexual Tino, living with HIV in rural Zimbabwe, might be saved, by whatever slightest chance.

8.4 Ethical government of the self: Implications for life and death

Descriptive themes ‘tinovanyangadza’, ‘tinovasembura’, ‘tinovasemesa’ [disgust] and ‘vachirikungofa sembwa’ [they are still dying like dogs] emerged as the main ways in which PLWHA and especially homosexuals, sex workers and ex-prisoners living with
HIV/AIDS were viewed by non-PLWHA in society. As already discussed in Section 7.3.1–7.3.2, these terms invite understanding of what society considers ‘immoral’ and non-ideal. The terms signal emotions of ‘dislike’, ‘disgust’ and ‘contempt’, which all tend to motivate low rankings of PLWHA. The expressions also invoke a sense of expendability, and unimportance, or rather an expendable population framing. The expendable population framing is significant because it points to many forms of labelling (refer to Sections 7.3.1–7.3.3): ‘kufa sembwa’ [die like dogs], ‘kusemesa’ [disgust], ‘varwere’ [the ill, the sick, and the mentally disturbed], ‘makuva’ [graves]. These forms of labelling present language as a cold discursive space negotiated by other social factors, including religion, deprivation and unemployment of PLWA, and poorly remunerated, frustrated health workers (Section 6.2.4).

Here, the discourse of PLWA as victims, and especially groups, coined as ‘key affected populations’, is perpetuated (refer to Section 8.3.1 above). But, as Sections 7.7.4–7.3.6 show, PLWA refuse this victimisation and offer a counter-narrative that presents them not as expendable populations, but as ‘Tinoshingirira’, ‘Vanotsvagatsvaga’, ‘Takunda’ – ‘perseverers’, ‘improvisers’ and ‘victors’ respectively. Taken together, these expressions give a sense of agency, which acts through interpretations of resilience or ‘resiliencers’ as an identity of PLWA and as a way of valuing-up the self. Indeed, the Oxford Dictionary defines ‘resilience’ as ‘the ability to last (survive), adapt (improvise) and ability to bounce back (conquer)’, which sums up the expressions by PLWA. Notions of devaluing PLWA as expendable populations and those of PLWA valuing themselves as perseverers are indicative of governing others and the self, respectively. As outlined in Section 3.3–3.4, when taken together the conceptions of governing others and governing the self are also called the ‘ethical government of the self’, as Dean (2010) presents them. It is a dimension of government which Foucault (2004) terms conduct of conduct. Here, the ethical government frames the ways of representation of PLWA, use and habits of language that produce and reproduce fields of meaning located in everyday conduct of PLWA. Labelling and identifying PLWA as expendable populations signals an identity or a value assumed by PLWA in the eyes of those without HIV infection. Also, the counter-narrative of resilience is an identity of agency coined by PLWA to assert value which they assign to themselves in society. Contrary to Foucault’s governmentality, which fails to acknowledge that people in themselves may have agency, this study shows that agency of PLWA signifies a power of enablement.
on the part of PLWHA to resist power over and reframe it in ways that shapes their survival.

8.4.1 PLWHA as expendable populations – implications for life and death

8.4.1.1 Governmentality, media and expendability

The expressions by non-PLWHA, of ‘tinovanyangadza’, ‘tinovasembura’, ‘tinovasemesa’ [disgust] and ‘vachirikungofa sembwa’ [dying like dogs], used to describe the value attached to PLWHA and especially homosexuals (LGBT), sex workers and ex-prisoners living with HIV/AIDS, are integral to the governmental problematising of populations. For this view, discourses about the immorality of PLWHA, particularly for LGBT and sex workers, in the Zimbabwe public domain are the products of the translation of the governmental domain of PLWHA sexual behaviour, in the media. For instance, the publicity of the president’s (Robert Mugabe) and former prime minister’s (Morgan Tsvangirai) homophobic rantings on the radio, television, social media and online newspapers is telling of such conduct (see Section 7.3.1). These media discourses are inherently governmental in that they inform processes of government conduct. These findings are consistent with Simpson (2009, p.130), whose extensive ethnography on men educated at a mission school in Zambia, bordering Zimbabwe, suggests that homosexuality is seen as ‘vile’ and ‘disgusting’, and that those practising it are regarded as ‘inhuman’ (Simpson 2009). But, although the narratives of Simpson (2009) do suggest a sense of devaluing homosexuals, he does not explicitly connect the VoHL with homosexuals living with HIV/AIDS – or how expendable they are in such societies – a task which is done in this study.

Also, HIV/AIDS in Zimbabwe has figured in the media as a problem of social governance, and is historically a distinct and unique domain of governmental attention (refer to Section 2.5). The health ministry, other GoZ ministries, activists, churches, media and academics – most agencies that are parties to public conversations about HIV/AIDS – are implicated in the governance of PLWHA (refer to Section 7.3.4–7.3.6 on resiliencers).

More specifically, as argued by Liamputtong (2013) and also discussed in Section 3.2.3 and in Section 6.2.2, HIV infection is viewed through the prism of sin, and those infected by it as deserving punishment for sinful behaviour associated with sex work,
homosexuality and/or multiple concurrent partnerships. Equally so, the early years of the epidemic in Zimbabwe were replete with the presentation of PLWHA according to prostitution (sex work) and anti-social stereotypes. Accordingly, media and anti-AIDS publicity campaigns were hostile to PLWHA rights, entitlements and claims (refer to FGDPWA-ChB in Section 7.3.1). The social implications and effects of such coverage – ranging from reproducing and popularising moral stereotypes, creating public climates of sex worker violence, and homophobia – contributed to conditions favourable to regressive government policies (criminalisation of sex work and homosexuality, Section 2.5.1) or inaction (lack of health services to [ex]prisoners and homosexuals, including those living with HIV).

The structure of media agencies (as organisations), and their role as disseminators of dominant viewpoints of the value of PLWHA by SGOs and other elite sources, suggests little hope for change in the reporting of groups of PLWHA, such as sex workers and LGBT living with HIV/AIDS. But the role of media as disseminators of dominant views of the value of PLWHA tends to overlook mundane media reporting and misses a larger picture which frames PLWHA (particularly sex workers and LGBT) as deviant and non-conforming, signalling expendability on the part of PLWHA. Starting from the assumption, along with Ericson and his colleagues (1987), that production of non-conformity among deviant people is an important media function, nonconformity, like crime, prostitution, homosexuality or mismanagement, as Ericson et al. (1987) observe, is a representation of bad news. Nonconformity is also the inevitable focus of societal conversations whose public domain exists through mass communications, where culture is made rational, and where the governmental discipline of systemic nonconformity is conducted. Here, the media exploits mass yearnings for drama and intrigue by presenting narratives of homosexuals in general, and LGBT living with HIV, as undeserving of sympathy, whose ‘heads can be chopped off’ (refer to Section 7.3.1). The news media becomes the main knowledge-broker, channelling the expendability of homosexuals, and thus enforcing how they are treated within society, including on HIV/AIDS needs. Thus media, as institutions, use news about sex workers or LGBT people to manage the general populations and they can, thus, be viewed as social control agencies themselves. They police how homosexuals living with HIV, for example, are treated at the health facility, such as in the case of Tatenda who was denied HIV testing at the HIV testing centre because of her homosexuality (Tatenda, LHIC025, Box 7.2). Thus, the media can control the normal conduct of people in communities, including especially the activities of other
control agencies such as clinics, particularly for LGBT people in general and those living with HIV in particular.

The networks of media institutions tend to involve networks between journalists and their sources, including SGOs, politicians, human rights activists, academics, and other related actors who may also act as representatives of government, the health ministry, or other relevant institutions. It is through such mundane networks of experts which makes the articulation of PLWHA as expendable populations become an integral part of the administration of government. Indeed, big sources of information, such as SGOs or politicians (such as Mugabe, in this case), give ‘established, dominant views of issues’ (Ericson et al. 1987, p. 23). As such, the role of SGOs and media regarding groups of PLWHA (sex workers and homosexuals) overlap and, in some respects, become part of each other. Thus, media as institutions and their sources are implicated as governmentality, rather in the valuation of PLWHA as expendable populations.

The notions of media as an institution that works with SGOs, politicians and the general public to shape the valuation of PLWHA as expendable people is considered in Foucault’s (1991) conception of governmentality. But, connecting the role of media in shaping the discourse around sex workers and homosexuals to governmentality brings out expendability of these populations as part of a larger process of social problematisation. This is novel. As already outlined in Section 3.3, governmentality is ‘the ensemble formed by the institutions ... analyses ... and approaches that allow the exercise of ... of power’ – it is the reason of the government (Foucault 1991, p. 102). Then Foucault (1988) goes on to describe the technologies of the self, as one of the approaches instituted by an ensemble of institutions which permit individuals on their own or with the help of others to effect changes on their beings for transformation towards becoming whole beings. In this case, once PLWHA emerge as non-conformers, deviant and perhaps expendable populations, those without HIV (non-PLWHA) will try to ensure that their behaviour does not lead them to the state or circumstances of expendable PLWHA.

Such labelling of PLWHA by non-PLWHA, using such derogatory expressions as ‘kufa sembwa’ [die like dogs], ‘kusemesa’ [disgust], ‘varwere’ [the ill, the sick, and the mentally disturbed], ‘makuva’ [graves], ‘sickening dead bodies’ and ‘death’, ascribes the victim status to PLWHA so that they become diminished moral beings who deserve punishment for their immoral actions (see Section 6.2.2). This way, the government
would have achieved its aim of managing populations from afar. For PLWHA, shame, embarrassment, self-hatred, self-stigma, closetedness, loneliness as suggested by C027 (Section 7.3.1) become everyday means of dealing with the ways in which PLWHA are valued in society. In Table 7.5, PLWHA used symbolic expressions, such as the ‘living dead’, ‘dirt’, ‘costs’, ‘dry fallen leaf’, and ‘useless’, to convey how they expressed their own value. In these expressions, as outlined in Section 7.3.2, PLWHA tend to be left alone, to their own devices (expendability), suggesting worthlessness which reinforces the notions of ‘kufa sembwa’ [die like a dog]. In the Shona Culture, ‘Imbwa’ (dog), when used to refer to a person, is one of the most common curse words, considered offensive, and used to do nothing but demean someone as stupid, useless, animal-like, and value-less. This can suggest devalued PLWHA, who are seen as expendable and allowed to die. HIV/AIDS, therefore, remains more than just an incurable virus that has devastated humanity; it continues to break down bodies, but it is not stopping at physical bodily destruction. Rather, it is destroying PLWHA through dehumanising processes that lead to premature avoidable mortality, or allowable deaths.

8.4.1.2 Governmentality, religion and the discourse of love and expendability

The findings highlighted in Section 6.2.2 suggest that the idea that HIV/AIDS is a punishment from Mwari ne Vadzimu [God and spirit mediums] is based on two assumptions: that homosexuality and sex work are ungodly conducts, and that such sinful conducts are punishable through suffering and disease. The findings in this thesis resonate with Cardinal Hume, a high-ranking English Catholic Priest, who wrote in his editorial to the London Times: ‘AIDS is better seen as a proof for the ...law that actions have consequences ... disorder inevitably damages and destroys’ (Hume 1987). Such language of damnation, as seen in Section 6.2.2 and from this quote, signifies how the church has since and continues to believe that homosexuals and sex workers are penalised for their immorality. But, as this study shows, there is an apparent conflict between the African Masowe Apostolicism or the Roman Catholic and mainline Protestant churches’ theological doctrines and the values of the dying and caring for all. It does not seem as if the church does value all equally, as it purports to – certainly not sex workers and homosexuals with AIDS. Such practices appear to abuse the unique position of the church as one of the biggest HIV care providers, for religious propaganda. Also, as findings in chapter 7.3.1–7.3.3 reflect, the manifestation of deep-seated fear, misunderstanding, and prejudice as homophobia, leads to rejection, alienation, isolation, and damaged self-
esteem. Combined, these effects play a significant role in the contribution to the decisions by the sex worker or homosexual in taking treatment, and if they do, it affects the success rate of the treatment as seen in Tino’s case. These findings resonate with the works of Simpson (2009) who talks about Hambayi, one of his respondents in his work detailing masculinities and HIV/AIDS in Zambia, Hambayi, at the age 40, condemned and rebuked homosexuality as something sinful, and remarked that those engaging in such conduct were going against ‘nature’ and were responsible for bringing AIDS. As did others, he blamed homosexuals for making ‘Zambia sick’, suggesting condemnation of homosexuality and its links to HIV/AIDS (Simpson 2009).

PLWHA incorporate spirituality (both African and Christian doctrines), reflected in Chapter Seven and Appendix 10, as a way to cope, to help reframe their value, and to bring a sense of meaning to their lives in the face of HIV. Such inculcation of religion in daily life appears to bring improvements in health-related quality of life and overall well-being. Findings in this study echo those from earlier studies that showed that greater levels of spirituality could be associated with resilience, a greater purpose to live and better overall health-related quality of life in people with HIV/AIDS. As such, religion can function as a source and a space through which agency manifest. See Coleman and Holzemer (1999), Tuck et al. (2001), Coleman (2003) and Cotton et al. (2006) for these narratives. But, there are harmful effects of religion for PLWHA, and especially homosexuals, who may be ostracised due to lifestyle issues associated with being HIV-positive. What is new in this study is how such coping is a mechanism of self-value where PLWHA get a sense of self-worth. Also important is how religion works as a mechanism to exclude, thus devalue PLWHA. Thus, religion can both value and devalue PLWHA.

In this study, religion emerges as a critical node for the workings of power over people’s consciousness. In Foucault’s dealings with power, religious organisations deploy the hegemonic power of language located in the discursive space and conceptualisation of power over others, by framing societal moral conduct. Further, the churches or Masowe that frame religious and ethical conduct like Foucault’s asylums or prisons (as disciplinary institutions), must thus be seen as parts of strategies of power and domination. Here the power of religion operates like a double-edged sword, containing Mudzimu unoera [holy power] (see sections 6.2.2) or Hushingi [perseverance as power of agency or enablement] (see Section 7.3.4–7.3.6), and finally to something like a brute
coercive force in condemnation of sex workers and homosexuality. It frames PLWHA as expendable populations but also as ‘resiliencers’ with agency, and as loved citizens.

8.4.2 PLWHA as resiliencers: implications for life and death

For more than 30 years, since the first HIV case was confirmed in Zimbabwe, the term HIV/AIDS continues to conjure images of death, desolation, and dehumanisation, despite the advent of HIV treatment (See Section 8.1.1 above). Thoughts about HIV/AIDS rarely coincide with views of laughter, inspiration, dignity, worth or life, but those of disgust, desolation, death, (*Kusemesa, Hambwa, Urwere nerufu*) (refer to Section 8.1.1 above). HIV remains, for the most part, fixed in the public mentality as a synonym for devastation, specifically the damage of the value and dignity of human life. But, most of the PLWHA in the semi-structured interviews, as well as in the FDGPWA, with whom I spoke, despite the life-altering and traumatic events, continued their life commitments, in various ways to stay alive in that period of their lives that followed their diagnoses. Most respondents saw the determination to stay healthy and alive as the essentials to surviving AIDS and to normalising life. Chapter Seven especially demonstrates accounts of the ‘will-to-live’, narratives on ‘improvising’, the joys of ‘conquest’, for being alive despite continued subjection to varying combinations of delight at their misfortune, gossip, belittling, or outright hatred. This is significant, as it also locates the power of agency, located in the narratives of will-to-live and perseverance for survival – something that Foucault failed to recognise or acknowledge in his dealings with power. Thus, as this study suggests, agency is not only about PLWHA’s ability to federate or to organise into small groups that can challenge government rule, but it is also about the power that values the self and the power that frames the self to survive against all odds of uncertainty.

In contrast, existing literature on HIV broadly explores the damaging effects of HIV and the benefits of prevention, treatment and care, but fails to grasp the indefatigability of PLWHA (see D’Augelli 1994, Phillips et al. 2008, Emlet et al. 2011, Dubrow et al. 2012 and, Kapadia et al. 2013). Also, the literature on HIV stigma describes high levels of discrimination without pointing to the resilience that so many PLWHA participants of this study broadly demonstrate (See Tarwireyi 2004, Grov et al. 2010 and Sambisa et al. 2010). While most PLWHA shared memories of a lost aspect of the self, their stories were largely testimonials of victory, survival, recovery and reclamation of personhood. HIV comes out as more than the virus that attacks the body, as it transgresses the mental, social and physical well-being of its victim (refer to symbolic constructs of value in Table 7.5
in Chapter Seven). Thus, PLWHA are more than just HIV vessels, but sophisticated persons who will try to manage their condition. Indeed, as they try, some triumph (as Mai Shingi in Box 7:8) and some fail (as Nyovorwai’s brothers; see Box 7.7). Understanding differences in their successes and failures requires a deeper consideration of stories of individual PLWHA. Although the treatment of the virus with ARVs is an absolute necessity, the findings (in Chapters Five, Six and Seven) suggest that ART alone is insufficient in addressing the well-being of the PLWHA.

8.4.2.1 Hybrid Healing, Value of Life and Survival - the Personhood

The notion of caring for the *munhu* – the personhood – is one element that was evident in the voices of the PLWHA interviewees (see C009, C014, C022, G074, G085, G091 in Section 6.2.1 and Appendix 10) and the nurse in Tatenda’s case (LHIC025 in Appendix 10). Each spoke of specific survival mechanisms that implicated the physical, spiritual and emotional, economic and/or social aspects of life. Some (Mai Shingi's case [LHIC013], C052, G104 and G097; see Section 7.3.2) spoke of adding religion through narratives of ancestral Gods (*Vadzimu ne Mhondoro*) as part of treatment, some mentioned Shona traditional spiritual cleansing and *mushonga* (herbs) (G098, G082, C056, C036 and LHIC013). Others spoke of Christian healing (G097, G088, C022 and G090; see Section 7.3.2), while others spoke of the family support, community involvement and good nutrition. But, they also articulately spoke about attending to the entirety of their *munhu* – to the connection between soul, body and spirit. This attendance to the personhood was evident in their conceptualisations of HIV treatment as something which was not formulaic but based on guesses and suppositions of what would prove to work for one to stay alive (see Section 7.3.1). Attendance to one’s body meant having to deal with the virus and consequently finding means and ways to attack the virus. This meant that PLWHA had to get ARVs, but this also meant that the ARVs had to be available and accessible. It also meant that the HIV treatment services had to be acceptable, and PLWHA had to finally make contact with the health facility to increase their chances of getting them. However, at each stage of attempting to get the ARVs, PLWHA continue to face challenges, including transport costs, increased diagnostic tests, food shortages, high user fees, and higher out-of-pocket costs, as summarised in Box 7.6. Thus, caring for one’s physical self meant having to address most of the challenges identified in Box 7.6. As discussed in Section 2.5.4, these challenges fall within a set of bottlenecks that Helliwell and colleagues (2013) note by identifying that 75% of
Zimbabweans lack not only income but also assets. The UNDP (2015) and OPHI (2015) also corroborate identifying nutrition and food security as another limiting factor, while the CSO and Macro (2007) identify financial barriers to accessing health services. Despite the presence of HIV treatment, it is worth noting that PLWHA continue to hybridise healing to maintain their resilience. Adapting to alternative hybrid healing increases their ability not only to attend to the ailing physical body, but also to manage emotional distress in a time laden with confusion and trauma, to cope with this life-threatening disease. It is along this revival of the personhood that PLWHA described their strategies for survival with an underlying belief that attention to the whole-person would yield victors.

