

**Engaging young men in biomedical HIV prevention
research: lessons from a community-based study in rural
KwaZulu-Natal, South Africa**

Sebastian Suárez Fuller

Thesis submitted for the Doctor of Philosophy

Research Department of Infection and Population Health
Institute of Epidemiology and Health Care
Faculty of Population Health Sciences
University College London

I, Sebastian Suárez Fuller confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Sebastian S Fuller

PhD Thesis: *Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa*

Abstract

Background:

Recent advances in biomedical HIV prevention highlight the importance of successfully engaging male participants, yet previous participant engagement methods have had mixed results. Participatory research and collaborative community development methods of engagement focus on the importance of culture and community and have been successful for engaging participants in research. However, these methods have not been used to engage male participants in biomedical HIV prevention intervention studies in the global south.

Methods:

The *Impilo Yamadoda: Men's Health Study* is presented as a case study to explore use of a "strategic community engagement method" based on theories of participatory research and collaborative community development to engage young Zulu-speaking men in a multi-phase HIV prevention intervention in rural KwaZulu-Natal, South Africa. This engagement method included the identification, recruitment, and training of local volunteers (Research Partners). Research Partners were responsible for: recruitment and implementation of a brief community-based men's health survey; collaborative planning of experimental phase recruitment (N=200) with researchers. Qualitative interviews with Research Partners (N=6) and participants (N=83; 8 focus groups, 20 interviews) were explored alongside analysis of the design, methods, and results of the *Impilo Yamadoda* study.

Results:

Research Partners were expected to collect ~300 (7/day) surveys; N=735 (12.9/day) were returned. Analysis of questionnaires confirmed data quality. Similar recruitment methods were used in the biomedical phase; 95.3% (223/234) of participants completed enrolment, including a behavioural questionnaire, blood sample, and randomisation.

Discussion:

Research Partners discussed the importance of community-level incentives to participants' decisions to engage in research during their training programme, which was confirmed through analysis of qualitative interviews and focus groups with participants. These findings suggest that methods of participant engagement such as the strategic community engagement method used in the *Impilo Yamadoda* study could be used to successfully engage participants in future biomedical HIV prevention studies in the global south.

Sebastian S Fuller

PhD Thesis: *Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa*

Acknowledgments

In completing this PhD I owe a debt of gratitude to the many people who have assisted me on this journey:

Professor Graham Hart and Dr John Imrie for their dedicated supervision;

My family, especially my mother, for her indefatigable faith in my abilities, and my grandfather, who did not live to see this work completed but always believed it would be;

To Paul Rodgers, for his love and support;

To all my friends and colleagues, especially: Roberto Marcelo Sánchez-Camus, Jenna Rossi Camus, Erofili Grapsa, Rebecca Geary, Katheryn Sullivan, Sonali Wayal, Lindsey Reynolds, Thomas Cousins, and Emilie Venables, for their constructive criticism, support, and friendship;

To the many people who assisted at the UCL *Centre for Sexual Health and HIV Research*, especially Andrew Copas, Catherine Mercer, and Pam Sonnenberg;

To the staff of *Africa Centre for Health and Population Studies* in their support hosting this research, especially Marie-Louise Newell, Victoria Hosegood, Colin Newell, Graeme Hoddinott, Mduduzi Mahlinza, Till Barninghausen, Nuala McGrath, Rhana Naicker, Suzette Grobler, Sonja Andrews, Zethu Luthuli, and Rene Stroebel;

To the fantastic *Impilo Yamadoda* study staff: Mlungisi Zungu, Ntombikayise Mncwango, Lungani Masinga, Nkluleko Mngomezulu, and Mpumelelo Mkwanzazi;

To the Research Partner organisations: Bethangwe Community Development Organisation, Inyala Securities, kwaMsane Youth Organization, kwaMshaya Community Development Organisation, Masibambisane Youth Organisation, Nkundusi Citizens, Nsolweni All Stars, Qakwini Citizens, Sisonke Youth Project, Siyakhula Youth Headed Household Organisation, South African Democratic Teacher's Union (SADTU), Sukumani Community Development, TOTA Youth Organisation, Ubuhle bekusasa, and Umkhumbi kaNkulunkulu, for their trust, hard work and dedication;

To the *African-European HIV Vaccine Development Network (AfrEVacc)*, a division of the *European and Developing Countries Clinical Trial Partnership (EDCTP)* for providing funding for the *Impilo Yamadoda: Men's Health Study*.

Finally, this thesis is dedicated to the hundreds of men and their families in the Hlabisa sub-district who helped this research move forward: without your openness and enthusiasm there would be nothing to report. Ngiyabonga umfowethu!

Table of contents		<i>Page no.</i>
i. Abstract		3
ii. Acknowledgements		4
iii. List of figures		8
iv. List of tables		9
v. List of abbreviations		10
1. Introduction		
I. Introduction		11
II. Thesis structure		15
III. Author's note: background and premises		18
2. Review of the context of HIV and health care in South Africa		
I. HIV epidemic in sub-Saharan Africa		21
II. HIV and the South African economy		22
III. Access to health care in the context of HIV and AIDS in South Africa		24
IV. The study area: Hlabisa sub-district, KwaZulu-Natal		31
V. Conclusions		33
3. Theoretical background part 1: research participation and masculinity		
I. Introduction		36
II. Emergence of a focus on men's health		37
III. Zulu masculinities		39
IV. HIV prevention and men's health research in South Africa		42
V. Participant engagement in health research in the global North		45
VI. Engaging men in biomedical health research		49
VII. Participation in <i>Africa Centre</i> HIV surveillance		53
VIII. Collaborative and participatory research methods		54
IX. Conclusions		56
4. Theoretical background part 2: culture, identity, and creating change		
I. Introduction		58
II. Defining community		58
III. Defining identity and cultural identity		61
IV. Creation of change		64
V. Participatory research models		66
VI. Towards a strategic community engagement method		68
VII. Conclusions		69
5. Methodology		
I. Introduction		72
II. Theoretical considerations to the protocol		73
III. <i>Impilo Yamadoda: Men's Health Study</i>		73
IV. Analytical protocol		74
V. Phase 2 survey implementation		76
a. Questionnaire construction and analysis		78
VI. Research Partner involvement		79
a. Survey implementation evaluation (chapter 7)		80
b. Purposive sampling of Research Partners to in-depth interviews (chapter 8)		80
c. Research Partner in-depth interview implementation (chapter 8)		82

d. Analysis of Research Partner interviews (ch. 7 & 8)	82
VII. Participant motivations to research engagement (chapter 9)	84
a. Individual and focus group interviews with survey participants	84
b. Individual in-depth interview and focus group analysis	86
c. Phase 4: experimental study	90
d. Baseline recruitment and enrolment	92
e. Randomisation	94
VIII. Conclusions	96
6. Survey data: descriptions of participants	
I. Introduction	97
II. <i>Africa Centre</i> demographic surveillance data	99
III. General demographic characteristics	101
a. Age	101
b. Education and employment status	102
c. Marital status	105
IV. Social group membership	107
V. General health, HIV/AIDS, and interest in health	110
VI. Willingness to participate in health research	114
a. Likert-type scale	117
VII. Limitations	122
VIII. Conclusions	124
7. Research Partners part 1: the process of implementing a strategic community engagement method	
I. Introduction	127
II. Methods of engagement	127
III. Identification and recruitment of potential Research Partner organisations	128
a. Contact with potential Research Partner organisations	130
b. Capacity assessment of potential Research Partner organisations	131
c. Research Partner training	131
IV. Results of Research Partner recruitment	133
V. Research Partner training outcomes	135
VI. Phase 2: survey administration process outcomes	138
VII. Conclusions	141
8. Research Partners: Part 2: qualitative data exploring the process of a strategic community engagement method	
I. Introduction	144
II. Methods	145
III. Descriptions of Research Partners	146
IV. Research Partner motivations to participate	156
V. Conclusions	161
9. Participant recruitment to the <i>Impilo Yamadoda</i> experimental phase	
II. Introduction	164
III. Process outcomes: phase 4 experiment recruitment	164
IV. Conclusions	173

10. Qualitative analysis for participant motives for research engagement	
I. Introduction	175
II. <i>Umahlalela</i> , (if you are just sitting): self-descriptions and daily life	176
III. Self-reported motivations to engagement	183
IV. The role of incentives and reimbursements	187
V. Conclusions	190
11. Conclusions and implications	
I. Introduction	192
II. Contextualising methods of collaborative community engagement	192
III. Theory of the strategic community engagement method	195
IV. Main study findings	197
V. Contextualisation of the study findings	201
VI. Benefits and drawbacks of the strategic community engagement method	204
VII. Implications	207
v. References cited	209
vi. Appendices	
1. Ethical review board approvals	230
2. Phase 2 survey	240
3. Research Partner involvement	249
4. Phase 3 qualitative interviews with participants	261
5. Phase 4 experiment	280
6. Five steps to support strategic community engagement in research	320

List of figures	<i>Page no.</i>
Figure 1.1: Diagram depicting use of data to test the research questions	14
Figure 2.1: Map depicting the nine provinces of South Africa	24
Figure 2.2: Location of the Hlabisa sub-district in the KwaZulu-Natal province	31
Figure 5.1: <i>Impilo Yamadoda</i> phases of implementation	74
Figure 5.2: Inclusion criteria for participants to phase 3 interview	84
Figure 5.3: Transcription and translation process to prepare IDI and FGD data for analysis	87
Figure 5.4: Analysis process for IDI & FGD data	89
Figure 5.5: Phase 4 experiment design	90
Figure 6.1: <i>Impilo Yamadoda</i> study area, Africa Centre ACDIS surveillance area depicted in grey	99
Figure 6.2: Percentage of age-eligible potential participants to phase 4 experiment	102
Figure 6.3: Employment status of phase 2 survey participants compared to men within the Africa Centre HSE Jan-Jun 2010 round	104
Figure 6.4: Adjusted employment status of phase 2 survey participants	105
Figure 6.5: Marital status of P2 survey participants compared to men within the Africa Centre HSE Jan-Jun 2010 round	106
Figure 6.6: Survey participants and voluntary HIV testing	113
Figure 6.7: <i>Impilo Yamadoda</i> phase 2 survey questions focused on willingness to take part in health research	114
Figure 6.8: <i>Impilo Yamadoda</i> phase 2 survey Likert-type scale questions	117
Figure 6.9: Revised <i>Impilo Yamadoda</i> phase 2 survey Likert-type scale questions	120
Figure 7.1: Partnership comparison, by types of organisations approached	133
Figure 7.2: Example of Informal Contact method: South African Democratic Teacher's Union (SADTU) contact flow	134
Figure 7.3: Comparison of recorded questionnaire (N=709) and contact sheet (N=538) returns by Research Partners and Africa Centre fieldwork staff	138
Figure 7.4: Geographic distribution of survey acceptance rates overall using unadjusted participation rate log	140
Figure 9.1: Five targeted community enrolment locations (phase 4)	166
Figure 9.2: Daily participant enrolment in phase 4	169
Figure 9.3: Participation at Men's Health Fairs	170
Figure 9.4: Phase 4 participant requirements	171
Figure 9.5: Phase 4 experiment design, showing numbers of participants eligible at each stage	172
Figure 11.1: Feasibility and acceptability of elements of the strategic community engagement method	203

List of tables	<i>Page no.</i>
Table 5.1: Researchers, participants, and partners in the <i>Impilo Yamadoda</i> study	76
Table 5.2: Research Partner IDI purposive sampling	81
Table 6.1: Phase 2 survey population (N=735) demographics	101
Table 6.2: Two-way contingency table for age and education grade completed	103
Table 6.3: Two-way contingency table between employment and education status	104
Table 6.4: Two-way contingency table between age groups and marital status	107
Table 6.5: Phase 2 survey participants' organisational membership	108
Table 6.6: Significant variables in phase 2 survey participants' organisational membership, eligible versus not eligible	109
Table 6.7: Odds ratio between eligibility to phase 4 experiment and non-eligible, by social group membership	110
Table 6.8: Survey respondent interest in health education programmes	111
Table 6.9: Two-way contingency table between reported health status and willingness to participate in research	115
Table 6.10: Cronbach's Alpha test for reliability of Likert scale, missing values excluded	119
Table 6.11: Cronbach's Alpha test for reliability of Likert scale; high item correlations including missing values	120
Table 6.12: Cronbach's Alpha test for reliability of Likert scale; high item correlations excluding missing cases in scale and outcome variables	122
Table 8.1: Main and sub-themes across Research Partner interviews	145
Table 11.1: Findings from investigation of main research question and the effect on the phase 4 biomedical experiment design	201

Sebastian S Fuller

PhD Thesis: *Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa*

List of abbreviations

List of abbreviations

ACDIS: *Africa Centre* Demographic Information System

Africa Centre: *Africa Centre for Health and Population Studies*

AfrEVacc: *African-European HIV Vaccine Development Network*

AHBS: AIDS health belief scale

AIDS: Acquired immunodeficiency virus

AR: Action research

ART: Anti-retroviral therapy

AZT: Azidothymidine anti-retroviral treatment

CAB: Community advisory board

CBO: Community-based organisation

DBS: Dried blood spot sample

DSA: *Africa Centre* demographic surveillance area

EDCTP: *European Union Developing Countries Clinical Trial Partnership*

FBO: Faith-based organisation

FGD: Focus group discussion

HIV: Human immunodeficiency virus

HSE: *Africa Centre* household socio-economic survey

IDI: Individual in-depth interview

IMF: International Monetary Fund

KPI: Key person interview

KZN: KwaZulu-Natal

MMC: Medical male circumcision

MDG: Millennium development goals

MDP: *Microbicides Development Programme*

MSM: Men who have sex with men

NGO: Non-governmental organisation

PAR: Participatory action research

PR: Participatory research

PLWHA: People living with HIV/AIDS

PMTCT: Prevention of mother to child transmission of HIV

RCT: Randomised controlled trial

SOP: Standard operating procedure

TAC: *Treatment Action Campaign*

TasP: Treatment as prevention

VCT: Voluntary counselling and testing for HIV infection

YEP: *Africa Centre* youth engagement programme

I. Introduction

The question of how to involve men in HIV prevention intervention trials has recently been brought to the forefront of public health research with the anticipation of biomedical advances that may help prevent the spread of HIV. Less is known about men's engagement with health in the developing world than in the global north. Yet nowhere are biomedical advances in HIV prevention more necessary than sub-Saharan Africa, which with only 12% of the world's population accounted for 68% of the world's people living with HIV/AIDS in 2010 (1). Southern Africa is disproportionately affected by the HIV epidemic; in 2009, 34% of people living with HIV globally resided within the ten countries that comprise the Southern Africa region (Angola, Botswana, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Zambia, and Zimbabwe) (2). The involvement of African men, who account for an HIV prevalence minority yet are the main source of female infection, is essential to assuring the success of HIV prevention programmes in Southern Africa (1, 3, 4).

It has been said that men are more difficult to engage in health research than women (5), a mirror of their comparatively low and/or late uptake of health care services (6). Low engagement of men in health research is particularly concerning given that men's involvement in HIV prevention research in endemic areas such as South Africa has been linked to women's adherence in biomedical trials (7), and reductions in partner violence (8, 9). It is becoming clear that even the success of female-initiated HIV prevention methods is linked to male involvement (10, 11). Yet there remains little understanding of specific practices that can be employed to engage men in the global south in biomedical HIV prevention intervention research.

Results from short-term research projects show that community-based male-specific health programmes work well in garnering the interest of men (12-16). However, the effects of community-based and peer-led methods for recruiting men into biomedical prevention research programmes are still unclear.

Participatory methods have been explored for increasing the public's interest in health research, and many studies have been implemented with favourable results (17). These studies

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 1: Introduction

work with members of potential participant and stakeholder groups with the goal of conducting research that is highly acceptable to researchers and participants alike (17). However, while participatory research is seen as site-specific and contextual (17), there is little investigation of the use of participatory methods to inform conduct of biomedical health research in the global south, and no participatory health research studies involving biomedical design that engage primarily with male participants.

This thesis seeks to engage with the gaps in the literature regarding use of participatory methods to engage men in biomedical health research in the global south. To that end, the design, methods, and implementation of the *Impilo Yamadoda: Men's Health Study*, set in rural KwaZulu-Natal, South Africa, is used in this thesis as a case study.

The *Impilo Yamadoda* study was part of the *African European HIV Vaccine Preparedness Network (AfrEVacc)* of the *European Union Developing Countries Clinical Trial Partnership (EDCTP)*, a research network focused on engaging people across Southern Africa with HIV prevention intervention research, and specifically vaccine trial research. Based on the specific capacity of each site, protocols in the AfrEVacc consortium were developed to increase the feasibility of successful trial of an HIV vaccine. Based at the *Africa Centre for Health and Population Studies*, the *Impilo Yamadoda* protocol outlined a pragmatic, multi-component, multi-method study to explore key issues in men's health and address logistical questions around the successful engagement and retention of men in biomedical HIV prevention research studies (18). It should be noted that although the AfrEVacc consortium focused on development and implementation of vaccine trials, the *Impilo Yamadoda* study was primarily concerned with recruitment and retention in biomedical HIV prevention research generally, and so there was no mention of vaccine trial research in the *Impilo Yamadoda* study.

In the *Impilo Yamadoda* study, four research phases follow sequentially: community familiarisation (phase 1) informs a quantitative survey (phase 2); data, process and administration outcomes from this survey inform the qualitative component (phase 3). The fourth phase, an experimental trial of recruitment and retention methods over time, takes into

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 1: Introduction

account data collected in the first three phases. The four-phase *Impilo Yamadoda* study will be discussed as a dataset that allows exploration of the process of research implementation, and specifically, the effects of “a strategic community engagement method”: working collaboratively with community members who implemented aspects of the *Impilo Yamadoda* research and informed recruitment practices throughout the study.

Due to the iterative nature of this investigation, there are two questions that this research seeks to answer. The first question this investigation seeks to answer is: “Can participatory research methods be used to encourage men’s participation in biomedical health research in the global south?” This question concerns evaluation of the factors contributing to the engagement of participants in the *Impilo Yamadoda* study and assessing which, (if any), of the lessons learned from implementing the “strategic community engagement method” might be applied to research in similar settings.

The second question this thesis seeks to answer is more specific: “What factors contributed to the engagement of young men in Kwa-Zulu Natal in the *Impilo Yamadoda: Men’s Health Study?*” Data used to investigate this question are comprised of information collected through the process of implementing the *Impilo Yamadoda* study, which includes data on the process of implementing the research as well as survey questionnaire and qualitative interview data. In addition, interviews were conducted with community members who implemented *Impilo Yamadoda* research in order to gain a greater understanding of their relationship to the researchers, their communities, and the participants they engage with the *Impilo Yamadoda* study. (see Figure 1.1, page 14).

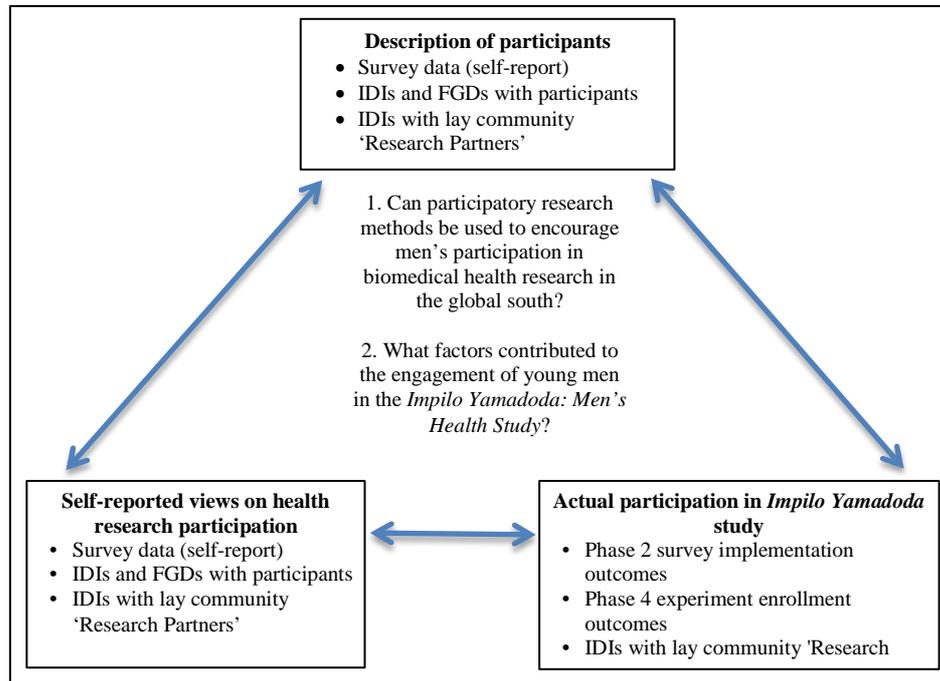


Figure 1.1: Diagram depicting use of data to test the research questions

Investigation of the implementation of the *Impilo Yamadoda* research protocol is central to an investigation of the research questions described above. Data from implementation processes contextualise the findings from the research. Quantitative data collected from *Impilo Yamadoda* participants via a brief community-based survey help to inform our understanding of the participant population. Qualitative data from in-depth interviews and focus groups with survey participants give depth to the survey data and add insight into participants' motivations for engaging with the *Impilo Yamadoda* study. A second qualitative dataset was then purposively collected to explore the experiences lay community members had while implementing *Impilo Yamadoda* research. Data from the process of implementing the survey and recruiting participants to the experimental phase of research allow for an evaluation of the recruitment and implementation process. Combined, these data allow a multi-faceted and rich description of the factors that contributed to the engagement of young men in Kwa-Zulu Natal in the *Impilo Yamadoda: Men's Health Study*, as well as understand the usefulness this method may have for encouraging men's participation in other biomedical health research studies in the

global south.

II. Thesis Structure

This thesis was conceptualised as a pragmatic social science study, and so topics of research were structured by the research questions and resulting analyses were directed by what the participants emphasised (19). The literature reviews in the next three chapters will introduce key issues framing the research questions.

As was mentioned above, it has been seen that research participation efforts are generally context-specific (17). With that in mind, geographic and temporal contexts of health shape the structure of the first literature review chapter: topics are explored on the international to local scale and through specific important times in historical context. These topics are then brought into focus with a specific description of the study area.

As this thesis is essentially focused on individual and community change in relation to health research participation, theories from the fields of social psychology, anthropology, and community development are reviewed in two theoretical background chapters. The first of these chapters focuses on research participation and masculinity by initially discussing how ‘men’s health’ came to be of interest in public health and health research, and then moves to a discussion of the literature on Zulu male identity, which is brought together in a review of men’s health research in South Africa. Participant engagement in health research is then discussed, with a focus on ‘willingness to participate’ literature and why these studies cannot give a more complete understanding of the mechanics of participant engagement. How some of the most influential biomedical research studies have presented their engagement strategies is then explored. With this understanding of how participant engagement strategies are approached, appraised, and reported on in biomedical health research, we can then understand where the gaps are within these essential stages of research planning and implementation. Alternative research models are then reviewed in this chapter to gain insight into how these

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 1: Introduction

methods have been used; specific uses of participatory research methods in South Africa allow an understanding of how these methods have been used in this part of the world.

The main focus of part 2 of the theoretical background to this research (chapter 4) is to gain an understanding of the theories behind participatory methods of research. In the first sections of this chapter, concepts of identity, community, and culture are defined. With these definitions, the discussion moves forward to focus on models of community change and participatory research methods; these theories are applied to create the “strategic community engagement method” used to encourage participation in the *Impilo Yamadoda* study.

The fifth chapter, “Methodology,” outlines the methods and protocol of the research used in the development of this thesis. All analysis methods and the rationale behind these methods are described in detail in this chapter. As the thesis focuses on an investigation of a specific methodological technique and its affects, this chapter is essential to understanding the context in which the resulting analysis is based.

The first data-driven chapter, chapter 6, brings forward a descriptive statistical analysis of the men who became participants in the *Impilo Yamadoda* study via their participation in a brief community-implemented men’s health survey. Over 700 Zulu-speaking men participated in this phase of *Impilo Yamadoda* research, and 81 of these participants formed a sub-sample for the qualitative research phase. These participants formed the seed sample for the final phase of *Impilo Yamadoda* data collection. With this in mind, the descriptive analysis of the survey participants presented in chapter 6 is essential in framing the picture of who engaged with the study and why. This chapter will serve as both a descriptive background and to highlight key issues young men in this cohort engaged with in their decision-making processes to participate in HIV prevention research.

In chapter 7, “Research Partners part 1: the process of implementing the strategic community engagement method,” the roles and dynamics of the individuals who were identified and volunteered to partner with the *Impilo Yamadoda* study are reported on. The specific community engagement method that drives the recruitment of the various stages in the *Impilo*

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 1: Introduction

Yamadoda study (detailed in the methodology chapter) was contingent on the engagement of the Research Partner team. It has been recognised that a good rapport between researchers and participants is essential in implementing social science research effectively (20). The importance of this dynamic and its impact on participant engagement with *Impilo Yamadoda* is explored in chapter 7. Data describing the survey administration process gives insight into the usefulness of the specific community-based engagement method to engage potential participants. Formal individual in-depth interviews and informal discussions with volunteer administrators, as well as field observations and discussions with research team staff, give depth and meaning to outcomes from the survey administration process; these data are introduced and discussed in chapter 8: “Research Partners: Part 2: qualitative data exploring the process of a strategic community engagement method.”

Chapter 9, “Participant recruitment to the *Impilo Yamadoda* experimental phase” reports on outcomes from the process of participant recruitment to the *Impilo Yamadoda* experiment. These data were gathered during the process of recruiting participants to the experiment phase, and allows insight into how the strategic community engagement method worked in this biomedical research setting.

Throughout this thesis voice is given to topics that were introduced by participants as they reflected on the topic of benefits of and barriers to research participation. In this way topics were allowed to emerge from the data that were not anticipated yet became central to exploration of the research questions. For example, during early implementation of the *Impilo Yamadoda* study, the importance of the ‘felt needs’ of participants began to present itself; researchers, community stakeholders, volunteer research administrators, and study participants all have different needs that must be identified and then met for a project to be successful. Chapter 10, “Qualitative analysis of participant motives for research engagement,” is focused on furthering an understanding of the *Impilo Yamadoda* participants’ motives for engaging with the study. Descriptive data from in-depth interviews and focus group discussions regarding participants’ expectations of research engagement are supported by outcomes of the recruitment

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 1: Introduction

to the *Impilo Yamadoda* experiment presented in chapter 9. An explanatory analysis of why these men chose to engage with the research is presented in chapter 10.

In chapter 11, critical concepts and conclusions reached throughout the thesis are summarised for clarity and then taken further a discussion of the implications of this analysis. This discussion returns to the review of methods of research engagement discussed in the literature review and theoretical background chapters of the thesis. Findings in earlier chapters are reviewed to explore how the strategic community engagement method used in the *Impilo Yamadoda* study may work to improve future research programme implementation in similar resource-poor settings.

III. Author's note: background and premises

The research this thesis encompasses results from my opportunity to direct and critically reflect on the *Impilo Yamadoda: Men's Health Study*. The *Impilo Yamadoda* study was community-based, participatory social science research, as was the sub-study that this thesis reports on. As such, I am aware of the limits of objectivity and the impact of a researchers' power position on the research he or she undertakes; this can be argued to be essential to participatory and community-based research (21). It is thus useful to situate myself as both the director of the main research study and the chief investigator of the research presented in this thesis.

I come to this research with a varied history in public health, community development, and social science research. Growing up in an economically deprived area in the diverse urban landscape of New York City in the 1980s, I had an early interest in the impact of wealth on the quality of life, and particularly on housing and urban landscapes. As a result, I obtained my first degree in cultural theory, and soon thereafter, earned a master's degree in cultural anthropology with a focus on qualitative methodologies (New School for Social Research, 1999 and 2001, respectively).

Concurrent to my education I was active in community-based work, which led to my first

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 1: Introduction

major collaborative, participatory, action-oriented, work as co-founder of the BLANK collective, a social justice organisation focused on urban gentrification and abandonment. While active in the community, I gained my first professional research job as a longitudinal qualitative researcher on a US National Institutes of Health study. Although I did not have any formal post-secondary public health training at that time, working in public health came naturally to me as the only-child of a life-long health educator. My emerging health research career then led me to Philadelphia, PA, where I began to see how my interest in community-based work might have an outlet in health research; my post leading qualitative research and coordinating the media campaign for a men's behavioural HIV prevention intervention merged my skills as an organiser and as a qualitative researcher.

Desiring more hands-on public health work in areas of the world that needed it most, I left my emerging career in research to volunteer in Ghana as a health, water, and sanitation volunteer with the US Peace Corps. In Ghana I continued my education in community development work, learning through reading and practicing concurrently. In Ghana it was made clearer than ever to me that the key to community change was through collaborative, multi-level, community action. While the people in the small village I lived with on the borders of Ghana and Burkina Faso wanted me to answer to their questions and provide solutions, my limited local experience left me with more questions than answers. My good friend and local counterpart and I had long discussions about how to discover what the community needed, and how I could help with those needs within the two years of my service. There were systemic barriers that could not be overcome; yet real progress was made in forging partnerships in the midst of the status and power imbalances between Ghanaian government representatives and the rural farmers I lived and worked with. The realities of *doing* (performing) community-based work in the developing world paralleled the theoretical concepts I learned in my university education and coalesced into something at once theoretical, ideological, and pragmatic.

While there were many fleeting and several tangible victories during that time, the most meaningful were those that were sustainable: the development of a centralised water and

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 1: Introduction

sanitation committee for the village, so that needs could be identified, agreed upon, and actioned; forging ties between the regional health and education authorities and a local youth-focused community-based organisation. These small changes were achieved through time and continued dedication to work *with* people to create real and sustainable change.

It is with this background that I came to the UK to pursue a PhD in sexual health research at University College London. Here my goal was to complement my pragmatic understanding of sexual health and community development with a deeper understanding and robust theoretical basis in public health research. Holding an understanding of social science, pragmatic health research, and community-based development, I attempt to bridge the divides between these fields to create a deeper understanding of how to use these diverse methodological tools to encourage effective methods of community-based research participation in fixed-design models of health research.

Chapter 2: Review of the context of HIV and health care in South Africa

I. The HIV epidemic in sub-Saharan Africa

An estimated 2.6 million [2.3 million–2.8 million] people became newly infected with HIV in 2009 (2). While HIV incidence is falling globally, the majority of new infections continue to occur in sub-Saharan Africa, where an estimated 1.8 million [1.6 – 2.0 million] people became infected in 2009 (2). Sub-Saharan Africa continues to have the world’s highest number of people infected with HIV: of 33.3 million [31.4 - 35.3 million] adults and children living with HIV globally in 2009, an estimated 22.5 million [20.9 – 24.2 million] of those were in sub-Saharan Africa (2). While the number of new infections in sub-Saharan Africa declined by almost 26% in 2010, the region accounted for 70% of new HIV infections globally that same year (1). Deaths from AIDS-related causes have declined 20% (an estimated 320,000 people) between 2004 - 2009, reflecting the advances in treatment that extend the lives of those infected (2). Since 2000, the HIV epidemic in sub-Saharan Africa has stabilised, with adult HIV prevalence on the decline (22).

Within sub-Saharan Africa there are significant sub-regional differences in the HIV epidemic; while Western Africa has relatively low HIV prevalence rates, Southern Africa retains the highest prevalence rates for a single sub-region in the world (2). Trends in Eastern Africa show that this is the only sub-region to see significant declines in prevalence rates over time, with the mid-to-late 1990s showing an approximate 4% decline from a median prevalence of 12.9% to 8.5% at the turn of the 21st century (23). HIV prevalence trends in West Africa were stable with a median prevalence of 3 - 4% between 1997 - 2002 (23). Central African countries reported a median HIV prevalence of about 5% between 1997/98 and 2001, (with the exceptions of Central African Republic and Cameroon, which reported higher rates) (23). More recent data suggest a decrease in 12 countries across the Central and West African sub-regions (Benin, Burkina Faso, Democratic Republic of Congo, Gambia, Ghana, Guinea, Liberia, Mali, Mauritania, Niger, Senegal, and Sierra Leone) to HIV prevalence rates at or below 2% (2). Within Southern Africa, overall median prevalence of HIV infection increased from about 5%

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 2: Review of the context of HIV and health care in South Africa

in 1990 to 21.3% in 1997/98 and 23.8% in 2002 (23). In 2009, Southern Africa accounted for 34% of people living with HIV and 34% of AIDS-related deaths globally, with Swaziland seeing the world's highest adult prevalence at 25.9% of the population (2).

The HIV/AIDS epidemic in the Southern African sub-region is quite different to that of the rest of the world. In the global North, and virtually all areas outside of Southern Africa, HIV infection is found in specific subsets of the population: men who have sex with men (MSM), sex workers, and injection drug users are disproportionately affected (2, 22). As seen in the statistics above, Southern Africa, particularly Swaziland, Lesotho, Botswana, and South Africa, face the highest numbers of HIV infected people in the world (1, 2). While there are areas where injection drug use and unprotected anal intercourse between men are key factors in the HIV epidemic, the high prevalence rates reported in the Southern African region indicate a generalised HIV epidemic with heterosexual sex as the primary mode of transmission (2, 24). The use of different research methods, such as sentinel surveillance, and more recently, national population-based surveys, show that the majority of those infected with HIV are heterosexual women who have acquired the virus from their primary male sex partner (23).

II. HIV and the South African economy

In 2009, of an estimated 33.3 million HIV infections worldwide, 5.6 million of these people lived in South Africa, the highest concentration of people infected with HIV worldwide (2, 25). Trends data estimate that HIV prevalence rates in the nine provinces of South Africa have differed from that of the rest of Southern Africa. Contrary to the rest of the sub-region's high prevalence rates in the early 1990s, prevalence rates remained below 5% in South Africa until 1994, with the highest increase reported between 1995 and 1996 to about 15%. From 1996, countrywide HIV prevalence grew to catch up with the trends in the rest of the region; in 2002, South African and Southern African sub-regional HIV prevalence rates equalised at just under

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 2: Review of the context of HIV and health care in South Africa

24% (23). HIV prevalence rates in South Africa vary widely between provinces, ranging from just over 15% in the Western Cape to approximately 39% in KwaZulu-Natal (26).

The burden of HIV/AIDS in South Africa is so high that the implications of the epidemic go beyond the lives of those infected and have become a nationwide economic concern. One of these nationwide economic concerns is the current national health budget, and other concerns relate to poverty and unemployment, which correlate with poor health outcomes. If current costs continue, anti-retroviral treatment (ART) for HIV infection will account for nearly 50% of all health budget expenditures (27). To economists what is even more worrying is the unemployment rate – estimated in 2010 as nearly 25%; this means that South Africa has one of the highest national rates of unemployment in the world (national ranking of 173 of 200) (28).

Approximately 57% of South Africans live in poverty, and KwaZulu-Natal province accounts for 61% of the nation's total number of people living under the poverty line (29). The poverty faced by the majority of South Africans is underlined by the knowledge that South Africa is one of the most unequal societies in the world. Global estimates of inequality in distribution of family income are measured by the Gini index (a totally equal society would measure 0.0% and a totally unequal society measure 100%): South Africa's Gini index in 2005 was 65% (30). KwaZulu-Natal ranks as the nations' province with the highest poverty gap, (a measure of disparity between the wealthiest and poorest residents), at 22.5% (29). KwaZulu-Natal is the most economically unequal province in one of the most unequal countries in the world.

In the midst of a global economic recession, South Africa, along with much of the Southern African region, has grown dependent on an influx of foreign aid to meet the 2015 Millennium Development Goals (MDG) (31). These monies began to scale back in fiscal year 2009/10, continuing a trend since 2008 (32). International donor spending for the AIDS response dropped from US\$8.7 billion in 2009 to US\$7.6 billion in 2010 (1). The International Monetary Fund (IMF) estimates that average economic growth across Africa would show 5.8% growth in 2012 (33), a figure higher than the bleak 2009 estimate of 1.5% (34), as developing

country economies gained unexpectedly amidst the continued global recession. Although an improvement over the 2009 estimate, the current projected slowdown will still affect development goals across the continent; a 7% economic growth rate is considered the minimum rate needed to overcome expected population increases (34). Additionally, South Africa's current recession (the first in 17 years) is thought to have created ripples across the sub-region's smaller economies (34). Regardless of the poor economic climate, increase in access to health care for the most vulnerable of the population remains essential; it has been argued that today's changes in health access for the people of South Africa will determine health and social economic inequities for future generations to come (1, 27, 35).

III. Access to health care in the context of HIV and AIDS in South Africa



Figure 2.1: Map depicting the nine provinces of South Africa (36)

With the highest number of people living with HIV worldwide (2), it is indisputable that all South Africans have been affected by HIV/AIDS in some way. Yet, as Didier Fassin communicates in the introduction to his formidable work on experiences and politics of AIDS in this country, it is important to recognise that not all people are affected in quite the same way,

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 2: Review of the context of HIV and health care in South Africa

or for the same reasons (37). Fassin argues that the differing views and experiences of HIV/AIDS in South Africa

...must be made comprehensible; [HIV/AIDS] must be viewed and analyzed from the diverse local vantage points, encompassing the tensions and contradictions of local experiences, in the scientific arenas as much as the townships, among political leaders as well as village inhabitants. (37)

Those in the field of social medicine have spent time discussing how economics and the politicisation of poverty have resulted in real health outcomes around the world, both in the past and present (38, 39). The dual burdens of poverty and disease have also been connected to politics in Paul Farmer's work, primarily in Haiti, and more recently, Elisabeth Pisani's work on HIV prevention in Asia (40, 41). The connection between public health and poverty is perhaps most popularly argued by Paul Farmer, who, as a medical doctor and anthropologist, examines not only the cause but the perpetuation of disease burden in the developing world (40, 42). Farmer and others discuss how the relationship between structural violence and health become *biosocial* concerns, which must be addressed not only through biomedical solutions, but also social programmes, in order to create healthy egalitarian societies (42-44). Indeed, few in the field of health can ignore the link between poverty and disease (38, 42). Those who believe all medicine is inherently social argue that it is only with an interdisciplinary approach, such as linking social science and medicine, that we can successfully overcome global inequalities in health (39, 45, 46). However, as Farmer sates: "this awareness is seldom translated into formal frameworks that link social analysis to everyday clinical practice" (42). Despite some successes, (Uganda is the most often cited success story for HIV prevention although even this has been challenged (47)), the HIV epidemic increases relatively unchecked in the developing world (22).

In South Africa, Mark Hunter argues for a look at the interplay of the history and present structural violence of poverty and social divisions in the post-apartheid era of the AIDS epidemic (48). The political and socio-economic forces of colonialism and apartheid have shaped current health, demographic, and epidemiological transitions (25, 49, 50). Importantly,

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 2: Review of the context of HIV and health care in South Africa

the people of South Africa have been directly involved in the transition to the current democratic governance of the country (49, 51, 52). The extraordinarily high burden of disease faced in the rural KwaZulu-Natal province is part and parcel of the political climate in South Africa; this is a topic of concern to politicians, doctors and lay people alike (49, 53).

The political history of HIV and AIDS in South Africa, especially regarding treatment, has been well documented by popular media and scholars (50, 54-57). The history of apartheid from 1948 to its official dissolution by democratic election in 1994 has been similarly well-documented, most popularly in personal account of the struggle that has been published since 1994; the impact of apartheid on the people of South Africa has been introduced to the greater world by these poignant memoirs and autobiographies (51, 58, 59).

The damage that the institutionalised discrimination of apartheid has done in relation to the social determinants of HIV infection in South Africa is ever-present yet remains difficult to quantify (60). As AIDS began to emerge in the early 1980s, South Africa was entrenched in a violent upheaval of its government; throughout the 1980s people in segregated townships across the country resisted apartheid, resulting in a government-declared State of Emergency from 1986 - 1990 (51). By 1988 30,000 South Africans were known to have been detained for participation in the resistance to overthrow the apartheid system, with the strongest push coming from the main resistance leadership party, the African National Congress (ANC) (61). Political pressure by the international community in the form of sanctions is largely thought to have influenced the fall of apartheid, the laws of which were repealed by 1991 (52). By 1993 a multiracial, multiparty, transitional government took over, and 1994 saw the election of Nelson Mandela representing the ANC in the office of president of South Africa (52). By this time HIV and AIDS were already on the rise in South Africa (50). Nelson Mandela addressed HIV/AIDS as a problem in 1992, with the intent to start a National Strategic Plan to combat the virus' spread; however, it was not until the major restructuring of the institutionally unequal South African health system began that any real progress could be made (62).

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 2: Review of the context of HIV and health care in South Africa

Health care for the majority of South Africans was severely impacted by decades of discrimination and oppression enforced under apartheid (63). During apartheid, health centres were segregated, and the health system itself was fragmented with huge disparities from area to area across the country (8). In 1997, the publication of the “White Paper for the Transformation of the Health System in South Africa” sought to equalise health care for all South Africans in recognition of former apartheid disparities:

Prior to 1994 the South African health system was built on apartheid ideology and characterised by racial and geographic disparities, fragmentation and duplication and hospi-centricism [sic] with lip service paid to the primary health care approach. (64)

In the period between 1994 and 1999 a major restructuring and expansion of the health service sector took place, resulting in notable changes including a focus on primary health care. During this time more than 700 new clinics were built and nearly 2300 existing clinics received new equipment (64). Free antenatal and children’s health care services were also provided, giving services to people in the poorest parts of the country, notably the so-called Black African “homelands” of apartheid era, of which the majority of KwaZulu-Natal province is comprised (63, 65). The result is a more comprehensive national health system: standardised treatment plans were created, primary health care began to be offered without cost to users, national immunisation programmes have reduced poliomyelitis and measles, and availability of essential drugs has increased within the public health system (63). Despite these major improvements, inequities remain in the South African health care system across the country today; relatively wealthy provinces such as Western Cape provide services that the poorer province of KwaZulu-Natal cannot (56). While progress has been made in redistribution of resources (i.e., medicines and trained health care workers) between geographic areas from a five-fold difference in 1992/93 to a two-fold difference in 2005/6 (63) there are disparities in care across provinces, and even within districts (56), reflecting heterogeneous family wealth distribution and access to basic amenities (29).

Echoes of apartheid can also be found in the South African response to the country’s early HIV epidemic, from the slow response during Nelson Mandela’s presidency to the

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 2: Review of the context of HIV and health care in South Africa

reluctance of President Mbeki to provide his citizens with the globally recognised standard of care for treatment of HIV and AIDS. It has been said that President Mandela was reluctant to fully address HIV as a problem because early apartheid government prevention programmes focused on reducing sexual transmission were initially seen as a weapon to reduce the population of Black South Africans (52). Treatment with the anti-retroviral drug Azidothymidine (AZT) to prevent onward transmission from HIV infected mothers to their newborns was rejected on the basis of its high cost in 1998, and by the time President Mandela left office in 1999, 4 million South Africans were estimated to be infected with HIV (52). Newly elected President Mbeki furthered Mandela's passive response and actively resisted accepting Western medical treatment for HIV directed at the mostly Black HIV infected population (66, 67). With an estimated 10% of the population living with HIV, President Mbeki could no longer ignore the growing epidemic; as a result Minister of Health, Manto Tshabalala-Msimang, turned to traditional medicines and nutritional supplements for treatment of HIV and AIDS, leading to the former Minister's popular nickname "Dr Beetroot" (68). Minister Tshabalala-Msimang not only questioned the efficacy of anti-retroviral therapy (ART) for HIV and AIDS but also suggested that their toxicity would lead to further illness on the part of patients receiving the drug and questioned the scientific evidence that AIDS is caused by HIV; Mbeki and his administration took the controversial stance that poverty and institutionalised inequality caused AIDS and refused to take part in provisions for Western medical treatment for the growing numbers of HIV positive South Africans (49, 52, 67, 69).

It has been suggested that the hope for a Black African traditional medicinal cure for HIV/AIDS held by many sub-Saharan Africans is the result of a history of oppression of Black Africans by White settlers that goes beyond the time of institutionalised apartheid; a rich history of traditional medicine has largely been supplanted by Western medicine (70, 71). In the 1930s there were fewer than 10 Black doctors in the (formerly named) Union of South Africa and graduating classes of doctors between 1968 - 1977 show 3% of those graduates to be Black South Africans (63). Alternatively, a review of the literature on traditional medicine in Southern

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 2: Review of the context of HIV and health care in South Africa

Africa reveals a history of treatment that predates colonial records (72). Indigenous traditional healers significantly outnumber Western medical doctors in South Africa – in 1995 a study revealed roughly 200,000 traditional healers compared with 25,000 Western medical doctors, and estimated that 80% of Black South Africans used the services of these traditional healers, often as a first effort to remedy illness (73). South African traditional healers known locally as *Inyanga* (the Zulu term for “herbalist”), are almost exclusively male (73), and are often consulted for the treatment of sexually transmitted infections (STIs); in a 1998 study in KwaZulu-Natal, 14% of patients presenting STIs at a primary care clinic had first consulted an *Inyanga* for a cure (74).

Efforts have been made to legitimise traditional medicine in South Africa: since the early 1990s multi-national donor groups such as the joint United Nations programme on HIV/AIDS (UNAIDS) have recognised that a collaboration between the medical community and traditional healers would be an important step forward for the national health systems of sub-Saharan Africa (75). NGO special task groups focused on HIV/AIDS prevention and treatment have published recommendations for partnerships between traditional and Western medical establishments (76). Additionally, the South African Department of Health has called for inclusion of traditional healers as part of the continuum of care programme for HIV/AIDS care and treatment (77).

Despite political inroads, collaborative traditional and Western medical treatment of HIV/AIDS and other chronic infections remains a contentious issue. Western medical and traditional healing practices are well known to be ideologically dissimilar in their definitions of illness, treatment, and wellness. *Inyanga*, for example, are often called to treat underlying spiritual disturbances as much as cure the resulting physical symptoms, while Western medical treatment stems from a philosophy of discrete physical and spiritual worlds (70, 72, 75). Additionally, the majority of traditional treatments are seen by the Western medical establishment as more detrimental than curative; the common traditional treatment of multiple enemas, for example, weakens the body of a healthy person and may be quite harmful for a

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 2: Review of the context of HIV and health care in South Africa

person with a weakened immune system (73). On the side of the traditional healers, *Inyanaga* are resistant to 'giving away' the secret treatment plans and medicinal recipes that form the main source of their livelihoods, yet Western medical establishments deem this transparency essential in maintaining regulations for its standards of medical care (77). New studies have shown that the majority of *Inyanaga* will refer patients with chronic conditions to Western medical doctors, yet much distrust remains on both sides of these potential collaborations (78).

In 2003, a major victory was scored for groups of people living with HIV/AIDS (PLWHAs) seeking anti-retroviral treatment (ART) in South Africa. Patients turned activists, most notably the Treatment Action Campaign (TAC), mounting pressure from the international scientific community, and international sanctions are thought to have finally led to the capitulation of President Mbeki's anti-ART policy (79-81). While the *2007-2011 HIV & AIDS and STI Strategic Plan for South Africa* has been internationally lauded as an example of good policy (63), the majority of the estimated 5.5 – 5.7 million South Africans currently living with HIV are still not receiving these life-saving medicines (26, 35, 54, 82). An estimated 330,000 lives between 2000 - 2003 could have been saved but for the anti-treatment policies of President Mbeki and Minister Tshabalala-Msimang (35).

The reluctance of the Black African population in South Africa to test for HIV is related to distrust of the Western medical establishment. Rumours of sinister experimentation on Black Africans by White medical researchers continue in many countries in Africa, linked from the past to health and health research practices today (83). It is well documented that stigma surrounding HIV/AIDS infected people leads to low testing rates for HIV (76, 84). While much is being done to reverse this trend, testing rates for men in South Africa, particularly Black men, remain low. As a result, unaware of their own status, these men continue to put their partners at risk of infection.

IV. The study area: Hlabisa sub-district KwaZulu-Natal

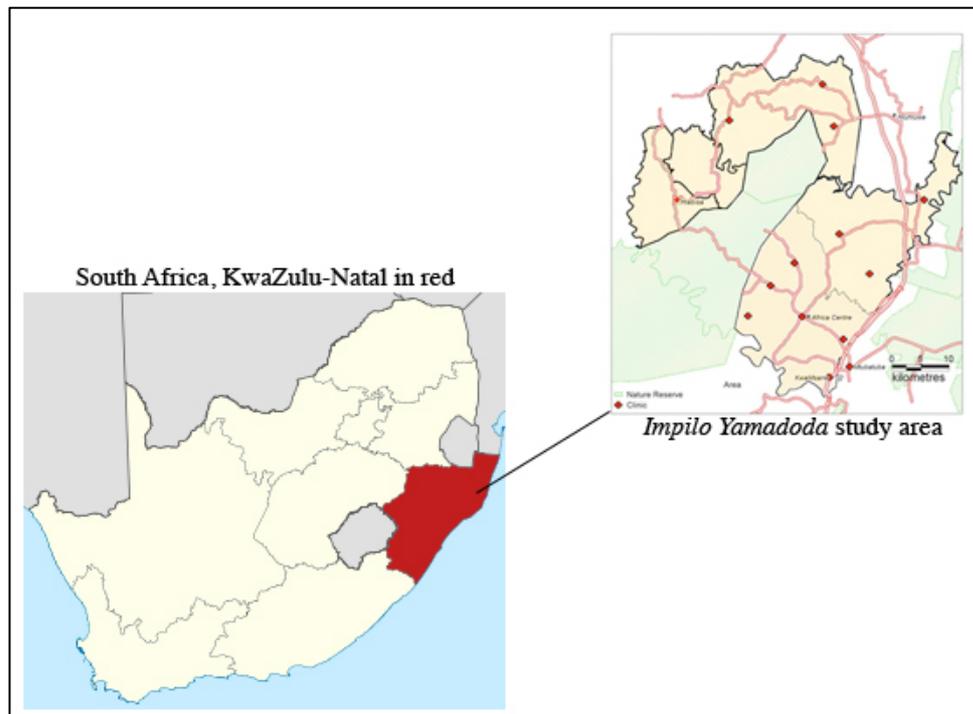


Figure 2.2: Location of the Hlabisa sub-district in the KwaZulu-Natal province

The research for this thesis was conducted in the Hlabisa health sub-district of KwaZulu-Natal, South Africa and hosted by the Wellcome Trust funded *Africa Centre for Health and Population Studies*. The Hlabisa sub-district is located in the Umkhanyakude district, on the northern coast of the KwaZulu-Natal province (Figure 2.2, this page). A small section of the study area is well researched as part of the *Africa Centre Demographic Information System* (ACDIS), started in 2000, and monitors longitudinal vital events in a population of about 100,000 residents and non-residents (85). While the *Africa Centre* demographic surveillance area (DSA) forms only a portion of the Hlabisa sub-district, demographic data on the study area reported below are based on *Africa Centre* ACDIS reports.

The population of KwaZulu-Natal province is young, with nearly half of the population (46.8%) under the age of 20 years and little over 17% above the age of 44 years (86). Within Umkhanyakude district 40.6% of the population is under 14, making this district among those with the highest proportions of young people in KwaZulu-Natal province (87). The mean age for this district is 23.6 years (87). Population density in the Hlabisa sub-district is varied (20 -

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 2: Review of the context of HIV and health care in South Africa

3000 people/km in the *Africa Centre* Demographic Surveillance Area) (88), with highest densities in the three townships under municipal authority and sparsely populated isolated homesteads in rural areas under ‘traditional’ or ‘tribal’ authorities.

Across the Umkhanyakude district in 2007, 33.6% of households had electricity, the lowest proportion of households with electricity in the province. That same year 31.5% of households in the Umkhanyakude district had piped water and just under 15% (14.8%) of households had either flush or chemical toilets (87). Infrastructure is equally heterogeneous across the study area, with municipally controlled areas experiencing a high quality of facilities, whilst in the traditionally controlled lands, sometimes just across the road from the municipal area, access to indoor plumbing and electricity is non-existent or erratic.

The unemployment rate among males in KwaZulu-Natal is 20.4%, only slightly higher than the national average (19.3%), and unemployment affects a large section of the working age population (87). The principal sources of income for many households within the Hlabisa sub-district are waged employment or state-funded social grants. A much lower percentage of income is generated by (non-industrial) agriculture (88), despite farming and gardening initiatives of local non-governmental organisations (NGOs). Much of waged employment is outside of the study area, reflected in the circular migration patterns of the adult workforce; informal interviews with key informants reveal that most adult men within the sub-district return to the primary household on a daily basis, commuting from major employers in Richard’s Bay, just outside the boundaries of the study area (89).

In 2007, KwaZulu-Natal province had the highest proportion of HIV infected antenatal clinic attendees (39%) as well as the highest number of infected people in the general population (15.8%) of any province in South Africa (87, 90). HIV prevalence in antenatal clinic attendees in the Umkhanyakude district was 39.8% in 2007 (87). Population-based HIV testing within the *Africa Centre* demographic surveillance area (DSA) started in 2003 (88), allowing for a more accurate estimate of prevalence in the study area. In 2007, it was reported that HIV prevalence in residents of the DSA peaked at 51% [95% CI 47-55%] among women aged 25 -

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 2: Review of the context of HIV and health care in South Africa

29 years and 44% [95% CI 38-49%] among men aged 30 - 34 years; overall 21.5% of residents aged 15 - 49 years were infected in 2007 (91).

With *Africa Centre's* demographic surveillance beginning in 2000, and the addition of HIV surveillance in 2007, the population of the DSA is familiar with health research activity. In addition to the core demographic surveillance project, *Africa Centre* has been part of important biomedical HIV prevention research, such as the recently completed vaginal microbicide Pro 2000 trial to test the safety and effectiveness of this drug in reducing new HIV infections in women (MDP 301). Larger research studies, such as MDP 301, took place within the entire Hlabisa sub-district, exposing residents outside of the DSA to research activities. As a result, these larger research projects broadened DSA residents' knowledge of research, highlighting key differences between participation in surveillance type research versus clinical trials. To this end *Africa Centre* had developed a well-established and active Community Advisory Board (CAB). The *Africa Centre* CAB continues to serve as a community liaison infrastructure for participants and stakeholders to research activities and provides a model foundation for HIV prevention research studies.

While *Africa Centre* has conducted research for 11 years, to date much of this research has been either surveillance or specifically focused on women and/or children. Although surveillance research tells us a great deal about the household structure and HIV status of area residents (and non-residents), little information can be deduced about men's refusal to take part in biomedical research activities such as HIV testing as part of research (91), or their low attendance at local health care facilities.

V. Conclusions

The epidemiological considerations of conducting HIV prevention research in Southern Africa are many; this region continues to account for the highest prevalence of people living with HIV in the world (1, 2). It has been said that the extraordinarily high burden of HIV

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 2: Review of the context of HIV and health care in South Africa

disease in South Africa affects the country's economy, with the high cost of provision of health care for the infected population accounting for nearly 50% of all health care budget expenditures (27). This is concerning in this current global economic climate of uncertainty as South Africa continues to remain dependent on foreign aid to meet its population health care goals (31). In addition, South Africa faced a 25% unemployment rate in 2010 (28), and the most recent Gini index ranked the country as having one of the most unequal societies in the world (30). Further, the province of KwaZulu-Natal, where the *Impilo Yamadoda* study took place, ranked as having the nations' highest disparity between the wealthiest and poorest residents (29).

While great strides towards restructuring of the South African health care system have taken place since Nelson Mandela's democratic election to the office of President of South Africa in 1994, access to, and quality of, health care remains dependent on factors such as individual wealth and area of residence (29, 56, 62-64). In addition to structural barriers for access to health care for poor South Africans, echoes of government-led AIDS denialism have been thought to fuel ideological barriers to health care uptake, such as the stigma surrounding HIV/AIDS; it was not until 2003 that South African policies denying anti-retroviral treatment for people living with HIV were overturned (79-81). The stigma surrounding people living with HIV/AIDS has been linked to low rates of testing for HIV (76, 84), a trend that continues among men specifically, despite focused efforts to increase testing in this group (13, 15, 16).

The *Impilo Yamadoda* study took place in the Hlabisa sub-district in the Umkhanyakude district of KwaZulu-Natal, South Africa. A small section of the Hlabisa sub-district is well researched as part of the *Africa Centre for Health and Population Studies* demographic surveillance research. Data collected as part of the *Africa Centre Demographic Information System* (ACDIS) HIV surveillance research show that a continued very high prevalence of HIV infection continues in this area (91). In addition to this high burden of HIV disease, residents in the Umkhanyakude district reported the lowest levels of access to electricity of any district in KwaZulu-Natal in 2007, a marker of the poverty these residents face (87).

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 2: Review of the context of HIV and health care in South Africa

The historical and present day burdens of poverty and disease faced by the people of the Hlabisa sub-district are essential factors in understanding the research presented in the thesis; it was within this historical and epidemiological context that the *Impilo Yamadoda: Men's Health Study* was implemented. With this in mind we move forward in the next chapter to review theoretical underpinnings of the strategic community engagement method used in this research study.

Chapter 3: Theoretical background part 1: research participation and masculinity

I. Introduction

This chapter will begin with a review of the literature consulted during the initial study design period prior to design of the participant engagement strategy and implementation of the *Impilo Yamadoda* study.

The study of potential participant engagement in health research has largely comprised: descriptive accounts of actual participant engagement techniques used in research studies and speculative studies where potential participants are asked about their views on health research engagement. In addition, there is a growing literature on participatory methods of research implementation, which encourage potential participants to become involved in research by focusing research programmes on issues that members of the target community have identified as problematic. As we will see below, there are few studies that describe participant engagement practices that utilise lessons learned from descriptive accounts of successful engagement, speculative studies, and participatory research methodology. Even fewer studies use these lessons to inform biomedical research study engagement.

This thesis utilises both speculative and descriptive techniques to recount and then explain the decision-making process behind male Zulu-speaking participants' decisions to engage with our health research study. To that end, the next sections of this chapter will engage with a discussion of the field of men's health. In order to better understand the specific context of working with Zulu men, Zulu culture and masculinity will be described. This section of the review will further the previous chapters' discussion of the geographic, cultural, and temporal setting of the research undertaken in this thesis. This is then continued in a review of the current literature on men's engagement with health research in South Africa, which then leads us to a discussion of how men have engaged with biomedical HIV prevention research specifically. Lastly, examples of how alternative research methods, such as participatory action research

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 3: Theoretical background part 1: research participation and masculinity

(PAR), have been utilised in research in South Africa, will lead us to the theoretical discussion of the next chapter.

II. The emergence of a focus on men's health

It was not until the early 1990s that men became a topic of interest for health programme planners (92-95). In fact, focusing on men's health seemed to be in opposition to improving women's health; it has been suggested that theories of feminism have greatly impacted health care (92). Yet research in gender dynamics and sexuality has shown that in areas of the world that bear the heaviest burden of the HIV epidemic men are often the gatekeepers of women's sexual health (96-98). Additionally, researchers such as Sternberg and Hubley have shown that when men are more engaged in health care women's health improves (99).

On an international scale, it has been reported that men's engagement with health services continues to be lower than that of women (100, 101) and as Cameron shows, men's disadvantage in health is greater than that of women:

For every age group, male mortality is higher than that of females, life expectancy is lower for men, men tend to use primary health services less than women, are more likely to delay help-seeking when ill and are more likely to adopt health damaging or 'risky behaviours, for example smoking, drinking, violence, fast-driving. (92)

As with all forms of identity, masculinity is not biologically determined but socially constructed and performed (102-104). It is understood that a gendered sense of masculinity, that is, men behaving in a way that is reflective of a traditional sense of male behaviour, puts them at increased health-risk: finding it difficult to express health-related fears (6); denial of weakness or vulnerability; unrelenting interest in sex (105); and health care seen as women's 'business and responsibility' (106). These stereotypical concepts together place masculinity at odds with protective health practices and inform the ideological hegemony (107) of masculinity found in the majority of the world's populations. As part of an ideological hegemony, men's risk increasing practices are seen as normative and static, even as they are fluid in actuality.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 3: Theoretical background part 1: research participation and masculinity

Ideological hegemonies are a set of ideas that become so entrenched in a culture as to be seen as immutable, which itself both shapes and give credence to practices. This is especially true in marginalised communities; it is thought that enforcing dominant concepts with overt practice allies those emulating a practice to those in power. Therefore constructing masculinity, particularly by men on the margins of society, is equated with construction of an elusive sense of power (105).