8.4.2.2 Responsibilisation

The strategies for survival signal a narrative where PLWHA strive to add value to themselves and be valued. Survival strategies and adding value to themselves are connected as they both respond to the physical, social, spiritual and mental well-being of PLHWA. Although these strategies for survival by PLWHA emerge as counter-narratives by PLWHA on their value, they would also appear as approaches of governmentality itself. I say this because PLWHA who are taking ARVs, such as C029, C056, G083 and G110 (see Appendix 10), are told that their adherence to ARVs must be rated as crucial to prevent the development of drug resistance, as Mai Shingi was told (see Box 7.8). Like Mai Shingi (LHIC013) and G080 (see Section 7.3.2), PLWHA know that controlling the number of HIV viruses in the blood requires the correct and consistent use of a lifelong regimen of ARVs taken daily at almost the same time. As part of the treatment, PLWHA are told to eat healthy, to exercise, and not to drink alcohol or smoke in order to maintain the benefits of ARVs (refer to G080 in Section 7.3.2). More interesting, is that even before getting the ARVs, PLWHA must attend the treatment-ready counselling sessions to be prepared for treatment, this is also an opportunity for the PLWHA to demonstrate that they can take the ARVs in the correct and responsible manner. The responsibility of PLWHA is also shown by the individual living with HIV first completing the diagnostic tests, such as liver function tests and other inspections and examinations with health workers (see Box 7.6 in Section 7.3.3). But, this individual required for effective ART is remarkably similar to what Lemke (2002) also described as responsibilisation. Lemke (2002, p. 15) describes responsibilisation as ‘… strategy of rendering individual subjects “responsible” … entails shifting the responsibility for social risks such as illness … into the domain for which the individual is responsible and transforming it into a problem of “self-care”. This concept of the responsibilised PLWHA is generally part of public health
discourse, and involves expectations for PLWHA, like other patients without HIV, to take responsibility for their own health as clearly stated by an SGO, EI:6 (in Section 5.2.2). This dimension of public health discourse, as discussed in Section 3.3.1, is presented as a form of politics in which the government essentially outsources the responsibility for ensuring the well-being of the population by governance-at-a-distance. Here, effect of the power of the government (SGOs) are rendered invisible as it retreats behind the mundane, everyday practices of public health administration of HIV/AIDS. While the PLWHA view themselves as survivors, who have conquered not just the effects of the virus on the body but the social effects of HIV on the psychology, it appears that PLWHA are in effect responsibilised to do what they have done – to survive.

8.5 Conclusion

The aspects of ‘episteme of government’, ‘techne of government’ and ‘ethical government of the self’ at the centre of discussions in this chapter served two overlapping purposes in as far as addressing the research question that this chapter aimed to answer and the overall analytical framework for this thesis. The research question that this chapter aimed to answer was: What are the implications of valuations of PLWHA on their lives or conversely allowable deaths. The three analytics of government enabled the analysis of ways of valuation of human life. These dimensions connected the study’s theoretical understanding of valuation of human life (as a multi-attributed process understood from a human rights – episteme, health economics – techne, and moral perspective – government of the self) with the ways in which SGOs, non-PLWHA and PLWHA frame the value of PLWHA in Zimbabwe (as highlighted in Chapter Three). They, therefore, enabled a balanced analysis of the various ways of valuations of PLWHA and the implications for their lives and deaths.

Episteme of government has enabled the analysis of the ways in which expertise (SGOs) and know-how/institutional arrangements (rights, laws, and policies) work together in framing the value of PLWHA. Firstly, on the know-how aspect, the analysis has shown that Kodzero and Mitemo (rights and laws) for PLWHA are presented as governmental obligations toward PLWHA; because these obligations are relevant to the planning, design, execution and monitoring of HIV/AIDS policies, laws, and programmes (policies). Based on these obligations, the GoZ can be understood as constitutionally and legally responsible for instituting policies and programmes that uphold the right to health
and reduce the impact of HIV/AIDS. The chapter argues that the governmentality of *Kodzero ne Mitemo* model makes PLWHA govern themselves, becoming (lay) experts in their own right. It is thus reflexive acting as an automatic technique that connects the ‘telos’ of equality and freedom that rights represent, connecting with the desires of PLWHA to be valued as equal, legal, political citizens that can seek constitutional protection. Secondly, the governmentality of *Kodzero ne Mitemo* model is executed by experts. Through guiding and managing the expertise and collection, analysis, and presentation of statistical information, the SGOs can describe how human rights are promoted and protected by SGOs in the health ministry. It also alerts us to the experts (SGOs) who operationalise the rights and policies for PLWHA. We can, therefore, question the nature of their networks that tend to conceal workings of power under the umbrella of policy experts. This is significant, because, as this chapter shows, SGOs form an interlocking network of experts who influence mundane everyday practices (valuation) through actions that are normalised and presented as ways of HIV/AIDS decision-making and governance. Thus, governmentality presents responsibility as an assumed rather than conscious process, making it rather easy to get away with allowable deaths. Finally, governmentality of *Kodzero, Mitemo neKubatana* reveals processes whereby PLWHA are governed through a discourse that claims to emancipate them (valuing-up) through their rights. But as this chapter has argued, government by SGOs is bettered by becoming less obvious because it manifests itself in forms that do not depict the presence of authority (but rather networks of experts). Also, it is more entrenched because it is within everyday operational practices of expert networks.

Techne of government revealed the ways in which a calculative rationality frames the value of PLWHA in two ways: as statistical representations and as citizens. Firstly, the chapter has argued that statistics work as a technology of governmentality because they make the SGOs’ discourse on policy management – and specially to ensure equitable access to HIV/AIDS services is visible. Thus, the SGOs are constructed as promoters of the discourse on justice, fair access to HIV services and rights of PLWHA. Thus, the MoHCC has, similarly, constructed a discourse about ART coverage, using statistics to show gaps in coverage as a bargaining card to gain access to international funding. But, using statistical data, the SGOs also construct a discourse through which the most vulnerable PLWHA can be identified, and these can be labelled as key affected populations which are visibilised as abnormal and thus become devalued citizens. Within their everyday spaces in the communities they live in, KAPs begin to be treated with
suspicion, stigma and sometimes discrimination as people do not want to be associated with the abnormalised citizen. Statistics as governmmentality become a means for valuation of human life by defining who should be (in)visibilised and (ab)normalised and thus (de)valued and allowed to die or live. Secondly, valuing PLWHA as clients brings out a practical restraint upon the duty of the GoZ to take active steps to preserve life. Inasmuch as HIV/AIDS care should be provided under constitutional provisions of the right to health care, and progressively in light of the available resources, SGO actions may render some PLWHA less able to access care or, worse still, die from preventable causes. While the death of PLWHA is not the intention of SGOs, governmentality can also work to result in loss of life instead of its preservation. In addition to the absence of clearly defined approaches to valuing health in the MoHCC, the lack of both knowledge and expertise in estimating the Potential Years of Life Lost due to premature mortality opens up possibilities for allowable deaths without any means of monitoring by the citizens, who could challenge denial of potentially life-saving ARVs.

The ethical government of the self brought out the framing of the value of PLWHA in two ways: as expendable populations and as resiliencers. Firstly, the expendable populations perspective implicates media as institutions, working through networks as disseminators of dominant viewpoints by SGOs on the value of PLWHA, particularly sex workers and LGBT living with HIV/AIDS. Media, as does religion, functions as a disseminator of dominant views of the value of PLWHA, tending to frame PLWHA (particularly sex workers and LGBT) as deviant and non-conforming, signalling expendability on the part of PLWHA. Nonconformity, like crime, prostitution, and homosexuality, is a representation of ‘bad news’, and is the inevitable focus of societal conversations whose public domain exists through mass communications, where culture is made rational, and where the governmental discipline of systemic non-conformity is conducted. Here, the media exploits mass yearnings for drama and intrigue by presenting narratives of homosexuals in general, and LGBT living with HIV, as undeserving of sympathy and who can be allowed to die. While religion works as a space for inclusion, and propagates messages of love, inclusivity and tolerance, it also frames a language of violence in the condemnation of sex work and homosexuality as immoral conducts. Thus, it works to both value and devalue the personhood of PLWHA.

Secondly, the resilience perspective on one hand comes out as a counter-narrative of value by PLWHA to challenge the narratives of disgust, desolation and death framed by those
who have not lived with HIV. Such resilience may signify agency of PLWHA. On the other hand, they are also approaches of governmentality itself, whereby government essentially outsources the responsibility for ensuring the well-being of PLWHA by governance-at-a-distance. Here, the effects of the power of the government (SGOs) are rendered invisible, as they retreat behind the mundane, everyday practices of HIV/AIDS care administration. While the PLWHA view themselves as survivors, who have conquered not just the effects of the virus on the body but the social effects of HIV on the psychology, it appears that PLWHA are in-effect responsibilised to survive.

Taken together, these various ways of framing the value of PLWHA – citizens, statistical representations, clients, expendable populations and resiliencers – although framed by various groups, they all function as approaches of governmentality. But, Foucault failed to recognise the workings of power from the self, the power of enablement of the self, which in many ways represents agency. Like Kerr (1999), Foucault’s totalising power lacks in so many ways, especially in failing to recognise the power of self-value. While the resiliencers’ framing can be argued from notions of Foucault’s responsibilisation, the framing does enable PLWHA to survive, although the rest of society can render them expendable and thus allow them to die from otherwise preventable causes. These are allowable deaths which can be understood as premature, avoidable deaths that occur, on the basis that nothing could have been done under the prevailing conditions to prevent them, despite existence of alternative means to prevent them.

Broadly, this chapter has analysed the study’s findings and highlighted literature and new contributions of the research. The next chapter provides the thesis summary and its conclusion.
9 CONCLUSION: ALLOWABLE DEATH AND THE VALUATION OF HUMAN LIFE. A STUDY OF PLWHA IN ZIMBABWE

9.1 Introduction
This chapter concludes the thesis by summarising the findings for each research question and reflecting on the study. This study has sought to investigate the ways in which the value of human life is framed and the implications of such ‘valuations of life’ for life, or death. Drawing upon a social constructivist epistemology and qualitative methods, the study focused on people living with HIV/AIDS (PLWHA) in Zimbabwe, to investigate how their value is framed by senior government officials (SGOs) in health policy, people infected with HIV (PLWHA), and those not infected by HIV (non-PLWHA). Specifically the study asks:

- In what ways do health policy decision-makers frame the value of people living with HIV/AIDS (PLWHA) in Zimbabwe?
- In what ways do people not infected with HIV (non-PLWHA) frame the value of PLWHA in Zimbabwe?
- In what ways do PLWHA in Zimbabwe frame their own value?
- What are the implications of valuing PLWHA, for their lives, or, conversely, deaths?

To answer these questions, this study draws on notions of ‘governmentality’ as an analytical and methodological lens through which we investigated and understood the ways in which the value of PLWHA is framed. Using three analytics of governmentality: episteme, techne and the ethical government of the self, the study’s key findings suggest five ways in which the value of PLWHA was framed by SGOs, non-PLWHA and PLWHA. While there are some contradictions within and between groups of study participants in the ways they frame the value of PLWHA, the study finds a general consensus within and between these groups in the manner in which they tend to value PLWHA. These ways are: citizens, statistical representations, clients, expendable populations and resiliencers. This chapter presents a summary of these key findings for each research question in the first section. In the second section, I reflect upon two key areas of the thesis, which are: methodology and analytical framework. Finally, I end with concluding remarks.
9.2 Revisiting research questions and summary of key findings

This thesis was designed to address four specific research questions:

i. In what ways do health policy decision-makers frame the value of people living with HIV/AIDS (PLWHA) in Zimbabwe?

This question was mainly addressed in Chapter Five. Reflecting on the responses discussed in Chapter Five, this work found three major ways in which the value of PLWHA is framed: citizens, statistical representations and clients. While there were some contradictions among SGOs in the ways they framed the value of PLWHA, the study found a consensus within the group in the manner in which they tended to value PLWHA.

Firstly, from a ‘citizen’ perspective, PLWHA, like other citizens, have social rights, can access HIV treatment and have the agency to claim their resources for health, which can all have an impact in reducing the risks of death. The power to claim the law’s protection tends to be viewed as an aspect which reinforces the elements of legal citizenship that not only guarantee rights to people but also demands their responsibility to ensure that the rights are fulfilled, thus increasing the chances for survival. Through federating, PLWHA are valued as actors who actively federate, giving them access to allegiance from other members of the group. This guarantees not only loyalty and support from other group members, but also it is an expression of political freedom and psychological citizenship in which PLWHA’s collective identity can facilitate a sense of belonging and, consequently, strengthen social cohesion and contribute to the social integration of PLWHA. Taken together, these equal (through rights), legal (through laws) and political (through federating) aspects of citizenship tend to have an impact in promoting life and reducing the likelihood of premature death. But, by subjecting these framings of value to the episteme of government, the study showed that SGOs as experts and know-how (as the rights, laws, and policies), work together by governing through a discourse that claims to emancipate (valuing-up) PLWHA through their rights (see Chapter Eight). This claim to emancipation betters SGO governing by making SGO governance less obvious, because emancipation through rights, laws and policies manifests itself in forms that do not depict the presence of authority (but networks of experts). Also, such kinds of governance through rights is more entrenched because it is within everyday operational practices of expert networks, making it all the easier for SGOs to deny responsibilities for any premature deaths and thus, get away with allowable deaths. But, SGOs are as much
policy makers as they are policy takers, I do acknowledge the significant role played by the Ministry of Finance which determines the resource allocation formulae. I also acknowledge the policy environment created by politicians and other sector ministries such as education, infrastructure, community development among other. Such policy space can facilitate or impede the manifestations of allowable deaths.

Secondly, from a statistical representation perspective, PLWHA, as are other citizens not living with HIV, are subjected to statistical surveillance. Using statistics as a calculative rationality used by SGOs to advance the discourse on advancing the rights of PLWHA visible. Here, the SGOs emerge as the promoters of the discourse on promoting the rights of PLWHA by identifying areas where HIV response gaps, such as ART coverage, exist, using statistics. Once the gaps have been identified, they are then used as a bargaining card to gain access to international funding. But, using the same calculative rationality of statistics, SGOs construct a discourse through which some sub-groups of PLWHA are labelled as ‘key affected populations’, and consequently visibilised as non-conformers needing government help. At the community level where these identified sub-groups of PLWHA live and work, they are consequently viewed as abnormal or non-conformers, whose behaviour is not acceptable, and they thus become devalued citizens. Within their everyday spaces in the communities in which they live, KAPs begin to be treated with suspicion, stigma and sometimes discrimination, as people avoid association with the abnormalised citizen. Statistics as governmentality become a means for framing the VoHL by helping SGOs to identify PLWHA, who should be visibilised and (ab)normalised and thus (de)valued and allowed to die or live.

Finally, from a ‘client’ perspective, PLWHA are customers who gain access to health services through monetary payments or other valuable considerations, such as state budget allocations that introduce a degree of rationing (Chapter Two). Health service providers employ various economics and mathematics-based calculations to weigh costs against benefits to determine budget priorities (Chapter Five). This also forces the clients (PLWHA) to behave in ways that increase their chances of receiving services (Chapter Eight). This intersects with other characteristics of PLWHA. Those with lower purchasing power struggle to access life-saving antiretroviral drugs due to costs implications, so individual wealth can confer value on the lives of the wealthy. This brings out a practical restraint upon the duty of the GoZ to take active steps to preserve life. Inasmuch as HIV/AIDS care should be provided under constitutional provisions of the
right to health care, SGO actions may render some PLWHA less able to access care or, worse still, die from otherwise preventable causes.

ii. In what ways do people not infected with HIV (non-PLWHA) frame the value of PLWHA in Zimbabwe?

This question was addressed mainly in Chapter Six. Non-PLWHA tend to agree with SGOs that PLWHA are rights-holders who should be protected by the law, and that the GoZ is constitutionally and legally responsible for instituting policies and programmes that uphold the right to health and reduce the impact of HIV/AIDS, thus increasing the chances of survival of PLWHA. But taking the views of those who differed, including the views from PLWHA, about how non-PLWHA frame their value, the findings show that PLWHA are framed from an expendable populations perspective. Although not all PLWHA were framed this way; it was mainly homosexual people living with HIV who were seen as deserving punishment of HIV for practising homosexuality. Religion, which tends to shape the moral conduct of Zimbabwean society, frames the practice of homosexuality as conduct that functions to threaten normality (heteronormativity) and invokes violence against gay men and lesbians, including their rejection from services, thus denying them the needed HIV/AIDS services. It is likely that expressing oneself as a homosexual in Zimbabwe is seen as provocative and lacking the enculturation of ‘Hunhu’ (personhood) which determines one’s value, a symbol of African identity. Also, prisons as institutions ‘authorise’ or legitimate torture on gay men by turning a blind eye to the violence against homosexual people as they use anti-sodomy laws (which are also disciplinary tools) to justify their actions. It appears that the penalties, therefore, of dealing with homosexuality openly, in a prison setting, can be difficult if not dangerous, as they inadvertently lead to HIV infection. In the community, and at home, gay people attempt to keep their sexuality a secret. Lesbians and gay men, bisexuals and transgendered (LGBT) people, and especially those living with HIV, experience societal hostility, discrimination and stigma once the homophobic others know of their homosexuality and their HIV. But these notions of expendable populations implicate the media. The media emerges as an institution working through networks of diverse sources of information, functioning as a key disseminator of dominant viewpoints of SGOs on the value of PLWHA, particularly LGBT living with HIV/AIDS. The media, through newspapers, radio and/or television, publishes and retells hostile comments about LGBT people made by the national leadership. Consequently, hospitals and clinics contribute to
these public prejudices against LGBT people by denying them the services they need and humiliating them. Media, as disseminators of dominant views of the value of PLWHA, tend to frame PLWHA (particularly LGBT) as deviant and non-conforming people, signalling expendability on the part of PLWHA. Nonconformity, like crime, prostitution, homosexuality, is a representation of ‘bad news’ and is the inevitable focus of societal conversations. Here, media like religion, exploits mass yearnings for drama and intrigue by presenting narratives of homosexuals, in general, and LGBT living with HIV in particular, as undeserving of sympathy and who can be allowed to die. Homosexuals living with HIV are devalued, degraded, humiliated and denied health services and consequently allowed to die.

iii. In what ways do PLWHA in Zimbabwe frame their own value?

This question was addressed in Chapter Seven, to establish the ways in which PLWHA frame their own value. Findings from this question show that when combined with HIV/AIDS, poverty works as a constant reminder of not only of the nearness of death but also a constant reminder of ‘loss of dignity’. Also, negotiating the reality of, on the one hand, knowing that lifesaving ARVs that can stall a lifetime of expected death are now available, and, on the other, knowing the impossibility of getting them, was in itself an impossible frontier and another reminder of their expendability. There is an element of inevitability about such loss of dignity and hopelessness among the poorest living with HIV in Zimbabwe, given that at the end of 2014 Zimbabwe was one of the world’s poorest countries, with 75% of its population experiencing poverty (see Chapter Two). Although there were these undertones of loss of hope in the face of exclusion, humiliation and abject poverty, there are PLWHA who stated how they ‘conquered’ the disease simply by staying alive. While some PLWHA were able to survive stigma and catastrophes and lived to tell their stories, some PLWHA, perhaps equally as brave, were dead. But those who lived strove to create a counter-narrative around their value. They try to redefine their value by fighting for survival as individuals on a daily basis and by moving forward – the will-to-live, despite the grimmest prospects. Resilience is the most illustrative aspect of what PLWHA coined as a victory – perseverance and improvisation. Resilience is further illustrated in the fortitude of spirit that is evidenced despite the reality of the nearness of death, hunger, being alone and stigma. Agency seems to be drawn from these spaces of redefinition of self-value by PLWHA. PLWHA have been able to draw international sympathy, and it is through them that the MoHCC survived the decades-
long economic crisis because the cause of PLWHA maintained donors such as PEPFAR, the Global Fund and the Health Transition Fund in Zimbabwe (see Table 2.4 in Section 2.5.3 and See Box 5.2 in Section 5.3.1). But, although the resilience perspective comes out as a counter-narrative of value by PLWHA to challenge the narratives of disgust, desolation and death framed by those who have not lived with HIV, they are also tactics of governmentality itself. Here, the responsibility of the GoZ to ensure the well-being of PLWHA is placed in the hands of PLWHA, who establish ways of coping, adapting and transforming in order to survive. In this way, the effects of the power of the government (SGOs) are rendered invisible as they retreat behind the mundane, everyday strategies for survival of PLWHA. While the PLWHA view themselves as survivors, who have conquered not just the effects of the virus on the body but the social effects of HIV, it appears that PLWHA are, after all, responsibilised to survive, without which they can be allowed to die.

iv. **What are the implications of valuing PLWHA, for their lives or, conversely deaths?**

Answering this question draws from the three research questions summarised in (i)–(iii) above. Taken together, the key findings suggest that framing the value of PLWHA has implications for survival or death of PLWHA. Firstly, framing PLWHA as citizens presents them as emancipated, equal, legal and political citizens who have social rights, and who can participate, belong and can access HIV treatment, which can have an impact in reducing risks of death. This view of emancipation through rights frames PLWHA as valued citizens. But, such kinds of rights governance are more entrenched because it is within everyday practices of expert networks, making it all the easier for SGOs to deny responsibilities for poor service delivery and any premature deaths on the notion that rights come with responsibilities that are co-shared with PLWHA.

Secondly, framing the value of PLWHA from a ‘client’ standpoint forces the clients (PLWHA) to behave in ways that increase their chances of accessing HIV care, thus, those PLWHA with lower purchasing power struggle to access ART due to cost implications. Thus individual wealth can confer value on the lives of the wealthy. Those who are poorer are allowed to die.
Thirdly, framing the value of PLWHA from a statistical representation perspective advances the role of SGOs in promoting the rights of PLWHA by rendering them visible. Visibilised PLWHA can be used as means to gain access to international funding, which can be used to increase the chances of survival for PLWHA by bringing such services as ART. But, using the same calculative rationality of statistics, SGOs also construct a discourse through which some subgroups of PLWHA are labelled as ‘key affected populations’ and consequently visibilised as non-conformers or deviants in society. Such visibilisation increases their chances of victimisation, violence, stigma and consequently increases their chances of death.

Fourthly, framing the value of PLWHA from an expendable populations perspective, speaks largely about subgroups of PLWHA, who fail to adhere to the norms of behaviour prescribed by the government, or their local communities, and consequently they are regarded as expendable populations who may be allowed to die. These sub-groups would include those with lower ability to purchase services (the poor) and homosexuals, sex workers and prisoners. They are subjected to normative regulation that can undermine their citizenship and allow them to die.

Finally, framing the value of PLWHA from a resilience perspective presents PLWHA as survivors with agency, who, through willpower, determination and hard work, have coped, adapted and transformed to emerge not as victims but as ‘resiliencers’. They try to redefine their value by fighting for survival on a daily basis that increases chances of survival. But, this resilience of PLWHA is also a tactic of governmentality whereby SGOs place the responsibility of well-being on PLWHA, without being obvious in their tactics. Should PLWHA fail to be resilient (responsibility), they can be allowed to die.

Central to these ways of framing the value of PLWHA are notions of allowable deaths. These emerge as premature, avoidable deaths that have been left to occur under conditions that could have been avoided (amenable to change). But there is a conviction on the part of institution (government, community, clinic, household) that the death happened because nothing could have been done under the prevailing conditions to prevent it. From this understanding, allowable death can be interrogated in diverse contexts, including warfare, human medical experiments, global health governance, migrants and refugees, disasters, racism, public health outbreaks, religious conflicts and anti-homosexuality narratives.
9.3 Reflections on the thesis

In this section, I reflect upon three key areas of the thesis, which are the methodology, analytical framework and future research.

9.3.1 Methodological reflections

This work was designed to investigate the ways in which the value of PLWHA is framed in health policy and in society by those living with and those infected by HIV/AIDS, using the Zimbabwe HIV/AIDS epidemic as a case study. A qualitative case study situated in the constructivist epistemology was used because it claims that truth is relative and that it is not dependent on one’s perspective, enabling participants and the researcher to co-construct knowledge (Guba and Lincoln 1994). This knowledge co-construction was especially helpful as it enabled voices of the researched to shape the knowledge agenda, central to the ‘how’ questions found in the analytics of governmentality (Bröckling et al. 2011). Using governmentality as both an analytical and methodological lens, through which we can investigate and understand the ways in which the value of PLWHA is framed in the Zimbabwe HIV/AIDS case study, not only resulted in significant findings, but also produced lessons which can be applicable in understanding how the value of human life is framed in other contexts.

With the wide range of issues to be understood in investigating the ways of framing the value of PLWHA, using qualitative methods, I was concerned about maintaining rigour. This related to issues of the validity and reliability of my study, and especially ensuring that findings and analyses would enable someone else to appreciate the rigour and depth of the study, and that another researcher in similar contexts would, within limits, have almost similar experiences as mine (Mays and Pope 1995). As already discussed in Chapter Four, the use of different methods of enquiry, and deliberately seeking knowledge from a broad range of sources (e.g. as many as 111 semi-structured interviews with PLWHA, life history interviews with PLWHA, FGDs with PLWHA and with non-PLWHA, interviewing SGOs), facilitated triangulation which assumes rigour in this study. As Woodhouse (1998) expresses, validity is obtained through the generation of explanations to account for what a range of respondents have said, and pursuing further enquiry until a researcher feels able to explain satisfactorily all the evidence the study has generated. A meticulous and thorough sampling was also essential to ensure rigour.
Specifically, to access hard-to-reach groups of PLWHA, respondent-driven sampling (RDS) (see Chapter Four) was used to identify and recruit PLWHA for interviews and FGDs. The approach allowed seeds (initial participants) and recruits (recruited participants) to recruit, rather than simply identifying participants exerting social influence where the researcher had none. The recruitment chain was made sufficiently long, allowing for deeper penetration of PLWHA networks, demonstrating agility for representativeness, useful for understanding the valuation of human life in policy and at the local community level where everyday interactions shape the phenomena of value. RDS has shown that it can be used for purposes of sampling and recruitment alone, particularly for hard-to-reach PLWHA sub-populations. It ensures a stable representative sample using non-probability sampling techniques. Also, by combining RDS with participant moderate observation, I deepened understanding, to look beyond the words, and to place myself in the life experiences of PLWHA and their context. This way, I managed to examine more than just what was said, seeking an inner voice in their accounts. Subjecting the findings to a governmentality framework using the analytics of government, episteme, techné and the ethical government of the self, the study not only identified the ways of framing the value of PLWHA, but also analysed the ways of valuations and their implications for life, or deaths, of PLWHA.

### 9.3.2 Reflections on the study’s conceptual framework

What is new, and central to this study, is how the value of human life is framed in policy. Significant in this is how allowable death emerges as a consequence of government action: governing through rights, statistics and responsibilisation (See Chapter Eight). The slave history, despite the extensive literature, does not provide adequate theoretical conceptualisation to understand the valuation of human life and the implications of such valuations on life or death, which may have consequences for the wider contemporary world.

To understand the valuation of human life and its effects, this study has shown that governmentality is essential for organising a model of understanding the valuation of human life in health policy. The notion of governmentality was especially useful because it provided practical ways of understanding the everyday actions of government, with non-PLWHA and PLWHA as tactics or technologies of government employed by the state to manage its populations. This study shows that, for one to understand allowable death in policy, one could consider integration of the following analytics of government:
i) Episteme of government  
ii) Techne of government  
iii) Ethical government of the self

These three arms of analytics of government not only help in understanding how the valuation of human life is framed but also its implications for life or, conversely, allowable deaths of a population in question. But, Foucault, an atheist himself, fails to acknowledge that power can manifest from the bottom with such elements as religion. The willpower for survival can create power of enablement and to resist the power-over. Governmentality fails to acknowledge that agency can come from the very hidden spaces of human life value, or from people’s power, to reclaim their personhood. Foucault came to recognise in his later work that he had not given sufficient consideration for the way in which the self is capable of self-invention. Thus the critiques, such as these argued by Kerr (1999), deserve further attention in light of the power of agency, enablement and resilience emerging from this study. This is especially pertinent, as the study demonstrates in Chapter Seven, by highlighting the ways some PLWHAs – ‘resiliencers’ – fashion for themselves another identity beyond that of simply ‘dirt’ or ‘dog’, that of disobedient materiality, that refuse to die under extraordinarily difficult and life threatening circumstances

9.3.3 Implications for further research

This study reflects on issues for further research by bringing out the concept of ‘allowable death’ as one with relevance in the Zimbabwean context. ‘Allowable deaths’ emerge as premature, avoidable deaths that have been allowed to occur under conditions that could have been avoided (amenable to change). There is, however, a conviction on the part of the organisation or individual (government, community, clinic, household, SGOs, individuals) that the death happened because nothing could have been done under the prevailing conditions to prevent it. This opens up new areas for further research. Also, at the global level, as Universal Health Coverage is now embedded in the 2030 agenda for Sustainable Development Goals (SDG), the concept of ‘allowable death’ becomes crucial as an explicit means to discuss the enforcement of human rights to “leave-no-one-behind”. Putting the concept of ‘allowable death’ along with policy discussions on premature mortality has significant implications for decisions made along the path toward Universal Health Coverage with respect to balancing the extension of ART and inclusion
of ‘all’ people. It is, as such, an appropriate time to consider the concept of ‘allowable death’ in policy and practice, by both the GoZ and civil society, if we are concerned about how to promote the ‘VoHL’ to best foster more social justice through enforceability of health rights.

9.4 Concluding remarks

In this chapter, I have sought to summarise findings to each of the research questions related to the ways in which i) senior government officials ii) PLWHA and iii) non-PLWHA frame the value of PLWHA in policy and everyday practice in Zimbabwe. The study also reflected on implications of valuing PLWHA, for their lives and, conversely, their deaths. The study shows that calculative rationalities, institutional arrangements and discursive framings are applied in health policy and in society, to frame the value of PLWHA - mainly as clients, citizens, statistics and expendable populations. Although these ways of framing may carry undertones of valuing the lives of PLWHA, they also tend to devalue the lives of PLWHA as expendable people. But PLWHA’s counter narrative to value their lives as resiliencers gives a sense of disobedient materiality, which emerges as agency or power of enablement, resistance and resilience for survival.

The chapter has reflected on the study methodology, analytical framework and also brings out issues for further research by identifying the concept of allowable death’ as one with relevance in the Zimbabwean context. But the concept also provides explicit means to discuss social justice through enforceability of health rights. Putting the concept of ‘allowable death’ along with the ‘Black Lives Matter’ movement in the U.S, LGBTQ movements worldwide, and the HIV/AIDS movement in Africa connects the rallying cries for the value of human life. Each different in its core objectives, they have each questioned ‘if human life is valued or not’ and protested against allowable death, humiliation and discrimination. The tenets of the arguments in all these movements are that all lives matter, all lives have value and lives need to be accorded their inherent value and worth. These are historical but also current examples of cases in which particular social groups have not been valued enough to be counted, even upon death.
REFERENCES


Erickson, B.H. (1979) ‘Some Problems of Inference from Chain Data,’ Sociological Methodology 10(1)276-302


Feinstein, J. S. (1993) ‘Relationship Between Socioeconomic Status and Health: A Review of the Literature,’ *Milbank Quarterly* 71(1)279-322


Development, CEHURD, in the Regional Network for Equity in Health in East and Southern Africa, EQUINET Discussion Paper 81


258


Appendix 1: Elite Interview Guide

Research question: In what ways do senior government officials (SGOs) in health policy frame the value of PLWHA in Zimbabwe

1. Policy and legal framework of HIV/AIDS (*The Episteme dimension*)
   - What ideals, beliefs or goals does the health ministry use to establish appropriate public sector interventions for HIV and AIDS? and what are the implications for this kind of governance/management?
   - Have there ever been major disagreements about the policy of how to distribute resources fairly or is everyone agreed on the means to do this

2. Calculative Devices (*The Techne dimension*)
   - What criterion is used to distinguish appropriate and inappropriate public sector interventions for HIV and AIDS
   - How does the method of choice take into account the extent to which the intervention treats people with dignity?
   - What decision-making techniques do you use to assess the trade-offs between HIV responses interventions in cases where multiple objectives or competing interests exist
   - Are PLWHA treated the same as (any different from) others who aren’t living with HIV in the community? In what ways?
   - Do you think HIV services for HIV are available in Goromonzi and Chitungwiza? What are these services? Are they adequate? So what are your plans to make everyone get the life saving medications?

3. Discursive framings (*The ethical government of the self*)
   - Are there words that have been said by other senior government officials that you feel should not have been said about PLWHA? *(probing: example - derogatory terms or pronouncements that insinuated that Government did not care enough for PLWHA?)*
   - Do you think PLWHA believe that you care about them enough? Why do you say that?
Appendix 2: Semi Structured Interview Guide

**Interview Number…………………………..**

**A: DEMOGRAPHIC CHARACTERISTICS**

1. Observe and record the sex
   - Male………………
   - Female………………

2. How old are you?
   …………………………………………………………………

3. What is the highest level of school you attended
   - No Schooling ……… Primary……… Secondary Higher………..

4. What is your religion?
   - Traditional ………..Roman Catholic ………
   - Protestant ……………Pentecostal……………
   - Apostolic Sect………….Muslim…………..……
   - None………..Other………..

5. What is your marital status?
   - single, never married, not in a relationship
   - married or domestic partnership
   - widowed, in a relationship
   - divorced, in a relationship
   - separated, in a relationship

6. Where was your HIV test done?
   - Central Hospital
   - Provincial Hospital
   - District Hospital
   - Rural Hospital
   - Rural Health Centre
   - Urban Municipal Clinic
   - Family Planning Clinic
   - School Based Clinic
   - Other Public Sector (Specify)
   - Mission Hospital/Clinic
   - Private Medical Sector
   - Private Hospital/Clinic
   - Private Doctor.
   - New Start Centre
   - School Based Clinic.
   - NGO Vct Centre
   - Other Source
   - Mobile Vct
   - Home
   - Correctional Facility
   - Other Private (Specify)

7. Are you currently taking ARVs?
   - Yes…………………………..
   - No…………………………..

8. Where do you get your ARVs from?
   (only for those currently taking ARVs)
   - I buy them from a private facility local
   - I buy them from a private facility in another area/district
   - I get them for free from my local clinic.
   - I get them for free from a health centre in another area/district
   - Someone buys them for me.
   - Other (specify)
9. **Employment Status**

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>employed for wages</td>
<td>self-employed</td>
</tr>
<tr>
<td>out of work and looking for work</td>
<td>out of work but not currently looking for work</td>
</tr>
<tr>
<td>a housewife/ a househusband</td>
<td>a student</td>
</tr>
<tr>
<td>retired</td>
<td>unable to work</td>
</tr>
<tr>
<td>other(specify)</td>
<td></td>
</tr>
</tbody>
</table>

**B: CALCULATIVE DEVICES (THE TECHNE DIMENSION)**

10. What HIV/AIDS services are available in your area? And which of these HIV/AIDS services do you use and why (Why do you prefer these services relative to others- probe why if there is a preference over modern medicines)?

...........................................................................................................................................................
...........................................................................................................................................................

**C: DISCURSIVE FRAMINGS (THE ERHICAL GOVERNMENT OF THE SELF)**

11. How do you perceive the treatment you get from the health facility in comparison to non HIV patients? *(kubatwa ne kurapwa zvese)*

...........................................................................................................................................................
...........................................................................................................................................................

12. In your opinion, what can be done to improve the treatment of PLWHIV at a health facility *(kubatwa ne kurapwa zvese)* (probe the way there received, valued,cared for and the provision/supply of the medicines)

...........................................................................................................................................................
...........................................................................................................................................................

13. What are your views on the way i) policy makers and ii) other people not infected by HIV, in this community perceive *(hukoshi)* worth and dignity of PLWHIV?

...........................................................................................................................................................
...........................................................................................................................................................

14. Do you think they value your life? *(Vanokoshesai here hupenyu hwennyu? (explain your answer))*

...........................................................................................................................................................
...........................................................................................................................................................

15. How do you value your life? *(munozvikoshesa hupenyu hwennyu sei? Sei muchiti hupenyu hwennyu hwakakosha)* ...........................................................................................................................................................
Appendix 3: Life-history Interview guide

Probing the following areas in discussion

1. General life-story of respondent, provoked by the question – Could you please tell me about yourself?
2. Age- what year where you born? How old are you?
3. Level of schooling - what is your highest level of education
4. Where and when the HIV test was done? How did you choose this place? Where you ill when you got tested? What happened? Tell me how you felt, tell me your experience? Who was there with you? Who in this community was there for you?
5. Current status on ARVs – Are you currently taking ARVs? When did you start? How has been your experience?
8. Religion – which religion are you? What does your religion say about your HIV status? What about ARVs? Or support and care?
9. Marital status – are you married? Or ever been married? Is your partner living with HIV too? Also taking/not taking ARVs?
10. What have been some of the challenges living with HIV so far? How have you dealt with some of these?
11. Probing about Value
   - Do you think Government officials even those living with HIV view themselves as any different from PLWHA in this community? Why?
   - What are the HIV/AIDS services available in this community? And which of these HIV/AIDS services do you use and why?
   - Do you think you are respected (valued) as others without HIV in the community? Why?
   - If you were to equate the value or the worth of your life to ‘something’ what would it be? Why?
   - Do you think the ministry of health or NAC view you value in that way too? Why?
### Appendix 4: Elite Interview Respondent and schedule

<table>
<thead>
<tr>
<th>*Code</th>
<th>Respondent characteristics and role</th>
<th>Years of experience in Government</th>
<th>Date of interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>EI:1</td>
<td>Technical Elite, Senior Government Official, MoHCC in Curative services: Medical Doctor, MBChB</td>
<td>30</td>
<td>13 May 2014</td>
</tr>
<tr>
<td>EI:2</td>
<td>Technical Elite, Senior Government Official, MoHCC, Nursing services - Nurse, BSc</td>
<td>20</td>
<td>14 June 2014</td>
</tr>
<tr>
<td>EI:3</td>
<td>Development Elite, Senior NGO liasing with the Global Fund, Zimbabwe National Association of people living with HIV/AIDS, Community groups liason: Nurse, Diploma Certificate</td>
<td>8</td>
<td>12 February 2014</td>
</tr>
<tr>
<td>EI:4</td>
<td>Technical Elite, Senior Government Official, MoHCC: AIDS and TB; Medical Doctor, MBChB</td>
<td>20</td>
<td>15 June 2014</td>
</tr>
<tr>
<td>EI:5</td>
<td>Technical Elite, Senior Government Official, MoHCC: policy, planning, monitoring and evaluation: Economist, BSc</td>
<td>12</td>
<td>16 March 2014</td>
</tr>
<tr>
<td>EI:6</td>
<td>Political Elite, Senior Government Official, MoHCC; Medical Doctor, MBChB</td>
<td>30</td>
<td>17 June 2014</td>
</tr>
<tr>
<td>EI:7</td>
<td>Technical Elite, Senior Government Official, MoHCC; Economist, BSc</td>
<td>6</td>
<td>18 June 2014</td>
</tr>
<tr>
<td>EI:8</td>
<td>Technical Elite, Senior Government Official, NAC; Medical Doctor MBChB</td>
<td>15</td>
<td>19 June 2014</td>
</tr>
<tr>
<td>EI:9</td>
<td>Development Elite, Senior NGO official, CDC/PEPFAR- Statistician, MSc</td>
<td>6</td>
<td>20 July 2014</td>
</tr>
<tr>
<td>EI:10</td>
<td>Political Elite, Senior Government Official, MoHCC; Medical Doctor, MBChB</td>
<td>17</td>
<td>27 June 2014</td>
</tr>
</tbody>
</table>

*MBChB - Bachelor of Medicine and Bachelor of Surgery degree  
*BSc- Bachelor of Science  
*MSc – Master of Science  
*MoHCC- Ministry of Health and Child Care