In the global north, the outcome of studies looking to engage men in health have led health programmes to place a growing emphasis on intercepting men's 'lifestyle'-producing risk factors (106). The resulting programmes focus on men to the exclusion of women, and have worked to carve a niche for the speciality of men's health research. In the public health speciality of HIV prevention, subdividing the field by identity and behaviour has matched well with a focus on the HIV epidemic in the developed world, which, as noted in the previous chapter, is highest among certain population sub-groups.

Intercepting 'lifestyle'-producing risk factors has produced mixed results in the 'special populations' HIV/AIDS health promotion field of the global North, with more success reported in substantive interventions that have addressed specific segments of the population, such as men who have sex with men (MSM) (108-110), and Black and Latino men (111). Outside of MSM-specific HIV prevention programmes few scientific evaluations of health care programming targeted specifically for men have taken place (95).

Engaging men in constructing positive masculine identities is seen as a foundational step in encouraging men towards healthy behaviour and positive social interaction (12, 112); however, a lack of infrastructure for men's access to continuous and primary health care remains (113). Throughout sub-Saharan Africa health care is focused on antenatal and child health, providing women with a clear entry point to the health care system. African men are left with limited access to male-centred health care (113). As a result of this lack of infrastructure, health promotion campaigns that seek to focus on men's behaviour change in the developing world are left with little recourse but to target their messages to men's 'responsibility', which in

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 3: Theoretical background part 1: research participation and masculinity

and of itself is a concept drawn from the ideological hegemony of masculinity (114, 115). This is particularly true of sexual health and family planning campaigns, which form the bulk of men's health programming in the developing world (100, 116). Thus there is minimal focus on men's health care access in the developing world while a culture of blame continues to surround men's risk-increasing behaviour. Widespread views of men in the public health sector include: men as perpetrators of violence (especially rape and partner abuse), as practicing patriarchal behaviours (e.g., lack of autonomy of women in sexual partnerships), as engaging in multiple and concurrent sexual partnerships, and, as refusing to participate in prevention practices (e.g., condom use). This image of the African male is used by the majority of public health campaigns across sub-Saharan Africa, despite a growing body of masculinities and male-centred health research providing a much more complex picture (8, 48, 117-120). The section below will focus on studies of Zulu masculinities in order to deepen our understanding of what it meant to be a Zulu man at the time of the *Impilo Yamadoda* study recruitment.

III. Zulu masculinities

Zulu masculinities have been explored from early ethnographic studies (72, 121, 122) to recent work examining the impact of the current local and global economic situations and the burden of HIV in South Africa (120, 123). Much of the literature focused on Zulu men is contextualised by family; historically to be a father and household head is the highest social status a Zulu man can achieve (72, 121, 124, 125). Thus an essential element in understanding Zulu masculinities is uncovering the meanings of the historical and contemporary role of the father in Zulu culture.

Throughout history, warfare, systematised oppression, and poverty have helped to shift the construct and performance of Zulu masculinity (126). AT Bryant reports that in pre-colonial times, Zulu boys moved through a strict social system to become men (72). Before the age of 14 – 16, boys took the responsibility of looking after the family's herd of cattle (72). After this, the

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 3: Theoretical background part 1: research participation and masculinity

boys would accompany their father (*baba*) on journeys; this was traditionally the first time boys would leave the family homestead (*umuzi*) (72). Aside from these journeys, the largest amount of time between boyhood and manhood was spent in the regiments training to become men and defend the Zulu homelands (72). Along with their age-mates, boys would be sent to one of the Zulu king's military homesteads (72). In these regiments boys learned to take up the mantle of manhood through respect for ones' elders and hard work (72). These young Zulu men spent ages 20 – 40 largely in the regiments, with occasional leave to return to the family *umuzi* (homestead) (72). After time in the regiments it was expected that young men return to the family and marry shortly after their return (72).

Today's young Zulu men no longer travel to the regiments. Nor is it inevitable that these young men travel to work on migrant contracts throughout the prime years of their early adulthood, a rite of passage that parallels manhood rites common during much of the nineteenth and twentieth century (52, 127). However, many young Zulu men see the path to manhood as involving fathering children and multiple partnerships, a dynamic that is at once complicit with and in contrast to the traditional role of the Zulu man (72, 123).

It has been said that there is a history of men having multiple sexual partnerships both prior to and within marriage (i.e., polygamy) in Zulu culture (123). Yet Zulu men who take multiple partners without intending to marry, or those with multiple wives that cannot be supported, do not earn respect in Zulu society (123, 124). A young Zulu man must first marry and set up an independent household to become respected; fathering children outside of marriage does not make a man *baba* (father) (124). In fact, even today, if a man impregnates a woman outside marriage a "penalty" fee (*inhlawulo*), most usually in cash or cattle, must be paid to the woman's family before the child can take his name (124).

In contrast to a man who has fathered children outside of marriage is *baba*, the respected man. Eileen Krige reports that *baba* was "respected and feared and his commands obeyed" (121). Importantly, *baba* is meant not only to describe biological parentage but more broadly to describe the male head of the family unit:

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 3: Theoretical background part 1: research participation and masculinity

...baba is a term for an older man (though age need not necessarily be calculated in years) who is fulfilling, or is called to fulfil, a role of care, protection and provision in relation to 'children'. (Again, a child is not necessarily someone who is very young). (125)

As seen above, a respected man must be married. However, before marriage can take place a Zulu man must first pay *lobola*, (bride price) to the family of his prospective wife (48, 72, 121, 123, 124). *Lobola* is a significant financial burden, reportedly amounting to up to £2000 (128). In KwaZulu-Natal the payment of eleven cows (or the cash equivalent) is seen as a time-honoured Zulu tradition, though earlier accounts report *lobola* cost as flexible, largely symbolic, and never amounting to more than 4-5 head of cattle (121, 123). Historical reports indicate that as the owner of all things in the household, the father of the prospective husband would normally be responsible for his son's *lobola* payments (121). The traditional meaning behind the practice of *lobola* is debatable; some view the payment as a symbol of the great worth of his prospective wife, as a token of friendship between the two families of the betrothed, or as a reduction of women's value to that of so many livestock (72, 121, 128). While views of *lobola* are important to the perception of women in this society, this traditional transaction is just as important to how men are perceived. The ability of a man to pay *lobola* (either by himself or via his father) proves his ability to provide for his future wife and family (124, 129). Once married and his separate household set up, the Zulu man is seen as an adult man and can do as he wishes as he has earned the respect of his own family and that of the larger community (120).

With costs of *lobola* far outside the achievable in an economic climate where young Black African men are disproportionately unemployed, the distance between boyhood and becoming *baba* can seem insurmountable (125). Men who are unable to pay *lobola* due to lack of economic opportunity continue to have sexual relationships and often produce children, as being a parent is seen as one of the most important marks of adulthood in South Africa (124, 125). In rural areas such as the Hlabisa sub-district where this research takes place, expectations of payment of *lobola* (and, if necessary, *inhlawulo*) supersede those in urban areas, perhaps for

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 3: Theoretical background part 1: research participation and masculinity

the very reason that economic opportunities in rural areas tend to be fewer (124). Paradoxically, producing children outside marriage can cause more difficulty to a young Zulu man attempting to become the respected *baba* in his community; if a man cannot pay *lobola* it is unlikely he will be able to afford a penalty fee (*inhlawulo*) for his illegitimate children, even if he wants to (124). The inability to pay may lead some men to deny paternity of children, even if others in the community believe they know who the biological father is (124). Lack of economic opportunity then leads these young men to a decreased social standing in their communities, a frustration, anthropologist Mark Hunter has said, which leads to a sense of powerlessness over this most essential aspect of their lives (124).

This review leads us to understand the history and current context that young Zulu men found themselves in at the time of the *Impilo Yamadoda* study and as such will provide important information during the data analysis process, where we seek to understand the reasons behind participants and potential participant's decisions to engage in the *Impilo Yamadoda* study.

IV. HIV prevention and men's health research in South Africa

Following the review of Zulu masculinities, a review of the men's health research in South Africa can be better situated. The Zulu tribal group is the largest ethnic group in South Africa, and so much of the men's health research literature from South Africa necessarily involves Zulu men.

Much work has been done to better understand men's relationship to health seeking behaviour in South Africa (117, 119, 130). Montgomery's work in KwaZulu-Natal focused on men's involvement in the family and has challenged the image of the Zulu male as uninvolved with family and care within households affected by HIV/AIDS (117). Rabe's qualitative work in the South African coal mining industry gives insights into this population's perceptions of masculinity and fatherhood (130). A study examining HIV positive men's experiences in

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 3: Theoretical background part 1: research participation and masculinity

accessing ART in KwaZulu-Natal found a complex picture, including men's awareness of the risk that attending health care facilities would have on their community and/or family status (119). This study also found that confidentiality and professionalism was of utmost importance to these men and determined their actual or desired health seeking activities (119). Contrary to stereotypical connotations of a so-called "Black African male identity," these studies show that men's desire to engage with health is based on a complex mix of social, historical, and personal experiences.

A special focus was given to men's health at the 4th Southern African AIDS Conference (Durban, 2009). A review of the conference proceedings exemplifies the variety of recent or on-going HIV prevention intervention programmes focused specifically on South African men. The *You can count on me* campaign (Ruth Becker, presenter) is a grassroots awareness campaign with a focus on men's role in prevention of mother to child transmission of HIV (PMTCT) (14). This campaign found that men responded favourably to the intervention specifically because community peers recruited them to the programme (14). An additional finding noted that men who refused to go to clinic, informing the investigators that clinics were "female spaces," could be more easily convinced to test for HIV at male-centred mobile Voluntary Counselling and Testing (VCT) units associated with the campaign (14).

Monde Mgwele of the Olive Leaf Foundation in Cape Town presented similar results from the male-centred VCT campaign run in the high HIV incidence peri-urban township Khayelitsha (13). Men responded to questions as to why they refused the offer of clinic attendance (and subsequent HIV testing) by saying "clinic is for women and babies." Further data from this programme revealed that men accounted for only 30% of VCT for HIV in the area (13). A male sexual health clinic successfully promoted via local radio increased male HIV testing in the township (13). *The Tutu Tester*, a mobile men's health clinic with HIV testing capacity run by the Desmond Tutu HIV Foundation (also set in the Western Cape), focusing on asymptomatic testing and risk reduction, also found similar results: men sought health care more often at this male-centred venue than at standard local clinics (16).

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 3: Theoretical background part 1: research participation and masculinity

Helen Struthers presented her male-centred study investigating health seeking behaviour, again relating specifically to VCT (15). This study of men in Soweto, a high-density township of Johannesburg, reported barriers to VCT and other health-seeking behaviours on all levels: personal, community, and systemic (15). On the individual level men said that they believed that health was important, and told investigators that they engaged whenever possible in the protective behaviours of good nutrition, exercise and personal hygiene (15). Yet men were concerned about the possible collapse of their families and community as a result of actual or possible health-seeking behaviour: “what will others think?” if they were thought of as ill or went to the clinic (15). Additional community-related barriers included men citing the clinic as a female space where women “gossip” about the men that they see there (15). Systemic issues included reports of men feeling disrespected by the predominately female health service staff at clinics, blamed for the health related problems of women, and aversion to treatment of their ailments by female nurses (15). Struthers reported that if men get to clinic and receive treatment they have a higher adherence rate than women; however, if stigmatisation of men persists in the health sector it only leads to increased secrecy and isolation (15).

Studies involving South African men in relation to the high rate of violence – one of the highest national rates of violence in the world – have also taken place. Catherine Campbell’s study on violence and the family amongst her study group in Durban linked high rates of violence to gender inequality, race and class oppression (131). Continued male violence perpetrated towards women in South Africa, and specifically the high rate of rape and its effect on the spread of HIV, has led to deserved attention by health researchers; a recent study of rape and men’s health in South Africa reported that 27.6% of the men in the study group had raped a woman or girl over the course of their lifetime (112). The same study found that 42.4% of the men in the study group had been physically violent to an intimate partner (as defined as a current or ex-girlfriend or wife) and there was a significant relationship between men who had been physically violent to a partner more than once and having HIV (112).

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 3: Theoretical background part 1: research participation and masculinity

As a consequence of this research, there are a number of interventions focused on lessening sexual violence in South Africa. These programmes have achieved some success; *Sonke Gender Justice Network* is working to encourage men to take an active role in the lives of orphans and vulnerable children and in so doing hopes to reduce the influence of male stereotypes of promiscuity, dominance and risk-taking (132). The *Network's* "One Man Can" campaign, an intervention across South Africa focused on lessening male perpetuated violence, builds on correlations between violence and civil rights and found that once men felt that their rights were protected, their rates of HIV testing increased (133). *EngenderHealth's* implementation of the "Men As Partners" programme works with the understanding of the historically patriarchal system in South Africa, the limits of women's power in sexual health decisions, and the challenges traditional constructions of masculinity pose for HIV prevention. "Men As Partners" thus uses existing masculinities research to inform what is essentially an HIV prevention-via-behaviour-change programme (134).

With this understanding of the research conducted currently in South Africa our picture of the geographic, cultural, and temporal context of the *Impilo Yamadoda* study is complete. The following sections focus on a review of the theoretical considerations of the participant engagement method of the *Impilo Yamadoda* study, and in so doing allow us to gain contextual understanding of how researchers have previously approached the polemic of participant engagement.

V. Participant engagement in health research in the global North

A review of literature on increasing participation in research yields similar results to the emergence of the men's health field; the literature on participation focuses on studies in the global North. Many of these studies, largely from the United States, are in response to minority groups' under-representation in health-related research (135-139). While it is debated that minorities are in fact under-represented in health research studies (140), there is an undeniable

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 3: Theoretical background part 1: research participation and masculinity

history of exploitation of African Americans in the United States in health research, specifically in reference to the Tuskegee syphilis study, which took place between 1932-72. Although the specific impact the Tuskegee syphilis study had on minorities participation in health research is debated, it is agreed that at the very least the Tuskegee syphilis study built on and reinforced mistrust of the medical establishment among minority groups in the United States (141-144).

Unpacking minorities mistrust of health research, Hussain-Gambles' review of the literature focused on ethnic minority representation in biomedical trial research discusses how views of research and racism contribute to barriers to trial participation (135). This thematic review was based mainly on literature from the United States and United Kingdom and found that minorities, and specifically south Asian ethnic groups, were under-represented in the reviewed trials (135). Multiple factors, from financial (increased trial costs are associated with minority inclusion in RCTs) to social-cultural and language barriers, were found to influence minority inclusion in the reviewed trials (135). Financial cost estimates were based on assumptions about the need for specific and multi-tiered recruitment to encourage minority participation, the extra cost of hiring staff with appropriate cultural and linguistic competencies, and the need for translation of participant information sheets and other trial documents into languages other than English (135, 145). The assumptions of the extraordinary costs associated with including women and minorities in biomedical trials, (as are cited above), have been challenged, yet it remains clear that special effort is needed to include minorities who are not fluent English speakers in trials taking place in the US and UK (145, 146).

Language barriers and socio-cultural factors were described by health-providers as leading to misconceptions about potential minority participants (135). Additionally, health-providers described discomfort with explaining complex trial procedures to patients whose first language is not English, and this was linked to patients mistrust of health professionals, especially during the consent process prior to trial enrolment (135). Importantly, Hussain-Gambles states that the lack of inclusion of ethnic minorities in biomedical trials is reflective of inequalities elsewhere in health, as well as on a larger socio-economic scale (135).

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 3: Theoretical background part 1: research participation and masculinity

Recommendations within the literature to facilitate minority inclusion in biomedical research range from pragmatic ways to exhibit cultural sensitivity such as not using gel-caps (which contain gelatine and thus are unlikely to be Halal) when attempting to include south Asian populations in medical RCTs, to increasing health providers' training in order to overcome common cultural misconceptions and feel more comfortable explaining trial procedures to minorities who may be eligible to participate in clinical research (135).

As was mentioned above, published investigations into the inclusion of minorities in biomedical research in the global North have mainly come from the United States. In addition to the investigations into the Tuskegee syphilis study noted above, this special interest may be due in part to the United States National Institutes of Health (NIH) Revitalization Act of 1993, which focused on the inclusion of women and minorities in clinical research (147-150). The NIH Revitalisation Act of 1993 sought to increase the participation of women and minorities in clinical research, based on the premise that medical research should include an understanding of the variability of human physiology by gender and ethnicity, and so stated:

In the case of any clinical trial in which women or members of minority groups will be included as subjects, the Director of NIH shall ensure that the trial is designed and carried out in a manner sufficient to provide for valid analysis of whether the variables being studied in the trial affect women or members of minority groups, as the case may be, differently than other subjects in the trial. (147, 148)

This act, additional legislation clarifying and enforcing the act, and the ensuing discussion by scholars and clinical researchers, allowed for significant change to the design and implementation of health research in the United States reflective of the active recruitment of women and minorities into clinical trials (147-150).

In the United Kingdom, the issue of equal representation in clinical research has historically been less attended to. However, in recent years the United Kingdom National Health Service (NHS), the Research Councils UK (RCUK), the UK National Research Ethics Service (NRES) and the UK National Institute of Health Research (NIHR), have supported an increased focus on including patient and public involvement (PPI) in research (17, 151). With this change of focus in mind, a systematic review was recently carried out by the INVOLVE project team,

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 3: Theoretical background part 1: research participation and masculinity

which is a UK-based national advisory group that supports greater public involvement in NHS public health and social care research (152). INVOLVE is funded by and part of the United Kingdom National Institute of Health Research (NIHR) (152). The INVOLVE systematic review investigated the evidence of the impact of public involvement of health and social care research.

A major finding from the INVOLVE review was that the evidence for the effectiveness of engagement methods can be subjective, as the impact of these methods are often difficult to measure because of the site-specific nature of the methods of engagement used (17). Yet despite the variation in robustness of reporting procedures and variable evidence of impact, many of the studies reviewed found the same results of involvement: “the benefits and costs [of patient and public involvement in research] are being consistently reported [across trials]” (17). The benefits of participant engagement that many studies reported was: improved clinical trial design, and a sense of increased confidence in the use of relevant outcome measures (17). These benefits were further seen to result in an increase of the scientific validity of results, patient satisfaction, and an improved understanding and view of research among participants (17).

Challenges the author's noted in conducting the systematic review were: that the terms researchers used in reporting their participant/patient engagement programmes were diverse, which made systematic reviewing more difficult, and that reporting of engagement methods were similarly inconsistent (17). Additionally, when reviewing the literature it became clear that some researchers feel that pre-clinical research such as qualitative interviews and focus groups should be included as part of their participant engagement plan, while others feel that these activities should be classified as research and so should not be considered an engagement activity (17).

One study from the United Kingdom discussed how use of qualitative research embedded in a randomised trial of prostate testing for cancer and treatment improved patient consent to randomisation over time (153). Donovan et al outline not only increases in consent to randomisation but also the specific changes made to achieve the increase: changes in the order

that treatment arms were presented to patients, changes in terminology to describe treatment arms to avoid misconceptions, and changes in how equipoise and randomisation was presented to patients (153). This study is a good example of how qualitative research can be seen as a bridge between patient engagement and research, as it gives pragmatic advice on how patient information was received before and after the suggested changes were implemented (153).

VI. Engaging men in biomedical health research

The above review of how Donovan et al used qualitative research to inform RCT procedures moves our discussion from a general look at participation in health research to that of participant engagement in biomedical research specifically; we can see in the discussion above that the field of biomedical health research has specific concerns for potential participants (153). One of the most important considerations of biomedical health research, and particularly research focused on evaluation of interventions, is that it is recommended to follow a fixed design (154). While some debate the usefulness of the model, the widely recognised ‘gold standard’ of biomedical intervention research evaluation is the randomised control trial (RCT) design (154-157). Therefore, the literature discussing potential problems with participant engagement in this research focuses on the procedures consistent with most biomedical RCT designs.

In the sub-field of biomedical HIV prevention intervention research, participant concerns may be centred on procedures during enrolment and throughout the research (158, 159). Enrolment to biomedical HIV prevention intervention research includes procedures such as provision of blood for HIV testing (e.g., vaccine trials and circumcision trials), which may include the enrollee receiving their HIV and other sensitive medical test results. Continued participation in these trials may mean undergoing medical procedures involving multiple follow-ups in clinical settings (e.g., medical male circumcision), injection or other use of experimental medicines (e.g., HIV vaccine research; microbicide research; pre-exposure

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 3: Theoretical background part 1: research participation and masculinity

prophylaxis for HIV [i.e., PreP]; and test-and-treat trials [i.e., TasP]), and/or detailed investigations of participants' sexual networks, partnerships and practices (160-162). While this investigation is primarily concerned with participant enrolment, during recruitment is the time when potential participants would usually be informed about the procedures necessary for continued engagement in the research, and thus these procedures would be a consideration in potential participants' decision to enrol in research. Any or all of the above-mentioned procedures necessary for engagement with biomedical HIV prevention intervention research may be cause for potential participant concern.

With that in mind, various studies have examined reasons surrounding the difficulty of engaging with men in health-related research (5, 163-166). Most of these studies have concentrated on the social cultural reasons behind low recruitment to short term and qualitative projects. As we have seen above, biomedical health research has specific factors that may concern potential participants, and so research into men's barriers to participation in short term and qualitative research may not be applicable to the biomedical research setting. Less is known about men's motivations to participate in biomedical HIV prevention research.

The *Impilo Yamadoda* study sits between biomedical and non-clinical models of health research. The literature on participant engagement in biomedical health research was consulted chiefly because the *Impilo Yamadoda* study aims included testing different incentives to retain participants in the study's experimental phase; because of the inclusion of this biomedical aspect, potential participants may view the study to be clinical in nature. The research for this thesis focuses specifically on the enrolment of participants into the *Impilo Yamadoda* experimental phase. As the *Impilo Yamadoda* experimental phase was constructed as a simplified version of a full-scale biomedical HIV prevention intervention study, investigating which procedures have been found to be successful in generating potential participant interest in enrolling in the study was an important factor in the decisions to employ particular methods for this research. It should be noted here that the *Impilo Yamadoda* study did not have complex requirements for participant enrolment or continued engagement with the study. The *Impilo*

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 3: Theoretical background part 1: research participation and masculinity

Yamadoda study instead focused on two aspects of biomedical research participation: blood sample taking, and sharing of personal sexual history.

Trials of biomedical modes of HIV prevention are essential to developing new tools to prevent HIV infection. Yet research into HIV acquisition often faces difficulty with acceptance rates due to conflict between research needs and the target population's understanding of, and ability to adhere to, research procedures (167). Transferring what we know from studies on participation in biomedical research in the global North to that of studies conducted in the global south, we might expect that researchers and potential participants face similar problems. Yet publications of biomedical HIV prevention research conducted in the global south show us that engagement of participants is often based on ad-hoc methods, if it is reported on at all.

The relatively recent findings of the protective effects of medical male circumcision (MMC) on HIV acquisition have resulted in several clinical research studies in the Southern African region. In areas such as KwaZulu-Natal, where the practice of circumcision is not currently practiced as part of the Zulu cultural heritage, investigation of male acceptability of this practice has taken place (168). A literature review of publications on MMC research programmes does not reveal in-depth discussion of sampling methods, results of community acceptability of the research campaign, or reports of the acceptance rates of participants. Auvert's detailed publication reporting on the success of MMC as a biomedical mode of HIV prevention in Orange Farm, South Africa includes the following regarding the recruitment of research participants:

The recruitment of participants took place in the general population from July 2002 to February 2004. Information about the trial was disseminated in the community through meetings during the recruitment period. Precise oral and written information was delivered at the investigation centre to potential participants during a pre-screen visit. Participants were then informed that the impact of MC on the acquisition of sexually transmitted infections (STIs), including HIV, is not known. (169)

While we assume that, as per biomedical HIV prevention research ethical protocols (170, 171), preliminary community education or engagement was conducted prior to recruitment, no information was provided on these activities. While it is true that the article was not focused on

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 3: Theoretical background part 1: research participation and masculinity

recruitment methods, the limited information above cannot be considered advice future research teams engaging men in biomedical HIV prevention interventions could reproduce.

The acceptability of MMC has been studied fairly extensively with predictive uptake of treatment in mind (172). However, this should not be confused with community and potential participant acceptability of biomedical HIV prevention research projects; aside from a few well noted failures (173, 174), acceptability of research has garnered little attention. Bailey's well-known article (175) on the MMC randomised controlled trial (RCT) in Kisumu, Kenya offers insight into study recruitment methods but lacks information on response rate:

Participants were recruited via local newspapers, radio, fliers, and street shows by drama and musical groups. Recruitment began on Feb 4, 2002, and enrolment was completed on Sept 6, 2005. Public and private clinics were enlisted to refer patients with sexually transmitted infections, and peer outreach workers recruited participants from local youth organisations. Enrolled participants were each given up to three coupons valued at US\$1.25 for every peer they recruited for initial screening. (175)

It is useful to have the recruitment process explained, and detailed attrition rate data for the study is available (175). However, the article does not give insight into the acceptability of the research project from either the potential participant base or the larger communities affected. The lack of reporting on participant engagement methods in publications of trial results is worrying; as many researchers do not see the importance of robust engagement programmes it may be unlikely that they look for specific information on how to engage with participants when writing trial protocol.

If biomedical researchers do investigate barriers and facilitators to participant engagement, the literature on willingness to participate in biomedical HIV vaccine research gives a somewhat limited insight into participant concerns. A review of willingness to participate in HIV vaccine research showed that altruism is a major motivator, while testing HIV positive during pre-trial procedures is a major barrier to research participation in both South Africa and Uganda (176). In addition, a study in South Africa showed that an increased knowledge of the test vaccine and study procedures was correlated with willingness to participate (177). Another report from Uganda also cites increased knowledge as positively

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 3: Theoretical background part 1: research participation and masculinity

correlated with willingness to participate in HIV vaccine research, but also that men were less likely to feel vaccination was important for them than for women and children (178). None of the willingness to participate in research literature has focused specifically on young men in sub-Saharan Africa.

It is important for researchers to be able to accurately predict realistic recruitment timelines and attrition rates to meet study goals (154). Low community-level acceptability has been linked to high levels of participant attrition while comprehensive community engagement programmes foster good will in the community increasing research project acceptability (171, 179). Without clear and rigorous processes to rely on, researchers often begin a rigorous scientific trial by guessing at recruitment (180). As a result it is unclear how to successfully recruit men to biomedical research, and it has been assumed that men will be resistant to engaging with such research.

VII. Participation in Africa Centre HIV surveillance research

At the time the *Impilo Yamadoda* study was being implemented (2007-10), refusal to give blood specimens as part of research was a concern for the on-going *Africa Centre HIV* surveillance research. Due to steadily declining acceptance rates of HIV testing (particularly among men (91)), which is considered an integral part of the surveillance project, a reflexive practice study was undertaken (181) with the aim of understanding and then reversing this trend. After extensive qualitative research was undertaken as part of the reflexive practice to elucidate the reasons behind low acceptance rates, an unexpected deterrent was uncovered (181).

In the HIV surveillance project's inception, researchers attempted to provide a service in connection with the surveillance. In so doing participants were given the option to receive a named HIV test (VCT) concurrent with their participation in the surveillance project. During the reflexive practice study it became clear that men had been refusing to give blood because of a

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 3: Theoretical background part 1: research participation and masculinity

widely held belief that HIV test results cannot remain confidential. In addition, community members did not understand that they could give blood as part of research and opt out of receiving their HIV test results.

In part due to recommendations from Cousins' social science study, the protocol to participate in *Africa Centre* HIV surveillance research was changed during the time of *Impilo Yamadoda* study implementation to de-link individual participant blood samples to their HIV test results. This meant that HIV surveillance participants were no longer able to receive their HIV test results. Preliminary statistics support this method to increase men's participation in biomedical research in the *Africa Centre* Demographic Surveillance Area: comparing participation of individual resident 18-35 year old males in the same time periods (week blocks 01-25) in 2009 and 2010, a 5% increase in participation was evidenced after the protocol change¹. While limitations exist [for example, during this time the blood collection method changed from dried blood spots (DBS) to micro-capillary samples], this increase in participation suggests that application of results from a targeted social science study could help to improve rates of uptake of the offer to participate in biomedical research in this population.

VIII. Collaborative and participatory research methods

As an alternative to methods to increase participation in biomedical research as described above, there is a large body of literature describing research enacted and/or designed with community members' active input (182-187). The methods of these research studies rely on a nuanced view of community development and work with community members to design with the goal of implementing research programmes of high interest to all who are involved. The methods and theoretical underpinnings of participatory and collaborative research are of central concern to the methodology for the research for this thesis, and so will be explained in detail in the next chapter. The review below discusses how participatory research models have been

¹ Personal correspondence, Dr Abraham Malaza, Epidemiologist, *Africa Centre for Health and Population Studies*, 2010.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 3: Theoretical background part 1: research participation and masculinity

implemented in South Africa and in so doing highlights the ideological and methodological contrast from the biomedical research models described above.

A literature review shows that there are many examples of use of collaborative, participatory, and action-based research methods in health related research. There have been numerous studies using participatory methods in South Africa; it could be argued that this methodology is particularly well suited to the country, as the socio-political history of South Africa has roots in community-based action (49, 51, 52, 188). Penzhorn's study of the feasibility of using a participatory research approach in a suburb of Pretoria, South Africa, for determining Coloured women's issues and concerns found that the approach was useful for identifying participants' needs and recommends that this approach be used more universally in research (183).

Mosavel discusses how their community-based participatory research study, which took place on the outskirts of Cape Town, South Africa, helped to re-define the research focus from cervical cancer to that of 'cervical health,' a term that was found to be not only more understandable, but also to encompass issues that were more relevant to local women (188). This reframing of their research was seen as a "vital first step in gaining the interest and trust needed to conduct successful community-based participatory health interventions" (188).

Ansari discusses how community partnerships with outside 'experts' must be built on mutual appreciation of the diversity of the groups' skills and assets (189). In his examination of five community partnerships for health in South Africa he finds that while community members had great appreciation of the technical experts' knowledge and skills, that respect was not always reciprocated, resulting in lost opportunities for knowledge transfer as well as dissipating enthusiasm for the programmes on the part of local participants (189).