### Appendix 5: Focus Group Discussion Schedule

<table>
<thead>
<tr>
<th>*Code</th>
<th>District</th>
<th>Composition</th>
<th>Date of interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. FGD-GorA</td>
<td>Goromonzi</td>
<td>10 Non-PLWHA</td>
<td>14&lt;sup&gt;th&lt;/sup&gt; December 2013</td>
</tr>
<tr>
<td>2. FGD-ChA</td>
<td>Chitungwiza</td>
<td>12 Non-PLWHA</td>
<td>21&lt;sup&gt;st&lt;/sup&gt; December 2013</td>
</tr>
<tr>
<td>3. FGDPWA-ChA</td>
<td>Chitungwiza</td>
<td>10 PLWHA</td>
<td>4&lt;sup&gt;th&lt;/sup&gt; March 2014</td>
</tr>
<tr>
<td>4. FGD-ChB</td>
<td>Chitungwiza</td>
<td>12 Non-PLWHA</td>
<td>8&lt;sup&gt;th&lt;/sup&gt; March 2014</td>
</tr>
<tr>
<td>5. FGDPWA-ChB</td>
<td>Chitungwiza</td>
<td>10 PLWHA</td>
<td>23&lt;sup&gt;rd&lt;/sup&gt; March 2014</td>
</tr>
<tr>
<td>6. FGD-GorB</td>
<td>Goromonzi</td>
<td>10 Non-PLWHA</td>
<td>19&lt;sup&gt;th&lt;/sup&gt; April 2014</td>
</tr>
<tr>
<td>7. FGDPWA-GorA</td>
<td>Goromonzi</td>
<td>11 PLWHA</td>
<td>10&lt;sup&gt;th&lt;/sup&gt; May 2014</td>
</tr>
<tr>
<td>8. FGDPWA-GorB</td>
<td>Goromonzi</td>
<td>11 PLWHA</td>
<td>17&lt;sup&gt;th&lt;/sup&gt; May 2014</td>
</tr>
</tbody>
</table>
Appendix 6: Life History Interview Schedule

1) sex workers, 2) apostolic church network 3) young people born with HIV 4) Ex-Prisoners 5) not receiving ART and, 6) Support / home-based caregiver network. 7) Gays and lesbians

<table>
<thead>
<tr>
<th>*Code</th>
<th>pseudonym</th>
<th>District/Ward</th>
<th>Ref Chapter</th>
<th>Date interview of</th>
<th>of</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 LHIG111</td>
<td>Nyovorwai</td>
<td>Goromoni; Deera</td>
<td>5</td>
<td>25 May 2014</td>
<td></td>
</tr>
<tr>
<td>2 LHIG078</td>
<td>Tino</td>
<td>Goromoni; Gutu</td>
<td>6</td>
<td>01 June 2014</td>
<td></td>
</tr>
<tr>
<td>3 LHIC025</td>
<td>Tatenda</td>
<td>Chitungwiza; Seke</td>
<td>6</td>
<td>01 June 2014</td>
<td></td>
</tr>
<tr>
<td>4 LHIC025</td>
<td>Bernard</td>
<td>Goromoni; Mangwiro</td>
<td>6</td>
<td>14 June 2014</td>
<td></td>
</tr>
<tr>
<td>5 LHIC013</td>
<td>Mai Shingi</td>
<td>Chitungwiza; St Marys</td>
<td>7</td>
<td>21 June 2014</td>
<td></td>
</tr>
<tr>
<td>6 LHIC011</td>
<td>cLARA</td>
<td>Chitungwiza; St Marys</td>
<td>7</td>
<td>22 June 2014</td>
<td></td>
</tr>
</tbody>
</table>

Appendix 7: Focus Group Discussion- Non-PLWHA Participants

<table>
<thead>
<tr>
<th>Goromoni</th>
<th>Chitungwiza</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agritex Officer</td>
<td>Teachers</td>
</tr>
<tr>
<td>Apostolic Church Chiefs,</td>
<td>Nurses from Zengeza Clinic</td>
</tr>
<tr>
<td>Community Working Group on Health Nurse</td>
<td>Nurse from Chitungwiza Central Hospital</td>
</tr>
<tr>
<td>Health Centre Committee Chair</td>
<td>Nurse from St Marys Clinic</td>
</tr>
<tr>
<td>President’s Department (CIO);</td>
<td>ZANU PF representative</td>
</tr>
<tr>
<td>Rural District council Village</td>
<td>MDC representative</td>
</tr>
<tr>
<td>Heads Women AIDS Support Network</td>
<td>Health Centre committee Chair</td>
</tr>
<tr>
<td>Women Representatives Youth</td>
<td>Chitungwiza Town Council Representative</td>
</tr>
<tr>
<td>Representatives Zimbabwe National Army;</td>
<td></td>
</tr>
<tr>
<td>Zimbabwe Republic Police; Women</td>
<td>Local Women</td>
</tr>
<tr>
<td>Action Group NGO representative</td>
<td>Local Men</td>
</tr>
<tr>
<td>National AIDS Council representative(DAC)</td>
<td>Men Sports representative</td>
</tr>
<tr>
<td>Men Sports representative</td>
<td>Women Sports Representative</td>
</tr>
<tr>
<td>Women Sports Representative Local</td>
<td>Local business Representative</td>
</tr>
<tr>
<td>business Representative Village Health Worker</td>
<td>NGO representatives</td>
</tr>
<tr>
<td>Women in farming representative</td>
<td>ZiCHIRE</td>
</tr>
<tr>
<td>ZANU PF representative</td>
<td>Community Working Group on health</td>
</tr>
<tr>
<td>MDC representative</td>
<td>Youth Action Zimbabwe</td>
</tr>
<tr>
<td>Teachers</td>
<td>NCDPZ</td>
</tr>
<tr>
<td>Teachers</td>
<td>National AIDS Council representative(DAC)</td>
</tr>
<tr>
<td>Men Sports representative</td>
<td>Zimbabwe National Army;</td>
</tr>
<tr>
<td>Women Sports Representative Local</td>
<td>Zimbabwe Republic Police;</td>
</tr>
<tr>
<td>business Representative Village Health Worker</td>
<td>President’s Department (CIO);</td>
</tr>
<tr>
<td>Women in farming representative</td>
<td>Councillor</td>
</tr>
<tr>
<td>ZANU PF representative</td>
<td>Community Health worker</td>
</tr>
</tbody>
</table>
Appendix 8: Field Work Calendar

* See full code names in Table 4.12 (main thesis)

<table>
<thead>
<tr>
<th></th>
<th>Sep - 13</th>
<th>Oct - 13</th>
<th>Nov - 13</th>
<th>Dec -13</th>
<th>Jan - 14</th>
<th>Feb -14</th>
<th>Mar - 14</th>
<th>Apr - 14</th>
<th>May - 14</th>
<th>Jun - 14</th>
<th>Jul - 14</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st</td>
<td>MoHCC</td>
<td></td>
<td></td>
<td>C025</td>
<td>G057;</td>
<td>G084;</td>
<td>G108</td>
<td>LHIG07</td>
<td>MoHCC</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>G058;</td>
<td></td>
<td>G077;</td>
<td></td>
<td>8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>G059</td>
<td></td>
<td>G078</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2nd</td>
<td>Gor</td>
<td>Consent forms to seeds</td>
<td>Ch</td>
<td>C019</td>
<td>G096</td>
<td>G087</td>
<td>G109</td>
<td>EI:7</td>
<td>MoHCC</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>MoHCC</td>
<td></td>
<td>C032</td>
<td>Ch</td>
<td></td>
<td>G111</td>
<td></td>
<td></td>
<td>MoHCC</td>
<td></td>
</tr>
<tr>
<td></td>
<td>archival research</td>
<td>Gor</td>
<td>MoHCC</td>
<td></td>
<td>C033</td>
<td>FGDPWA-ChA</td>
<td>G097</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>MoHCC</td>
<td></td>
<td>C036</td>
<td>Ch</td>
<td></td>
<td>G098;</td>
<td></td>
<td></td>
<td>MoHC C</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>G088 G085</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>archival research</td>
<td>Gor</td>
<td>MoHCC</td>
<td></td>
<td>C004</td>
<td>C037</td>
<td>Ch</td>
<td>G094</td>
<td>Gor</td>
<td>MoHC C</td>
<td>MoHCC</td>
</tr>
<tr>
<td>7th</td>
<td>MRCZ ethics app submission</td>
<td>Gor</td>
<td>Gor</td>
<td>C007</td>
<td>C042</td>
<td>Ch</td>
<td>Gor</td>
<td>LHIC02</td>
<td>MoHCC</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>archival research</td>
<td>Gor</td>
<td>Gor</td>
<td>C009</td>
<td>C043</td>
<td>FGD-ChB</td>
<td>Gor</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>MoHC</td>
<td>MoHCC</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9th</td>
<td>archival research</td>
<td>Gor</td>
<td>Gor</td>
<td>C011</td>
<td>C035</td>
<td>Gor</td>
<td>G099;</td>
<td>G089</td>
<td>Gor</td>
<td>MoHC C</td>
<td>MoHCC</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>archival research</td>
<td>Gor</td>
<td>Gor</td>
<td>C006</td>
<td>C041</td>
<td>G060</td>
<td>G093</td>
<td>FGDPWA-GorA</td>
<td>MoHC</td>
<td>MoHCC</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11th</td>
<td>MoHCC</td>
<td>Gor</td>
<td>C010</td>
<td>C040</td>
<td>G063</td>
<td>G100;</td>
<td>G092</td>
<td>G073</td>
<td>G076</td>
<td>MoHC C</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12th</td>
<td>MoHCC</td>
<td>Gor</td>
<td>C005</td>
<td>EI:3</td>
<td>G065</td>
<td>G091</td>
<td>G073</td>
<td>Gor</td>
<td>MoHC C</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13th</td>
<td>MoHCC</td>
<td>Gor</td>
<td>C012</td>
<td>Ch</td>
<td>G061</td>
<td>G090;</td>
<td>G101</td>
<td>Gor</td>
<td>EI:4</td>
<td>MoHCC</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sep - 13</td>
<td>Oct - 13</td>
<td>Nov - 13</td>
<td>Dec -13</td>
<td>Jan - 14</td>
<td>Feb-14</td>
<td>Mar - 14</td>
<td>Apr - 14</td>
<td>May - 14</td>
<td>Jun -14</td>
<td>Jul - 14</td>
</tr>
<tr>
<td>--------</td>
<td>----------</td>
<td>----------</td>
<td>----------</td>
<td>---------</td>
<td>----------</td>
<td>--------</td>
<td>----------</td>
<td>----------</td>
<td>----------</td>
<td>---------</td>
<td>----------</td>
</tr>
<tr>
<td>14th</td>
<td></td>
<td></td>
<td></td>
<td>MoHCC</td>
<td>FGD-GorA</td>
<td>C008</td>
<td>Ch</td>
<td>G062</td>
<td>G105</td>
<td>Gor</td>
<td>LHIG075</td>
</tr>
<tr>
<td>15th</td>
<td></td>
<td></td>
<td></td>
<td>MoHCC</td>
<td>C001</td>
<td>C026</td>
<td>C044</td>
<td>G067</td>
<td>G104; G102</td>
<td>Gor</td>
<td>MoHCC</td>
</tr>
<tr>
<td>16th</td>
<td></td>
<td></td>
<td></td>
<td>archival research</td>
<td>Ch</td>
<td>Ch</td>
<td>C021</td>
<td>C045</td>
<td>C034</td>
<td>C064</td>
<td>G107</td>
</tr>
<tr>
<td>17th</td>
<td></td>
<td></td>
<td></td>
<td>archival research</td>
<td>Ch</td>
<td>C002</td>
<td>C015</td>
<td>C038</td>
<td>G066</td>
<td>G068</td>
<td>FGDPW A-GorB MoHCC</td>
</tr>
<tr>
<td>18th</td>
<td></td>
<td></td>
<td></td>
<td>archival research</td>
<td>Ch</td>
<td>C003</td>
<td>C028</td>
<td>C039</td>
<td>G069</td>
<td>G072</td>
<td>G081</td>
</tr>
<tr>
<td>19th</td>
<td></td>
<td></td>
<td></td>
<td>archival research</td>
<td>Ch</td>
<td>Ch</td>
<td>C018</td>
<td>C013</td>
<td>C046</td>
<td>FGD-GorB</td>
<td>Gor</td>
</tr>
<tr>
<td>20th</td>
<td></td>
<td></td>
<td></td>
<td>archival research</td>
<td>Ch</td>
<td>Ch</td>
<td>C020</td>
<td>C047</td>
<td>C048</td>
<td>Gor</td>
<td>MoHCC</td>
</tr>
<tr>
<td>21st</td>
<td></td>
<td></td>
<td></td>
<td>archival research</td>
<td>Ch</td>
<td>FGD-ChA</td>
<td>C030</td>
<td>C049</td>
<td>EI:5</td>
<td>Gor</td>
<td>LHIC013 MoHCC</td>
</tr>
<tr>
<td>22nd</td>
<td></td>
<td></td>
<td></td>
<td>archival research</td>
<td>Ch</td>
<td>C031</td>
<td>C050</td>
<td>Gor</td>
<td>LHIC013 MoHCC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23rd</td>
<td></td>
<td></td>
<td></td>
<td>archival research</td>
<td>Ch</td>
<td>C023</td>
<td>C014</td>
<td>C056</td>
<td>FGDPW A-ChB</td>
<td>Gor</td>
<td>MoHCC</td>
</tr>
<tr>
<td>24th</td>
<td></td>
<td></td>
<td></td>
<td>archival research</td>
<td>Ch</td>
<td>C017</td>
<td>C055</td>
<td>MoHCC</td>
<td>MoHCC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25th</td>
<td></td>
<td></td>
<td></td>
<td>archival research</td>
<td>Ch</td>
<td>C032</td>
<td>C051</td>
<td>LHIG11</td>
<td>MoHCC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26th</td>
<td></td>
<td></td>
<td></td>
<td>archival research</td>
<td>MoHCC</td>
<td>C027</td>
<td>C052</td>
<td>G079</td>
<td>G086</td>
<td>MoHCC</td>
<td></td>
</tr>
<tr>
<td>27th</td>
<td></td>
<td></td>
<td></td>
<td>Approval from MRCZ</td>
<td>C016</td>
<td>C053</td>
<td>C054</td>
<td>G080</td>
<td>G082</td>
<td>MoHCC</td>
<td>EI:10 MoHCC</td>
</tr>
<tr>
<td>28th</td>
<td></td>
<td></td>
<td></td>
<td>Approval form Gor</td>
<td>C022</td>
<td>G083</td>
<td>MoHCC</td>
<td>MoHCC</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>29th</td>
<td></td>
<td></td>
<td></td>
<td>Approval form Gor</td>
<td>C024</td>
<td>G075</td>
<td>EI:1</td>
<td>MoHCC</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30th</td>
<td></td>
<td></td>
<td></td>
<td>Approval form Gor</td>
<td>C029</td>
<td>G077</td>
<td>MoHCC</td>
<td>EI:6 MoHCC</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>31st</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>MoHCC</td>
</tr>
</tbody>
</table>
## Appendix 9: Field work Timeline

<table>
<thead>
<tr>
<th>Field Activity</th>
<th>Timelines</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethical Clearance University of Manchester</td>
<td>June 2013-August 2013</td>
</tr>
<tr>
<td>Ethical Clearance Medical Research Council of Zimbabwe</td>
<td>September 2013 - November 2013</td>
</tr>
<tr>
<td>Semi-structured Interviews</td>
<td>December 2013- May 2014</td>
</tr>
<tr>
<td>Focus group Discussions</td>
<td>December 2013- May 2014</td>
</tr>
<tr>
<td>Life History Interviews</td>
<td>May 2014- June 2014</td>
</tr>
<tr>
<td>Elite Interviews</td>
<td>February – July 2014</td>
</tr>
<tr>
<td>Document Analysis</td>
<td>October 2012 – December 2015</td>
</tr>
</tbody>
</table>

## Appendix 10: Semi Structured Interview Respondents: A brief description

<table>
<thead>
<tr>
<th>Code</th>
<th>District / Ward</th>
<th>Year born/ Sex</th>
<th>Respondent characteristics and their networks that correspond with Seeds</th>
<th>Date of interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>C001</td>
<td>Chitungwiza Unit K</td>
<td>1975, F</td>
<td>She was a former nurse and a founder of a home-based care programme for PLWHA. She lost a husband to AIDS when she was 32 years old. She chairs the local HIV support group and is the focal person for the Zimbabwe National Association of People Living with HIV (ZNNP+). She linked group members to local activities supported by the National AIDS Council’s District AIDS Coordinator (DAC) and other NGOs. Now 39 years old, she has three children and her last-born son, aged seven, is living with HIV. She is on ART and so is her son. [Seed]</td>
<td>15&lt;sup&gt;th&lt;/sup&gt; December 2013</td>
</tr>
<tr>
<td>C002</td>
<td>CH St Mary’s</td>
<td>1965, F</td>
<td>She was a founder of a local HIV/AIDS support group for young people that were born with, and other people affected by and infected with, HIV/AIDS. Before she began her antiretroviral therapy (ART), she had been put on a waiting list at Harare hospital for 11 months. Prior to ART initiation, she had advanced HIV, suffered from tuberculosis and developed recurrent retinal opportunistic infections, which led to her losing one eye. At the time of the research, she was 49 years old. [Seed]</td>
<td>17&lt;sup&gt;th&lt;/sup&gt; December 2013</td>
</tr>
<tr>
<td>C003</td>
<td>Chitungwiza Unit F</td>
<td>1990, M</td>
<td>He was born with HIV and had lost both parents when he was seven. His uncle, who had four other children of his own, raised him, but he could not complete secondary school. At the time of the interview, he was 24 years old, unemployed and hoped to get married once he found a suitable partner, what he termed ‘my true love’. He was also an active community home-based caregiver and was on ART. [Seed]</td>
<td>18&lt;sup&gt;th&lt;/sup&gt; December 2013</td>
</tr>
<tr>
<td>C004</td>
<td>Chitungwiza Zengeza 4</td>
<td>1977, M</td>
<td>At a young age of 34, the 37-year-old was already a landlord after buying his four-bedroom house in Chitungwiza. He believed that he would not have managed to live in the city while living with HIV because ‘life is so expensive here if you are lodger, you need something that you can call your own. I feel sorry for young girls that’s why most of them get into prostitution and especially become ma small house [mistresses] of much older men, because life is cruel when you have HIV.’</td>
<td>6&lt;sup&gt;th&lt;/sup&gt; January 2014</td>
</tr>
<tr>
<td>C005</td>
<td>Chitungwiza St Mary’s</td>
<td>1973, F</td>
<td>The 41-year-old was waiting for a CD4 function test, which would be done a week after the interview at Chitungwiza Central Hospital, to prepare his for ARVs.</td>
<td>12&lt;sup&gt;th&lt;/sup&gt; January 2014</td>
</tr>
<tr>
<td>Code</td>
<td>District / Ward</td>
<td>Year born/ Sex</td>
<td>Respondent characteristics and their networks that correspond with Seeds</td>
<td>Date of interview</td>
</tr>
<tr>
<td>-------</td>
<td>----------------</td>
<td>---------------</td>
<td>---------------------------------------------------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>C006</td>
<td>Chitungwiza Unit D</td>
<td>1959, F</td>
<td>The 55-year-old had generalised ringworms all over her body; she said she was not taking one of her three combination ARVs because they were in short supply where she got them. She got her ARVs in another district as she felt that there was inadequate private counselling space at Chitungwiza Central Hospital.</td>
<td>10th January 2014</td>
</tr>
<tr>
<td>C007</td>
<td>Chitungwiza Unit D</td>
<td>1978, M</td>
<td>36 years old, born and raised at a mission school in Goromonzi by a headmaster and a mathematics teacher, his father and mother respectively. C007 was highly educated, holding advanced graduate degrees, an MBA to be precise. A self-made man, worked for an NGO in Harare. C007 was quite confident, and well spoken, and was highly knowledgeable about ARVs. His approach to the disease was that of an intellectual, and he relied on his understanding to explain his experience living with HIV and how policy-makers perceived his worth. When he spoke he rarely allowed distress to enter his recollections; he thought the government did not respect people like him much and neither did society. C007 was diagnosed with HIV/AIDS in 2012, although he traces his infection to 2004. He lived alone as a single man although he said he once had a ‘live-in girlfriend’ who died in 2004. He blamed the government for being slow on HIV interventions at the beginning of the pandemic and felt that if more resources had been channelled to health, ‘then not so many people would have died, including the woman that I could have married’. He thought that it was costly living with HIV as one needed to invest resources for frequent visits to the hospital, including a healthy diet among other demands for out-of-pocket costs.</td>
<td>7th January 2014</td>
</tr>
<tr>
<td>C008</td>
<td>Chitungwiza Takesure St Mary’s</td>
<td>1995, M</td>
<td>A 19-year-old teenage boy who lost both parents to HIV and who was born with HIV, lived and worked on the streets, took drugs and began to weave laundry baskets and clean cars on the streets to earn a living. C008 explained, ‘Taking ARVs I had to navigate how to buy material to weave baskets, cause my grandmother is very poor. That’s why I ended up here, sometimes I feel like I want to run away, because of how people view me, some think I chose to have HIV, but I was born with it, and I’m lucky that I am where I am today when most died.’</td>
<td>14th January 2014</td>
</tr>
<tr>
<td>C009</td>
<td>Chitungwiza Zengeza 2</td>
<td>1962, M</td>
<td>Leader at Mwazha Johanne Masowe African Apostolic Church, 52 years old, secretly taking ARVs but his two wives do not know although he hopes to tell them.</td>
<td>8th January 2014</td>
</tr>
<tr>
<td>C010</td>
<td>Chitungwiza St Mary’s</td>
<td>1963, F</td>
<td>From St Mary’s, the 51-year-old woman was turned away from the health services in Seke because the queues were always long and the nurses where few. Her daughter moved her to Chitungwiza, where C010 now lived. Even when she got to Chitungwiza she was turned away from the health services in Seke because she was initiated on HIV treatment at Chitungwiza Central Hospital. She believes that the National AIDS Council cares for PLWHA but the nurses do not. She believes that her life has value inasmuch as those she loved believed that she was still capable of loving them despite the HIV infection. ‘At the clinics, unobatwa sembwa, seusina kana basa [treated like dogs as you do not matter].’</td>
<td>11th January 2014</td>
</tr>
<tr>
<td>C011</td>
<td>Chitungwiza St Mary’s</td>
<td>1995, F</td>
<td>Born with HIV, Clara, a 19-year-old girl, whom they call shura at the ‘home’ where she spent most of her teenage years, is an entrepreneur owning a small hair salon. From her proceeds she could take care of herself including getting her monthly sanitary wear, deodorant, phone and getting transport fees to the hospital for her ARV supply.</td>
<td>9th January 2014</td>
</tr>
<tr>
<td>C012</td>
<td>Chitungwiza Zengeza 1</td>
<td>1973, F</td>
<td>‘Right, he died of meningitis, but I was pretty sure from what I was hearing from the radio at that point that it was AIDS. And, I was frightened but didn’t show it and especially that there wasn’t much I could do about it. But I knew in my mind that I probably was positive, I was only 25 and we had been living together since I was 19.’ C012 lost her first boyfriend to AIDS. She only began treatment ten years after the death of her boyfriend in 2008 when she was 35. She finally got married to a man who was also living with HIV and was two years her senior. They did not have any children and were not planning to have any. The 39-year-old said that she finally was living the life she had hoped for when she was 20 despite many years feeling like ‘Shit, uchingoshorwa [looked down upon]’.</td>
<td>13th January 2014</td>
</tr>
<tr>
<td>C013</td>
<td>Chitungwiza Mai Shingi St Mary’s</td>
<td>1965, F</td>
<td>Born 1965 with two children, lost husband to HIV, works as a cross-border trader between the borders of Mozambique, South Africa and Zimbabwe. C013 believed that handling and managing her responsibilities in raising her children was not an option but an expectation: ‘I feel like all that I have done in my life is to work for my children.’</td>
<td>19th January 2014</td>
</tr>
<tr>
<td>Code</td>
<td>District / Ward</td>
<td>Year born/ Sex</td>
<td>Respondent characteristics and their networks that correspondent with Seeds</td>
<td>Date of interview</td>
</tr>
<tr>
<td>------</td>
<td>----------------</td>
<td>---------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>C014</td>
<td>Chitungwiza St Mary’s</td>
<td>1969, M</td>
<td>A 45-year-old Seventh-Day Adventist who believes that going to church helps him to deal with HIV. He believes that the SDA cares for PLWHA emotionally including where to get expert help. He does not believe that health providers, especially public services, care about poor people in general.</td>
<td>23rd January 2014</td>
</tr>
<tr>
<td>C015</td>
<td>Chitungwiza St Mary’s</td>
<td>1968, M</td>
<td>A 46-year-old man who had been HIV-positive for one year, and he was not taking ARVs yet. ‘I’ve decided that CD4 count tests is less important to me than feeling like my body is managing well presently.’ C015 was a self-assured, confident and authoritative man who worked in government offices in Harare.</td>
<td>17th January 2014</td>
</tr>
<tr>
<td>C016</td>
<td>Chitungwiza Unit O</td>
<td>1987, F</td>
<td>The 27-year-old had a child with a married man whom she believes infected her with HIV. She was not on ARVs because she did not have the US$5 needed for consultation.</td>
<td>27th January 2014</td>
</tr>
<tr>
<td>C017</td>
<td>Chitungwiza St Mary’s</td>
<td>1982, F</td>
<td>At 32, she already had two children whom she has raised ‘well, despite doing it all by myself’. She lost a husband and friends to HIV and she believes that as long as children know that she is living with HIV and how she got it, it could help to make her children more careful about HIV.</td>
<td>24th January 2014</td>
</tr>
<tr>
<td>C018</td>
<td>Chitungwiza St Mary’s</td>
<td>1964, M</td>
<td>Was waiting for a liver function test at Marondera Provincial Hospital to prepare for his ARVs. The 50-year-old said it was better to get the tests done in province other than his own because he was not yet ready to let the wider community know about his HIV status.</td>
<td>19th January 2014</td>
</tr>
<tr>
<td>C019</td>
<td>Chitungwiza St Mary’s</td>
<td>1965, F</td>
<td>C019, 52, used to work in the Lever Brothers manufacturing industry before it got closed down soon after the economic crisis in Zimbabwe. She maintained regular HIV tests at work through the workplace programme on HIV because she suspected her husband was having affairs with multiple women on the side. She could not initiate condom use in the home as it could make her husband divorce her or abuse her and so she needed to be sure before she could confront her husband. But. Then, one day, she recalled, ‘I slept with him [sexual intercourse] and a few weeks later I had flu-like symptoms [a common sign of an early HIV infection]’. Seven months after that, she had her HIV diagnosis. C019 has never worked since then and has become one of Chitungwiza Central Hospital’s HIV patients.</td>
<td>2nd February 2014</td>
</tr>
<tr>
<td>C020</td>
<td>Chitungwiza Zengeza 5</td>
<td>1968, M</td>
<td>A 46-year-old man, quite active in local political meetings; he chairs the Zimbabwe African National Union – Patriotic Front meetings.</td>
<td>20th January 2014</td>
</tr>
<tr>
<td>C021</td>
<td>Chitungwiza St Mary’s</td>
<td>1958, F</td>
<td>The 56-year-old Seke resident believes that her life can be equated to a gum tree because of its healing properties and its propensity to grow taller than other trees around it. C021 lost her daughter to HIV. Her daughter was infected with HIV after her second marriage. C021 looks after her grandchildren, one of whom is also living with HIV and not on treatment.</td>
<td>16th January 2014</td>
</tr>
<tr>
<td>C022</td>
<td>Chitungwiza Unit N</td>
<td>1955, F</td>
<td>The 59-year-old lost a husband to HIV and was in denial for a long time before she began treatment. ‘I was very loyal to my husband, I was a perfect wife, always went to church, cooked for him and truly loved him. But then I married the devil himself. He cursed me by giving me this disease. I could not start taking the ARVs because my CD4 count was still above the required number until they changed the number to a bigger figure [from 200–350 cells/mm³] that make people treat me as if I was useless. I delayed ART initiation because it was difficult to understand why God had punished me to that extent despite my loyalty and faithfulness. I just continue to pray.’</td>
<td>28th January 2014</td>
</tr>
<tr>
<td>C023</td>
<td>Chitungwiza Unit B</td>
<td>1969, M</td>
<td>Taking ARVs, the 45-year-old widower believes that the value of his life is like a shining beacon that will live for eternity.</td>
<td>23rd January 2014</td>
</tr>
<tr>
<td>Code</td>
<td>District / Ward</td>
<td>Year born/ Sex</td>
<td>Respondent characteristics and their networks that correspond with Seeds</td>
<td>Date of interview</td>
</tr>
<tr>
<td>-------</td>
<td>---------------------</td>
<td>----------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>C024</td>
<td>Chitungwiza St Mary’s</td>
<td>1968, M</td>
<td>For 46-year-old C024, the voice that came through was that of facing and confronting hardships: ‘You know when I got diagnosed of HIV when I was only 31, it felt like a cold blow, a numbing cold slap that froze my being. But with time we relearn who we are and relearn to dive into the fire to save ourselves and those we love despite losing everything, honour respect, value and all that comes with human dignity. I lost my wife and lost respect and value in my children’s eyes but I fought to get that back.’</td>
<td>29th January 2014</td>
</tr>
<tr>
<td>C025</td>
<td>Chitungwiza Tatenda Seke</td>
<td>1987, F</td>
<td>The 27-year-old lesbian was quite butch-looking and identifies as a transgender man. He said he could not get tested (in either government or private testing centres) with his girlfriend because of his sexual orientation.</td>
<td>1st February 2014</td>
</tr>
<tr>
<td>C026</td>
<td>Chitungwiza St Mary’s</td>
<td>1966, M</td>
<td>The 39-year-old father was married but has a mistress who lives two households away, a married woman. C026 did not tell his mistress that he was living with HIV. C026 is not on ARVs because he is still on the waiting list.</td>
<td>15th January 2014</td>
</tr>
<tr>
<td>C027</td>
<td>Chitungwiza St Mary’s</td>
<td>1975, F</td>
<td>When asked when she was born, she said, ‘err, let’s see, erm, mmmm, I was born in—1975 here in St Mary’s, grew up here. I think, erm, I’m certain that I— I was born polygamous in nature, bisexual to some extent and definitely uh, alcoholic. I started drinking when I was 16 and never stopped. I had sex with men in my earlier years and discovered that uh, erm actually, I love women more hahaha. So and uh then the— the— the journey from the discovery of liking women too took a lot of twists and turns. So, ah, um, and I was, you know, it really opened up the sexuality in me, but unfortunately I was already infected with HIV and women are difficult to settle with because iii, here you will be stoned alive hahaha. But despite this HIV I really feel complete because I’m in love and she loves me back.’</td>
<td>26th January 2014</td>
</tr>
<tr>
<td>C028</td>
<td>Chitungwiza Zengeza 5</td>
<td>1996, M</td>
<td>Born with HIV, C028, an 18-year-old homosexual man, had a mix of feelings around his value of life. As he put it, ‘I have never really felt anything for girls. When I was 9, I always liked to look at my cousin’s boyfriend who was extremely gorgeous, you see even my voice refused to change much during these years when others’ voices have been changing, my aunt says it’s probably the pills [ARVs], but I know it’s because I’m really a girl inside. Soo-ou hahaha, I have this pumpkin (boyfriend), three years together now, he lives not far from my house, and I love him and he loves me. He knows I have it [HIV], but we always do it with a condom. My life is not going to be long for sure because there is no cure as yet and I have managed to get this far I don’t know how much time I have left so I will use that time just to be me, and loving men of course. The problem is, he is married to a woman, and he doesn’t want anyone to suspect that we are doing it [sexual intercourse]. Last week he was suggesting that we go to Plumtree, because he knows of a hideaway hahaha, enough with these stories! My point is, he values me and the rest don’t but because he is very important to me I believe that’s what counts. Forget the National AIDS Council it doesn’t even know we are here so I can say that those whom we are in love with value us, people, in general, are disgusted by us [PLWHA] and the government doesn’t even care about us [PLWHA] thank you very much!’</td>
<td>18th January 2014</td>
</tr>
<tr>
<td>C029</td>
<td>Chitungwiza St Mary’s</td>
<td>1972, F</td>
<td>A 42-year-old, on ARVs, who had been turned away from accessing services at the hospital due to long queues.</td>
<td>30th January 2014</td>
</tr>
<tr>
<td>C030</td>
<td>Chitungwiza Zengeza 1</td>
<td>1974, F</td>
<td>A 40-year-old woman who says she almost died of AIDS when she was 30 when all three partners including her husband died in a space of less than two years. ‘When I got out of hospital in Harare, I couldn’t walk, I hated everything and everyone. I had to relearn to love, to accept, to walk and to forget. I was mentally, emotionally and physically eroded, well depleted. I was a living dead. But I thought I needed a second chance in life and so I began to rebuild my body one step at a time. My family was most supportive especially my eldest daughter, she bathed and fed me on her own. She was 16 then. I told her how I got infected and where it led me. I knew I had to tell her then. I did not want her to fall into the same corner as me and end up losing her own life, me and her father. So it was hard. But here I am now. I persevered.’ She also leads the women’s session at kuMasowe [African Apostolic Church] every Friday at sundown to talk about how to survive with HIV.</td>
<td>21st January 2014</td>
</tr>
<tr>
<td>Code</td>
<td>District / Ward</td>
<td>Year of Birth</td>
<td>Year of Sex</td>
<td>Respondent characteristics and their networks that correspond with Seeds</td>
</tr>
<tr>
<td>-------</td>
<td>----------------</td>
<td>--------------</td>
<td>-------------</td>
<td>-------------------------------------------------</td>
</tr>
<tr>
<td>C031</td>
<td>Chitungwiza</td>
<td>1968, M</td>
<td></td>
<td>A 46-year-old who participates in monthly HIV/AIDS support group meetings, where he gets information regarding new HIV drugs, new combination therapies, nutrition and HIV/AIDS activities happening in the community. He says he wants to be one of the first to get cured once the cure has been discovered, so keeping in touch with others living with HIV in the group helps to keep him informed.</td>
</tr>
<tr>
<td>C032</td>
<td>Chitungwiza</td>
<td>1980, F</td>
<td></td>
<td>An unemployed 34-year-old who describes her experience based on the perceptions of society as ‘pane smoko [there is smoke]’. She believes that society is afraid because while it scientifically wants to understand what it means to live with HIV, oftentimes society wants to moralise it. It is in this moralisation perspective that C032 described ‘pane smoko’ to express the lives of PLWHA and how others not living with HIV value PLWHA particularly the poor PLWHA.</td>
</tr>
<tr>
<td>C033</td>
<td>Chitungwiza</td>
<td>1968, M</td>
<td></td>
<td>A 46-year-old man, married three times and divorced once and whose first wife is deceased. He lived with his third wife whom he had no children with as they both lived with HIV and decided not to have more children. C033 sees his worth in life as that of Muhammed Ali, an undefeated giant African boxer, who fought for a noble cause. He also believes that his value is like that of a diamond whose worth defies time, whose strength is beyond man and whose strength cannot be crushed by the hands of ‘man’.</td>
</tr>
<tr>
<td>C034</td>
<td>Chitungwiza</td>
<td>1974, M</td>
<td></td>
<td>A 40-year-old man, now husband to a 22-year-old woman, almost half his age, who lost his first wife when he was only 30. His first wife passed on when she was only 24. He could not get onto HIV treatment because there was a shortage and his wife died before she could get the ARVs. Much of his meaning of the value of his life is tied to his sobriety from alcohol and ‘Mogo’ [tobacco]. He often became overwhelmed with emotion as he shared his life events and would say, ‘Wait, I don’t want you to go. I want you to stay because I want to let it out, let me smoke a bit and I will come back.’ Use of alcohol and tobacco permeate his understanding of HIV and his life overall: ‘I told the doctor that I wasn’t going to stop smoking, because death is death, you can be killed by tobacco, or HIV or cholera or accidents, so it’s the same, what’s the point to taking a clean body to the grave? HIV is a cancer if you can’t deal with it using tobacco, haa you can die of stress hahaha….’</td>
</tr>
<tr>
<td>C035</td>
<td>Chitungwiza</td>
<td>1968, F</td>
<td></td>
<td>Living with HIV, the 46-year-old used to work as a sex worker in Chitungwiza and Harare Avenues. She said that because she managed to send all her children to school she did not feel the need to continue with sex work. She said she was aware that sex work would get her infected with HIV and other STIs and so she fully embraced the consequences as she did sex work to give her children a head start in life. C035 infected her late husband, who died of AIDS.</td>
</tr>
<tr>
<td>C036</td>
<td>Chitungwiza</td>
<td>1980, F</td>
<td></td>
<td>CO36, a 34-year-old woman uses Muriranyenze (herb) instead of ARVs. C36 argues that herbs that she had used for 11 years are more efficient than ARVs because herbs are organic. She is a former sex worker, and she doesn’t want anyone to know that she has HIV. She believes that when she dies it would be her time, she says she was not afraid of death, but death should be afraid of her because she has defied death many times.</td>
</tr>
<tr>
<td>C037</td>
<td>Chitungwiza</td>
<td>1979, F</td>
<td></td>
<td>The 35-year-old lost a partner to HIV and describes her life as ‘kubatwa sembwa unoita seusina basa’ [treated like a dog, it feels like you are useless and always devalued].</td>
</tr>
<tr>
<td>C038</td>
<td>Chitungwiza</td>
<td>1952, F</td>
<td></td>
<td>The 62-year-old was not taking ARVs because she believed that she was old enough to die and that there are other younger people who still need to enjoy their lives and need the ARVs, which are in short supply, more than she does.</td>
</tr>
<tr>
<td>C039</td>
<td>Chitungwiza</td>
<td>1973, F</td>
<td></td>
<td>CO39 got her HIV diagnosis at a local clinic when she was pregnant, five years before the interview in 2009. In 2014, the 41-year-old was not yet taking any medication to treat her HIV: ‘I only took navirapine when I was pregnant and stopped because I did not feel ready to be as compliant as I should be, I am still not ready and will do so when I am mentally prepared.’</td>
</tr>
<tr>
<td>Code</td>
<td>District / Ward</td>
<td>Year born/ Sex</td>
<td>Respondent characteristics and their networks that correspondent with Seeds</td>
<td>Date of interview</td>
</tr>
<tr>
<td>-------</td>
<td>------------------------</td>
<td>----------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>C040</td>
<td>Chitungwiza St Mary’s</td>
<td>1977, F</td>
<td>C040, a single 37-year-old mother, was worried about her cholesterol, a common side effect of HIV medicine, ‘I lost my husband who was as fat as I am to this disease [HIV]. I try to eat well and walk to the shops or hospital instead of taking a Kombi [public transport]. The problem is these HIV medicines make us look funny. This is what makes people think that we are not even worth anything.’</td>
<td>11th February 2014</td>
</tr>
<tr>
<td>C041</td>
<td>Chitungwiza St Mary’s</td>
<td>1976, F</td>
<td>A 38-year-old nurse with two children, got infected in the hospital and administered post-exposure prophylaxis but she still got infected. She believed that patients generally did not want to be treated by someone they knew was living with HIV and she felt that her value was demoted once colleagues and others in Chitungwiza began to talk about her HIV status.</td>
<td>10th February 2014</td>
</tr>
<tr>
<td>C042</td>
<td>Chitungwiza Unit K</td>
<td>1967, F</td>
<td>A 47-year-old, who was on HIV treatment, was a vendor who sold second-hand clothing and lost her teenage daughter to HIV six months before the interview.</td>
<td>7th February 2014</td>
</tr>
<tr>
<td>C043</td>
<td>Chitungwiza Unit D</td>
<td>1979, M</td>
<td>The 35-year-old has a doctorate degree from the University of Zimbabwe (DPhil, UZ). He has a steady income, is on ARVs and participates in the local HIV support group to support others.</td>
<td>9th February 2014</td>
</tr>
<tr>
<td>C044</td>
<td>Chitungwiza St Mary’s</td>
<td>1974, M</td>
<td>When she was diagnosed, at the age of 30, the 40-year-old said she ‘didn’t know anybody close whom I could talk to in confidence, and I felt lonely, terrified and ashamed. Plus, I was scared, that I would have skin lesions or warts or some terrible skin disease that everyone would see and out me for being HIV-positive.’ But, C044 began a community action group project against discrimination, which now has more than 200 people who reach out to her. She said: ‘It’s a huge responsibility but I feel quite honoured and very much appreciated and neither alone nor lonely.’ She was not yet taking ARVs as she felt she was not ready.</td>
<td>15th February 2014</td>
</tr>
<tr>
<td>C045</td>
<td>Chitungwiza Unit D</td>
<td>1973, M</td>
<td>C045 describes his endurance with AIDS as ‘value’ that could never be priced. When he lost his closest gay friend, who was also his sexual partner for many years, he felt lost and hollowed: ‘That’s when I began to write about my feelings and emotions in a book, I wrote as a way of just letting go. I have never been married and will not marry until the law can allow people to marry whomever they want and then, I will live with a man still.’ It is when he spoke about his sexuality that C045 became most animated, suggesting the centrality of sexuality in his own identity as a person. He was 41 years old and considered himself lucky to be alive.</td>
<td>16th February 2014</td>
</tr>
<tr>
<td>C046</td>
<td>Chitungwiza Zengeza 3</td>
<td>1960, M</td>
<td>Hypertensive 54-year-old grandfather of four, lived with his daughter and her husband. He is Catholic and believes that the church values his life more than the hospital does.</td>
<td>19th February 2014</td>
</tr>
<tr>
<td>C047</td>
<td>Chitungwiza St Mary’s</td>
<td>1960, M</td>
<td>When asked about her perceptions of the treatment that the 50-year-old got from the health services in her community, she quickly pointed out that it was only ‘now’ (2014) when she was getting comfortable with herself and being happy with her state of mind. ‘Before this, it was very difficult at the clinic because you know, that’s your first source of support where you need to be told that you won’t die soon, things will get better you know. You need hope. But I did not get it. I was treated as if the mortuary was closer to me than hope. In fact, the counselling space is right next to the mortuary and every day you are reminded of your death. I could not even go to school meetings for my children because I did not want anyone to suspect that I had it [HIV] because that would impact negatively on my children whom I also did not tell that I was ill for a long time. To be honest, the way they treat us at the clinic makes it difficult to know if we are valued or not, we know they don’t really care much.’</td>
<td>20th February 2014</td>
</tr>
<tr>
<td>C048</td>
<td>Chitungwiza Unit E</td>
<td>1973, F</td>
<td>Born in 1973, C048 was a self-sufficient vegetable vendor, 41 years old with two children, both HIV-negative. Husband passed on soon after the second child was born in 1993. ‘I mean; I’ve just been self-sufficient from a very young age when my husband died. I was just 20 then, and I did not know that I had it [HIV] then, maybe I did, but I just thought I was getting ill because I was stressed and still grieving and perhaps working too hard.’ Despite these demands, she indicates, ‘you see, it’s served me very well’. This suggested that her life successes living with HIV are directed in part by the expectations in early adulthood looking after her paternal orphan children.</td>
<td>20th February 2014</td>
</tr>
<tr>
<td>Code</td>
<td>District / Ward</td>
<td>Year born/ Sex</td>
<td>Respondent characteristics and their networks that correspondent with Seeds</td>
<td>Date of interview</td>
</tr>
<tr>
<td>------</td>
<td>------------------</td>
<td>----------------</td>
<td>-----------------------------------------------------------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>C049</td>
<td>Chitungwiza St Mary’s</td>
<td>1974, F</td>
<td>A 40-year-old who lost a spouse to HIV and who was turned away from health services on two occasions because the nurses were on strike.</td>
<td>21st February 2014</td>
</tr>
<tr>
<td>C050</td>
<td>Chitungwiza Unit J</td>
<td>1969, F</td>