In a later publication, Ansari discusses the specific challenges to community partnerships for health and their solutions, such as the differing values of the researchers and the community members, and how an iterative process of partner identification, and the researcher's immersion in the culture helped to foster communication and mutual understanding (190). Ansari states

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 3: Theoretical background part 1: research participation and masculinity

that “Participation is about moving away from a ‘us and them’ mentality towards a partnership of mutual benefits” and his research has found that when this is more fully realised, community partnerships can be most effective (189).

These studies importantly show that participatory methods of research are both feasible and acceptable in South Africa, and it is important to investigate how lessons from these studies can be used for the *Impilo Yamadoda* study participant engagement plan.

IX. Conclusions

When exploring a research question the first step is to understand the context in which it arises. The topic of this research is the investigation of how young Zulu men were engaged in the *Impilo Yamadoda: Men’s Health Study* in rural KwaZulu-Natal, South Africa. Compared to other countries in sub-Saharan Africa, the wealth of scholarship contextualising research in South Africa is both a blessing and a curse, as it is only with a broad review that the nuances in this investigation can be understood. The young Zulu-speaking men who make up the potential participant group for this study may base their decisions to participate in the *Impilo Yamadoda* study on the social, temporal, cultural and geographically specific contexts reviewed here. It is important to place participants’ decisions to enrol in HIV research within a setting that has seen the meteoric rise of an HIV epidemic in a political atmosphere of denial and lack of life saving treatment (2, 66, 67). Understanding that South Africa is a country with one of the world’s greatest disparities between rich and poor (191) gives meaning to the setting in which a young Zulu man living in the Hlabisa sub-district finds himself, struggling to become a respected *baba* within his family and his community (124).

How the *Impilo Yamadoda* study participant engagement strategy fits into this context is examined through a review of men’s engagement in health service provision and research. The idea that men should be recruited into research through a gendered engagement programme is brought forward with the field of men’s health research. How this field has emerged from its

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 3: Theoretical background part 1: research participation and masculinity

Western origins to engage men in the global south is reported through an exploration of biomedical HIV prevention research participation in sub-Saharan Africa. Advancements in the field of biomedical HIV prevention research are slowly moving forward in the battle against HIV infection [e.g. (169, 175)] and much is known about the potential acceptability of these prevention methods (168, 172).

The research described in this thesis uses a community-based engagement method involving genuine partnerships between members of community organisations and the research team to engage participants in the *Impilo Yamadoda* study. While the reviews in this and the previous chapter elucidate many factors that contribute to our knowledge of the setting in which the *Impilo Yamadoda* study, and the research into its engagement strategy that this thesis undertakes, the theoretical concepts framing this participant engagement strategy have yet to be explored. The next chapter will explore these theoretical concepts, moving between discussions of individual and community change and collaborative research engagement, in order to more fully describe the theoretical underpinnings of this work.

Chapter 4: Theoretical background part 2: culture, identity, and creating change

I. Introduction

In the previous chapter the existing literature on men's health research, Zulu masculinities, men's health research in South Africa, and potential participants' willingness to engage with health research was explored. While that literature is important to frame the research presented in this thesis, there remain gaps in the understanding of community change and social and individual identity that this thesis engages with. This chapter focuses on exploring the theories that inform the participant engagement strategies of the *Impilo Yamadoda* study. For example, key concepts such as "culture" and "community" are defined in the context of an explanation of change and creation of change in communities. These theoretical considerations include the reasons behind the change I made in the *Impilo Yamadoda* protocol from focusing on large employer organisations to small community-based organisations. In this chapter, the theory behind use of the researcher/participant 'Research Partners,' as well as the more traditionally defined participants in the *Impilo Yamadoda* survey (phase 2), qualitative interviews (phase 3), and experimental phase (phase 4) is explored.

II. Defining community

Ethicists and researchers agree that area-specific health research and local knowledge are necessary to meet participants' needs and researchers' goals, (170, 192). The introduction of small-scale pilot studies to precede the development of large research projects seeks to test the scientific feasibility of conducting research in specific locations (154). In addition, these pilot studies serve to increase the research teams' knowledge of potential participants and how to best recruit them (154). While these pilot studies are outlined as necessary by ethical research standards (170), and recent work has shown that researchers are increasingly looking to find new ways to engage participants in research (17), rarely do the results of social science studies

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 4: Theoretical background part 2: culture, identity, and creating change

directly inform the structure and function of the community engagement protocol for biomedical research studies (193, 194).

When looking at biomedical health research participant engagement programmes and early top-down models of community development a similarity can be found: in these top down models of development, a problem is identified by professionals outside of the community who then import resources to “solve” that problem (195, 196). In international development work, top-down models of community development have been criticised for being based on “community problems” identified by well-meaning poverty experts in the First World and imported whole-scale to the heterogeneous populations of the Third World, creating programmes of limited relevance to the populations they are meant to serve (40, 196, 197). These types of programmes, however well-meaning, perpetuate existing imbalances in power rather than engaging communities in productive and meaningful change (198, 199). To counterbalance these issues, it is advised that external professionals work with communities to identify a problem, and then reassess the practical application of the programme at multiple points to ensure it is meeting the needs of all those involved (196, 200). This collaborative and iterative process also ensures that those outside of the community are not directing the process but rather working collaboratively to shape change (196, 200).

The problem of outside influences directing (rather than collaboratively developing) community-based projects becomes even more complex in research settings. Power imbalances and differences of class, race, and cultural identity between researchers and the researched have been well documented by social scientists (201-203). These studies show that perceived or actual differences between researchers and participants gender, ethnicity, class, and age, can lead potential participants to make decisions on what and how to disclose to researchers (201, 203). In addition to these potentially divisive differences, there are often conflicting objectives between the research team and the host community; research endpoints do not always match the needs of potential participants (200).

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 4: Theoretical background part 2: culture, identity, and creating change

Without careful consideration of the abovementioned concerns, health research programmes, particularly those in the developing world, can fall short of community engagement goals: in both community development and research implementation, the best engagement plans are constructed with knowledge of the wants and needs of targeted communities (192, 204). To this end, researchers are expected to identify and liaise with leaders of the communities affected by research study implementation (170, 171, 179, 204, 205). However, without understanding our assumptions of how communities are formed there is no way that stakeholders' and potential participants' voices within research protocol design can be heard:

...if we use our own wants and values as the basis for determining what is universally needed by others, we reduce our effectiveness... We will be more likely to attribute such cooperation as we get to motives that our clients do not have, and will tend to have false expectations about the things that will interest them. (206)

Central to these false expectations are poorly imagined community needs created by those outside the community working within an erroneous framework delineating global communities of "the poor." A homogeneous notion of the needs of "poor communities" in today's world of migration, dislocation, and discordance in educational and socio-economic capital hardly rings true; if we cannot imagine a singular homogenous "poor community" in the global North, why should this exist elsewhere? Collaborative community development models attempt to redefine community in geographic and cultural-specific contexts of shared consciousness: "There is no 'poor community' outside of poor persons coming together to share their experience and act upon transforming it" (198). If our premise of community is incorrect our models of engagement suffer from lack of participant ownership (207).

A true collaboration of technical experts and lay people, such as is ideal in both the collaborative method of community development and the stakeholder-investigator relationship in research, can only be created from a contextualised understanding of fluidity in the formation of communities. With this understanding community becomes "any group that has something in common and the potential for acting together" (196). This definition, both broad and purpose-based, is the definition of community this thesis employs.

III. Defining individual and cultural identity

With community defined as a group of similar people with the potential to work together, there comes the question: “what makes these people similar or, identify in much the same way?” Before answering the question of how to engage with people, we must understand how people see themselves. Sociologists, psychologists, and anthropologists have contributed to a vast literature on how people see themselves, or “identity”. These three disciplines each come to the discussion with a different premise: psychologists start from the premise of the individual, while anthropologists and sociologists believe that culture or society must be the starting point for any study into human behaviour (208-210). Identity, or how a person views him or herself, (self-identity), and how people view others, can be thought of as the starting point into the discourse of why people do what they do; it has been said that who or what a person believes they are can begin to explain their actions (104, 206). It must be said that this premise should be treated with caution: it is understood that people do not always do what they think they will do, or should do (104). It is, however, the presumption of this thesis that people generally behave predictably; the more complete the understanding of a person or group of people the more reliable the prediction.

The choices we make as individuals have to do with who we perceive ourselves to be (104). This self-reflective identity can be influenced by a complex combination of factors: where we are from (geographically and biologically), where we are now, what we believe is expected of us, and what we expect from others similar to ourselves (104, 211). Those in the fields of social and cultural enquiry believe that who we are (and in turn, the choices we make) are influenced strongly by our cultural environment (208). In its most simple definition, culture is “the totality of ideas, skills, and objects shared by a community or society” (208). It then follows that much of what makes up who an individual is has a lot to do with what is considered appropriate/inappropriate amongst the people he/she lives and how he/she acts/reacts to those beliefs (104, 206, 211, 212).

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 4: Theoretical background part 2: culture, identity, and creating change

It is understood that culture can no longer be thought of as situated geographically; with the modern concept of cultural diaspora, culture can become detached from the geographic homeland and based largely upon an imagined identity of a people (213, 214). Allowing these complexities in our understanding of geographic bounding of the social permits the inclusion of migrants who are away, rather than simply including those members of who have returned to or never left the community. This results in a working definition of culture that is temporal and geographic as well as dynamic in that it allows for influences of other cultures (cultural shifts of modernity) that alter a “traditional” way of life. The working definition that this thesis employs is that: culture is both shared and individual, with aspects that change in a dynamic process based on the time and place of those who identify with it. While this means that no two people ascribing to the same cultural identity can describe their culture in exactly the same way, the premise above still applies: there are necessarily agreed upon and shared aspects of identity within cultures. This is important to understand moving forward, as the concept of cultural identity defined here is utilised in the analysis of data collected as part of the *Impilo Yamadoda* study; the men who become participants in the *Impilo Yamadoda* study choose to do this as Zulu men. To take this point even further: the participants of *Impilo Yamadoda* are Zulu men living within the Hlabisa sub-district where there is a very high incidence of HIV infection, and high levels of unemployment. The care taken in the previous chapters to describe the context of the study area, the HIV epidemic, and Zulu masculinity, is reflective of the importance of these aspects of our theoretical understanding of cultural identity.

A geographic and culturally specific context situates an awareness of identity that is at once communal and individual (206, 207). This communal/individual aspect of identity can also be seen as performative: people act and react to situations based on how others in their social sphere expect them to act and react (103, 104, 206). What people believe others think of their social identity causes people to perform identity in ways that either complement those beliefs or go against them (103, 104, 206). Importantly, regardless if people are reacting against their perceived social identity, there is no escape from the social world; people remain actors

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 4: Theoretical background part 2: culture, identity, and creating change

performing their identity in relation to how the larger social group sees them (103, 104, 206).

The individual thus becomes inextricable from the social/community.

The performative view of acting identity defined above can also be understood as not only in relation to the individual within a social group, but as actions of social groups within a larger society. In this way, the successful influence of social groups creates dominant viewpoints: the “common sense” or implicit norms of a society, such as discussed in the previous chapter as relating to masculine norms (107).

Antonio Gramsci defines the concept of implicit or dominant norms in society as cultural hegemony (107). In Gramsci’s cultural hegemony, norms are created by dominant groups and then spontaneously agreed to or coercively enforced (or a more subtle combination of the two) by subordinate groups (107). Importantly, this process is also defined as dynamic; implicit norms change in society, and this is made possible because no dominant group ever holds complete control within society, but only a series of dominant viewpoints that the majority adhere to (107). Taking this theory further, change can be viewed as an inherent part of society; social groups’ constant struggle for the dominant or agreed upon viewpoints of a society create periodic social change (107).

Understanding how hegemony and struggles for dominance in society create change is important because it has been reported that a way subordinate group seek to gain power is through performing actions reinforcing the dominant viewpoints (hegemonic concepts) in society (105). Thus one way that power is thought to be obtained by those with less power is through emulation of these hegemonic or dominant viewpoints, regardless of the actual effect of these performances (105). For example, Courtenay discusses how “Men and adolescent males who adopt traditional or stereotypic beliefs about masculinity have greater health risks than their peers with less traditional beliefs” (105). While enforcing “traditional” or dominant concepts of masculinity, these men are seen by society as “independent, self-reliant, strong, robust, and tough” yet also become at increased risk of a variety of health problems (105). Thus any changes proposed to reduce men’s risky behaviours must incorporate an understanding that an

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 4: Theoretical background part 2: culture, identity, and creating change

underlying rationale for performing risky behaviour is to gain greater access to the positive, power-increasing aspects of hegemonic masculinity.

IV. Creation of change in communities

In the last section culture was defined as a shared and individually defined self-identity of a people in a dynamic process based on the time and place. In addition, we saw that while change is a natural part of the formation/re-formation of cultures and communities, this does not mean that all change is purposive or positive. The creation of change thus becomes a topic of consideration as we seek to understand and create effective models of research engagement. It is to this end that the following section focuses: the creation of change from the viewpoint of individuals within communities.

The concept of creation of change moves us from a general understanding of change in communities towards knowledge of how to purposefully shift power dynamics in communities (197). Cooperative work towards change necessarily involves an acknowledgement of need for improvement of a situation by and for the individuals that are affected (196, 199). In this dynamic process of change, shifting an individual's representation within society changes the individual. Thus increasing an individual's status, or worth in the eyes of the larger community, becomes paramount in the process of creating community change (206). An individual's status must then change through a dynamic process involving individual action, shifting social norms, and the view of the social group (104, 206).

It is at this point worth mentioning studies on social status and social capital in health. The relationship between social capital and health has been studied in order to gain a deeper understanding of the links between social inequality and health (215-217). Social capital has been defined as the transactional relationship between individuals within a specific social group (216, 218). The value of social capital includes both social and material transaction within the group as well as with those outside of the group (216). The study of social status has brought

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 4: Theoretical background part 2: culture, identity, and creating change

forward consideration of the role of social and economic transaction to the study of community participation in health service provision (215, 216). Some criticise social capital theory for its narrow focus on the social group; these critics argue that the theory neglects the influence of the larger social sphere on the internal dynamics of the communities under investigation (215, 219). This criticism seeks to polarise the microelements of community-based change and systemic and macro shifts, focused mainly on political will for change (217). However, as the larger context of political boundaries of cultural identity is simply one layer in a complex understanding of culture, community, and self-identity, this is largely a specious distinction. The more important criticism of the theory is that it does not take into context the informal and fluid dynamics of community formation that this thesis argues is essential to an understanding of the process of creation of change (215).

Creation of change often cannot simply be brought about by the will to change on the part of individual's alone, but also requires a collaborative effort between those inside and outside of the community (200, 206). Collaborative methods of community change, such as Taylor-Ide's SEED-SCALE approach, and Goodenough's cooperation-based approach, stress the dynamic quality of community change, where change is not effected through a series of isolated incidents but created out of an interlinked process of collaboration between experts, lay people, and larger level societal influences (196, 206). The SEED-SCALE approach describes the community growth process as "a complex process, requiring a three-way partnership of top-down support from government, outside-in innovation from experts, and bottom-up hard work from local people" (196). This essential three-way partnership has been described as the most effective way to produce change in individuals as well as communities, and it is with this understanding of creation of change that this thesis moves forward (196).

V. Participatory research models

Action-oriented, participatory-based research, and, participatory action research methods are firmly rooted in the philosophy of the collaborative community development model, linking real-world communities with researchers for the specific goal of creating research that empowers and changes the people it investigates (182). While there are noted differences between the three methods, all of these approaches to research allow for collective enquiry by both those who would traditionally be called ‘researchers’ and ‘research subjects’ (182-186).

Participatory and action research models challenge the traditional understanding of knowledge; rather than an empirical concept, knowledge is understood as socially constructed (185). Participatory research comes from a premise that “science is socially constructed ... subject to reinterpretation, revision, and enrichment,” meaning that different ways of knowing are equally valued (185). Reason and Bradbury state that conventional academic research has a different purpose as there are “different ways of conceiving knowledge and its relation to practice” (185). Therefore the process of research, which is traditionally thought of as gathering empirical knowledge, becomes refocused on exploring ways of knowing and how this knowledge can be used to create positive change (182, 185). Participatory research relies on a bottom-up approach, much like the method of community development this thesis adopts, and understands that development best works in collaboration with the people who are most affected by the issues the programme addresses (108, 196).

Cornwall and Jewkes further define participatory research with this statement: “The key difference between participatory and conventional methodology lies in the location of power in the research process” (182). Thought by some to be a founding father of participatory research models, WH Goodenough brings an anthropological perspective to these methods (220). Goodenough’s theory involves a spiralling series of actions to encourage shared ownership by participants of a project, with each act of participatory action creating a greater sense of collaboration and thus ownership of the project (206, 220).

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 4: Theoretical background part 2: culture, identity, and creating change

Budd Hall discusses a distinction between two definitions of participatory action research (PAR), one which mirrors Cornwall and Jewkes' statement that the core of the method is a stance on power and its relationship to knowledge, and another, authored by Whyte in 1991 (187), which Hall states "portrays a depoliticised process" (184). While Whyte does not state linkages between his version of PAR with that of socio-political action theory, it can be argued that any social science research that aims to change participants is inherently political; the balance of power necessarily shifts within a collaborative process to create change (182, 196, 206).

While his processes are criticised, Whyte engages in a nuanced discussion of the distinctions between participatory research and participatory action research (186, 221). Whyte uses an example early in his career to differentiate these methods; participatory research is when "...the professional researcher invites one or more members of the organisation studied to play more active roles than simply those of passive informants" (187). Whyte then continues, discussing how the latter can be distinguished from participatory *action* research: "... in these projects I had not visualised the possibility of establishing more direct linkages between research and action. I therefore refer to them simply as participatory research" (186). For Whyte, it is the important addition of a stated premise of action, or change, that distinguishes participatory action research from participatory research. A further distinction Whyte makes is that action research (as opposed to PAR) may be designed without any participatory methods (221). With an understanding that participatory action research is forming research with action in mind, compared to participatory research that is designed to engage participants but with no overt goal of 'action' or societal change, we now have useful definitions of these models of research. These definitions are important to our understanding of the perspective methods and their distinct purposes; in practice both may more accurately be described as being on a continuum. Research using participatory methods describes a process, rather than a static methodology (222).

VI. Towards a strategic community engagement method

However robust the theory, it must be practically applied in order to understand its feasibility for use in different circumstances. The review of studies that used participatory and patient involved research in the previous chapter showed us that these models of research are feasible and acceptable in many areas of the world, including South Africa. Yet following the review we can see that there is little understanding of how these methods might be applied to recruitment methods for biomedical health research studies. Of specific concern to us is whether using the lessons learned in participatory methodologies as well as those from collaborative community development can lead to a “successful” participant engagement study as part of a biomedical health research design, such as was adopted for phase 4 of the *Impilo Yamadoda* study.

The participatory methods of research and community development reviewed above rely on flexibility in both research focus and approach; the *Impilo Yamadoda* study was modelled on a fixed randomised control trial (RCT) design. For the purposes of engagement this fixed design has limitation; RCTs are designed to limit external factors that might distort our understanding of the impact of the intervention (154, 155), and as such little can be done within this model to allow stakeholders or others any input into how the research is conducted. Yet, as was discussed in the previous chapter (Chapter 3, section 6), the RCT is still considered by many the highest standard evaluation methodology for health interventions (154, 155).

Drawing from theories of community change described above, the ‘strategic community engagement technique’ for the *Impilo Yamadoda* research utilises social and collaborative theories of community change, as well as lessons from participatory methods in research. With the understanding that collaborative efforts serve to create change, and that these theories, used in participatory research, work to encourage community and potential participant ownership in research, it becomes of interest to see if these concepts can help to bridge the gap between researchers’ and participants’ goals in experimental intervention research.

VII. Conclusions

This chapter began by explaining that while the previous two chapters contextualised this research within the sphere of health and specifically HIV prevention intervention research, as well as within a geographic, historic and cultural context, there remained a gap in understanding why this level of review is essential in this investigation. To that end, the theoretical premise that underlies the methodological decisions taken in both the implementation and analysis of this study has been examined in this chapter.

The concept of community was first explored here in the context of models of community development. The definition of community arising from this discussion is a pragmatic one, both broad and purpose-based: community is any group that has something in common and the potential for acting together. We then moved forward to explore how this definition can be utilised towards an understanding of culture. A simplistic definition of culture as geographically bound and static is essentialist and highly problematic when taking into account diaspora, fluidity, and multiplicity in the performance of identity formation. Thus the working definition that this thesis employs is that culture is at once a shared and individual self-defined identity with aspects that change as part of a dynamic process based on the time and place of those who identify with it. Communities can be seen as micro-elements of cultures and thus can be created within a geographic and cultural context to suit a specific purpose. With this understanding we can understand how change is a natural part of the formation and re-formation of communities and the individuals within them. Creation of change is purposeful direction of the naturally occurring process of community change.

With the premise that change is part of the natural fluid process of cultural, community, and identity formation, we then moved forward to examine models of change from the perspective of individuals within communities. This allowed for an explanation of how community change is used in this thesis: creation of change centres on shifting power dynamics in communities, and thus can only be achieved through cooperative work. We have reviewed cooperative change models that recommend work with local people who are aware of the local

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 4: Theoretical background part 2: culture, identity, and creating change

situation alongside technical experts (206). In addition to this 2-way cooperation model, we have seen that some theorists noted a need to bring forth advocacy on the extra-community level to address systemic processes that impede change (196). With this addition, we can move forward with the definition of community change used in this thesis: a three-way cooperation including “top-down support from government, outside-in innovation from experts, and bottom-up hard work from local people” (196). With this understanding of effective community change we can begin to re-focus this approach to see how it could be applied for use in research participation.

Participatory action research (PAR) follows models of bottom-up community development work that follow on the multi-tiered collaborative approaches that have been shown to be effective when implemented (196, 223). As can be expected, there are many studies that have shown research models of participatory research and participatory action research applied effectively; for our purposes it is particularly important that these approaches were found effective for research conducted in South Africa (183, 188-190, 221).

As PAR starts with the premise of collaboration, it follows that this type of research would start from a proactive approach to community engagement strategies rather than a problem-solving approach: rather than asking “what keeps men from participating in this study,” the question becomes “what study could be done that people would find meaningful and want to participate in?” It is important to reiterate here that *Impilo Yamadoda* is not PAR: there is no goal of action resulting from the research; the project cannot be seen as service delivery in addition to research; the researcher’s perceptions on study design and, ultimately, the major decisions of the project are still seen as central (187, 188, 221, 224). Yet the role of community collaborators is essential to the success of the *Impilo Yamadoda* study. We have found that the absence of “action” described above defines this more as a type of participatory research than participatory action research (PAR).

Using participatory practices, such as PAR models use, would necessitate a degree of flexibility in the experimental model that would not be possible in the implementation of

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 4: Theoretical background part 2: culture, identity, and creating change

randomised control trials (RCT) and similar models, such as the *Impilo Yamadoda* study experimental phase used. The premise of the strategic community engagement method developed for the *Impilo Yamadoda* study was that using the community change theory outlined in this chapter would allow us to build on the lessons from community development and participatory research models to encourage the participation of young Zulu men in the research study. This is of particular relevance to those researchers designing experimental studies of interventions with fixed designs (i.e. RCTs), as the literature review of the previous chapter has shown that collaborative and participatory methods have not previously been formally used as an engagement strategy for biomedical research studies based in the global south. Importantly, this uncovered the secondary research question of this thesis: “Can participatory research methods be used to encourage men’s participation in biomedical health research in the global south?”

The next chapter, focused on the methods used in the *Impilo Yamadoda* study, describes the how the strategic community engagement method was used to encourage participation in the study. This methodological discussion will describe the methods undertaken in the *Impilo Yamadoda* study, in order to gain a more full understanding of the factors contributing to the engagement of young men in Kwa-Zulu Natal in the *Impilo Yamadoda: Men’s Health Study*.

Chapter 5: Methodology

I. Introduction

This thesis explores two research questions: 1. What factors contributed to the engagement of young men in KwaZulu-Natal in the *Impilo Yamadoda: Men's Health Study*, and, 2. Can participatory research methods be used to encourage men's participation in biomedical health research in the global south? With that in mind, two main areas within this dataset are explored: the structure and implementation of the *Impilo Yamadoda* study community engagement strategy, and the data collected as part of the *Impilo Yamadoda* study.

In order to fully understand a target population (who and where), their actions (what), and motivations (why), researchers must use all available tools of investigation (224, 225). At the risk of sounding overly simplistic, the 'who, what, where, and why' of social research can be pieced into parts: demographic and behavioural surveys may answer 'who' 'where' and 'what', while qualitative methods such as ethnographic fieldwork, individual interviews and focus groups, can add depth to 'what' is being studied and answer the elusive 'why' questions. I see these methods not as discrete nor as necessarily feeding into a hierarchical order, either chronologically or philosophically, but as best used when interwoven, with one piece of data explaining and supporting the analysis of another. The protocol, as well as the structure of reporting in this thesis, is reflective of this theoretical viewpoint.

Unless noted, the University of KwaZulu-Natal Humanities and Social Science Ethics Committee and the University College London Ethical Review Board approved all study protocol and measures (Appendix 1.1, 1.2 and 1.3) prior to data collection. All names of individuals quoted in this work are pseudonyms as a reflection of best practice social science reporting procedure.

II. Theoretical considerations to the protocol

As can be seen from the preceding chapter, there are lessons to be learned from participatory research models that can be incorporated into *Impilo Yamadoda*; for example, we know that the premise that a project starts with can lead to quite different effects (196). With this in mind, the first stages of the *Impilo Yamadoda* study were designed not as participatory research with the premise of community collaboration, but as a *community-based* project; researchers from outside of the community have defined the problem to be addressed and then consult the community in how it might be solved (198). The *Impilo Yamadoda* participant engagement methods can be seen as straddling the line between a participatory research study and a conventional health research study. This was done purposely, as participatory research design does not fit well with the methods used to trial biomedical HIV prevention interventions. As described in the two chapters preceding this, these studies use empirical designs (e.g., randomised controlled trials) and it may not be possible to alter them as would be necessary using a pure participatory research design when collaborating with community members and other stakeholders. Thus, a strategic community engagement method was used: working collaboratively with community members to implement research and encourage participation in the *Impilo Yamadoda* study.

III. *Impilo Yamadoda: Men's Health Study*

The *Impilo Yamadoda: Men's Health Study* was part of the African European Vaccine HIV preparedness network (AfrEVacc) and the main study aim was to inform biomedical researchers how to best prepare for randomised control trials (RCT) of possible HIV vaccines in sub-Saharan Africa. The multi-method study designed to investigate this included four phases of research that followed consecutively (see Figure 5.1, page 74). Phase 1, or the community engagement phase, identified and engaged with community-based and employer organisations that were interested in partnering with the research project. The results of this engagement phase

informed phase 2: a short survey of the target population's health and health research beliefs that was implemented by volunteer Research Partners from identified organisations. Phase 3 was a qualitative research phase derived from a small purposively sampled subset of the phase 2 survey participants. Phase 4 then assimilated the lessons learned in the initial phases of community-engaged social science research; 200 young men in the community were recruited to take part in an experiment modelled to reflect essential elements of a full-scale biomedical HIV prevention RCT.

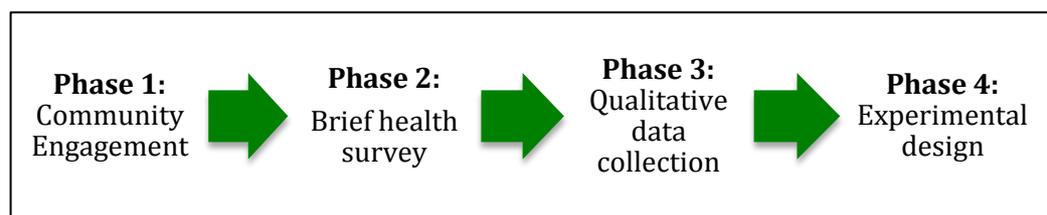


Figure 5.1: Impilo Yamadoda *phases of implementation*

IV. Analytical protocol

The protocol choices presented in this thesis were reflective of both the choice to base the strategic community engagement method for the *Impilo Yamadoda* study on theories of collaborative community development and participatory research, and that the main aim of this investigation was to analyse the results of that process. With this in mind, the protocol of this investigation closely matched that of the *Impilo Yamadoda* study.

This investigation followed an additive approach, with the results of one analysis informing the next. The process of implementing each of the phases during the *Impilo Yamadoda* study were analysed directly with the dataset they accompanied. For example: the phase 2 survey was analysed first as a quantitative dataset with the view to gather essential participant demographics; the analysis of these data is presented in chapter 6. The 7th chapter focuses on the data resulting from the process and effects of implementing the survey, in order to gain a better understanding of how the volunteer survey administrators (“Research Partners”) engaged with survey participants, and to evaluate the feasibility of using this method of data collection. The 8th chapter is an analysis of qualitative data collected to better understand the

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 5: Methodology

motivations the volunteer survey administrators Research Partners had for engaging with the *Impilo Yamadoda* study, and contributes to an analysis of the feasibility of the Research Partner-led survey administration. An understanding of the target population (initially presented through survey data in chapter 6) is deepened through data from individual and focus group interviews with *Impilo Yamadoda* participants in chapter 9. Process outcomes from recruitment and enrolment in the *Impilo Yamadoda* phase 4 experiment frame the analysis of qualitative interviews with the participants that is reported in chapter 9. Together, these data allow for investigation of the factors that contributed to the engagement of young men in the *Impilo Yamadoda: Men's Health Study* (research question 1, above).

While I oversaw all data collection during both the *Impilo Yamadoda* study (as Project Leader), and that of the data collected for the purposes of the investigation reported in this thesis, I was not always present during data collection activities. This decision was taken during specific data collection periods and will be noted in the appropriate sections below.

There are a variety of researchers, participants, and partners in the *Impilo Yamadoda* study; for easy reference, Table 5.1 (page 76) identifies the main individuals involved, their affiliations, and their role(s) in the research.

Individual(s) involved	Affiliation(s)	Role(s) in the study
<i>Impilo Yamadoda</i> Project Leader and PhD student	<ul style="list-style-type: none"> • <i>University College London</i> PhD student • Contract with <i>Africa Centre for Health and Population Studies</i> for the duration of the <i>Impilo Yamadoda</i> study 	<ul style="list-style-type: none"> • Input into the <i>Impilo Yamadoda</i> study protocol • Coordinate and direct the <i>Impilo Yamadoda</i> study • Analyse data for <i>Impilo Yamadoda</i> study objectives • Collect and analyse data to meet the objectives outlined in the thesis
<i>Impilo Yamadoda</i> Research Assistant	<ul style="list-style-type: none"> • Employee of <i>Africa Centre for Health and Population Studies</i> 	<ul style="list-style-type: none"> • Liaise between Research Partners and Project Leader • Administer qualitative interviews and focus groups with participants • Oversee data collection for the <i>Impilo Yamadoda</i> study experimental phase (phase 4)
<i>Impilo Yamadoda</i> Community Liaison Officer	<ul style="list-style-type: none"> • Employee of <i>Africa Centre for Health and Population Studies</i> 	<ul style="list-style-type: none"> • Liaise between Project Leader and <i>Africa Centre</i> Community Liaison Office • Liaise between Project Leader and <i>Africa Centre</i> Community Advisory Board (CAB)
<i>Impilo Yamadoda</i> Research Partners	<ul style="list-style-type: none"> • Volunteers or employees of community-based organisations, employer organisations, non-governmental organisations, or faith-based organisations • No contractual obligation to <i>Africa Centre</i> 	<ul style="list-style-type: none"> • Administer survey questionnaires and contact sheets • Advise on participant enrolment locations for the <i>Impilo Yamadoda</i> study experimental phase (phase 4)

Tale 5.1: Researchers, participants, and partners in the *Impilo Yamadoda* study

V. Phase 2 survey implementation

As stated above, data used in the first of the data-driven chapters was based on phase 2 of the *Impilo Yamadoda: Men's Health Study*. Phase 2 of the *Impilo Yamadoda* study took place between October 2009 and January 2010 with a convenience sample of Zulu-speaking men ages 16 or above in the Hlabisa health sub-district. These data were used to highlight essential social and demographic information of the participants. Survey data are brought forward on their own in chapter 6, as the process of implementing the survey is analysed in the proceeding chapter in

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 5: Methodology

relation to the role of the volunteer survey administrators, called “Research Partners,” who implemented this phase of research.

The questionnaire used in phase 2 was a short pen-and-paper health survey (see English version: Appendix 2.2) and was administered orally to participants by a trained interviewer in Zulu. Areas where survey administration took place were limited to communities in the Hlabisa sub-district where volunteer Research Partners lived and worked. As Research Partners administered the majority of these surveys in their own time, I was not present when those surveys were administered. However I observed all survey administration events used as practical training (see Chapter 6, which focuses on process analysis of the Research Partner team), and larger events where *Africa Centre* fieldwork staff were employed.

There was no eligibility restriction for participation in the survey phase beyond ability to provide verbal consent to the study and being a Zulu-speaking male with self-reported age ≥ 16 years at the time of data collection. Consent was taken verbally as the survey questionnaire contained no sensitive questions and any identifying data was kept separate from questionnaire responses. All consenting participants to the phase 2 research were given a study information sheet in Zulu explaining the study and their rights as a participant in the survey project (see English version, Appendix 2.1). As respondents were not asked to travel to survey sites and it took participants minimal time to take part in the survey, there was no reimbursement for participation in this phase.

Upon completing the questionnaire, all survey participants were given opportunity to provide the interviewer information with which to contact him for possible inclusion in future stages of the *Impilo Yamadoda* project. This contact sheet (Appendix 2.3) consisted of 18 items designed to gather age of the participant, mobile phone/landline telephone contact information, and primary locations where the participant socialised. Demographic information (age and location) was gathered specifically for use in purposive sampling for phase 3 interviews and was unlinked to the survey questionnaire in order to preserve participant anonymity.

a. Questionnaire construction and analysis

The survey questionnaire consisted of 35 demographic, health, and research interest questions. These questions were chosen specifically so that participants' basic demographic information could be assessed, and their interests in specific health-related topics and feelings about research could be identified. Basic demographic questions were compiled using questions validated in the *Africa Centre Household Socio-Economic (HSE) demographic survey*. All other questions we considered experimental, as they had not been validated in this context.

The Likert-type scale (questions 24-35; see Appendix 2.2) was based on Zagumny and Brady's AIDS Health Belief Scale (AHBS) (226) and sought to measure participants' interest and motivations for involvement in health research. Scale questions used three of the four measures of the AHBS indicators for behaviour change: perceived susceptibility (to HIV acquisition), benefits (of protective behaviour), and perceived barriers (to protective behaviour). The fourth category, severity, was not used in this survey as Zagumny's original study found that male participants showed no change in behaviour correlated to a self-reported understanding of the severity of the consequence of HIV acquisition (226). In the case of this survey, where participants' interest in health related research was being measured, categorical questions on benefits were constructed as 'benefits to engagement with research', and questions on perceived barriers were constructed as 'perceived barriers to engagement with research'. The category of perceived susceptibility remained as the original version of the AHBS as it was of interest to cross-analyse self-report of susceptibility to HIV acquisition against reports of interest in research engagement.

In preparing questionnaire data for analysis, the project research assistant entered each survey questionnaire into an Access database once. As a quality control measure, a random sample of questionnaires was entered into the database to cross check for data entry accuracy. As few errors were found it was determined that there was no need to double enter the entire dataset. Raw data from Access was then imported into STATA (version 11.1) where the data was then cleaned by checking for missing entries and labelling variables appropriately.

The initial method used in this thesis to assess association between variables was the Pearson's Chi Square test. One-way tables were used for a basic descriptive analysis of the sample and two-way tables assessed associations between variables. Likert-type scale data were first tested for inter-scale reliability using Cronbach's Alpha test and then analysed in STATA (version 11.1) using logistic regression. Logistic regression is a regression model used for categorical variables to investigate the relationship between outcome and explanatory variables. As all of the variables of interest are categorical or categorised, logistic regression is the most appropriate method to analyse them. Both saturated as well as stepwise regression models were used to determine which variable, if any, was most strongly associated with the outcome variable in these cases.

All figures reported, with the exception of "p values," are given to up to one decimal point.

VI. Research Partner involvement

The second data-driven chapter in this thesis is focused on the role of volunteers in organisations who were identified to partner with the *Impilo Yamadoda* study: the Research Partner team. Chapter 7, *Research Partners: Part 1: the process of implementing a strategic community engagement technique*, will describe the methods of Research Partner identification and selection as this aspect of the research is essential to an understanding of the feasibility of this method of research implementation. The following sub-section will instead focus on how the survey implementation was evaluated.

Sub-sections b and c will focus on the methods used in collection, preparation, and analysis of in-depth interviews with the Research Partners. In-depth interviews with Research Partners are analysed in chapter 8, *Research Partners: Part 2: qualitative data exploring the process of a strategic community engagement method*.

a. Survey implementation evaluation (chapter 7)

In order to evaluate the effectiveness of Research Partners to implement the phase 2 survey, both quantitative and qualitative data were used to describe this process. Survey participant contact sheets were entered in an Excel worksheet. A separate Excel worksheet was created to record Research Partner and *Africa Centre* fieldworker participation rates using data from completed participant follow-up logs (Appendix 2.4). Surveys analysed in STATA (version 11.1) and the two Excel worksheets described above comprise the total quantitative data collected for phase 2 of the research project.

Qualitative descriptions of the survey implementation process were derived in part from field notes. Informal interviews with Research Partners and *Africa Centre* fieldworkers during and after survey events, and when Research Partners turned in and collected survey materials, yielded further qualitative data. Informal discussions with project staff, and formal structured in-depth interviews with Research Partners (described below), completed the qualitative dataset used in this analysis.

b. Purposive sampling of Research Partners to in-depth interviews (chapter 8)

Research Partners were invited to take part in an in-depth interview to capture their range of experiences with survey administration. The University College London Research Ethics Committee and the University of KwaZulu-Natal Social Sciences and Humanities Research Ethics Committee granted approval for these interviews as an addendum to the main application, which centred on the first three phases of *Impilo Yamadoda* research (Appendix 4.10; 4.11). The selection for Research Partner invitation to interview was based on a purposive sampling framework (Appendix 3.3), which I created using participant acceptance rates of both the questionnaire and contact sheet components of the *Impilo Yamadoda* survey. Ten categories were generated to capture the variability of Research Partners' acceptance rates (see Table 5.2, page 81).

The acceptance of questionnaire and contact sheet completion by participants was 67.36% and 74.22% respectively. These acceptance rates were calculated dividing the sum of the questionnaires completed by the number of potential participants approached multiplied by 100 ($\% = 547/812 * 100$). The proportion of Research Partner contact sheets was similarly calculated; the number of contact sheets over the number of questionnaires completed multiplied by 100 ($\% = 406/547 * 100$). Where there are blank cells there were no Research Partners who fit the criteria (e.g., an above average questionnaire and an average contact sheet response). The one Research Partner with a below average questionnaire response rate and an above average contact sheet response rate was not available to interview. Twelve Research Partners were selected as appropriate to interview, with a minimum of 7 completing the purposive sample.

Category		Available to interview	Interviewed
Questionnaire	Contact sheet		
AA	BA	RP2, RP13 (n=2)	n=1
AA	A	0	
AA	AA	RP1, RP6, RP9, RP10, RP11 (n=5; n=4 available)	n=2
BA	BA	RP5, RP7 (n=2 available)	0
BA	A	RP4 (n=1)	n=1
BA	AA	0 (RP12 not avail)	
A	BA	RP8 (n=1)	n=1
A	A	RP3 (n=1)	0
A	AA	0	
None	None	RP15 - RP22 (n=8)	n=1

Key: AA= above average percentage; A= within 5% of average; BA= below average percentage

Table 5.2: Research Partner IDI purposive sampling

Eligible Research Partners were invited to interview at *Africa Centre* offices. Before arriving for the interview, the content and purpose of the interviews was explained to each potential participant in order to gain verbal assent. Special care was taken to ensure Research Partners understood that taking part in the interview was voluntary and their decision would not

carry any negative consequence or affect their involvement with the remainder of the research project. Prior to the interview, ability and understanding of consent was assessed using a short true/false quiz in Zulu (see English version: Appendix 3.4). Those participants willing and able to consent then signed a copy of the consent sheet. All participants in this phase of research were given an information sheet in Zulu explaining the research content and aims, as well as their rights as a research participant (see English version: Appendix 3.5).

c. Research Partner in-depth interview implementation (chapter 8)

I conducted individual in-depth interviews with Research Partners in cooperation with the lead *Impilo Yamadoda* research assistant. Interviews were conducted in both English and Zulu, with the dominant language being set by the comfort level of the participant. All interviews were taped and then uploaded as mp3 files. Interviews were transcribed (and translated where necessary), directly into English by a bilingual trained native Zulu-speaking transcriptionist.

Research Partners participating in these interviews received R100.00 (approximately £8.00) in the form of a store voucher. This reimbursement amounts to the cost of a return journey to *Africa Centre* for the furthest participant and is the same reimbursement participants in the phase 3 qualitative data component of the study received.

All digital recordings were deleted from tape recorders after being uploaded onto the *Impilo Yamadoda study* password protected folder on the share drive at *Africa Centre*, as per proper data protection protocol.

d. Analysis of Research Partner interviews (chapters 7 and 8)

Data collection and analysis of Research Partner IDIs was conducted myself using a grounded theory approach (227). The grounded theory technique necessitates preliminary analysis concurrent to data collection (227); after each interview field notes were reviewed for a preliminary analysis. Based on this preliminary analysis questions were adjusted within the

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 5: Methodology

general topic guide (Appendix 3.6) in subsequent interviews to gain further insight into areas that had not been adequately addressed, or to explore key concepts that had arisen in earlier interviews. The first section of the topic guide, which was used as an informal demographics assessment, remained the same throughout the Research Partner IDIs. The questions under this section match those of the phase 3 participant IDIs, in order to allow cross analysis of day-to-day activities between the two groups. After the preliminary coding of field notes, interview transcripts were coded alongside field notes I collected during interviews and at survey implementation events. Categories were developed through open coding of field notes and *in vivo* transcript codes.

In translation from Zulu to English, as well as in the case of those Research Partners who spoke English during interviews, linguistic subtleties are lost; coding is therefore concept-based rather than based on word use or word repetition (227). These categories were linked in a secondary coding stage to contextualise the data. The full list of codes found in this dataset can be found in the Chapter 8 introduction. Finally, key concepts in the data are reported in this thesis based on a case study approach.

The grounded theory approach uses a data-driven analysis approach, where it is possible to yield rich analyses through an in-depth investigation into a specific topic using a relatively small number of interviews (224, 227). This approach allowed interviews with a small sample of Research Partners (N=6) to create an accurate portrayal of their experiences with the survey project during a time period limited by on-going *Impilo Yamadoda* study activities. The resulting case studies contextualise the outcomes from the process of implementing the first two phases of the *Impilo Yamadoda* project, and so these data are presented in chapter 7 and 8, which analyse the involvement of Research Partners in the *Impilo Yamadoda* study.

VII. Participant motives for research engagement (chapter 9)

a. Individual and focus group interviews with survey participants

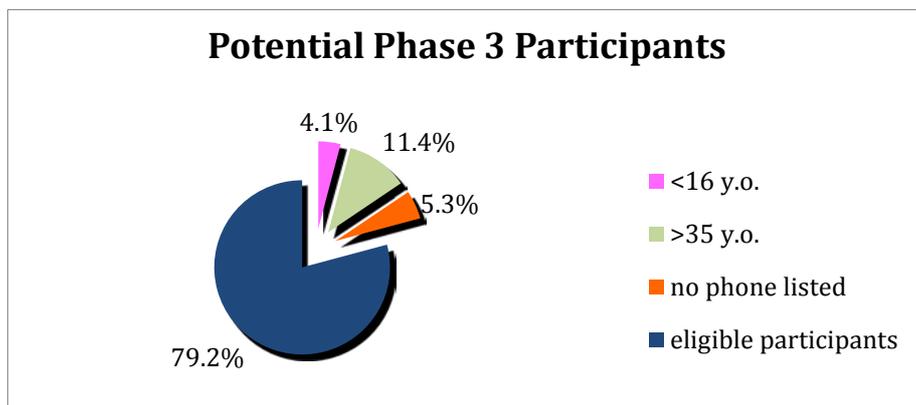


Figure 5.2: Inclusion criteria for participants to phase 3 interview

Inclusion criteria for the phase 3 qualitative component of the *Impilo Yamadoda* study was completion of the survey phase questionnaire, contact sheet, and being between the ages of 18 and 35, inclusive. As shown in Figure 5.2 (this page), a large portion (79%) of survey respondents who consented to leave contact information were considered eligible for participation in the qualitative phase. The purposive sampling framework for all IDIs and FGDs was directed by myself and administrated by the *Impilo Yamadoda* research assistant. The phase 2 contact sheet recorded age, socialisation area, and in several cases, social club name (reported spontaneously by participants). As a result, the purposive sampling framework was based on age, primary socialisation area, and social group membership (where noted). Ages were divided into age-range groups based on equal number of years in each group: 18-23, 24-29, and 30-35.

Participants for IDIs (n=20) were sampled for representation of the various age and socialisation locations of the participants. Wherever possible, potential participants were sampled for IDI so that each geographic location where men reportedly socialised with their peers was represented. Focus group discussions (FGDs) were also sampled to represent various ages and social locations of participants with sampling led by contact sheet data. Eight focus group designations were set: 25-35 year old men from the same geographic area; 21-24 year old men from the same geographic area; 18-21 year old men from mixed areas; 22-29 year old men from mixed areas; 30-35 year old men from mixed areas; mixed ages and mixed locations; mixed ages from the same location; and finally, as a result of a group of men spontaneously

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 5: Methodology

reporting the same social club, we sampled a group of 18-20 year old men in the same social club.

The research assistant used phone numbers listed on the contact sheet to call eligible men selected for invitation to participate in a qualitative interview. Potential participants were invited to either an IDI or a FGD. All IDIs were held at *Africa Centre* offices, as were 7 of 8 FGDs; one FGD, held with members of the same social group, was held at a community location convenient to the participants. The *Impilo Yamadoda* research assistant conducted all FGDs and IDIs with *Impilo Yamadoda* participants in Zulu. In the majority of cases I directly observed the consent process for FGDs, where this was not possible the *Impilo Yamadoda* Community Liaison Officer, who was previously trained in obtaining consent, was present. I was not present for interviews and focus groups past the consent process as it was thought that my presence as an observer might inhibit participant responses, and was also largely unnecessary as my Zulu language proficiency was not sufficient to allow for understanding of the majority of the interview.

Two FGDs and 8 IDIs were completed in November 2009. The remaining interviews were completed between March and June 2010. Participants were not permitted to interview in both an IDI and an FGD. In total 8 focus groups and 20 in-depth interviews were completed between November 2009 and June 2010.

Each interview participant was given both oral explanation of study procedures (presented one-on-one for IDIs and to groups for FGDs) and a study information sheet in Zulu (see English versions: Appendices 4.1 and 4.2 respectively). Ability to consent was assessed via a short true/false quiz (see English versions: Appendices 4.3 and 4.4) administered in Zulu; potential participants were not permitted to take part in an FGD or IDI until all the questions in the quiz were answered correctly and the consent form was signed. The *Impilo Yamadoda* Community Liaison Officer observed all study information and consent sessions. All FGDs and IDIs were audio recorded, with recordings deleted once they were uploaded to the secure access *Impilo Yamadoda* study folder at *Africa Centre*.

In-depth interview and focus group discussion topic guides were similar in nature (Appendices 4.5 and 4.6, respectively). Both topic guides were semi-structured and included the same themes of discussion, moving from a general discussion of daily activities (warm-up questions) to health and experiences with health care towards a focused discussion on health research. Additionally, both topic guides included two vignettes that were used to contextualise specific scenarios involving decisions to participate in research (see topic guides, Appendices 4.5 and 4.6). These vignettes provided the participants with a safe space in which to explore personal and complex decision-making; it was hypothesised that these vignettes would reduce social acceptability bias in the data (228). Topic guides were structured to reflect that focus groups are most useful in gaining knowledge about socially normative behaviour and beliefs while individual interviews are more successful at gathering outliers (224, 229, 230). IDI topic guides differed from FGD guides in that with IDIs personal experiences were sought, while in FGDs participants were treated as ‘community experts’ where we asked opinions arising not necessarily from personal experiences but from observations of their peers, social groups, and communities.

b. In-depth interview and focus group analysis

Audio mp3 files from all phase 3 interviews were transcribed verbatim into Zulu and then translated into English by bilingual native Zulu speaking project staff. Transcripts were kept bilingual to allow for mistranslations to be easily spotted. Once translated, English language portions of the transcripts were further edited for English language clarity in order to improve on readability. This process was done by me using MS Word track changes for transparency in the editing process. Two native Zulu speakers in the project team then reviewed these additional changes for translation accuracy and then these were reconciled in project team meetings (see Figure 5.3, this page).

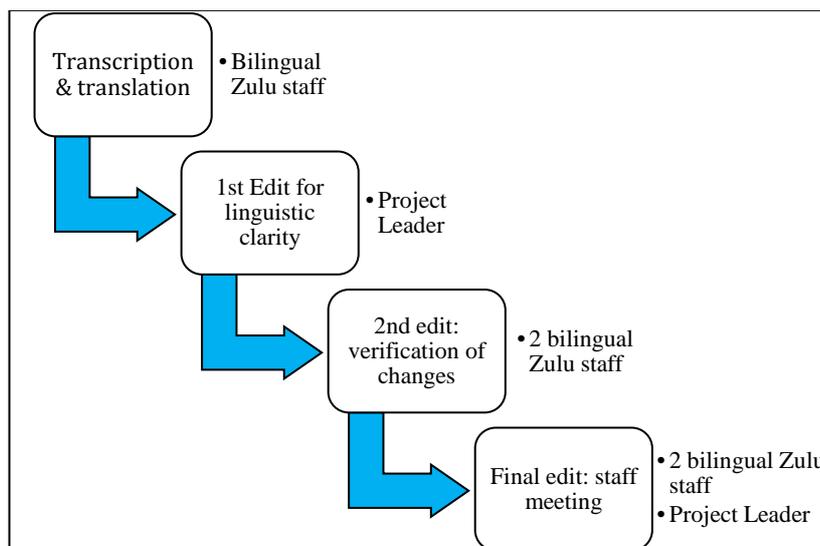


Figure 5.3: *Transcription and translation process to prepare IDI and FGD data for analysis*

While the above translation and reconciliation process was time consuming it allowed for both accuracy and consistency in translation and subsequent analysis of this rich dataset. These team reviews were also seen as a first analysis meeting where concepts that could not be directly translated into English were explained and noted and resulted in a greater practical understanding of Zulu cultural norms on the part of the lead analyst (myself).

Speech patterns during in-depth interviews often rely on the clarity of thought of the speaker; often interviewees struggle with topics that might not be thought of prior to the interview. This can lead to incomplete thoughts that are finished or brought back again in different sections of the interview. This is highly applicable in the Zulu language, where meaning is ascribed to many words based purely on context. For example, the word *impilo* in Zulu can be translated as “health” or “life,” depending on the context in which the word is used. In addition, common sayings were explained in team review sessions, allowing the richness of explanation to be brought forward in the resulting contextual analysis.

The resulting “clean” transcripts were prepared for analysis by me, using Excel worksheets to construct matrix style charts for analysis (231). FGDs and IDIs were analysed separately to reflect the different levels of questioning and differing question styles in the two

data collection methods; however, the themes identified were quite similar as can be expected from the similarity in the topics covered in both types of interviews (see Appendix 4.7).

As is typical in this type of analysis, an iterative process was used to construct the data matrix (231). Staff read the prepared transcripts individually to identify substantive concepts in the interviews. In addition, an *Africa Centre* researcher with qualitative expertise was brought into the analysis process, as he was thought to add valuable insight and verification of themes as a person unfamiliar with the research. All themes identified by each researcher were all spoken aloud and then written down individually, in order to allow transparent review of all views of the dataset to come forward. Duplication of similar themes was reduced via examples of themes read from transcripts by the person who identified them, and then discussed to determine overlap. After this reduction of duplication process was complete, common “themes” were agreed upon as a group. Individual staff members were then given a small portion of transcripts (n=4) to assign themes to the appropriate sections of data, or “index.” These indexed transcripts were reviewed and verified in a team meeting with project staff to assure consistency of indexing. Disagreements in indexing were discussed and then agreed upon. The remaining transcripts were apportioned and indexed. I then reviewed all transcripts for consistency of indexing. For data management and quality control assisting analysis, indexed transcripts were synthesised and then grouped in a matrix chart by theme by me (please see Appendix 4.7 for the full list of themes found in these datasets). The process of analysis for these data is further explained in Figure 5.4 (page 89). This matrix allowed interviews to be read across the chart by case, or vertically by theme across all interviews. Using the matrix as a guide, descriptive accounts of the data were identified and verified in a team analysis meeting. Explanatory analyses to detect patterns and associations in the dataset were conducted at the final stage of data analysis.

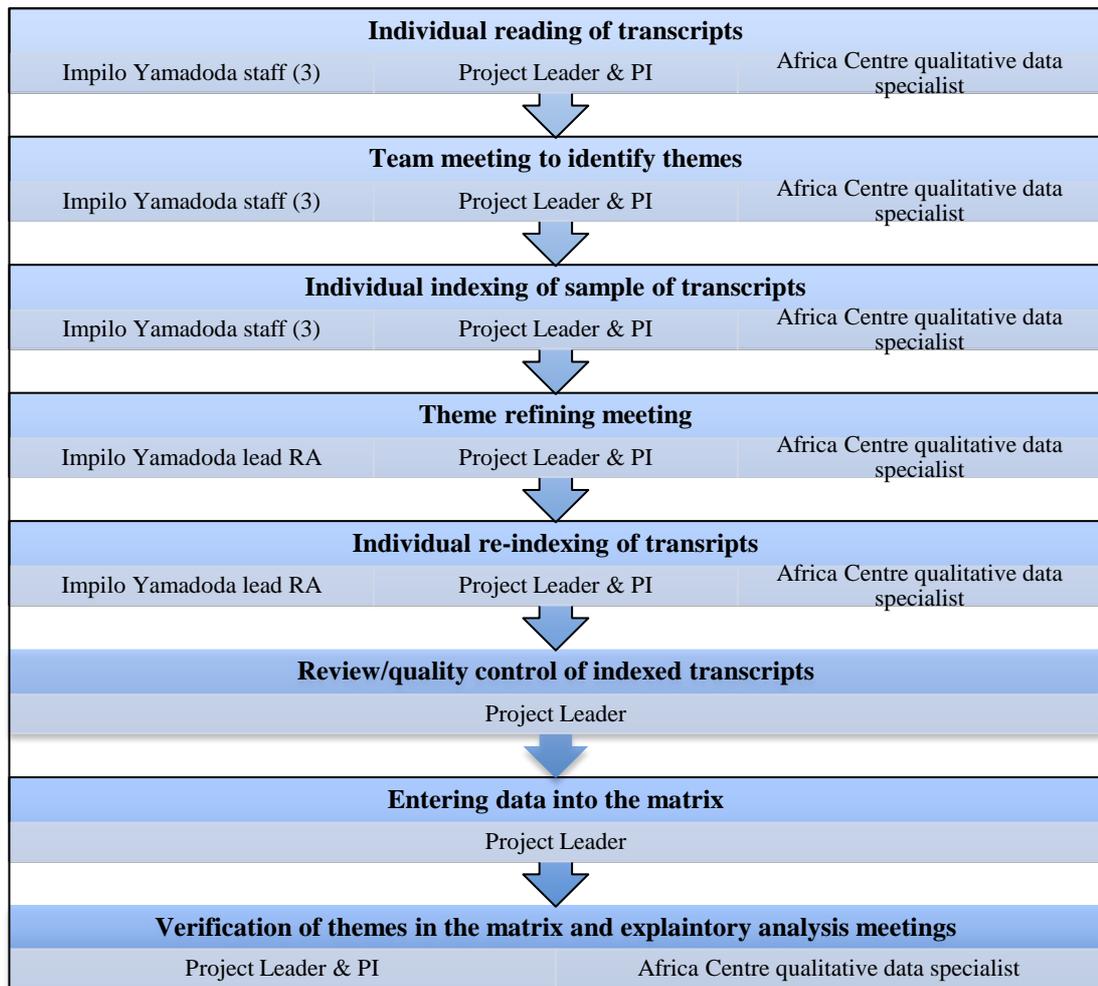


Figure 5.4: Analysis process for IDI & FGD data

While it is unusual to use two different styles of qualitative analysis in one investigation, the different circumstances and use of the two qualitative datasets under investigation here necessitated different analytical approaches. Grounded theory is best suited to small datasets with a focused area of investigation, such as the Research Partner interviews (227), while a matrix style analysis is best used when looking for common themes across larger bodies of data, and data that needs to be used for analysis in multiple investigations, such as the data from the *Impilo Yamadoda* phase 3 IDIs and FGDs (19, 224, 227). The matrix style suits this dataset as the topic guide for these interviews is complex and investigates a variety of themes. The resulting analysis across the IDI and FGD datasets allows easy recognition and reporting of common themes in multiple areas of inquiry.

c. Phase 4: experimental study

Recruitment of participants to the phase 4 experiment of the *Impilo Yamadoda* study began in July 2010. The aim of this phase of the *Impilo Yamadoda* study was to create an HIV prevention intervention experiment designed to approximate a full-scale randomised controlled trial (RCT), such as would be needed for an HIV vaccine trial. The *Impilo Yamadoda* study experimental phase specifically tested the feasibility and acceptability of two different types of blood collection (micro-capillary samples collected in the community and venepuncture collected at clinic), and two types of follow-up methods for questionnaire data collection (face-to-face versus mobile phone).

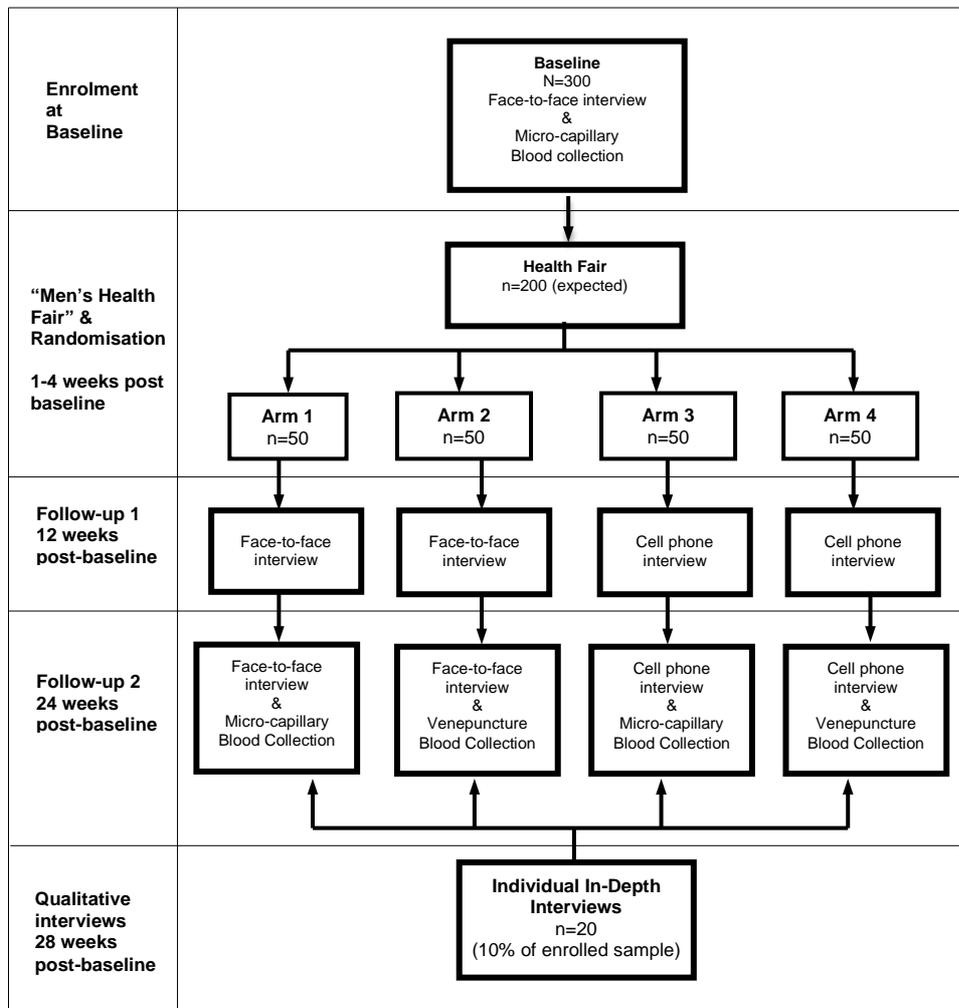


Figure 5.5: Phase 4 experiment design

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 5: Methodology

It should be emphasised at the outset that this phase of the study was not a full-scale randomised controlled trial. Nevertheless, the participants who enrolled in the phase 4 experiment consented to health research involving sensitive behavioural questionnaires and blood collection at baseline and during multiple follow-ups. The experiment followed a two-stage randomised design: participants completed a baseline self-reported behavioural questionnaire and blood specimen collection, followed by an intervention and three follow-ups (Figure 5.5, page 90).