<td>C050’s entire adult life is informed by AIDS; The 45-year-old was only 21 when she got infected by a man. She lost four of her seven boyfriends to HIV, one in her early 20s, one in her 30s, and two in her late 30s. C050 recalled the story of her infection in great detail and described Tawanda’s death, her boyfriend at the time, whom she believes infected her and whose death she witnessed when she was only 23 years old in 1992. C050 lives with her girlfriend, whom she has been involved with since 2004, when C050 was only 35.</td>
<td>22nd February 2014</td>
</tr>
<tr>
<td>C051</td>
<td>Chitungwiza Unit N</td>
<td>1975, M</td>
<td>Despite being on HIV treatment, C051, a 39-year-old man, did not think that the ARVs he was taking were helping him at all. He believed that the side effects were worse than taking the pills. ‘They make it so obvious to people that I have it [HIV], my life is miserable, Ismoko chaiiyo [it’s smoke].’ The 39-year-old did not have a source of income but said at times he went to Harare’s Robson Manyika Street to beg on the streets. On a good day, he said she could make between 5 and 15 US dollars.</td>
<td>25th February 2014</td>
</tr>
<tr>
<td>C052</td>
<td>Chitungwiza Zengeza 5 ext</td>
<td>1967, F</td>
<td>C052, a 47-year-old former nurse aid and also a home-based care giver in Zengeza 5 extension, lost a husband to AIDS.</td>
<td>26th February 2014</td>
</tr>
<tr>
<td>C053</td>
<td>Chitungwiza Unit M</td>
<td>1975, F</td>
<td>C053’s recollection of when and where he got tested for HIV was somewhat steeped in shame. A tall, dark chocolate and extremely beautiful 35-year-old female who identified her gender as a ‘transgender man’ relied heavily on her sexuality to convey her stories of value and HIV/AIDS. So I called her a ‘him’ to respect the transgender identity. Even when he recalled a time when he felt her life was of little value to others: ‘…many people think I look butch [a lesbian female who looks like a man] because I want to copy my brothers! No! I was raped by my own brother because they [family] thought if they did that I would begin to act more girlish! I do not feel like a girl, look here [showing me her phone pictures] this is me when I was 9 with my Dad fixing his car, see this is me playing football in Mbare [oldest African neighbourhood in Harare], even girls used to scream for me as early as grade 7. When I was in form 4 I was the boss at Zengeza [name of school withheld]. I’m still the boss. When I got raped I hated everyone in my family, I even wanted to commit suicide. In less than a year I had an STI, I was 23, then HIV testing came, eish, you know – somehow I just knew that I was positive.’</td>
<td>27th February 2014</td>
</tr>
<tr>
<td>C054</td>
<td>Chitungwiza Zengeza</td>
<td>1970, M</td>
<td>C054 is a 44-year-old NGO worker and father of four children, who are all HIV-negative. He waited for HIV treatment for many years that ‘seemed like a lifetime’ before he decided to go to the centre in Avondale, a place for PLWHA who needed information including on treatment and care. C054 believes that NGOs value PLWHA more than the government does.</td>
<td>27th February 2014</td>
</tr>
<tr>
<td>C055</td>
<td>Chitungwiza Unit A</td>
<td>1981, F</td>
<td>A 33-year-old woman who lost a child to HIV and survived two miscarriages</td>
<td>24th February 2014</td>
</tr>
<tr>
<td>C056</td>
<td>Goromonzi Chinamhora</td>
<td>1983, F</td>
<td>A 32-year-old sex worker, on ARVs and also using herbs such as Muremberembe, she perceives her life as a ‘virgin’: ‘My life is like a virgin, I’m ok, I feel like I’m still what I was before I started having sex, having HIV has not changed me or what I think about myself.’</td>
<td>23rd February 2014</td>
</tr>
<tr>
<td>G057</td>
<td>GOR Mwanza</td>
<td>1976, M</td>
<td>Incarcerated for eight years in one of Zimbabwe’s prisons (name of prison withheld). He endured homosexual rape as an inmate and reported that other inmates infected him with HIV because of ongoing sexual abuse while his requests for help from staff were ignored. He reported that his situation was similar to some of the inmates still incarcerated, and those out of prison with whom he still communicated on an ad-hoc basis. At the time of the</td>
<td>Manchester 2014</td>
</tr>
<tr>
<td>Code</td>
<td>District / Ward</td>
<td>Year born/ Sex</td>
<td>Respondent characteristics and their networks that correspondent with Seeds</td>
<td>Date of interview</td>
</tr>
<tr>
<td>--------</td>
<td>------------------------</td>
<td>---------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>G058</td>
<td>Goromonzi Gumbodete</td>
<td>1983, F</td>
<td>A 33-year-old former sex worker. In the past, she has had sexual intercourse with multiple partners including women – suggesting bisexuality. She had always known that she was attracted to both sexes but said only those women she had had sexual relationships with understood her sexuality. She had known of her HIV status six months prior to the study’s recruitment, her CD4 count was above 350 cells per mm3 and she was initiated on co-trimoxazole prophylaxis. At the time of recruitment, she had not yet begun ART. [Seed]</td>
<td>1st March 2014 Manchester</td>
</tr>
<tr>
<td>G059</td>
<td>Goromonzi Murape</td>
<td>1968, M</td>
<td>A senior member of the Johanne Masowe African Apostolic Church. He was aged 44, had two wives and five children. Only one child, from his young wife aged 26 years, lived with HIV. Both his wives were living with HIV, and they were not on ART. [Seed]</td>
<td>1st March 2014 Manchester</td>
</tr>
<tr>
<td>G060</td>
<td>Goromonzi Bosha</td>
<td>1988, M</td>
<td>Lost a father to HIV when he was 18. The 26-year-old got his HIV diagnosis when he was 23 and contracted it from his wife, with whom he has three children.</td>
<td>10th March 2014</td>
</tr>
<tr>
<td>G061</td>
<td>Goromonzi Show Ground</td>
<td>1986, M</td>
<td>A 39-year-old who never married and got infected on his first sexual encounter when he was only 22. He only suspected that he was HIV-positive when his one sexual encounter girlfriend died when he was 23.</td>
<td>13th March 2014</td>
</tr>
<tr>
<td>G062</td>
<td>Goromonzi Goremusanda</td>
<td>1975, F</td>
<td>When I asked how people without HIV in the community valued her life, G062 explained how her experiences made her ‘re-value’ and ‘up-value’ her life. The 39-year-old worked as a secondary school teacher at one of the boarding mission schools in Goromonzi. She spent most of her life in Harare’s Tafara neighbourhood before she moved to Mwanza in 2010. ‘…Living with HIV drove me to try to “fit in”. I began exercising, running every day and eating mainly vegetables, I stopped eating meat and occasionally had fish. After two years I had become fitter than what I was before HIV, I did not stop taking my ARVs. This helped me to psychologically know that I could defend myself from those who judge my value based on the effects of HIV, so technically, I was defending myself from victimisers. With a good body outlook, I had a lot of proposals from men and I was ready to start again. The funny thing I had to insist on condom use otherwise many men refused using condoms even when I told them about my HIV status. They would say no, if you had HIV it would show. Once I had to actually show my ARVs to just prove that I was serious. He kept coming back and we are married now. We have a child together who is also HIV-negative. So there are many things that can make PLWHA devalued but most certainly poverty and HIV do not work well together.’</td>
<td>14th March 2014</td>
</tr>
<tr>
<td>G063</td>
<td>Goromonzi Mapfumo</td>
<td>1992, F</td>
<td>G063, a 22-year-old woman, was raised by highly educated parents who owned many cows. Her father was a teacher and her mother a shopkeeper, whom she described as ‘accepting and supportive’ and who, according to G063, ‘outed’ her as HIV-positive ‘with dignity and respect’. G063 believed that her family valued her very much but health services treated her like a person who deserved to be ill because of ‘promiscuity, they are just too judgemental those people [health workers]’. She was once refused health services because she did not have her ID and they wanted parental consent, despite the fact she was already above 18.</td>
<td>11th March 2014</td>
</tr>
<tr>
<td>G064</td>
<td>Goromonzi Ndamba</td>
<td>1981, F</td>
<td>She put emphasis on how her support system valued her life and the relationship that she had with her circle of friends – the peanut butter making club and the candle making group that she had been a part of when she was still in secondary school. She referred to the nuns as ‘Shearly-Cripps’, the orphanage home where she grew up. She believed that the health care service did not value her as much as her ‘family’ did. She argued that the orphanage nuns were the ones that made her access ARVs earlier than others in similar predicaments, six years before the interview. G064 was recovering from tuberculosis (TB) at the time of the interview. The 33-year-old was still at the orphanage under directly observed treatment (DOTS) for TB. She was visibly ill and had a poor appetite.</td>
<td>16th March 2014</td>
</tr>
<tr>
<td>G065</td>
<td>Goromonzi Mwanza</td>
<td>1975, M</td>
<td>An unemployed 39-year-old man who lost his siblings to HIV.</td>
<td>10th March 2014</td>
</tr>
<tr>
<td>Code</td>
<td>District / Ward</td>
<td>Year born/ Sex</td>
<td>Respondent characteristics and their networks that correspondent with Seeds</td>
<td>Date of interview</td>
</tr>
<tr>
<td>-------</td>
<td>-----------------------</td>
<td>----------------</td>
<td>--------------------------------------------------------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>G066</td>
<td>Goromonzi Mudhuvwa</td>
<td>1967, M</td>
<td>A truck owner who ferries vegetables from farms to Boora growth point for farmers every morning and returns home after dark. He sells their produce and brings back money to the sellers every morning when he picks more produce. He charges labour for selling and transport to and from the market. He was 48, had three children and one wife, who, unlike him, were all HIV-negative.</td>
<td>17th March 2014</td>
</tr>
<tr>
<td>G067</td>
<td>Goromonzi Mwanza</td>
<td>1985, F</td>
<td>A 29-year-old mother of two girls, who was turned away from services because when she moved to her current location the hospital demanded paperwork from her previous location. She said it was difficult for her to get the papers because it meant a long journey to travel back to her previous location. She had to bribe powerful Zimbabwe African National Union Patriotic Front supporters to stand for her at the clinic for her to be continued on treatment.</td>
<td>15th March 2014</td>
</tr>
<tr>
<td>G068</td>
<td>Chitungwiza Unit J</td>
<td>1982, M</td>
<td>A 32-year-old teacher who equated his life to a tree, which he believed would live much longer and so would his value. He was not taking ARVs and believed that if it weren’t for ‘international aid’, many more PLWHA would still be dying of AIDS in Zimbabwe.</td>
<td>17th March 2014</td>
</tr>
<tr>
<td>G069</td>
<td>GOR Mangwiro</td>
<td>1975, F</td>
<td>G069, 39 years old, could not recall the date when she got diagnosed despite the eager attempts to remember. She lived most of her life in Mangwiro where she became HIV-positive. She worked as a caretaker at Boora growth point. Her only two children died before they got to the age of five. She said they would be about four and three years old at the time of the interview. She said maybe if she had had education maybe she could have had more care using condoms. She only managed to complete primary school and was taking ARVs from Murehwa Mission Hospital in another district. She thinks that people not living with HIV treat her and others like her as marara [dirt, filth], ‘Tiramara, Havana basa nesu [we are seen as dirt, they don’t care about us]’.</td>
<td>18th March 2014</td>
</tr>
<tr>
<td>G070</td>
<td>GOR Mwanza</td>
<td>1984, M</td>
<td>G070 was happy to be on HIV treatment. He hoped that the tuberculosis would not come back again. He said he was learning to live with scars from skin lesions and accepting them and braving the world that ‘does not value us at all, infy your family may value you and it’s not even a guarantee’. He was 30 years old at the time of interview.</td>
<td>1st April 2014</td>
</tr>
<tr>
<td>G071</td>
<td>Goromonzi Gutu</td>
<td>1993, M</td>
<td>The 21-year-old unemployed young man was tested for HIV when he lived in Harare at the age of 20 and was sent to his father’s rural home when he got ill. G071 now lived with his grandparents. He was yet to begin ARV treatment.</td>
<td>26th March 2014</td>
</tr>
<tr>
<td>G072</td>
<td>Goromonzi Gutu</td>
<td>1957, M</td>
<td>When asked when his HIV test was done, G072, a 57-year-old, said, ‘I— I can be honest with you because I think I can trust you, err you see it started kunombe [herding cows]. We started this thing [homosexuality] to teach each how to do it when we finally get girls. Usually the bigger boys did it on us and then it became addictive and then an everyday thing. Then we got to do it with smaller boys and became a part of me until I just couldn’t stop even when I married my wife. So continued to do it with other married man but when my friend’s wife died of HIV, I just knew that I had it. It was the most difficult time of my life because I had not had an affair with a woman but a man and I knew I had wronged my wife and my children. But if I had my way in this country, I wouldn’t have married a woman because I really feel it when I do it with another man not a woman. But what can you do here? You just marry for the sake of it. I’m glad I have children though.’ G072 regretted marrying his wife because he identified as gay but married because of societal pressure. He noted that he felt hollow and worthless because of the way people viewed him: ‘I think most just pretend to smile when they see you, but the truth is, I think most people here are disgusted by the idea of hungotshani (homosexuality) and even more so, when you have HIV.’</td>
<td>18th March 2014</td>
</tr>
<tr>
<td>G073</td>
<td>Goromonzi Rusike</td>
<td>1979, F</td>
<td>Moved to her rural home to do farming after three years in Harare looking for a job. G073 a 35-year-old woman, was unemployed and had lost a three-year-old baby to HIV when she was 30. She lived alone close to her parents’ home in Rusike communal lands. She feels that living with HIV is more painful socially than in the effects of the HIV itself. ‘Unenge uchita kunge urikusimwe viti [disgusting others]’. When I interviewed her she referred to me as ‘Vakuru’, a Shona term with many meanings such as powerful, senior, the ‘Boss’, among others.</td>
<td>12 April 2014</td>
</tr>
<tr>
<td>G074</td>
<td>Goromonzi Gumbodete</td>
<td>1971, F</td>
<td>A 43-year-old, with four children. Her first daughter has three children, she is 25, a second child is 24 and a qualified tailor, her third is a 22-year-old qualified builder and her last born son is 13 years old. She says she was always</td>
<td>26th March 2014</td>
</tr>
<tr>
<td>Code</td>
<td>District / Ward</td>
<td>Year of birth/ Sex</td>
<td>Respondent characteristics and their networks that correspond with Seeds</td>
<td>Date of interview</td>
</tr>
<tr>
<td>-------</td>
<td>----------------</td>
<td>--------------------</td>
<td>-------------------------------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>G075</td>
<td>Goromonzi Bernard Mangwiro</td>
<td>1978, M</td>
<td>Visibly ill 36-year-old male who knew that he had to walk long hours to the clinic to get his ARVs and also bring a US$1 security fee along with him, without which he would not get his ARVs. He thought of his value as having a big house which should live longer to protect one’s family in this generation and many more to come. He said its value is worth more than one human lifetime.</td>
<td>29th March 2014</td>
</tr>
<tr>
<td>G076</td>
<td>GOR Ndamba</td>
<td>1987, M</td>
<td>The 27-year-old from Ndamba ward is an avid believer of ‘kaMasowe’, (some African Apostolic Church activities), where he trusts he gets more HIV care than from hospitals that he referred as ‘judgmental’ based on his treatment from health workers. He believes that his resilience has made him the person he is today who has survived HIV in difficult times.</td>
<td>1st April 2014</td>
</tr>
<tr>
<td>G077</td>
<td>Goromonzi Fari Munyawiri ward in Mverechena</td>
<td>1983, F</td>
<td>A 31-year-old sex worker and self-employed entrepreneur who never married and believes that government should provide food packages to PLWHA because drugs do not work effectively without food. ‘It’s ridiculous that government says heee its helping us when we know it’s the donors, the least the government should do is to provide food.’</td>
<td>30th March 2014</td>
</tr>
<tr>
<td>G078</td>
<td>Goromonzi Gutu</td>
<td>1978, M</td>
<td>G078, a 36-year-old homosexual man, was incarcerated for several years and believes that he got HIV infected while in prison because of homosexual rape. Despite having been raped in the prison, G089, who was visibly ill and not on ARVs, said he would not return to the hospital because the health workers found out that he was a gay man, he would be treated harshly and would rather wait for death than go through the humiliation once again.</td>
<td>1st April 2014</td>
</tr>
<tr>
<td>G079</td>
<td>Goromonzi Mwanza</td>
<td>1987, M</td>
<td>He was born and raised in Mwanza but went to Harare when he was 20 to look for work. He lived in Harare’s Epworth District where he met a woman that he had a child with. He was a vegetable vendor and spent most of his night life between bars. After a serious illness at 24 he got tested at Parirenyatwa Hospital in Harare and was told that he had HIV. He began taking ARVs six months after diagnosis. He returned to the rural areas because he could not afford rental in Epworth. His wife is not living with HIV and neither is his son. At the time of the interview he was 27 years old.</td>
<td>26th March 2014</td>
</tr>
<tr>
<td>G080</td>
<td>Goromonzi Muchinda</td>
<td>1968, F</td>
<td>Although trained as a teacher, the 46-year-old was unemployed. She has two children each with a different father. She thinks that the value of human life cannot be measured or quantified but one can generalise how others view PLWHA. She thinks that PLWA’s value is not equal to the value of people not infected by HIV.</td>
<td>27th March 2014</td>
</tr>
<tr>
<td>G081</td>
<td>Goromonzi Madamombe</td>
<td>1992, M</td>
<td>A 22-year-old mother of three who lost a child to HIV. Married to a soldier who comes home once a fortnight from his national duty. His duty station is far from Goromonzi. G081 works at the local stores.</td>
<td>18th March 2014</td>
</tr>
<tr>
<td>G082</td>
<td>Goromonzi Chinganda</td>
<td>1957, F</td>
<td>The 57-year-old’s left leg was swollen and she could not walk for long distances. ‘Look at my leg, it’s like I have elephantiasis, but the doctors said it was not, it was cancer. I am ill all the time. I have tried everything including Chinese Tianchi herbal medicines, ARVs, Apostolic churches, Pentecostal churches and it does not go away. I’m just waiting for death; I am a burden to everyone I know. I think I am not valued and my life is like dust which is not needed everywhere and wherever it goes – like me, people believe that I can cause them illness the same way dust works.’</td>
<td>27th March 2014</td>
</tr>
<tr>
<td>G083</td>
<td>Goromonzi Dzvete</td>
<td>1971, F</td>
<td>G083 was very concerned about what she said; the 43-year-old took care to express herself carefully for my understanding. At first, I could not figure out why she spent quite a bit of time expressing herself and asking her</td>
<td>28th March 2014</td>
</tr>
<tr>
<td>Code</td>
<td>District / Ward</td>
<td>Year born/ Sex</td>
<td>Respondent characteristics and their networks that correspond with Seeds</td>
<td>Date of interview</td>
</tr>
<tr>
<td>-------</td>
<td>----------------</td>
<td>---------------</td>
<td>---------------------------------------------------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>G084</td>
<td>GOR Gutu</td>
<td>1963, M</td>
<td>The 51-year-old man, who liked to call himself using his totem, had an experience of HIV complicated by coinfection with diabetes, compromising his health to an even greater extent. During the interview he frequently visited the toilet, and, nonchalantly but frequently, mentioned how diabetes made his HIV experience the 'worst in the world'. He looked emaciated, perhaps malnourished, his ribs protruded and curved inward from his chest cavity, and loose skin sagged from his bones. 'Like I told you, I'm only 51 years old, I have lived with HIV for 10, but when I got diabetes that's when I began to look like this, it's worse when you are like this, unobatwa sembwa [treated like a dog].’ G084 had four children and four grandchildren. His Muroora (son's wife) looked after him in the rural area.</td>
<td>1st April 2014</td>
</tr>
<tr>
<td>G085</td>
<td>Goromonzi SS1:33 Chipikiri</td>
<td>1991, F</td>
<td>A young sex worker, 23 years old, who spoke very little. She believes that life is like ‘Covo kana Rugare [Kyle]’ because it’s always green. She was not taking ARVs and said if she was taking ARVs and other sex workers got to know about it, they would make her not get clients, so she would not disclose.</td>
<td>5th April 2014</td>
</tr>
<tr>
<td>G086</td>
<td>GOR Macheka</td>
<td>1968, M</td>
<td>The 46-year-old has been living with HIV for more than 15 years and lost many friends, his wife, sisters and brothers to HIV. He looked after his two children, his two late siblings and his mother. He is a cross-border trader and imports second-hand clothes (Mabhero) zvemaBhero in exchange for money, or barter trades with maize, beans and peanuts.</td>
<td>26th March 2014</td>
</tr>
<tr>
<td>G087</td>
<td>Goromonzi Dzvete</td>
<td>1966, F</td>
<td>48-year-old widow, lost a husband to HIV. Looks after her four orphaned grandchildren.</td>
<td>2nd April 2014</td>
</tr>
<tr>
<td>G088</td>
<td>Goromonzi Dvete</td>
<td>1976, F</td>
<td>When the 38-year-old was asked where she got her ARVs from, she said, ‘Ah, I get my ARVs from Murehwa, far away from the madness in these areas, and I like it that way. At the beginning I thought I was not going to live longer because there were no ARVs, people died like cockroaches, and I was prepared for death. When these medicines came, I knew that God was giving me a second chance to raise my children because Baba [husband] had passed on’. G088 was comfortable with herself, her body and its old scars: 'Look you see all the marks on my hands and legs? They are everywhere on my body, once I had big itchy hives that lasted for months, turning into watery pimples that were eating me alive, I knew I was rotting when I had these, and I waited for death, but now when I look at these scars the more reason I value my life. These people you see who pretend to like us ha! They do not, in fact, they do not even want us close to them because they think that my pimples can just come back alive and infect them huhahaha. My life is worth more than gold. It's priceless and matter how others value it, and I value it more. These ARVs have value too, just like my life.’</td>
<td>5th April 2014</td>
</tr>
<tr>
<td>G089</td>
<td>Goromonzi Ndamba</td>
<td>1981, M</td>
<td>Unemployed 33-year-old, who describes himself as very poor and his experience as ‘Chukatsva’, has been turned away from the clinic without ARVs because he did not have the US $1 ‘security’ fee.</td>
<td>9th April 2014</td>
</tr>
</tbody>
</table>
| G090  | Goromonzi Mangwiro | 1986, M      | Young man of 28 years who has never been employed believes that living with HIV is like a life spent in a never-ending pitch-black night, what he described as ‘chiraramo chehusiku hurefu’ [never ending misery and darkness] He believes that his experience with HIV is exacerbated by lack of income; he believes no one can be poorer than he was. ‘I have absolutely nothing, no parents, no siblings no one to trust and no income, I am poor and I have it [HIV] nobody can be as poor as I am. I’m not on ARVs because they say I have to get more tests in other hospitals, I can’t
<table>
<thead>
<tr>
<th>Code</th>
<th>District / Ward</th>
<th>Year born/ Sex</th>
<th>Respondent characteristics and their networks that correspond with Seeds</th>
<th>Date of interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>G091</td>
<td>Goromonzi Mwanza</td>
<td>1987, F</td>
<td>The 27-year-old woman works in a bottle store at Boora growth point. She got infected at 22 when she had visited relatives in Beithbridge. Her mother died of HIV when she was 17, her father has since married another woman.</td>
<td>12th April 2014</td>
</tr>
<tr>
<td>G092</td>
<td>Goromonzi Matienga</td>
<td>1976, F</td>
<td>When asked how old she was, G092, who had lived with HIV since 2005, said ‘I am 38 years old and got this disease from husband, a very unfaithful man who deservedly died because of it. When he died that’s when I thought it was wise to get tested in 2005.’ She not only blamed her late husband for infecting her, but also for making her bear five children whom she fended on her own. She was unemployed and could not work much in the fields for food.</td>
<td>11th April 2014</td>
</tr>
<tr>
<td>G093</td>
<td>Goromonzi Mapfumo</td>
<td>1967, F</td>
<td>G093 a 47-year-old perceived that living with HIV was his way of life, which gave him the courage to move beyond the established norms of the community and culture in which he was raised and which led to of self-value despite being reminded that his life was worthless in everyday interactions. He worked at a primary school as a preschool teacher, and he spoke about how his siblings, wife and children perished of AIDS. He described the way he navigated social contexts, even when colleagues and neighbours asked when he would get married again as a way of hinting to him that if he did not marry again soon then other people in the community would soon know that he, too, was living with HIV. For G093, his survival and ability to overcome the many challenges in his life are understood in terms of the value that he attached to his own life as a teacher and a community gardens coordinator.</td>
<td>10th April 2014</td>
</tr>
<tr>
<td>G094</td>
<td>Goromonzi Gutu</td>
<td>1966, F</td>
<td>G094’s early adult life experiences were shaped by marital rape and gender-based violence, perpetrated by her late husband. She was ‘happy’ that her husband had died of AIDS, although she was also living with HIV. She thought that living with HIV was better than living with an emotionally, sexually and physically abusive husband. She was 48 years old.</td>
<td>6th April 2014</td>
</tr>
<tr>
<td>G095</td>
<td>Goromonzi Arcturus</td>
<td>1959, F</td>
<td>The 55-year-old had two successful girls living overseas. One her ‘girls’, as she put it, was in London and the other lived in Berlin, both doing their advanced degrees. ‘They give me the strength to live on. I am more valued by them than any other person here. In fact, now that people know that my children are abroad, that’s when I get a bit of respect.’ G095 lived with a maid and a gardener whose wages were paid by her children.</td>
<td>3rd April 2014</td>
</tr>
<tr>
<td>G096</td>
<td>Goromonzi Gutu</td>
<td>1983, F</td>
<td>Had three natural abortions but never suspected HIV despite three admissions at the hospital until friend advised her to get tested for HIV in 2011. The 32-year-old is married and believes that the government hospitals need well trained health workers, she does not think that the ones manning the clinics have had adequate training as they are only trained for 18 months instead of three years.</td>
<td>2nd April 2014</td>
</tr>
<tr>
<td>G097</td>
<td>Goromonzi Dzvete</td>
<td>1963, M</td>
<td>The 51-year-old described his upbringing as informed by African Apostolicism, which he viewed as having had a favourable impact on his life. ‘Chipostori [African Apostolicism] has been a major influence.’ African Apostolicism adheres to the ‘demands’ of the holy spirit doctrine of sanctification and the practising of such rites as katsanya (fasting), which G097 says helped him to deal with his HIV ‘in many ways’. ‘I only began taking the ARVs when Mudzimu unoera [holy spirit] spoke to Mudzidzi Diadresch [holy man/prophet]. He was told to tell me to go and get tested, when I did I was already prepared, because the holy spirit had already done wonders, it had prepared me for journey that many failed to finish.’ G097 held strong beliefs that holy water helped his ARVs to function well. He was a well-respected man at his local Apostolic church which I visited one Friday (30 May 2014) after his invitation to see. G097 had one wife and three children. All of his children were yet to get tested for HIV at the time of the interview, but Norah, his wife, who was not yet on ARVs, like her husband, was waiting for the moment to be dictated by God through prophecy.</td>
<td>4th April 2014</td>
</tr>
<tr>
<td>G098</td>
<td>Goromonzi Dzvete</td>
<td>1983, F</td>
<td>From the age of 17, the 31-year-old spent most of her time alone studying for her O-level exams in a one-room hut behind the brothel at Boora growth point. As she grew up, the brothel keeper, who had no family living with her, and who was likely to be doing sex work herself, asked if G098 wanted a cleaning job at the brothel to which she agreed.</td>
<td>5th April 2014</td>
</tr>
</tbody>
</table>
In less than a fortnight after starting work, at the age of 19, G098 got into sex work. The brothel keeper was relatively easy-going and spent little time supervising her, and in less than a year G098 had two abortions and tested HIV-positive at the age of 20 in 1993. She continued to work at the brothel whenever she felt strong to work. G098 didn’t take ARVs whenever she lived with a sexual partner. Between 1993 and 2014, she tried starting a family three times, each with a different man. One left when he realized she was living with HIV and two of the men had families elsewhere. G098 did not want people to know that she lived with HIV because ‘unosvorwa [one is despised if living with HIV]’. When she is not using ARVs, she uses Gavakavara, [herb] to treat her wounds for stomach pains.