As the main aim of the *Impilo Yamadoda* phase 4 experiment was to explore the feasibility and acceptability of different blood collection and interview methods, the actual “intervention” in this study was the method of blood collection and interview technique. The Men’s Health Fair (discussed later) was an event that all participants were engaged in and did not differ based on random study arm allocation, and as such was not an intervention in the epidemiological meaning of the term as applied to RCTs (154).

As this phase of research included collection of bio-specimens, a separate ethics application was made to the University of KwaZulu-Natal Biomedical Research Ethics Committee. Ethical approval was granted by the University of KwaZulu-Natal Biomedical Research Ethics Committee before data collection took place (Appendix 1.6).

Participants were followed up either via face-to-face or mobile phone interview at 3, 6, and 12-month follow-up points. Blood specimens were collected for HIV testing at baseline and at both 6 and 12-month follow-ups. During the 6 and 12-month follow-ups, the second randomisation, that of blood specimen collection, came into play with half of the sample assigned to attend one of two designated local clinics for venepuncture sample collection and half having a micro-capillary sample collected in the community location of the participant’s choosing. Four weeks after the 6-month follow-up, a subsample of participants was invited to participate in an individual in-depth interview (Figure 5.5, page 90).

d. Baseline recruitment and enrolment

Impilo Yamadoda experiment eligibility requirements were open: any Zulu speaking male resident in the Hlabisa sub-district between aged 18-35 years inclusive at baseline, with a valid South African identity book (confirming their age and identity), and the ability and desire to consent to participation, was considered eligible. It should be noted that the original protocol included two follow-ups; the 3rd follow-up at 12-months post-baseline was added after additional funding was provided by the *Impilo Yamadoda* study funding body (EDCTP). While consent was originally planned for up to 8 months of participation, (reflected in consent sheets), participants were asked to re-consent prior to follow-up 3. Additional ethical approval from the University of KwaZulu-Natal Biomedical Research Ethics Committee was granted before follow-up 3 data collection began.

Recruitment to the phase 4 experiment was based on the methods of recruitment to the phase 2 survey; Research Partners worked in collaboration with the study team to secure appropriate times and locations for ‘enrolment events.’ These enrolment events were held at predesigned times and locations within the target communities. I was present at all enrolment events. The goal of these events was to have local spaces for potential participants to be screened, and if willing and eligible, to complete baseline questionnaire and blood specimen collection. Enrolment events played an important function to both inform community members that this last phase of *Impilo Yamadoda* was beginning and to provide “seed” participants to form the base of our enrolment group.

The phase 4 enrolment team consisted of two full time project research assistants and five part-time fieldworkers. All part-time fieldworkers were identified through the *Africa Centre* demographic surveillance team trained fieldworker reserves; these fieldworkers were not and had not previously been employed as *Africa Centre* surveillance staff at the time of phase 4 experiment recruitment. Fieldworkers were Zulu speaking males to match with the overall directive that *Impilo Yamadoda* be seen as ‘for and about’ Zulu speaking men. Identified fieldworkers were trained in the project baseline enrolment Standard Operating Procedure

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 5: Methodology

(SOP) (Appendix 5.2) and randomisation and intervention SOP (Appendix 5.3). Fieldworkers attended three half-day trainings, which I developed and were implemented in collaboration with field experts and Zulu-speaking members of the *Impilo Yamadoda* research team. One training day each was dedicated to baseline enrolment, micro-capillary blood collection (Appendix 5.4), and randomisation and intervention event procedures, respectively. Baseline enrolment procedure training included time for fieldworkers to practice implementing the consent and questionnaire forms. This training also included basics such as ethical treatment of research subjects, including informed consent and confidentiality. Micro-capillary blood collection training was conducted by a trained technician from Adcock Ingram, the company who supplies *Africa Centre* with blood collection equipment for many of the research projects conducted there. All fieldworkers were taught universal precautions for handling bio-specimens and practiced micro-capillary blood draw during this training. The *Impilo Yamadoda* project staff and I were also trained by the *Africa Centre* laboratory expert in the procedure for temporary storage and processing of micro-capillary specimens (Appendix 5.5).

After the formal training was complete, an informal on-the-job training was scheduled; the first 'enrolment event' was held at *Africa Centre* with ten potential participants identified from phase 2 survey contact sheets. This enrolment event was directly observed by me and held in-house in order to ensure all procedures were conducted correctly before launching these events in target communities.

Each potential participant completed the first stage of enrolment (baseline questionnaire and blood sample) in the same way. Potential participants were given study information sheets to read in Zulu (see English version, Appendix 5.6) and had that information explained aloud in groups. After all their questions were answered, interested individuals were directed to fieldworkers to begin the one-on-one enrolment process. Ability to provide consent was tested with a true/false quiz to assess their understanding of the study information that had been presented to them in groups a few minutes prior. After informed consent was obtained, participants continued on to complete a fieldworker-administrated pen-and-paper questionnaire.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 5: Methodology

Participants were then directed to a second fieldworker who collected each participant's blood sample in one 600 µl micro-capillary tube. Study ID codes were given to participants and recorded on individuals consent forms (see English version Appendix 5.7) and questionnaires (see English version Appendix 5.8). Questionnaires and blood samples were linked with a unique identifier (Appendix 5.9)

All initial participants enrolled in baseline were given two referral tickets, with a unique identifier linked to their Study ID code (see Appendix 5.10). Participants were instructed that they could give this ticket to a peer to aid their recruitment into the experiment; all participants who referred men that completed baseline enrolment received a study t-shirt as an incentive. Potential participants referred to the study through this method were asked to call or text message one of the two project research assistants for information on community enrolment events or to schedule an appointment to enrol at *Africa Centre* offices.

e. Randomisation

Participants completing baseline were informed that they could not be considered fully enrolled until they had been randomised to one of four study arms and participated in a "Men's Health Fair" organised by *Impilo Yamadoda*. The Men's Health Fair was planned to take place in two parts, with all participants attending one of the two identical fairs. Participant attendance at the first Men's Health Fair allowed us to predict how many additional individuals would need to be recruited in order to meet our target of 200 participants in this phase. The first of the two Men's Health Fairs took place after the first month of baseline enrolment. The second fair was scheduled to take place eight weeks after the after the start of baseline enrolment, however, attendance at the first fair was high (85%; 130/149) and baseline enrolment following the fair was fast enough to warrant scheduling the second health fair two weeks earlier than anticipated.

Men's Health Fairs were one-day events organised to deliver education on men's health topics that were identified by Research Partners and participants in the first phases of *Impilo Yamadoda* and familiarise participants with various organisations that provide health protective

services to young Zulu-speaking men. To this end, organisations identified in phase 1 were contacted to provide us with volunteers to present the services their organisations provide. Research Partner organisations as well as stakeholder organisations and traditional and municipal authorities were contacted to lend support. Organisations were asked by the research assistant to send up to two volunteers each, one of whom would be asked to give a brief (up to ten minute) oral presentation about the services their organisation could provide to the participants. All organisational representatives were asked to stay for the duration of the event so that participants could visit their tables and speak with them one-on-one. The premise of the Men's Health Fair was to provide a space for and about men's health where men would feel comfortable asking questions and speaking about health related issues.

Aside from providing an educational programme for participants, the aim of the Men's Health Fairs was to randomise and then un-blind participants to their mode of participation in the experiment. I was present to observe and oversee each of the two Men's Health Fair events.

Upon arrival participants were individually randomised and then un-blinded. Participants were given study information packets that corresponded to their specific study arm (see English versions: Appendix 5.11 - 5.14). After participants received randomisation allocation information, a fieldworker then directed the participants to receive their *Impilo Yamadoda* study mobile phone. All mobile phones were registered to participants' Study ID code and given with activated SIM cards and R50.00 (approximately £4) call credit pre-loaded. Basic operations of the study mobile phone (e.g., checking call credit balances and sending text messages) were demonstrated. Participants were then required to speak to a designated fieldworker who then explained the study arm allocation information inside their study packets.

After each Men's Health Fair, I cross-checked participant check-in logs (at entry point) against randomisation and mobile phone registry log to ensure quality control of data. Pen and paper participation logs recording dates and locations of participant recruitment to the Phase 4 experiment were transferred into Excel worksheets. Outcomes of participation rates to baseline

and attendance at the intervention and randomisation events were analysed using the aforementioned Health Fair attendance logs and Excel worksheets.

As this research is focused on participant engagement in HIV prevention intervention research rather than participant retention in research, this investigation does not include data from the Phase 4 experiment beyond enrolment.

VIII. Conclusions

The methodological considerations in this investigation are many; a multiple method protocol necessitated careful consideration of which analytical tools can be most effectively combined to result in robust analysis of the questions under investigation. Initially following the *Impilo Yamadoda: Men's Health Study* protocol as a loose guide in the protocol for this investigation, the research under investigation in this thesis necessitated some deviation from that protocol to more fully explore not only the actions of participants towards the research study but also their thoughts and motivations. The additional piece of data collected, in-depth interviews with a purposive sample of Research Partners, aids in our understanding of why these men decided to engage in the *Impilo Yamadoda* study.

This thesis uses outcomes from *Impilo Yamadoda* study implementation in addition to quantitative data collected from survey questionnaires, and qualitative data from individual in-depth interviews, focus group discussions, and field notes. The triangulated use of these data provide for the rich analytical framework presented in the following chapters.

Chapter 6:

Survey data: descriptive analysis of *Impilo Yamadoda* participants

I. Introduction

Survey data from the *Impilo Yamadoda* study were collected mainly as an experiment to observe the efficacy of community-based volunteer-led data collection. However, these data also provide good information on the demographic details and health research beliefs of the participant population of *Impilo Yamadoda*. These data serve to contextualise as well as aid our investigation of the factors that contributed to the engagement of young men in Kwa-Zulu Natal in the *Impilo Yamadoda: Men's Health Study*.

We must know the characteristics of the population under investigation to understand the factors that contributed to the engagement of *Impilo Yamadoda* study participants. Because a geographic subset of the *Impilo Yamadoda* study area is well researched as part of the *Africa Centre* demographic surveillance area, it would be remiss if these data were not discussed as the closest possible comparison group to the participants under discussion here. To that end, data collected via the 2010 *Africa Centre* Household Socio-Economic (HSE) questionnaire are presented here. The *Africa Centre* HSE is a subset of the main *Africa Centre Demographic Information Systems* (ACDIS) surveillance project; the ACDIS and HSE data collection processes are discussed below.

Several questions in the *Impilo Yamadoda* survey were designed to capture participants' willingness to take part in future men's health research studies. Questions were asked specifically addressing participants' desire to take part in HIV prevention education research, as well as HIV prevention research including the collection of blood samples. These questions were formulated after consulting the literature on potential facilitators and barriers to participating in biomedical research (discussed in chapter 3 [e.g. (176, 193, 232-234)]). For example, it has been found that potential biomedical research participants have indicated greater interest in engaging in research if they receive benefits for themselves or benefits for their community as part of their involvement (176, 234). Another topic of interest in the literature is

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 6: Survey data: descriptive analysis of *Impilo Yamadoda* participants

the concept of social stigma related to research involvement, or the perception that participation in HIV-related research would be viewed negatively within the community where research was taking place (233). In addition, several studies have cited that fear of personal harm resulting from research participation is a deterrent to study engagement (232, 233). Potential participants' knowledge of the effectiveness HIV-related research studies have for reducing HIV infection in individual participants (193) and/or for communities (234) have also been shown as determinants of research participation. These factors are explored for relevance within the *Impilo Yamadoda* survey sample by our construction of targeted questions about participants' attitudes, interest and knowledge of HIV related research. Variables such as pragmatic obstacles to participation, i.e. being too busy with work, school, or other commitments, are investigated via demographic data collected in the survey questionnaire (233). Other factors cited as important to participants' decision making process, such as correct understanding of study procedures (235), and mistrust of researchers or research aims (233), are investigated using an exploratory questioning technique more suitable to qualitative data collection and so will be discussed in later chapters of this thesis.

The *Impilo Yamadoda* survey data explore some aspects of inquiry that, although important to the aims of that larger study, are not central to the theme of this investigation. For example, questions 5-8 of the survey questionnaire (Appendix 2.2) are focused on participants' access to mobile phones. The responses to these questions were important for planning the phase 4 experiment of *Impilo Yamadoda* where mobile phones were used to contact participants, but are not relevant to this investigation. The discussion in this chapter is limited to analysis of data that allows an understanding of the *Impilo Yamadoda* participants and their possible motivations and barriers to engaging in later stages of the study.

II. *Africa Centre* Demographic Surveillance Data

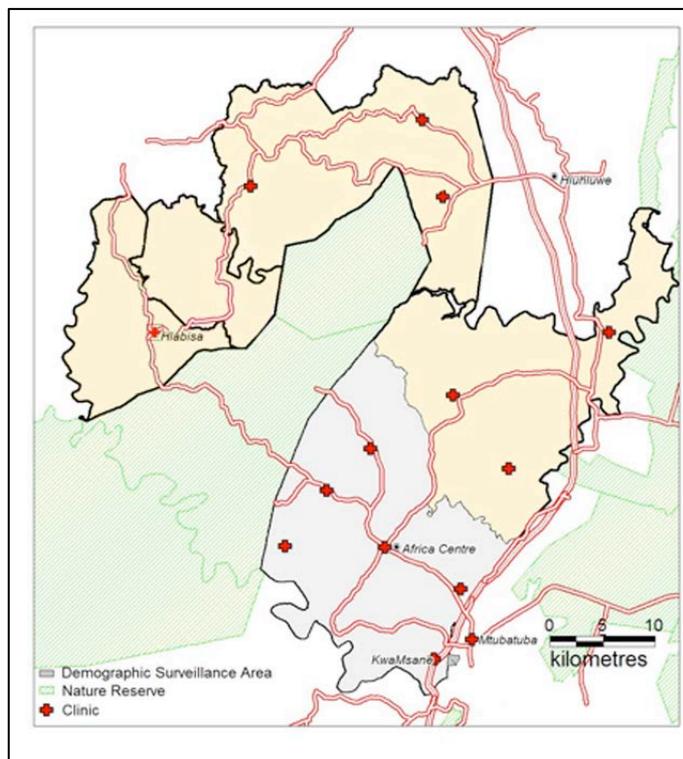


Figure 6.1: Impilo Yamadoda study area, Africa Centre ACDIS surveillance area depicted in grey²

The *Africa Centre Demographic Information Systems* (ACDIS) surveillance area is situated within the larger *Impilo Yamadoda* study area; Figure 6.1 (this page) is a map of the entire *Impilo Yamadoda* study area with the *Africa Centre* Demographic Surveillance Area depicted in grey. Fieldworker teams collecting *Africa Centre* demographic data visit households within the Demographic Surveillance Area (DSA) three times per year; HIV surveillance is collected once per year and household socio-economic (HSE) data twice per year (88). As with other *Africa Centre* surveillance data, HSE data is collected by proxy respondent, (i.e., a volunteer member from each household). Individuals' demographic information is collected by noting responses from the proxy respondent for each member of the household; fieldworkers arrive at the household with pre-populated information collected in the previous HSE round, and this is updated in each new data collection round. New members of the household (birth or in-migration) are recorded separately and added to the database. Deaths and out-migrations are

² Map courtesy of *Africa Centre for Health and Population Studies*, via personal correspondence, 2009.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 6: Survey data: descriptive analysis of *Impilo Yamadoda* participants

noted and recorded similarly. All individuals in the household are thus accounted for under the surveillance project.

As per the ACDIS eligibility requirements “all households with current residency who resided in a bounded structure are considered eligible for the HSE questionnaires” (236). For the purposes of ACDIS, a *bounded structure* “is a building, or a group of buildings, on land belonging to a single person or organisation, and used for one main purpose” (85). Individuals’ *current residency* is determined by the individual in question, or if s/he is not there the proxy respondents’ belief that the individual in question normally lives within the bounded structure at the time of the questionnaire implementation (85).

Data used from the HSE refer to the “individual information” categories that were collected on male members of household within the *Africa Centre* DSA. HSE data presented here are a portion of the total number of records for males from the 2010 (Jan-June) HSE round and were provided specifically for the purpose of this thesis by Colin Newell, Senior Database Scientist at *Africa Centre*. As with the *Impilo Yamadoda* survey data, I analysed all data from the *Africa Centre* HSE in STATA version 11.1. In most cases, in order to provide direct comparison with the *Impilo Yamadoda* survey data variables, I generated new categorical variables in the original HSE dataset. In all HSE variables, with the exception of marital status, the missing value is defined; the marital status variable has no missing but includes a “not applicable” value.

III. General demographic characteristics

Characteristics	N (%)
<i>Age</i>	
16-17	26 (3.5)
18-23	341 (46.4)
24-29	196 (26.7)
30-35	79 (10.7)
36+	87 (11.8)
Missing	6 (0.8)
<i>Marital Status</i>	
Married	49 (6.7)
Engaged/not yet married	25 (3.4)
Single	644 (87.6)
Widowed	5 (0.7)
Divorced	5 (0.7)
Missing	7 (0.9)
<i>Highest education grade completed</i>	
Grade 1-6	46 (6.3)
Grade 7-12	631 (85.8)
Tertiary	15 (2.0)
None	19 (2.6)
Missing	24 (3.3)
<i>Currently employed</i>	
Yes	152 (20.7)
No	574 (87.1)
Missing	9 (1.2)

Table 6.1: Phase 2 survey population (N=735) demographics

When looking specifically at the demographic make-up of the phase 2 survey population, we can see that there are several distinct characteristics. These characteristics are discussed in detail below, in the respective subsections. Table 6.1 (this page) outlines the basic descriptive demographics of the *Impilo Yamadoda* survey participants.

a. Age

It is clear that a high percentage of men in the survey population were under the age of 36. In comparison, 2011 provincial estimates place 39.30% (2027882/5159983) of the male population in KwaZulu-Natal between 15-34 (237), while 88.1% of the *Impilo Yamadoda* survey population was between 16-35 years old at the time of data collection.

The *Impilo Yamadoda* protocol stipulates that a main aim of the study was to “develop

guidance and recommendations ... regarding recruitment and retention for community samples of young adult men for biomedical, vaccine and behavioural HIV prevention trials from rural and peri-urban settings in South Africa” (18). With this in mind, the target group of interest was Zulu-speaking men between the ages of 18-35. It was for that reason that the research team explained to the Research Partners that although all Zulu-speaking men over the age of 16 were welcome to participate in the survey, we were particularly interested in the responses of young adult men between ages 18-35. As a main indicator of potential eligibility to biomedical research was age, we can see in Figure 6.2, (this page), that Research Partners were successful in targeting this demographic.

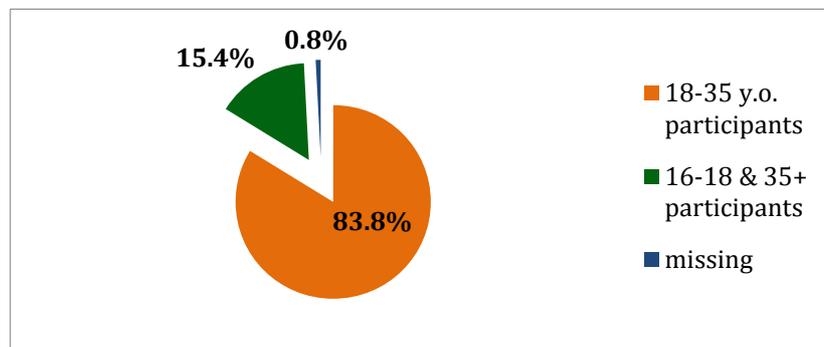


Figure 6.2: Percentage of age-eligible potential participants to phase 4 experiment (N=735)

b. Education and employment status

A first look at the categories of education in Table 6.1 shows that 85.8% (631/735) have completed grades 7-12. Although age may not always relate to education year, as students may enrol late and/or may not remain in school continuously, 2007 national data report that $\geq 95\%$ of South Africans remain in school until age 16 (238). Investigating the association between age and highest education grade completed among our survey participants (Table 6.2, page 103), establishes a valid association ($P < 0.001$).

Age category	Education grade completed					
	None	Primary (grade 1-7)	Secondary (grade 8-12)	Tertiary	Missing	Total
16-17	0 (0.00)	4 (15.4)	22 (84.6)	0 (0.0)	0 (0.0)	26 (100.0)
18-23	7 (15.8)	9 (2.7)	311 (91.2)	2 (0.6)	12 (3.5)	341 (100.0)
24-29	5 (2.5)	11 (5.6)	167 (85.2)	7 (3.6)	6 (3.1)	196 (100.0)
30-35	4 (5.1)	7 (8.9)	63 (79.7)	5 (6.3)	0 (0.0)	79 (100.0)
36+	2 (2.3)	34 (39.1)	45 (51.7)	1 (1.1)	5 (5.7)	87 (100.0)
Missing	1 (16.7)	0 (0.00)	4 (66.7)	0 (0.00)	1 (16.7)	6 (100.0)
Total	19 (2.6)	65 (8.8)	612 (83.3)	15 (2.0)	24 (3.3)	735 (100.0)
Pearson chi2(20) = 152.1831 P=<0.001						

Table 6.2: Two-way contingency table for age and education grade completed

In 2009, KwaZulu-Natal province accounted for 23.1% of the national total of enrolled learners and the highest number of ordinary public (state-funded) schools in South Africa (239). In addition, in 2009 the province had a 99% gross enrolment ratio of males enrolled in primary level (grades 1-7) and 82% in secondary level (grades 8-12) (239). With this in mind, it can be expected that within a large population of school-age men in KwaZulu-Natal, many will be enrolled in school. It should also be noted that it is generally recognised that Black South Africans gained a higher access to both primary and tertiary education after the abolishment of the apartheid school system (240). The changes in education for Black South Africans after 1994 are reflected in the survey data; the oldest survey respondents were most commonly associated with the lowest education grade completion (grades 1-7) (52.3%; 34/65) and the highest percentages of respondents completing at least one year of tertiary education are those in the 22-29 (53.3%; 8/15) and 30-35 (33.3%; 5/15) age ranges.

When comparing the survey item regarding participant employment status to *Africa Centre* HSE data, it is evident that employment status of the survey participants differs from the general population of the sub-district, (see Figure 6.3, page 104). While a portion of those survey participants reporting unemployment may be explained as due to the larger overall

unemployment rate of rural (57.1%) versus urban (37.8%) residents of KwaZulu-Natal (240), it does not explain that nearly 90% of the survey participants reported unemployment.

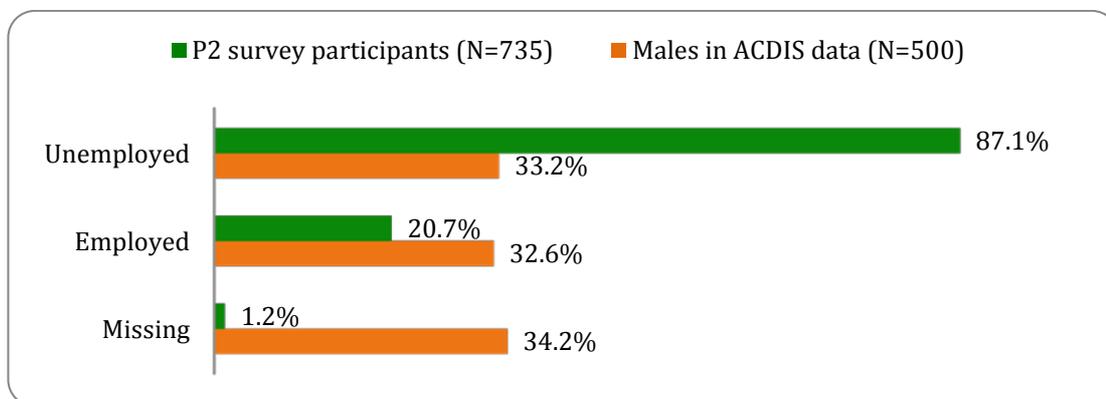


Figure 6.3: Employment status of phase 2 survey participants compared to men within the Africa Centre HSE Jan-Jun 2010 round

Employment Status	Education Status (grade completed)					Total
	None	Primary (grade 1-7)	Secondary (grade 8-12)	Tertiary (grade 13+)	Missing	
Employed	7 (4.6)	14 (9.2)	120 (78.9)	9 (5.9)	2 (1.3)	152 (100.0)
Unemployed	12 (2.1)	50 (8.7)	485 (84.5)	6 (1.0)	21 (3.7)	574 (100.0)
Missing	0 (0.0)	1 (11.1)	7 (77.8)	0 (0.0)	1 (11.1)	9 (100.0)
Total	19 (2.6)	65 (8.8)	612 (83.3)	15 (2.0)	24 (3.3)	735 (100.0)

Pearson chi2 (8) = 21.6620 Pr = 0.006

Table 6.3: Two-way contingency table between employment and education status

There is a statistically significant association ($P=0.006$) between employment and education status, (Table 6.3, this page). While it could be expected that a higher percentage of unemployed participants might report completing less education, this does not bear out in the analysis. Instead, we see that those in the *secondary* education status category have the highest rate of unemployment (84.5% 485/735). While there is, unfortunately, no item on this questionnaire that directly asked participants if they are still enrolled in school, it is possible that a large percentage of those participants were currently in school. In this way education status could be presenting as a confounder to employment status. As it was not explicitly asked of participants to report current attendance in school there is no obvious way to control for this. However, item 15 asks those participants reporting unemployment to describe what they do during the time

while others are at work (Appendix 2.2); a percentage here report current school attendance. The resulting responses for this item were separated into 5 categories: *unemployed* (n=273), *underemployed* (n=90), *looking for work* (n=60), *schooling* (n=149), and *missing* (n=14). Separating those men who report that they have some type of work they do ('underemployed:' defined here as sporadic waged employment, piecework, or unwaged work such as cattle herding or ploughing fields), and those reporting full-time education (as explained above), from our percentage of unemployed participants, drops the figure to 37.1% (273/735), as shown in Figure 6.4 (this page). It should be noted that the 'underemployed' category was included here as our participants were specific in differentiating waged employment from sporadic income generating activities; those participants who reported that they were 'employed' referred only to regular waged employment. While the adjusted unemployment percentage for the phase 2 survey demographic matches the *Africa Centre* HSE unemployment percentage more closely (phase 2 survey: 37.1%; HSE: 33.2%), the employment rates remain disparate (phase 2 survey participants: 20.3%; HSE: 32.6%).

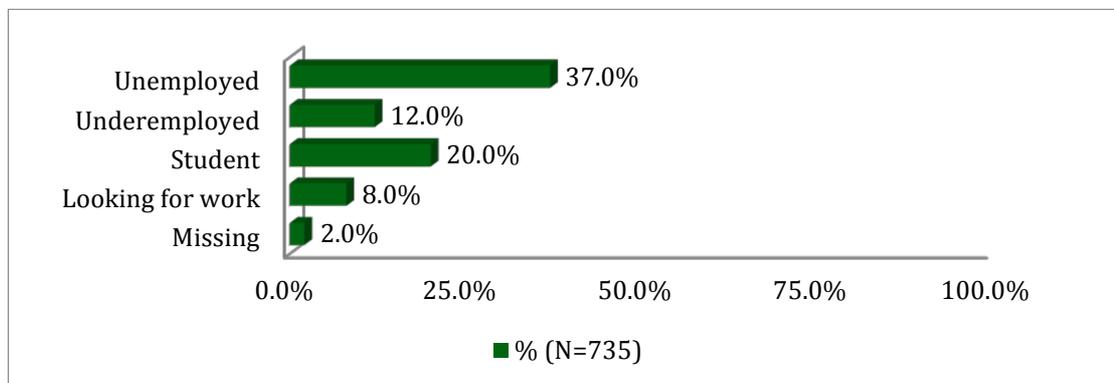


Figure 6.4: *Adjusted employment status of phase 2 survey participants*

c. Marital Status

As can be seen in Figure 6.5 (page 106) there was a significantly ($p < 0.001$) greater percentage of unmarried respondents in the survey (using 'single' and 'engaged' variables 669/735; 91.0%) as compared to the HSE data of the same period (299/500; 59.8%).

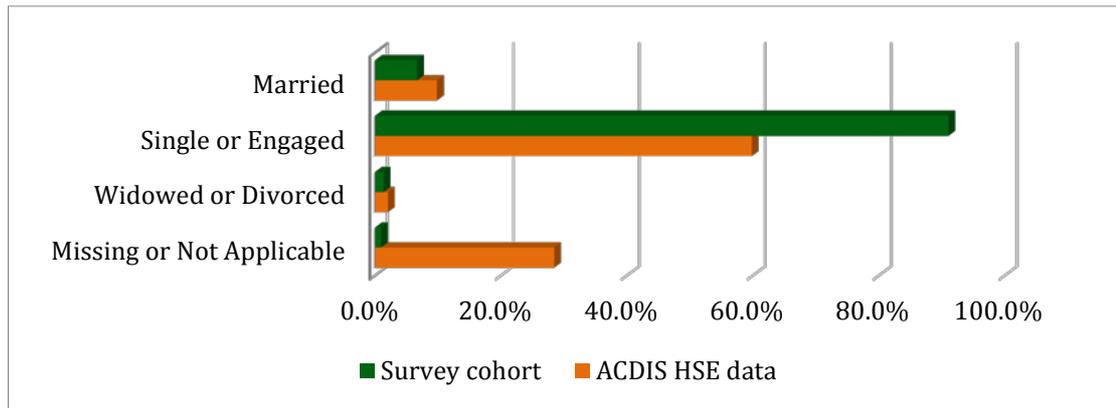


Figure 6.5: *Marital status of P2 survey participants compared to men within the Africa Centre HSE Jan-Jun 2010 round*

The high percentage of men reporting that they are unmarried (single or engaged) can be seen as validating the survey data. It would be expected that the age and employment status of the respondents would correspond to marital status; marriage among people within Zulu traditional areas, such as this study area, occurs later into adulthood than is true of many cultures in the global North. This is partially reflective of the large financial burden of the *lobola* ('bride price'), which, as explained in the literature review, can cost the prospective husband up to £2000 (128). With a participant group including a large percentage of unemployed young Zulu speaking men it would be surprising to find that a high percentage were married. Testing the association between age and marital status shows this hypothesis bears out (Table 6.4, page 107), the majority of married respondents (61.2%; 30/49) correlate with the 36+ year-old age category.

Age category	Marital Status				Total
	Married	Single or Engaged	Divorced or Widowed	Missing	
16-17	0 (0.0)	26 (100.0)	0 (0.0)	0 (0.0)	26 (100.0)
18-23	2 (0.6)	338 (99.1)	0 (0.0)	1 (0.3)	253 (100.0)
24-29	2 (1.0)	191 (97.4)	0 (0.0)	3 (1.5)	284 (100.0)
30-35	15 (19.0)	62 (78.5)	2 (2.5)	0 (0.0)	79 (100.0)
36+	30 (34.5)	48 (55.2)	8 (9.2)	1 (1.1)	87 (100.0)
Missing	0 (0.0)	4 (66.7)	0 (0.0)	6 (33.3)	6 (100.0)
Total	49 (6.7)	669 (91.0)	10 (1.4)	7 (0.9)	735 (100.0)
<i>Pearson chi2(15) = 284.1197 P = 0.000</i>					

Table 6.4: Two-way contingency table between age groups and marital status

IV. Social group membership

During survey implementation planning, Research Partners suggested several ways that they might encourage young men to participate. During that discussion, sport, and particularly football, was mentioned. This led to one of the Research Partners working with the study team to organise a two-day football playoff match in his area. The resulting match generated 17.4% (121/735) of the total collected questionnaires. Data from the survey reflect the recruitment methods used. This is particularly evident in the variable on community organisation involvement, where 56.3% (n=414) report belonging to a sports group (see Table 6.5, page 108); unsurprising when considering the large percentage of surveys collected during a sporting event. In effect, the survey data on men's organisational involvement both reflect and validate the process data from the survey implementation, (discussed in detail in the next chapter).

Social membership group	Yes (%) N=735
Sports group	414 (56.3)
Church group	142 (19.3)
Youth group	106 (14.4)
Choir or music group	95 (12.9)
Study group	72 (9.8)
Burial society	71 (9.7)
School committee	47 (6.4)
Other	46 (6.3)
Missing	40 (5.4)
Water committee	36 (4.9)
Community garden group	33 (4.5)
Traditional authority	32 (4.3)
Farmer's association	27 (3.7)
Community policing forum	28 (3.8)
<i>Stokvel</i> ³	28 (3.8)
Development committee	24 (3.3)
Men's association	22 (3.0)
Informal traders group	20 (2.7)
Community health worker	17 (2.3)

Table 6.5: *Phase 2 survey participants' organisational membership*

There is a small group of survey respondents who do not fall within the 18-35 year old age group (15.4%), and although this unequal distribution may skew the results, this is nonetheless an important group to look at as it was of primary concern to understand how to engage those young men that would be considered eligible to join the *Impilo Yamadoda* phase 4 experiment. Knowledge of the social affiliations of this population were thought to help to locate prospective phase 4 participants as well as give insight to the interests of this sub-group of participants. To that end, a variable was created that separates the small percentage of men who, at the time of data collection, reported their age as below 18 years and above 35 ('not eligible') from those respondents whose reported age fell between 18-35 years ('eligible'). Using a chi square test, it was found that there is a statistically significant difference in

³ *Stokvel* in this case refers to informal or semi-formal savings or investment scheme, where money is collected from a group of individuals on a regular basis and from which they receive a lump sum payment.

distribution between the eligible and not eligible participants in the majority (12/17) of social groups that were asked about (Table 6.6, this page), which serves to inform us that the ‘eligible’ participant sub-group are likely to be found in different social groupings than those 16-17 or 36 years and above.

Social group membership	Eligible (%)	Not eligible (%)	P Value
Sports group	46 (40.7)	364 (59.1)	p<0.001
Church group	31 (27.4)	111 (18.0)	p=0.020
School committee	23 (20.3)	24 (3.9)	p<0.001
Study group	19 (16.8)	51 (8.3)	p=0.005
Water committee	18 (15.9)	18 (2.9)	p<0.001
Tribal authority	15 (13.3)	17 (2.8)	p<0.001
Community garden group	14 (12.4)	19 (3.1)	p<0.001
Community policing forum	14 (12.4)	14 (2.3)	p<0.001
Farmer’s association	10 (8.8)	17 (2.3)	p=0.002
Youth group	9 (8.0)	97 (15.7)	p=0.031
Men’s association	7 (6.2)	15 (2.4)	p=0.032
<i>Stokvel</i>	9 (8.0)	19 (3.1)	p=0.013

Table 6.6: Significant variables in phase 2 survey participants’ organisational membership, eligible versus not eligible

In order to gain further information about the difference in social group membership and ‘eligible’ participants, a parsimonious model of forward logistic regression was used to determine which social groups were most strongly associated with the 18-35 year old ‘eligible’ respondents (Table 6.7, page 110). The results from this test show that ‘eligible’ respondents were more likely to be involved in sport and youth groups (P=0.001, OR 2.15, 95% CI 1.37 – 3.38; P=0.002, OR 3.33, 95% CI 1.53 – 7.24, respectively). Membership in a school governing body (P<0.001, OR .19, 95% CI .087 - .40), community garden group (P<0.001, OR .20, 95% CI .09 - .43), and study group (P=0.004, OR .39, 95% CI .21 - .74), was highly associated with those respondents outside of the ‘eligible’ age group, while membership in a community policing forum (P=0.071, OR .40, 95% CI .15 – 1.08), and church group (P=0.08, OR .63, 95% CI .38 – 1.05), was less so, but still kept within the P≤0.1 regression model. The high association of youth and sports group membership with ‘eligible’ participants is not particularly surprising considering that within the ‘not-eligible’ group there is a higher percentage of men 36

years and above (77%; 87/113) than those in the 16-17 year age group (23%; 26/113). However, it is of interest to note that study group membership was associated with the older ('not eligible') subset of the population.

	Odds Ratio	P> z 	95% Conf. Interval
School governing body	0.19	0.000	0.09 - 0.40
Community garden group	0.20	0.000	0.09 - 0.43
Sports group	2.15	0.001	1.37 – 3.38
Youth group	3.33	0.002	1.53 – 7.24
Study group	0.39	0.004	0.21 - 0.74
Community policing forum	0.40	0.071	0.15 – 1.08
Church group	0.63	0.078	0.38 1.05

Table 6.7: Odds ratio between eligibility to phase 4 experiment and non-eligible, by social group membership

V. General Health, HIV/AIDS and Interest in Health

Other variables that are useful to investigate are centred on participants' interest in health. Exploring what topics of health these men were interested in gives greater understanding of the types of health research programmes they might be willing to engage with, as well as insight into who they are as individuals beyond their basic demographic profile.

Survey question 18 asks participants to indicate which 'aspects of health' they are interested in learning about (Appendix 2.2); administrators were instructed to read each item and ask if the participant was interested in learning more about it, (i.e., "Are you interested in learning about diabetes?" and so on). Participants thus answered each question with either an affirmative or negative answer. Due to this, each variable is treated as a dichotomous 'yes/no' response. The percentages listed in Table 6.8 (page 111) assume every variable was asked of each participant and boxes left un-ticked are thus considered 'no/not interested'.

Health topic	Yes (%)
HIV/AIDS	501 (68.2)
STI (other than HIV)	408 (55.5)
Alcohol use	308 (41.9)
Using traditional & western medicine together	231 (41.4)
Tobacco use	275 (37.3)
Diabetes	268 (36.5)
Blood pressure	239 (32.5)
Heart disease	225 (30.6)
Violence	173 (23.5)
Mental health issues	172 (23.4)
Male circumcision	169 (23.0)
Vehicle safety	167 (22.7)
Physical or sexual abuse	154 (20.9)
Men's nutrition & fitness	153 (20.8)
Other	42 (5.7)

Table 6.8: Survey respondent interest in health education programmes

As is shown in Table 6.8 (this page), participants indicated interest in the variables *HIV/AIDS* (68.2% 501/735) and *STIs other than HIV* (55.5 408/735) more than any others. High reported interest in receiving this information may be due to social desirability bias, or participants' desire to report interest in education about HIV and other STIs because it is expected of them to do so. Despite the best efforts of the research team to portray the *Impilo Yamadoda* study as general men's health research, *Africa Centre's* association with HIV research and AIDS service delivery is very well known in the community. This is especially true as information publicised to the target communities indicated our interest in the topic of HIV as an aspect of the research. It is thus likely that this study was discussed in the community as focused on HIV/AIDS research, and together with the well-known high HIV prevalence in this area, may explain why men interested in this study reported being particularly interested in receiving education on HIV and other STIs. This reported high interest in receiving information about HIV and other STIs will be cross analysed with qualitative data from in-depth interviews and focus group discussions among *Impilo Yamadoda* participants in phase 3 (discussed in detail in Chapter 9).

Other education programmes of high interest to men were *alcohol use* (41.9% 308/735) and *tobacco use* (37.3% 275/735). In addition, the variable regarding education in the *use of traditional and Western medicine together* was not only chosen by a high percentage of participants (41.4% 231/735), but also reported by survey administrators as the most discussed item during informal reporting sessions.

The use of traditional medicine (*muthi*, in Zulu) plays an important role in Zulu culture; a dialogue of health cannot be had without engaging with the topic of traditional healing and traditional medicines (241). While modern Zulu culture often faces a push/pull dynamic in relation to health, the much-publicised “traditional Zulu beliefs” of South African President Jacob Zuma (49) have highlighted the friction within Zulu communities between the need for both modern responses to health care and validation of traditional practices. As a result, it is not surprising that a subsection of young Zulu speaking men in rural KwaZulu-Natal would be interested in a way to pursue traditional responses to illness whilst seeking the health care of Western medicine; this participant group may have a vested interest in the topic of using Western and traditional medicine together.

When participants were asked to self-report their general health status, 54.42% (400/735) chose the option *excellent/very good/good*. With the remaining choices, *fair* received the second highest percentage (32.9%; 242/735) while only 7.9% (58/735) reported their health status as *poor*. Interestingly, while we might expect younger participants to report better health status, there was no statistical significance between reported health status and respondent’s age ($P=0.09$). Just over half of the survey respondents knew someone who had tested for HIV (55.1%; 405/735, Figure 6.6, page 113). Additionally, 51.0% (375/735) reported that they voluntarily tested for HIV at some point prior to survey completion (Figure 6.6, page 113).

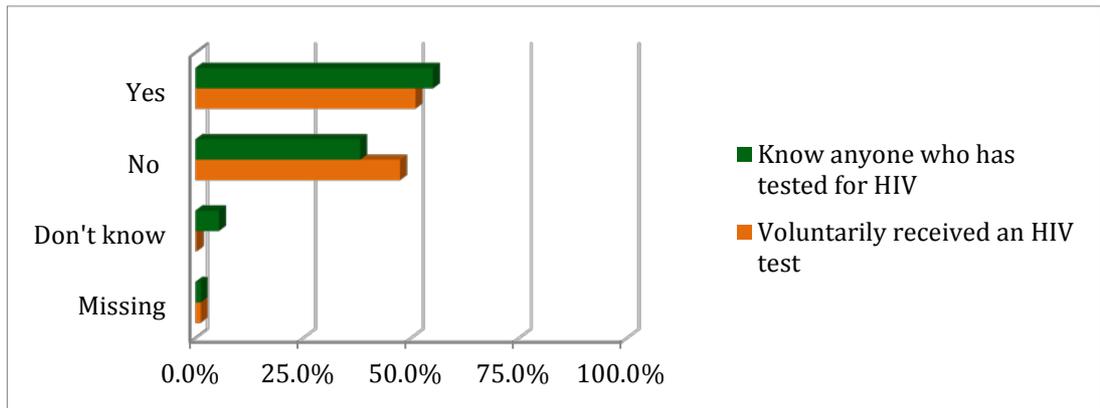


Figure 6.6: Survey participants and voluntary HIV testing

The South African National Communication Survey 2009 reports that 52% of “African” men between 25-49 years had received an HIV test in the last 12 months and know their status; it is unclear how many of these include voluntary HIV tests (31). National survey statistics for South Africa (2005) report that among males respondents 15 and above who consented to be tested for HIV as part of the survey, 26.4% (N=11938) self-report previous volunteer testing for HIV (242). Reported voluntary HIV testing rates among men in this study area are higher; among all those accessing VCT services at home or through mobile testing units in the Hlabisa sub-district between November 2010 and January 2011, 37% of the monthly average (N=720) were males 16 years and above⁴. Although more recent national and KwaZulu-Natal specific data on voluntary HIV testing were not available at the time of this submission, analyses of similar high HIV prevalence provinces in South Africa indicate that voluntary testing is likely to have increased in recent years (243). However, the available data show continued under-utilisation of voluntary HIV testing among males in South Africa (242, 243), making *Impilo Yamadoda* survey participants report of nearly double the percentage of the 2005 national testing figures surprising. It is also interesting that these participants reported voluntary HIV testing at a 15% higher rate than the adult men over the entire Hlabisa sub-district. High rate of previous VCT for HIV among the survey participants may indicate that our recruitment methods may be

⁴ Personal communication, Lungile Makhonza, Coordinator: Home and Mobile HCT Programme, *Africa Centre for Health & Population Studies*, February 2011.

reaching a participant base that is more involved in their own health care, and thus may be more likely to join health research than the general population.

VI. Willingness to Participate in Health Research

<p>21. We are interested in developing programmes that give information to men on the different ways that help to prevent the spread of HIV. Would you be willing to be a research participant in a HIV prevention education programme for men?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No * Q. 24</p> <p><input type="checkbox"/> Don't know/Undecided</p>
<p>22. If the following programmes to learn about HIV prevention were to take place, which would you be willing to participate in?</p> <p><i>Tick all that apply</i></p> <p><input type="checkbox"/> Condom use education</p> <p><input type="checkbox"/> Men's discussion group on health & sexuality</p> <p><input type="checkbox"/> Circumcision education</p> <p><input type="checkbox"/> Other (<i>indicate which</i>) _____</p>
<p>23. In a future part of the <i>Impilo Yamadoda</i> study we will be asking men if they will give us a blood sample, so we can estimate how many men that participate in <i>Impilo Yamadoda</i> have HIV. The person taking the blood samples will not be able to tell if a man has HIV, they will not do a test for HIV or be able give you a test result. The blood samples will go to a laboratory where they are checked to see if any are HIV-positive. This will be done by someone with special training, who will also not be able to tell who the blood samples belong to. To be clear, this is not an HIV test where you can find out the result and learn if you have HIV. We are not asking you to give a sample now. However, if you would like to know where you can get an HIV test and learn the result (VCT), we can tell you places to go after this interview. Knowing this, would you be willing to give a blood sample as part of research to help identify more effective HIV interventions for men?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Undecided</p>

Figure 6.7: *Impilo Yamadoda phase 2 survey questions focused on willingness to take part in health research*

Willingness to participate in health research was analysed first by exploring the responses to the question “would you be willing to be a research participant in a HIV prevention education programme for men?” (Figure 6.7, this page, question 21). Possible responses were *yes*, *no*, or *don't know/not sure*. Among the entire survey population (N=735), 60.95% (n=448) indicated *yes*; 17.8% (n=131) indicated *no*; and 7.5% (n=55) indicated *don't know/not sure* (13.7%

responses were *missing*). There was no statistically significant difference ($P=0.178$) in willingness to participate in research between the overall survey population and those who were age-eligible to participate in the phase 4 experiment. A relatively large percentage, 13.7% ($n=101$), did not answer the question and so are considered *missing*. When testing a dichotomous *missing/not-missing* variable for willingness to participate against age, along with the variable as categorised (described above) there was no statistically significant difference between the two results. In addition, when looking at the effect of the missing values on the Likert scale analysis, the missing values did not alter the results significantly. As was discussed above, 54.4% reported their current health status as *excellent/very good/good* and 60.9% reported that they would join a future health research study. There was an increasing percentage of participants willing to participate correlated with decreasing reported health status, as can be seen in Table 6.9, (this page).

	Health Status				
Willing to Participate	Excellent/Very Good/Good	Fair	Poor	Missing	Total
Yes	214 (53.5)	171 (70.7)	44 (75.9)	19 (54.3)	448 (60.9)
No	76 (19.0)	38 (15.7)	8 (13.8)	9 (25.7)	131 (17.8)
Undecided	22 (5.5)	24 (9.9)	5 (8.6)	4 (11.4)	55 (7.5)
Missing	88 (22.0)	9 (3.7)	1 (1.7)	3 (8.6)	101 (13.7)
Total	400 (100.0)	242 (100.0)	58 (100.0)	35 (100.0)	735 (100.0)
Pearson chi2(9) = 61.5970 P=>0.000					

Table 6.9: Two-way contingency table between reported health status and willingness to participate in research

This finding indicates that participation in research among the survey population is significantly associated with a connection between personal health needs and participation in health research. The association between research and health care might be expected as previous research studies [e.g., (244)] have provided free health care as part of a benefit package to participation;

many of the men in the survey population would have been aware of the health care benefits to past research studies in this area. This potential motivator for participants to engage in research will be explored further in the qualitative analysis presented in later chapters of this thesis.

A subset of participants who indicated *yes* or *don't know/not sure* to Question 21, (“would you be willing to be a research participant in a HIV prevention education programme for men?”) was asked to choose one or more from a list of hypothetical HIV prevention education programmes; 73.3% (423/577) indicated interest in *condom use education*; 50.6% (281/555) indicated interest in *men's discussion group on health and sexuality*; 30.2% (163/539) indicated interest in *circumcision education*; and a small percentage (6.4%; 34/518) chose *other* and wrote-in answers such as “ARV [use]”, “abstinence”, “TB education”, “importance of knowing HIV status”, and “seeking medical care”.

Those participants who answered *yes* or *don't know/not sure* to question 21 were given a scenario in question 23 where participants in a hypothetical research programme were asked to give blood for anonymous HIV testing in a scenario where they would not get their test results (see Figure 6.7, page 114). The item then asked if this was a research programme they would be willing to take part in: “...would you be willing to give an anonymous blood sample as part of research?” (Appendix 2.2, Question 23). While n=680 were eligible to respond, 594 participants (87%) answered this question, and 86 (13%) were considered missing. Of those who responded, 72.0% (428/594) indicated *yes*, 13.0% (77/594) indicated *no*, and 15.0% (89/594) indicated that they were *undecided*. As might be expect from the response to Question 21, there was no statistically significant difference ($P=0.674$) between the overall survey population and those eligible to participate in the *Impilo Yamadoda* phase 4 experiment. The high percentage of survey participants indicating willingness to give blood as part of research may be due to the prospective nature of these questions; intent to participate may not indicate future participation.

a. Likert-type scale

24. My participation in HIV prevention research helps to improve the health of my community <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neutral <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
25. I am more likely to participate in HIV prevention research if I am paid for my participation <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neutral <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
26. I am more likely to participate in HIV prevention research if I receive information about how to maintain good health as part of my participation <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neutral <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
27. I am more likely to participate in HIV prevention research if I receive health care as part of my participation <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neutral <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
28. I am too busy to take part in HIV prevention research <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neutral <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
29. I do not know other men who participate in HIV prevention research <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neutral <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
30. I think I will enjoy participating in HIV prevention research <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neutral <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
31. There are ways to prevent becoming infected with HIV <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neutral <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
32. If I participate in HIV prevention research it is possible that people will think I have HIV. <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neutral <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
33. People in my community would like it if I participated in HIV prevention research <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neutral <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
34. Some people claim that giving a blood sample as part of research can give you HIV. I believe this is true. <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neutral <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
35. I believe that only traditional medicine can effectively prevent HIV <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neutral <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree

Figure 6.8: *Impilo Yamadoda phase 2 survey Likert-type scale questions*

A Zulu language version of the 12-item Likert-type scale questions shown in Figure 6.8 (this page), was used to understand the motivations behind a respondent’s indication of willingness to participate in research (or not). Likert-type scale data were analysed with the

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 6: Survey data: descriptive analysis of *Impilo Yamadoda* participants

underlying premise that the four variables in each measure were similar enough to concepts in the validated AIDS Health Belief Scale (AHBS) model that it was not necessary to retest validity of each question within the measures separately (226). As discussed more fully in methods chapter (section V a) the Zagumny and Brady AHBS sought to measure participants' indicators for behaviour change in preventing HIV acquisition. The focus of the revised scale in this study was on interest and motivations for involvement in health research, however the structure and, to a lesser extent, the wording of the items used remained true to the original scale. Testing the validity of these questions, and thus the validity of the overall scale, is beyond the scope and purpose of this thesis, and so is a limitation of this analysis. However, a Cronbach's alpha test was conducted to assess the reliability of the scale, the results of which are examined in this section.

Participants were asked to respond to each item on a scale from strongly agree to strongly disagree, depending on how he felt about the statement (see Appendix 2.2, preamble to Likert-type scale). Each of the 12 questions was scored between 1-5, with 1 the lowest and 5 the highest correlation with the predicted response. The 12-items were then collapsed into three measures: *Perceived Individual and Community Level Benefits to Research Engagement* (hereafter, *perceived benefits*); *Perceived Barriers to Research Engagement* (hereafter, *perceived barriers*); and *Perceived Susceptibility to Acquire HIV Infection as a Result of Research Engagement* (hereafter, *perceived susceptibility*). Each of these measures was comprised of four questions that sought to show different aspects of respondents' perceptions towards participation in HIV prevention intervention research. The resulting score of each measure fell between 4-20 (as each question would have a score between 1-5), with 4 indicating least and 20 indicating most agreement with the measure. A response of *strongly agree* to the individual question "My participation in HIV research helps to improve my health in the community" would be given a score of 5 in the *perceived benefits* measure, and so on. An individual's combined score of 20 in the 4-question *perceived benefits* measure would indicate high importance of this measure in the decision to engage with research.

In order to check the reliability of the scale, each item was inputted into a Cronbach's Alpha test. First including missing values and then excluding them tested the impact of missing values on the analysis. There was no significant difference between the two tests. The results shown in Table 6.10 (this page) use the Cronbach's Alpha with missing values excluded from the analysis. As can be seen, the test shows that the changes made to the scale, including changes in the individual items and translation from English to Zulu, proved that this complete scale is not reliably testing perceptions towards HIV research in this population.

Item	Observations	Sign	Item-test correlation	Item-rest correlation	Average inter-item covariance	Alpha
Q.24	624	+	0.60	0.50	0.14	0.58
Q.25	624	+	0.53	0.38	0.14	0.59
Q.26	624	+	0.66	0.56	0.13	0.57
Q.27	624	+	0.58	0.47	0.14	0.58
Q.28	624	-	0.35	0.15	0.16	0.64
Q.29	624	+	0.26	0.05	0.17	0.66
Q.30	624	-	0.59	0.46	0.14	0.58
Q.31	624	-	0.39	0.24	0.16	0.62
Q.32	624	-	0.27	0.05	0.17	0.66
Q.33	624	-	0.50	0.37	0.15	0.60
Q.34	624	-	0.43	0.23	0.15	0.62
Q.35	624	-	0.44	0.24	0.15	0.62
Test scale					0.15	0.63

Table 6.10: Cronbach's Alpha test for reliability of Likert scale, missing values excluded

While the entire scale is not reliable, questions 24-27, and questions 30 and 33 (see Figure 6.8, page 117) show higher reliability than other questions (item test >0.5). Questions 24-27 were originally conceived to form the previously defined measure *perceived individual and community level benefits to research participation*; questions 30 (*I think I will enjoy participating in HIV prevention research*) and 33 (*People in my community would like it if I participated in HIV prevention research*) are, on face value, reasonable items to collapse with the *perceived benefits* measure into one revised scale. When these six questions are used together, the resulting scale scores acceptably high on the Cronbach's Alpha test (Alpha, 0.76;

see Table 6.11, this page). This revised scale was then used to measure participants *perceived individual and community-level benefits to engagement with HIV prevention research* (Figure 6.9, this page).

Item	Observations	Sign	Item-test correlation	Item-rest correlation	Av. inter-item covariance	Alpha
Q.24	705	+	0.67	0.52	0.33	0.73
Q.25	705	+	0.67	0.47	0.31	0.74
Q.26	705	+	0.76	0.64	0.30	0.70
Q.27	705	+	0.70	0.55	0.32	0.72
Q.30	705	-	0.70	0.52	0.31	0.73
Q.33	705	-	0.59	0.38	0.35	0.76
Test scale					0.32	0.76

Table 6.11: *Cronbach’s Alpha test for reliability of Likert scale; high item correlations including missing values*

24. My participation in HIV prevention research helps to improve the health of my community <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neutral <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
25. I am more likely to participate in HIV prevention research if I am paid for my participation <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neutral <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
26. I am more likely to participate in HIV prevention research if I receive information about how to maintain good health as part of my participation <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neutral <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
27. I am more likely to participate in HIV prevention research if I receive health care as part of my participation <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neutral <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
30. I think I will enjoy participating in HIV prevention research <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neutral <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree
33. People in my community would like it if I participated in HIV prevention research <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neutral <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly Disagree

Figure 6.9: *Revised Impilo Yamadoda phase 2 survey likert-type scale questions*

Question 21, “would you be willing to take part in future HIV prevention education research programmes for men?” was then used as an outcome variable to determine the effect of the scale. As iterated above, this outcome variable was multivariate, and so a sensitivity analysis

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 6: Survey data: descriptive analysis of *Impilo Yamadoda* participants

was conducted to determine treatment of *don't know/not sure* responses. In addition, the outcome variable contained a relatively large missing percentage (13.7%); a sensitivity analysis was performed in order to test treatment of these missing values. These sensitivity analyses consisted of implementing a logistic regression model against all variations in the outcome variable (randomly assigning “don't know” and/or “missing” to either ‘yes’ or ‘no’ responses); there was no change in statistical significance between the models. After this sensitivity analysis I determined that there was no strong benefit to using one version of the outcome measure against the other. Because there was no significant difference randomly assigning ‘missing’ and ‘don't know’ values in the models, the model was fitted with the original outcome measure, which drops missing and don't know values.

Logistic regression was used to determine if the outcome *willingness to participate* was predictable using the reliable scale. The results of the logistic regression test on the revised scale show that the scale is a statistically significant predictor (OR 1.18, $P < 0.001$, CI 1.09 – 1.29).

STATA models of logistic regression exclude all cases where missing values are present and the Cronbach's Alpha test was run to exclude cases with missing values in the scale items without accounting for missing values in the outcome variable. With this in mind, the new scale's reliability with the missing values in both the outcome variable and the scale items ($n=555$) was tested to check if missing cases were skewing the results. As the outcome variable was tested excluding missing values this is unlikely to be skewing the results of this test, however, missing cases in the likert-type scale items may affect the results if they were not missing randomly. The Cronbach's Alpha test in Table 6.12, (page 122) shows a small but likely insignificant difference (Alpha=0.75) when compared with the test excluding only the scale missing cases (Alpha=0.76). Therefore we can be confident that excluding missing values did not significantly alter the results and that the likert-type scale is an accurate predictor of willingness to participate in research.

Item	Observations	Sign	Item-test correlation	Item-rest correlation	Average inter-item covariance	Alpha
Q.24	555	+	0.62	0.45	0.29	0.72
Q.25	555	+	0.68	0.46	0.26	0.72
Q.26	555	+	0.74	0.60	0.25	0.68
Q.27	555	+	0.67	0.52	0.28	0.70
Q.30	555	-	0.69	0.52	0.26	0.70
Q.33	555	-	0.60	0.39	0.29	0.74
Test scale					0.27	0.75

Table 6.12: Cronbach's Alpha test for reliability of Likert scale; high item correlations excluding missing cases in scale and outcome variables

VII. Limitations

It should be noted that all completed questionnaires collected as part of the *Impilo Yamadoda* survey phase (N=735) are included for this statistical analysis, while in calculating process indicators such as acceptance rates they are not (n=709). Quality control checks were done as survey administrators turned in the phase 2 survey forms; participation rate logs were checked against the actual numbers of returned questionnaire and contact sheet forms. As a result, reporting on the questionnaire and contact sheet participation rates was good overall: questionnaire reported returns matched actual returns (96.5%, 709/735), and contact sheets were even more accurately reported (99.0%, 538/543). However, the inconsistencies in reporting resulted in 3.5% (709/735) of completed questionnaires excluded from the process analysis. There was no discernable pattern to the inconsistencies in reporting participation rates so it is likely that this is due to human error rather than purposeful false reporting.

Although all survey administrators were trained, they were still volunteers and so they exhibited limitations that might not exist if professional research staff were used exclusively for the survey administration. While several items show our data on the whole to be reliable and valid, slight inconsistencies in administration (i.e., mistakenly skipping over items in the questionnaire) should be noted as a limitation of this dataset. With this in mind, wherever a large percentage of missing values in a variable of interest were found, a sensitivity analysis

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 6: Survey data: descriptive analysis of *Impilo Yamadoda* participants

using a Chi Square test was implemented with a variable with few missing values (e.g., age) in order to check against the possibility of skewed results. Wherever these missing values proved problematic they have been presented previously in the chapter.

The use of a convenience sample for quantitative data collection and the reliability of the resulting analysis of these results has been debated (245). However, the decision was taken during *Impilo Yamadoda* protocol design that a participant sample recruited via community volunteers providing valid findings for this exercise was more important than generalisable findings (246). The results of the analyses show that the use of these data to describe this particular population of participants is not compromised, although the purpose and limitations of the generalisability of these data must be kept in mind. As this was not a random sample, the findings may not be generalisable to the larger population (155, 246). The sample created here was a convenience sample constructed purposely to recruit men who might be suitable candidates for a biomedical HIV prevention intervention, and with the intention of knowing more about those men specifically. As is demonstrated by this analysis, this aim was likely met and the men in this community-based study may be unique to that of the general population of men in the Hlabisa sub-district. Rather than describe the population of men in this area, which is done more accurately with surveillance data such as that provided by the *Africa Centre* HSE, data provided in this chapter provides insight to the population of men included in this research study.