G099: Goromonzi
Bosha
1978, F
A 36-year-old woman who lives alone with a 7-year-old grandson. G099’s daughter, a teenage mother, works in Harare as a maid and helps G099 with money for the bus fair to go to the clinic and to get food while G099 looks after her grandson. G099 believes that the gumtree not only helps her relieve her flu symptoms but also represents the value of her life in the form of a gumtree because of its healing properties and its resilient character because it can withstand long spells of droughts.

G100: Goromonzi
Bosha
1961, F
The 53-year-old has worked as a maid in Harare ever since she was 13 years old. She got married to a man when she was 35. When her son was two years old, she realised she had HIV. She worked with her employer for three years until the employer left Zimbabwe to England. Thereafter she struggled to get employed and moved back to the rural areas and now works as a cross-border trader selling mabhero (second-hand clothes) that come from European countries through the Beira Maputo Port in Mozambique. She lived for ten years without any treatment. In retrospect, she thought the ten years were as good as death, she believed to have died of stigma, discrimination and physical pain from co-infections and especially wounds that took time to heal.

G101: Goromonzi
Chinyika
1978, F
Her mother was born in Nyasaland, now Malawi, and lived in the central parts of Ntcheu District before she moved to Southern Rhodesia, now Zimbabwe, in 1970. In 1978, G101 was born. She was raised by her single mother in Mwanza before they moved to Chinyika communal lands, where she and her siblings completed secondary school, and she worked as a shopkeeper at the local stores. She gets her ARVs in Harare at Gomo Central Hospital, where she goes every three months. Before accessing ARVs, she was on a waiting list for three years before her siblings decided to take her to Harare. She used her younger siblings’ Harare address to prove that she was from Harare. She does not have children of her own but continues to work very hard at the local shop.

G102: Goromonzi
MuNyawiri
1979, F
Had a great sense of humour, a big love of life expressed in her words and throughout our conversation, as G102 (35 years old) spoke with great honour and respect for her life as a catholic devotist growing up in Harare, and whose formative years and emerging adulthood were informed by the relationships she developed serving as a helper in the church. Despite being HIV-positive and battling cervical cancer, G102 was self-assured and confident that the support and acceptance she got from her friends gave her the assurance that when she dies she will have a decent burial.

G103: Goromonzi
Mapfumo
1971, M
43 years old, not on treatment. Lives with his wife, also not on treatment.

G104: Goromonzi
Chidhawu
1962, M
Unemployed 52-year-old polygamist who has been living with HIV for ten years. He believes veganism is the best way to deal with HIV. He does not eat meat and meat products. He only eats ‘roots, seeds and leaves, ARVs are tricky because they make you less able to cope and once you begin them you have to continue. I will only get them when I’m very ill, That’s when I will start, not now. My immune system works well. I also know ‘ mushonga ye yedichivanhu [traditional medicines], which help to boost the immune system, so with my kind of diet and the right muti [traditional medicines]you will be home and dry.’

G105: Goromonzi
Rusike
1996, M
The experiences of G105, an 18-year-old, with his mother were not similar to his life with his other relatives, friends and at school for those who knew about his HIV status where he was bullied as a child because of his HIV status and because he was perceived as a Ngochani (homosexual). Despite his mother’s support, these bullying experiences are
informative of the way that G105 perceived his worth in life, including his subsequent reliance on tobacco and alcohol. G105 got tested for HIV after his girlfriend had died and when his mother encouraged him to get tested barely four months before the interview.

<table>
<thead>
<tr>
<th>Code</th>
<th>District / Ward</th>
<th>Year born/ Sex</th>
<th>Respondent characteristics and their networks that correspondent with Seeds</th>
<th>Date of interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>G106</td>
<td>Goromonzi Chinamhora</td>
<td>1968, F</td>
<td>Lost a brother and a husband to AIDS. The 46-year-old woman thought that her life was more valued before her HIV infection. Her husband passed in 1994 as a result of pneumocystis pneumonia.</td>
<td>16&lt;sup&gt;th&lt;/sup&gt; April 2014</td>
</tr>
<tr>
<td>G107</td>
<td>Goromonzi Arcturus</td>
<td>1979, F</td>
<td>Born and raised in Arcturus, her parents both worked at the mine. The 39-year-old believed that once people in her community get to know that one is HIV-positive one is treated like ‘tirimarara [we are dirt], tsvina [faeces] and tinovasemese [we disgust] them’. She said this is why most people neither disclosed their HIV statuses nor sought help from the clinic for fear of stigma which was entrenched in all structures systematically.</td>
<td>16&lt;sup&gt;th&lt;/sup&gt; April 2014</td>
</tr>
<tr>
<td>G108</td>
<td>Goromonzi Mwanza</td>
<td>1968, F</td>
<td>A vibrant 46-year-old NGO worker who did her work across wards stretching from Arcturus, Bosha, Mwanza and Gutu. She lost a family member to HIV and dedicates her life to helping others living with HIV.</td>
<td>1&lt;sup&gt;st&lt;/sup&gt; May 2014</td>
</tr>
<tr>
<td>G109</td>
<td>Goromonzi Goremusandu</td>
<td>1968, F</td>
<td>46 years old, improvises to survive with HIV, began HIV treatment late when the disease was at an advanced stage, reacted badly to most of the medicines before she was put on a combination that ‘helped’ her. Was looking for work for many years and could not get employed. She believes that she could not get employed because of the economic meltdown and also because of her HIV status.</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt; May 2015</td>
</tr>
<tr>
<td>G110</td>
<td>Goromonzi Deera</td>
<td>1986, M</td>
<td>A young teacher, 28 years old, on ARVs, who believes that while rights are important for PLWHA to negotiate universal HIV treatment coverage (for everyone), they are not adequate because they are ‘mostly on the surface [tokenistic]’. He perceives government as a ‘machinery that plays tricks with its people by making them believe that it is sincere when it isn’t using rights talk’.</td>
<td>16&lt;sup&gt;th&lt;/sup&gt; April 2014</td>
</tr>
<tr>
<td>G111</td>
<td>Goromonzi Deera</td>
<td>1963, F</td>
<td>A 51-year-old woman who lost her brothers to HIV, looking after 12 orphans. She is on ARVs.</td>
<td>3&lt;sup&gt;rd&lt;/sup&gt; May 2014</td>
</tr>
</tbody>
</table>
Appendix 11: Documents accessed from the Zimbabwe National Archives and the Health Ministry’s Library services

<table>
<thead>
<tr>
<th>No.</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Reference</td>
</tr>
<tr>
<td>---</td>
<td>----------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
Appendix 12: Ethical Clearance – Medical Research Council of Zimbabwe

REF: MRCZ/A/1781

Fortunate Machinga
Institute of Development Policy and Management
University of Manchester
Oxford Road
Manchester M13 9PL

APPROVAL

27 November, 2013

RE: Valuation of Life: Biopolitics rationalities

Thank you for the application for review of Research Activity that you submitted to the Medical Research Council of Zimbabwe (MRCZ). Please be advised that the Medical Research Council of Zimbabwe has reviewed and approved your application to conduct the above titled study.

This approval is based on the review and approval of the following documents that were submitted to MRCZ for review:

a) Study proposal dated 27 February, 2013.
b) Informed Consent Form Version 1.1 dated 1 November, 2013 (English and Shona).

APPROVAL NUMBER: MRCZ/A/1781

This number should be used on all correspondence, consent forms and documents as appropriate:

- TYPE OF MEETING: Full Board
- EFFECTIVE APPROVAL DATE: 27 November 2013
- EXPIRATION DATE: 26 November 2014

After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ Offices should be submitted three months before the expiration date for continuing review.

SERIOUS ADVERSE EVENT REPORTING: All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ Offices or website.

MODIFICATIONS: Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Offices is required before implementing any changes in the protocol (including changes in the consent documents).

TERMINATION OF STUDY: On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Offices or website.

QUESTIONS: Please contact the MRCZ on Telephone No. (014) 791792, 791191 or by e-mail on mrcz@mrcz.gov.zw.

Other:

- Please be reminded to send in copies of your research results for our records as well as for Health Research Database.
- You’re also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours Faithfully,

MRCZ SECRETARIAT
FOR CHAIRPERSON
MEDICAL RESEARCH COUNCIL OF ZIMBABWE

293
Appendix 13: Life History Interview Excerpts

Box 0:1: Appendix 13 - Tino’s Case – Goromonzi (LHIG078)
As a native, it was disturbing to acknowledge how well I was managing to keep up with the silent agony embedded in the stories, I was told and the pain I could see in front of me. I was witnessing what I would express as ‘Okayed slow death’ It seemed like it had been ‘okayed’, routine, yet unaccounted for, and I felt as if I partook of it in my newly acquired indifference. The fate of Tino, a 35-year-old ex-convict would remain unassimilated to me. To give death a place in reality and my thoughts, because, my research about understanding the context of allowable death was unbearable. Are homosexual people not human enough? It was not only the legal environment that denied their existence [at the time of the research] but also the home. Why was Tino not on ART like other PLWHA? Where did he come from? Did he always live here at his parent’s home? Maybe that is why he asked me to interview him at his home. His story was powerfully unique and is worth writing. Tino had been incarcerated since 1999 at Chikurubi Maximum Prison and was released at the beginning of 2010. ‘Sometimes I just sleep inside when I feel too weak.’ Tino pointed at his round hut bedroom. At the prison, ‘ncvimbo yacho yaviedikiki, taigara semapepete, munogona kunge muti 15 mu cell one’ [the space was very small, we lived like cockroaches, and you can be 15 or more in one small prison cell]. His body wasted, and his lips fissured and ulcerated. He expressed his speech with his bony hands, long emaciated arms stretched to express his words; his brown skin had lost its lustre and lacked moisture. He had a permanent grin on his face, acquired from continued ailing and squeals from sharp pains emanating from his chest. Temperatures were high, the heat was intense, the flies were nagging and teasing, and he continually waved his hand from right to left chasing off the aggressive houseflies. Tino was skin and bones; he spent most of his afternoons sitting on the ‘rakukwe’ [reed mat] outside, with his back resting against the walls of his round hut bedroom. At the Prison, Tino and his inmates would be restricted to their putrid cells between ‘3 late afternoon and 7 the next day in the morning sitting including when those jail guards are eating from morning, like at around 11 to around one in the afternoon. We did not have beds, so we slept ‘pamasaga’ [mats from remains of used cotton bags]. We hardly had soap, we skipped baths, some coughed a lot and spit Phlegm in the same room we lived and slept, our blankets were lice infested, and some had pus oozing from their wounds. Some had HIV, we were not given condoms, and some died in the cells. We hardly had nurses come to see us. When I started coughing, my partner [Homosexual partner] was also coughing. We both knew that we had TB: we just did not talk about it because it was not abnormal in the cells. In fact, before Kidza [not real name], mushakabvu [deceased] died; he endured painful, raw pricking sores of herpes for months. It was unbearable. Most of the inmates were ill, and some could not control ‘tsvina dzekuzasi, dzaingobuda, unenge worwara’ [dirt (faeces, pus, STI discharges) coming out from down there, you [one] would be ill]. So, when I finally came back, I was tested and was HIV positive, I was not surprised. But how they treated me at the clinic there, I should have died in Prison, its worse out here’. His face began to fall, almost as if ashamed; he lowered it slowly, his chest caved inwards exposing his sharp shoulders, which crawled into one another. His pale left palm pulled to his face, and then the right clasped the left supporting his face, and he began to sob. Deep, irrepressible, hurting sobs. He wept. ‘I am as good as dead here, I wait for death each day, they all do, everyone appears to have authorised it. You just can’t be homosexual and HIV positive in this country, they all reject you’.

Box 0:2: Appendix 13 - Bernard’s Full Story – Goromonzi (LHIG075)
While the signpost at the rural health centre read: ‘Clinic open times, Monday to Friday: 7 am to 4 pm; Saturday and Sunday 7 am to 12 pm’, PLWHA had already packed the place by 6:15 am when I arrived to meet up with Bernard and his wife. The sun was already up, women and men, young and old had walked all the way from their households to the clinic. Bernard had walked for 40 minutes, ‘one needs to come early so that you get a place in the front of the queue, and we’re many, so we get here early. Mai Shingi [Bernard’s wife] wakes up earlier because she needs to clean the yard and heat the water to treat my infected leg before we can walk together to the clinic. ‘I asked you to come here because I want you to see things, you will see how they treat us here, we are treated like vanhu venhando [no direct English translation—it could mean, a useless person, a person without worth]. You will see the time they will serve us. At 9.00hrs, I could see the nurse walking nonchalantly from her house a few hundred meters from the clinic. On one hand she was holding some keys, on the other, she was biting a Mango. As she approached the clinic door, she threw the mango seed into a bin that was lying next to the clinic door. There were buzzes as people greeted her ‘good morning’ in different Shona accents’ Mangwanani Sister’, others ‘mamuka here? Ko makadzi henyu sister, I thought some were greeting her so that they could get noticed, perhaps in a way to buy good treatment from the nurse when it was their turn to get service. After about 20 minutes in her treatment room, it was almost 10:35 am, she officially opened the clinic. I had hoped that another health worker would come, but on this occasion, she worked alone. ‘Vemupiriitsi endai kuseri uko, wese anonoka you will be served kuma4, chop chop tione handina time’ [Those on pills, go behind the wall there, whoever was late will be served later around 4, chop chop, I don’t have time]. Make sure if I call your name you come and get your green file, [the green file contained the patients’ personal information and record on ARV history]. When Bernard’s name was called, his wife crept and sped to get his file, and the nurse retorted, ‘Are you also Bernard? Did I not call Bernard? Did you not pick up your file a few minutes back? She tried to tell the nurse that Bernard could not walk easily because he had a deep wound on his leg, but she was not given a chance to speak. The nurse was unforgiving. At that moment, I felt the urge to go and tell the nurse to stop, but if I did, I would deny myself the opportunity to learn more and see what would happen next. So I kept watching and listening like others, as I sat helplessly next to Bernard. Bernard narrated how such situations had become a norm and that if I stayed longer I would see more. Bernard finally got his ARVs at 1215hrs, but the queue was still long. The nurse looked tired as she locked her treatment room and resigned for lunch at 1357hrs, ‘I’m off to lunch, I’m not paid for working overtime’.
Box 0.3: Appendix 13 - Mai Shingi’s Full case (LHIC013)

I was born in Mupereki, Mhondoro, Zimbabwe, in 1965. We were born 9 and, I’m the [counting fingers on her hand] the 7th. My two younger sisters born after me died, including the twins born just before me. They all died after the death of our mother and father who passed on in 1991 and 1993. Because we were so many, like my three other sisters, I did not go to school, only the 5 boys went to school. I got married in 1983 to Maxwell (not real name) from the same village kwaMupereki (Mupereki). He was a police officer working in Harare and frequently visited our rural home after the war, and that’s when we would see each other. We knew each other when we were very young; he was a little older than I was, he was ten years older because he was born in 1955. He left the village to fight matororo - maBhunu aSmith [the terrorists - Ian Smith’s White man] during the war. I don’t remember the actual year he left because I was young, but he told me that he may never come back. I missed him a lot. He did not return until after independence in 1980. When I saw him I could not recognise him; he was very strong and very fit. He was wearing a very clean Policeman’s uniform. His cap was like the ones worn by the Rhodesian police. I just knew that we would get married, and we did in 1983. I had my first child Shingirayi in 1984 and in 1986 I had my second, Taraisi. Baba Shingi [Shingi’s father -Maxwell] came monthly to see the children back in our rural home and to see me. He brought groceries, clothes and money. In 1989, he did not come for almost 6 months, and I went to Harare in Glenview where he lived because I was worried that something could have happened. The door was locked so I waited until midnight when he finally got home. He was with a woman, whom I think was a prostitute. Ha! I beat the woman thoroughly. You know when you was young I used to fight with the boys when we were herding cattle hahaha, so she really felt my fist blows. I was angry; I don’t think she dared to come back to Max. We got in the house, and I beat him too. I took off to the rural areas the following morning. He came home after another two months; his visits were no longer regular. Sometimes he would send things through the bus conductor from Nyamweda buses in Mhondoro, and it continued like that until I decided I was going to move to Harare with the kids in 1991. I was farming alone in the rural areas; he was not sending money for seeds and fertiliser. It was tough to find food to cook for people who came for ‘Nhimbe’ [working together to help each other with planting, weeding or harvesting]. All my chickens had been finished. I was angry. When we moved, Shingi was in grade 2. There was no warning we just went there. In the same year, we moved to the Kembe [Police camp] where he [Max] was given a house because we could not fit in his one room where he was a lodger in Glenview. In 1995, Baba Shingi fell ill, very ill, in 1998 he died and on his death certificate, they said it was TB. That’s when it all started haaa iwe! [you!]. First, I also had TB, in the same year, that he died, but luckily, I was treated and recovered well. I thanked the ancestors. I was tested for HIV and yes, he had given it to me because of his prostitution. We were evicted from the Kembe in 1999 and I could not contain going back to the rural areas. I began the project yemagardern Kuma sewage, kuseri kwembali nemuzasi memajaraworo [urban small-scale local gardens close to the sewage area, my backyard, and roadside verges along the durawalls]. I was now living kuC [Seke, Unit C] here in Chitown [Chitungwiza]. I had to send my girls to school, I had to pay rent, I needed to get my herbs, go to the clinic, and I needed food, many things. I refused to die. I fell sick, many times and I think I died countless times, but I refused to die. I said Vadzimu [ancestral family spirits] help me. Mwari [God] help me. I sent those two girls to boarding school selling the verges, I was also selling Morina, Gavakava, Mowa and other herbs to others who had HIV. Many HIV positive friends that I met when I was selling the herbs and Verges died. New ones came, and newer ones still come today. In 2007, I started taking my ARVs. Shingi was finishing her degree kuUZ [University of Zimbabwe] and Tari followed the footsteps of her sister (she broke into a smile then into an irresistible, girlish victorious laugh), these hands worked. Things were getting difficult, and I had just started mapiritsi [the ARV pills]. The nurses told me that I must drink the pills at the same times every day with food without mistakes. Like, it’s supposed to be close to perfect to avoid the virus getting cleverer [developing drug resistance]. The pills made me exhausted. I needed more food than before. It meant that I needed to ensure that I ate well and keep my herbs to maintain the benefits of treatment. They changed my combination many times [ARV drug regimens] until the ones I take now, but I suffered. When I was using Zidolam [ARV drug19] my FBC [Full Blood Count] was too low, my nails got purple for 6months. That’s when I dropped it [Zidolam] and went back to stellansov [ARV] and from nowhere I was told that Stellansov was no longer there but only Zidolam20. It aged me. Look at me now, I look like a bull, thin legs, thin hands, look at my stomach, it’s like I’m pregnant. But all this is nothing, what’s important is that I’m still alive, my children are all working. Tari is now with an NGO in Harare, Shingi is married and working in Australia. They are the ones who bought me this house and put these [pointing at the] tiles you see on the floor. I never imagined getting to this age (she broke into another cheerful laughter)

---

19 Zidolam is a single table used in the treatment of HIV. It is a combination of Zidovudine, Lamivudine and Nevirapine ARV drugs. It reduces pill burden.

20 ‘Zidolam a combination antiretroviral therapy may cause changes in body shape due to changes in fat distribution. These may, among other effects include loss of fat from legs, arms and face, increased fat in the abdomen (belly) and other internal organs, breast enlargement and fatty lumps on the back of the neck (‘buffalo hump’)’ (Zidolam tablets, package leaflet: information for the user). The cause and long-term health effects of these conditions were unknown at the time of the research
Appendix 14: Map of Zimbabwe
Appendix 15: Further notes and materials on Methods

a) Participant observations
As a moderate observer, I rented a room (which, here, I call my home) at the Mwanza local store area, which was about 1.5 kilometres from Mwanza primary school and about 3 km from Sabhuku Mwanza’s premises. My home in Mwanza was about 500 metres away from Mwanza Rural Health Centre. The place is connected to Juru Growth Point by a road, which meandered through 10km of a dusty stretch from where I lived. In Chitungwiza, I lived in Seke Unit D, a few hundred meters from Chitungwiza main service centre – by Zimbabwean standards, a big city mall – in the Chitungwiza town centre. My home was close to a police station, a community hall and about 2 km from Chitungwiza Central Hospital. Participant observation provided the opportunity to observe the physical characteristics of the environment and the activity patterns of PLWHA. Through participant observation, I gathered information about the community and its members and observed the community’s day-to-day operations. I also used the method to promote my visibility as a researcher to gain the trust of the community members.

b) Sampling of senior officials in the Ministry of Health and Child Care

<table>
<thead>
<tr>
<th>The elite (SGOs)</th>
<th>Sampling of senior officials in the health ministry</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Political elites</strong></td>
<td>The MoHCC political elites considered for interview included the Minister of Health and Child Care and his Permanent Secretary for Health. The posts of the Minister and the Permanent Secretary for Health are appointed, nominated and assigned functions by the President of Zimbabwe in terms of the new Zimbabwe constitution’s Section 205 and 104 respectively (Government of Zimbabwe 2013).</td>
</tr>
<tr>
<td><strong>Technical elites</strong></td>
<td>The technical elites were carefully selected from three divisions in the MoHCC i.e. the Division of Policy, Planning, Monitoring, and Evaluation; the Department of Finance; and the Technical Support Division (MoHCW 2001). Technical Support Division: The Directorate of Epidemiology and Disease Control, and the Directorate of AIDS and TB were considered. These directorates are responsible for the technical and professional business of the MoHCC including ensuring appropriate health policies, and that a just regulatory environment is in place. Both the epidemiology and disease control; and the AIDS and TB directorates coordinate prevention and control of epidemics of HIV/AIDS/TB/STIs. They are responsible for the development of a policy framework to facilitate effective health service delivery to the population served. They facilitate provision of technical support to ensure the availability and accessibility of diagnostic, treatment modalities and management for HIV/AIDS and STIs. The Division of Policy, Planning, Monitoring and Evaluation: This division is responsible for coordination of general policy development and review, human resources planning and development, coordination of the public sector investment programme and general administrative functions of the ministry. The Finance Division: The division compiles budget estimates of the MoHCC and donor funds to facilitate the rational and equitable allocation of the budget to the operational levels. Furthermore, the unit also monitors the disbursement and utilization of the Health Services Fund, grants to urban local authorities, rural district councils, missions, the National AIDS Council and central hospitals.</td>
</tr>
<tr>
<td><strong>Development elites</strong></td>
<td>The development elites were sampled from a non-government organisation working directly with the health ministry on HIV- and AIDS-related matters. Thus, the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM), the United States Centers for Disease Control and Prevention (CDC) and the World Funded CORDAID were considered. These elites were the primary institutions that had partnered with the MoHCC on HIV-related issues, at the time the study was conducted. The agreement between the GFATM and the MoHCC takes the form of a multilateral agreement (contracts amongst many governments); that of CDC and the MoHCC is</td>
</tr>
</tbody>
</table>
The elite (SGOs) Sampling of senior officials in the health ministry
bilateral (between two governments), and that of CORDAID and the MoHCC was based on a memorandum of agreement between a development organisation and the government. These development elites are constitutive of Foucault’s ‘ensemble’ or institution.

c) Key seed traits and interaction with the study research questions

<table>
<thead>
<tr>
<th>Research question(s)</th>
<th>Key trait</th>
</tr>
</thead>
<tbody>
<tr>
<td>In what ways do i) SGOs and ii) non-PLWHA frame the value of PLWHA?</td>
<td>PLWHA who had been turned away from the treatment center and/or put on a waiting list</td>
</tr>
<tr>
<td>To what extent do such valuations of life allow PLWHA to die?</td>
<td>PLWHA who had lost a family member from AIDS</td>
</tr>
<tr>
<td>What are the implications of valuing PLWHA, for their lives or, conversely, their deaths?</td>
<td>Sex and sexuality – as it intersects with HIV status, sex and sexuality – become the embodiment of a complex social exclusion process and the rationalization for massive health inequities. Women tend to experience little worth and dignity in society relative to their male counterparts. As shall become clear in Chapter Five and subsequent sections, individuals who engage in same-sex practices are considered as people with little value, lower than the worth of ‘animals and insects’ in the Zimbabwean socialisation. As such, it is likely that they may experience more stigmas discrediting their lives and reducing them to degraded persons. In the recruitment process, ensuring a fair representation of women and men (sex) and inclusion of LGBT who live with HIV (sexual identity) and ex prisoners was prioritised. Physical outlook and wellbeing of the person: PLWHA have double stigma attached to them. First, those PLWHA not on treatment are likely to be ill, most often, relative to those on treatment. Their illness may be overwhelming not only for the people who have it but also for their caregivers and families. The impact on caregivers, family and societies can be physical, psychological, social and economic. This raises questions of their worth, dignity and value in communities. Second, those people on HIV treatment experience unforeseen side effects. Such side effects as lipodystrophy have become common due to the prolonged use of ARVs and are likely to be used as proxy indicators for a person living with HIV. Lipodystrophy, like other side effects, affects the physical outlook of a person, which may resultantly affect their confidence and self-worth. To this end, the study recruited both the frail (visibly weak) because they were not taking medication and those taking ARVs but suffering from side effects.</td>
</tr>
<tr>
<td>What are the implications of valuing PLWHA, for their lives or, conversely, their deaths?</td>
<td>Ethical, religious, spiritual belonging: When these traits interact with HIV status, they are likely to act as structural inequities that make PLWHA more likely to encounter new strains of HIV (re-infection) and less likely to treat it. This has implications on re-emergence of opportunistic infections and non-adherence to medical treatment; both are critical threats to the health of those living with HIV and increase susceptibility to preventable death. Strong religious beliefs and practices may increase vulnerability to disease and stigma that may suggest that people with particular ailments are different from others. Such judgments look beyond illness and add negative social baggage associated with the disease. This trait reinforces a characteristic relevant to the recruitment process. Thus, a diverse network of PLWHA belonging to various spiritual entities had to be included. The urban/rural differentials in HIV prevalence ratios tell a story (whatever the story). However, more strikingly, place of residence is a social index of isolation and destitution, disregard, and disempowerment rather than a proxy for different sexual attitudes or behaviour. Thus, recruitment of participants also considered that</td>
</tr>
</tbody>
</table>

In what ways does society and policy decision-maker, in particular, frame the value of PLWHIV?
Research question(s) | Key trait
-------------------|------------------------------------------------------
participants of varying sexual orientations from across the municipalities in Chitungwiza and Chieftainships in Goromonzi District were considered.


d) **Field activity timeline**

<table>
<thead>
<tr>
<th>Field activity</th>
<th>Timelines</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethical clearance: University of Manchester</td>
<td>June 2013–August 2013</td>
</tr>
<tr>
<td>Ethical clearance: Medical Research Council of Zimbabwe</td>
<td>September 2013–November 2013</td>
</tr>
<tr>
<td>Semi-structured interviews</td>
<td>December 2013–May 2014</td>
</tr>
<tr>
<td>Focus group discussions</td>
<td>December 2013–May 2014</td>
</tr>
<tr>
<td>Life history interviews</td>
<td>May 2014–June 2014</td>
</tr>
<tr>
<td>Elite interviews</td>
<td>February–July 2014</td>
</tr>
<tr>
<td>Document analysis</td>
<td>October 2012–December 2015</td>
</tr>
<tr>
<td>Participant observations</td>
<td>November 2013–July 2014</td>
</tr>
</tbody>
</table>

e) **Examples of pseudonyms used during the fieldwork exercise**

<table>
<thead>
<tr>
<th>Study site/organization</th>
<th>Data collection exercise</th>
<th>Name</th>
<th>Example codes used</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Elite interviewee</td>
<td>EI:2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>PLWHA semi-structured interviewee</td>
<td>G108 or C057</td>
<td></td>
</tr>
<tr>
<td></td>
<td>PLWHA Life history interviewee</td>
<td>LHIG11 or LHIC013</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Focus group discussion – Goromonzi District, A</td>
<td>FGD-GorA</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Focus group discussion – Goromonzi District, B</td>
<td>FGD-GorB</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Focus group discussion – Chitungwiza A</td>
<td>FGD-ChA</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Focus group discussion – Chitungwiza B</td>
<td>FGD-ChB</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Focus group discussion with PLWHA – Goromonzi District, A</td>
<td>FGDPWA-GorA</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Focus group discussion with PLWHA – Goromonzi District, B</td>
<td>FGDPWA-GorB</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Focus group discussion with PLWHA – Chitungwiza A</td>
<td>FGDPWA-ChA</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Focus group discussion with PLWHA – Chitungwiza B</td>
<td>FGDPWA-ChB</td>
<td></td>
</tr>
</tbody>
</table>