After a brief pilot of the survey, there were small changes made to the questionnaire. These changes were mainly to the style and format of the questionnaire, however, the wording of some items was also altered for clarity in Zulu. Several scale questions were reversed to read as positive statements rather than negative ones (i.e., “I will not enjoy participation in HIV prevention research” was changed to “I will enjoy participation in HIV prevention research”). These changes were not seen to affect the validity of the earlier questionnaire and so were included in the dataset and largely accounted for when entering the forms into the Access database.

VIII. Conclusions

The data presented in this chapter indicate that the survey population represents a subset of the population of men within the study area. These men, mostly young, single, and un/under-employed, may be more interested in health and health research engagement than that of the general population. Men taking part in this survey indicated their interest in health education and, in particular, HIV and STI education (68% and 55% respectively). Their interest in health education is linked to their willingness to take part in HIV research via the strong associations found in the Likert-type scale analysis. Willingness to participate was strongly associated with perceived individual and community level benefits, including receipt of health education and health care, as well as the belief that participation in research improves community health.

It is useful in the interpretation of these results to return to the context mapped out in the chapters 2 and 3. The survey data shows that the men who form this survey participant group are disenfranchised: economically and socially disadvantaged with low percentages of waged employment and marriage. Being a 'youth' in South African demographic definitions ranges from ages 16-35, well into the years that European and North American cultures would describe as early adulthood. This is partially reflective of Zulu culture in modern society; for Zulu men in particular, adulthood is an increasingly difficult status to obtain, with ownership of cattle, one's own home, and marriage, traditionally recognised as chief indicators of adulthood (124). While the traditional societies within the Zulu homeland are changing, an idealised male identity represented by *baba* still carries weight, as in many cases these men are the literal fathers and grandfathers of our participants.

Social disenfranchisement is indicated not only through basic indicators of age, marital, and employment status, but throughout the survey data. While many of the men in our participant group report membership in social groups, more than half of them report membership in a sports group, the social group associated with youth (247). In contrast, groups

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 6: Survey data: descriptive analysis of *Impilo Yamadoda* participants

associated with men in higher status indicated by community law and disciplinary administration such as the *Traditional authorities* was indicated by 4.3% of respondents. It is telling that of those men who are unemployed, when asked what they do all day the largest category of response was *stay at home* (45.8%; 125/273). More men indicated that they disagreed or strongly disagreed with the statement that they were *too busy to take part in health research* (43.2%; 307/711) than indicated the reverse (30.9%; 220/711).

The question could be asked as to whether it is surprising that these young men are reporting interest in health research. These outcomes indicate that participants' interest in health and health research is related to their desire to make positive impact on themselves and their community. Most men (88.8%; 642/723) indicated that they agree or strongly agree that participation in health research improves the health of their community – the highest percentage of agreement of any item in the Likert-type scale for *perceived individual and community-level benefits to research participation*. It is of note that the items measuring individual and community level benefits were the only ones to reliably measure participant views on HIV research participation. This indicates that men may be interested in taking part in something that has potential to improve their communities. What is not clear are the reasons these men have for their interest in improving their communities. The *Impilo Yamadoda* phase 2 survey offered no form of reimbursement for participation and still the majority of men indicated willingness to participate in future health research studies. The question remains what personal stake men had for involving themselves in a research project, beyond their beliefs that their engagement would have positive impact on their communities.

At the beginning of this chapter it was proposed that the data from this survey analysis will contextualise as well as aid our investigation of the factors that contributed to the engagement of young men in Kwa-Zulu Natal in the *Impilo Yamadoda: Men's Health Study*. While the data presented here are not sufficient to fully explain these participants' motivations for engagement in health research, they do provide a foundation with which to outline this investigation. With the descriptive analysis from this dataset we have found that these

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 6: Survey data: descriptive analysis of *Impilo Yamadoda* participants

participants may be engaging in the *Impilo Yamadoda* study to have an opportunity to be involved in something that will be helpful to their communities. These data show that it may be important to focus specifically on community, rather than individual level benefits to research participation, and to investigate which of these might factor strongly in the decision to engage with research. The next chapter focuses on how the *Impilo Yamadoda* Research Partners encouraged the men in their local areas to participate in the survey and furthers our investigation of the factors contributing to the engagement of young men in Kwa-Zulu Natal in the *Impilo Yamadoda: Men's Health Study*.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 7: Research Partners: the process of implementing a strategic community engagement method

Chapter 7:

Research Partners: the process of implementing a strategic community engagement method

I. Introduction

This chapter focuses on the process of the strategic community engagement method to encourage participation in the *Impilo Yamadoda* study. Investigation of what happened during the *Impilo Yamadoda* survey implementation is central to the exploration of factors that contributed to the engagement of young men in Kwa-Zulu Natal in the *Impilo Yamadoda: Men's Health Study*.

II. Methods

It has been said that studying process can shape a qualitative analysis (227), and this is the case with the dataset presented below. This chapter will fully explicate the process of research implementation that led to the data collected and analysed in the survey chapter presented prior to this. This analysis will frame the next chapter, which focuses on Research Partners' experiences with implementing the *Impilo Yamadoda* survey explored in qualitative interviews with Research Partners. Together chapters 7 and 8 will build a more complete understanding of both the process and implications of working with lay community people to engage young Zulu speaking men in rural KwaZulu-Natal, South Africa in the *Impilo Yamadoda: Men's Health Study*.

Two elements of the *Impilo Yamadoda* study are explored in this chapter: 1. a detailed explanation of how Research Partner organisations and the volunteer Research Partners were identified and recruited into the *Impilo Yamadoda* study, and 2. response rates of the *Impilo Yamadoda* survey questionnaire and contact sheet.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 7: Research Partners: the process of implementing a strategic community engagement method

III. Identification and recruitment of potential Research Partner organisations

Potential partner organisations were identified using a variety of social science community identification methods. The initial core project team: one Community Liaison Officer, one research assistant, and the Project Leader (myself), worked with both internal *Africa Centre* departments and external organisations to locate potential research partner organisations. Oversight of this process was given by the Principle Investigator. Internal departments: the External Relations, Community Liaison, and Research Support Unit, all provided the project team with information that was used as a foundation for our identification process. *Africa Centre* resources also included various previous and on-going research programmes [e.g., Microbicides Development Programme (MDP 301); *Africa Centre* Youth Engagement Programme (YEP)], and the *Africa Centre* Community Advisory Board (CAB), all of which provided insight into potential organisations' suitability. External organisations consulted during this process chiefly comprised local South African government offices, such as the Mtubatuba and Hlabisa Municipality offices, and the local Department of Social Development. Formal and informal meetings and programme presentations by the *Impilo Yamadoda* research team to individuals within these stakeholder organisations led to identification of several organisations that were contacted for possible research partnership.

As the *Impilo Yamadoda* study protocol stipulated that the research study was primarily interested in the process of engaging men in biomedical research the protocol did not stipulate the necessity of a representative sample of partner organisations from within the geographic bounds of the study area (18, 154, 246, 248). However, the locations of potential partner organisations were mapped out by the research team and special effort was made to seek out organisations in under-represented areas within the sub-district. This was done primarily because inclusiveness in partnering organisations was theorised to foster good will towards the study within the targeted communities, and so was part of the strategic community involvement method developed for the study (196, 223).

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 7: Research Partners: the process of implementing a strategic community engagement method

The *Impilo Yamadoda* protocol delineated that the initial goal for the project was to identify local organisations and then assess willingness and capacity to partner with the research project. Of particular interest was to find if there were local organisations with the capacity to recruit volunteers who could administer a short health survey with their male colleagues and peers. Further, the identified organisations would be expected to host aspects of the experimental phase, including bio-specimen (blood) collection.

As large employer organisations have pre-existing infrastructure including occupational health offices, the principle investigator theorised that our research would intersect with large organisations' health-related needs and thus these employers would welcome partnership. This theory was informed by the knowledge that at the time of the start-up for the project (early 2009) several local employment organisations had recently approached *Africa Centre* seeking assistance in the form of HIV prevention education programming for their employees⁵.

Excluding *Africa Centre*, there are six major industry employers, [agriculture (n=3), energy (n=1), and mining (n=2)], in and around the Hlabisa health sub-district, four of which house workers within the study area. Additionally, there are two large provincial wildlife reserves, a World-Heritage Wetlands site, and dozens of small private game lodges, all of which employ a variety of skilled and semi-skilled staff within the study area and or the near-surrounds. All of these large organisations and many of the smaller employer organisations were identified at the outset as potential partner organisations.

With the understanding that smaller organisations have access and insight to the *Impilo Yamadoda* target population, we did not fail to seek these organisations out. The literature reviews in chapters 3 and 4 show that community based organisations have often factored in community development work because of their interest and involvement on the local level (196, 223).

⁵ Personal correspondence, Rhana Nackier, Head of Research Support Unit, and Mbongiseni Buthelezi, Head of External Relations, *Africa Centre for Health and Population Studies*, 2009.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 7: Research Partners: the process of implementing a strategic community engagement method

Potential partnering organisations were identified as eligible if they had a strong connection or constituency with young Zulu speaking men; however, Research Partner organisations did not have to be led by members of the target population (i.e., Zulu-speaking men aged 18-35) in order to be considered eligible. Implied within the project protocol was that Research Partners, who comprised volunteers from within the partnering organisations, should be as close to being members of the target population as possible. This followed as we were interested in an engagement process mirroring collaborative community development practice; as Goodenough states, the more activities that are engaged in collaboratively, the better a sense of ownership the participants have over the project they are working towards (206).

a. Contact with potential Research Partner organisations

After the initial identification process, the study team worked to establish contact with potential Research Partner organisations. The process used to contact these organisations was systematic in order to ensure that the research team employed every possible method of contact to include interested organisations. Contact with organisations was on going through a four-month period, with most Research Partner organisations identified by the end of the third month. The results of the attempts of the research team to maintain on-going contact with organisations were varied. However, there was no organisation contacted that explicitly refused to participate in the research project. Passive refusal was determined as failure to return or re-establish contact. If it was determined that the organisation was not interested there was a last attempt to contact, (via voice message, email, or letter), with the message that we would no longer attempt to contact their organisation but remained open to contact by them, should they decide to contact the research team for further information.

b. Capacity assessment of potential Research Partner organisations

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 7: Research Partners: the process of implementing a strategic community engagement method

After initial contact had been made to assure organisational interest in the research programme, capacity for partnership was assessed via questionnaire (Appendix 3.1). The capacity assessment questionnaire sought to record number, gender, and age composition of personnel. In addition, operating hours of the potential partner organisation was collected, as was their previous experience collaborating with other agencies and previous experience with research. The study research assistant spoke either in person or over the phone with a representative from each potential Research Partner organisation to administer this assessment and gauge their level of interest in partnering with the *Impilo Yamadoda* study. Most potential partners noted little or no organisational or personal experience working with researchers and had few personnel within the organisation.

Through our fieldwork we found that the dozens of small community based organisations (CBOs) within the study area were often managed and facilitated by a small number of highly motivated individuals, most of who have a fundamental interest in improving their communities. Despite their lack of research experience these organisations can be seen as having ideal members to partner with as they are already working to motivate their peers in the communities they live and work within. As a result, rather than using the assessment questionnaire results as an inclusion/exclusion tool these data were used to assess the baseline training requirements for the volunteer team. As a result the principle investigator and I decided to work with all previously contacted organisations that sent volunteers to the Research Partner training; this became the new inclusion criteria for partnership.

c. Research Partner training

All Research Partner organisations that were identified and assessed in the initial community engagement phase were asked to provide 2-4 volunteers as representatives to become Research Partners. The number of volunteers was determined by the size of the organisation; larger organisations were requested to have up to 4 representatives, smaller

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 7: Research Partners: the process of implementing a strategic community engagement method

organisations a maximum of two. The smallest CBOs had one representative each due to the fact that these individuals are, in many cases, the main catalysts of their organisations and/or there were no other eligible members to send. Volunteers were invited to *Africa Centre* for training; it was after this training that the Research Partner identification was complete and the study team knew for certain who the team of volunteers was.

Impilo Yamadoda is not the first research project to use lay community members to administer research. It must be recognised that while the topics of the training offered to our volunteers were considered best practice recommendations for training of lay community members in research administration and research literacy, the length of the training was not (224, 249, 250). While it was intended that I oversee the training programme and its adherence to best practice recommendations, I was unable to return to South Africa to oversee Research Partner training due to visa processing delays. The principle investigator then remodelled the Research Partner formal training programme to meet the project's budgetary and time constraints. As a result, formal *Impilo Yamadoda* Research Partner fieldwork training was a 6-hour training that included a basic overview of the purpose of the study, ethics of recruitment, confidentiality, and training survey instruments (questionnaire and contact sheet). In addition, as was requested by the participants, a basic HIV education component was added to the training. The training was delivered by the *Impilo Yamadoda* research assistant and community liaison officer. After the training programme all Research Partners completed an evaluation form. The form used was supplied by the *Africa Centre* community liaison office and has been used in trainings at *Africa Centre*.

While the formal training was limited, there were several opportunities to provide Research Partners with informal training throughout phase 2 survey implementation. Initial informal trainings were participatory sessions where the research team led discussions of project goals and Research Partners came forward with spontaneous suggestions to locate and recruit men to the research. In addition, each time the survey was administrated in collaboration with

the study team or completed survey instruments were returned, the project research assistant met with Research Partners to provide practical advice and correction.

The Research Partner training sessions were assessed by me through use of qualitative data collected through informal interviews with the *Impilo Yamadoda* study staff, completed training evaluation forms (Appendix 3.2), and formal Research Partner in-depth interviews (IDIs).

IV. Results of Research Partner organisation recruitment

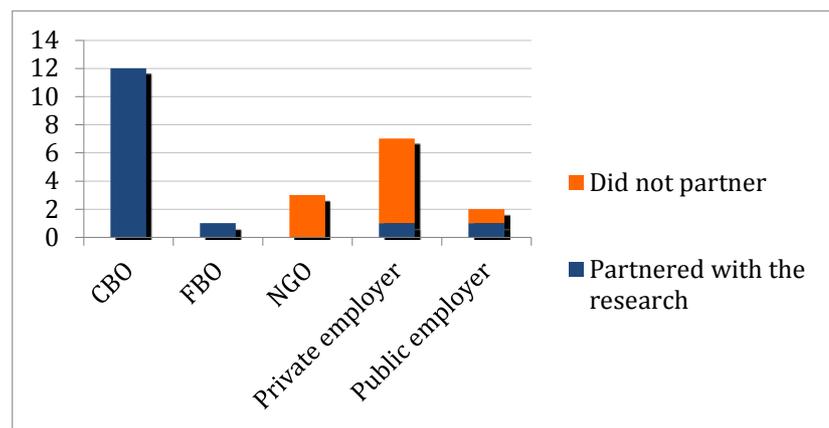


Figure 7.1: Partnership comparison, by types of organisations approached

As we have seen from the discussion in chapter 4, communities are made from dynamic networks of individuals and membership in a community is dependent on shared activity, or, the process of ‘doing’ (performing) culture at a specific point in time (104, 206, 211). The more often activities are shared, the deeper a sense of identity those participants will feel towards others in their group (206). From this premise it was clear that the organisations partnered with the research study must be integrated within local communities of men. More than 48% (n=12) of organisations identified as potential Research Partners were small CBOs: six private employers, two public sector employers, one faith based organisation (FBO), and three non-governmental organisations (NGO) were identified (Figure 7.1, page 133). In comparison, those organisations that showed willingness to participate, as assessed by sending representatives to

the training, were comprised of 80% CBOs (n=12). One FBO, one public sector employer, and one private sector employer were also included (Figure 7.1, page 133).

Slow start-up with larger organisations was mostly a result of strict hierarchy within the organisations and our own lack of familiarity with their processes of communication. Heads of organisations were typically difficult to reach yet essential to ensuring long-term success; heads of organisations acted as gatekeepers for the people who would be working with us directly on the project. Securing partnership with large organisations involved numerous meetings: a typical structural example was with the local branch of the South African Democratic Teacher's Union (SADTU) (see Figure 7.2, this page).

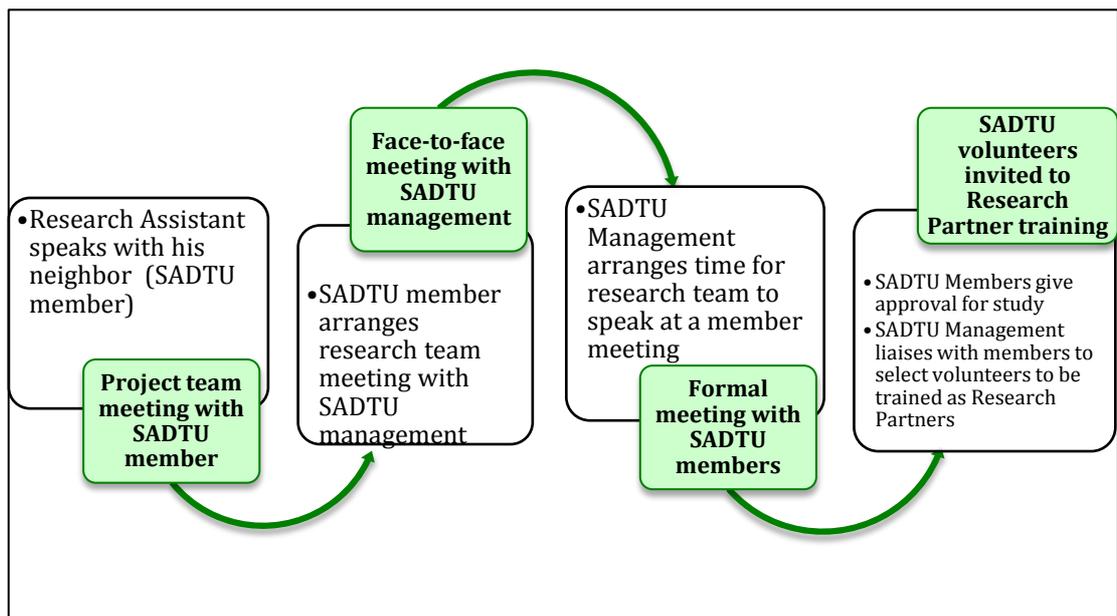


Figure 7.2: Example of Informal Contact method: South African Democratic Teacher's Union (SADTU) contact flow

In the case of SADTU (Figure 7.2, this page) informal contact was first made with a young man in the organisation who was interested in our project. This contact then worked to secure a meeting for the research team with the local executive branch of the organisation. After the research assistant presented to the executive branch and was given a favourable response we presented the project at another meeting to the members. Finally, the most interested members

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 7: Research Partners: the process of implementing a strategic community engagement method

in the executive branch worked to identify and contact men who were willing and able to work with the *Impilo Yamadoda* team. This process was very time consuming considering that each step took one week or more to complete; the SATDU contact process took 5 weeks. Added missteps such as necessary rescheduling or adverse events happening within the partner organisation (e.g., personnel or familial deaths, holidays, changes in organisation leadership) and time spent in recruitment can become even further extended.

Conversely, smaller organisations with fewer personnel, and thus less structure, were substantially easier to establish working partnerships with. With small organisations we often met with the leaders of the organisations directly. In nearly every case, these same men were willing and eligible to work with us as Research Partners themselves. Contact with these organisations was followed up via direct calls to the men who became our Research Partners.

V. Research Partner training outcomes

Men that were identified as volunteers by the Research Partner organisations were invited to participate in one of two identical Research Partner trainings. The methodology behind that training programme is described above (section III, c).

At the end of these training sessions, assessment forms designed by the *Africa Centre* training team were given to Research Partners (see Appendix 3.2) Analysis of these forms provides limited data: most Research Partners reported that they “greatly enjoyed” the training and the few that responded to the “suggested improvement” section asked for a longer training session. In addition to the probable acceptability bias of these reports, the training was conducted entirely in Zulu, yet the assessment forms were designed and completed in English. The limited English literacy of the Research Partners may undermine the reliability of the assessment forms.

Directly following the formal Research Partner training sessions, I returned to South Africa and the core research team contacted the volunteers to begin planning survey

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 7: Research Partners: the process of implementing a strategic community engagement method

implementation. In order to compensate for the majority of volunteers with no previous experience in research administration and limited formal training session, I planned in-service training and direct observation sessions of survey implementation. Research Partners were first instructed that they must come to the research team with their ideas for when, where, and how gatherings of men could be arranged for survey administration. Research Partners planned these survey administration events in collaboration with *Impilo Yamadoda* staff. As part of this collaboration, it was expected that the study grant would provide a small amount of resources if any were needed to assist the process. In turn, the Research Partners were expected to provide a community space and potential participants for these events. At this time there was no monetary payment planned for the Research Partner volunteers or their organisations.

It was required that all Research Partners be observed administering the survey before they would be given a packet of questionnaires and contact sheets to administer to men on their own. Acknowledging the limits of the formal training programme and relative inexperience of the Research Partners, the intent of this direct observation was to provide a slow start-up to increase the volunteers' capacity and competence with the work. The research team attended subsequent and larger survey events in order to assist with survey implementation on a case-by-case basis.

Initially the research team found it necessary to provide potential dates for all observed survey events. In a few cases, Research Partners told the team to come at "any time" to meet with men in their communities only to find poor turn-out on arrival; after probing the circumstances around the issue it was found that the volunteers had felt reticent to impose on the researchers' schedules. Despite this, in most cases Research Partners were able to successfully organise a small group of his constituents as potential participants. At these initial events Research Partners both participated and observed the research assistant as he informed the small gathering about the project, and administered the survey and contact sheet to those who were willing to participate. After all participants were attended to, the research assistant sat with the Research Partner and checked the survey and contact sheet forms he administered.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 7: Research Partners: the process of implementing a strategic community engagement method

During these quality control checks the research assistant initiated informal discussion about the event itself; how did the Research Partner feel about administering the survey? Recruiting the participants? Was there anything that he felt could be improved upon? These informal feedback sessions were primarily meant to increase Research Partners' self-efficacy in research administration. In addition, the research assistant and community liaison officer listened to Research Partners' setbacks and successes, as part of an iterative process to improve the quality and delivery of research training to the Research Partners.

Research Partners who participated in the observed survey administration exercise were considered 'active' while those who did not, 'inactive'. More than half of the trained Research Partners were active during the research collection (54.5%). In all cases Research Partners who were inactive were unable to meet the requirement of a directly observed survey implementation event. It is unclear if these volunteers would have found time to administer the survey at their leisure if this requirement was lifted; however, it was felt that the in-service training made possible via the observed survey event would improve data quality significantly enough to warrant this as an exclusion criteria.

When analysing the breakdown of active versus inactive Research Partners in survey administration (Figure 7.3 page 139), the only public sector employer Research Partner organisation was eliminated from the group. The private sector employer who sent four volunteers to the training was reduced by 50% as only two were active, while 3 of 4 volunteers the faith-based organisation (FBO) sent were active; nine of 12 volunteers based in community-based organisations (CBOs) were active in survey administration. It is highly likely that this self-selection process allowed the research to move forward with a volunteer team who were both willing and able to administer the survey, and so was a key factor in the success of the *Impilo Yamadoda* survey.

VI. Phase 2: survey administration process outcomes

Survey implementation was conducted between October 2009 and February 2010 with a two-month break in-between while changes were made to the survey instrument. During this break there was also a key staff change; the lead research assistant left the project and a new research assistant was recruited and trained.

Phase 2 survey implementation took twice as long as anticipated due to these delays; however, in actual days/returns, the results exceeded expectations. The *Impilo Yamadoda* protocol delineated an expected $n=300$ (≤ 6 weeks; 7/day) while $N=735$ (8.14 weeks; 12.9/day) were returned; 74% (543/735) of survey respondents agreed to leave contact information for inclusion in future research. There were several times where *Africa Centre* fieldwork staff and/or the research assistant were called in to assist the Research Partners with survey administration. Specific times when *Africa Centre* fieldwork staff were employed were times when there was a survey event where not enough Research Partners were able to come to the event to handle potential participant demand (e.g., a football match). The *Impilo Yamadoda* research assistant administered surveys alongside a Research Partner during the observed survey administration exercises. Research Partners collected the majority of survey questionnaires and contact sheets (Figure 7.3, page 139), and more importantly, were the only individuals responsible for bringing potential participants to survey events.

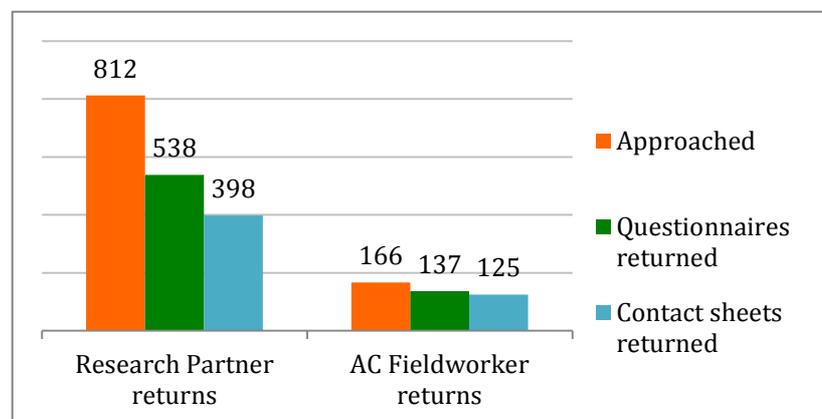


Figure 7.3: Comparison of recorded questionnaire ($N=709$) and contact sheet ($N=538$) returns by Research Partners and Africa Centre fieldwork staff

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 7: Research Partners: the process of implementing a strategic community engagement method

As can be seen in Figure 7.3 (this page), in comparison to Research Partners (RPs), *Africa Centre* fieldworker staff (FWs) had higher rates of acceptance to both the questionnaire (RPs: 66.3%; FWs: 82.5%) and the contact sheet (RPs: 74%; FWs 91.2%). It is unclear if these results are correlated with the higher level of training and experience the *Africa Centre* fieldworkers had, or if this indicates that community members have lower acceptance of peer-led health related research administration as compared to professionally trained fieldworkers. In order to uncover the effect of Research Partner training on *Impilo Yamadoda* survey acceptance, participation rates over time are juxtaposed with the amount of training Research Partners received.

During the survey administration process Research Partners returned completed survey materials to the research centre. While the Research Partners were at *Africa Centre* with their survey materials, the data was checked for consistency and the Research Partners were informally given further training. Those Research Partners whose participation rate logs indicated low levels of acceptance (below 70%) of the survey and or the contact sheet were asked about their contact methods and given advice by the project research assistant. Thus in examining survey acceptance in relation to Research Partner training, it could be expected that an increase in training over time would be correlated with an increase in participant survey acceptance. However, just as the data from training sessions are not valuable assessment tools, process outcome analyses from in-service training give unclear results. Participant acceptance of the questionnaire and contact sheet shows no clear trend over time. These results suggest that there was no correlation between participant acceptance of the survey and increased Research Partner training over time. As Research Partner administration training may not have influenced survey returns, further review of this process data may hold insight to influences on participant acceptance.

As has been discussed in the survey data chapter, geographic location may influence participant involvement. Therefore it is important to review the survey process data to see if there are correlations between geographic distribution of recruitment and participant acceptance.

When looking at the geographic distribution of phase 2 survey data collection, we can see that there are variations in acceptance rates among different geographic area types (Figure 7.4, this page).

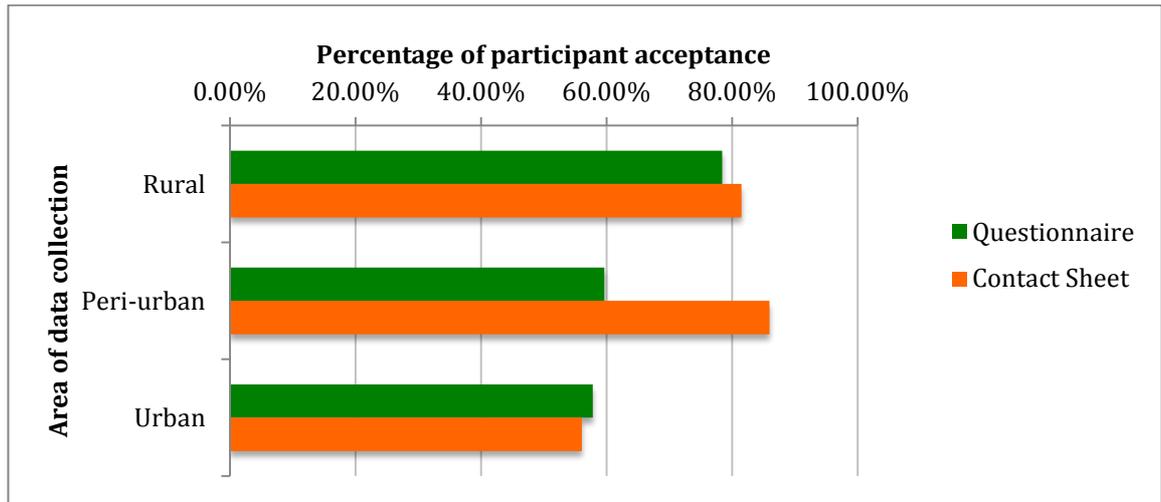


Figure 7.4: *Geographic distribution of survey acceptance rates overall using unadjusted participation rate log*

Looking at questionnaire acceptance rates, those working in the sparsely populated ‘rural’ areas had a higher overall acceptance rate (78.45; 335/427) than those in ‘peri-urban’ townships or the ‘urban’ town centre. This might be expected as a high percentage of rural areas covered in the survey implementation are outside of the *Africa Centre* Demographic Surveillance Area (DSA); men in the sub-district outside of the DSA have had little opportunity for inclusion in *Africa Centre* research activities and so might be more enthusiastic to become involved.

Another point to be made is the response rate in peri-urban areas: while participation rate to the questionnaire was lowest overall in peri-urban areas (54.90%; 185/337), those that did agree to participate were most likely to agree to complete the contact sheet (85.95%; 159/185). This may indicate different tactics for recruitment being used by survey administrators in peri-urban areas, or, it may suggest that differences in geographic areas within the male population of the sub-district may necessitate different recruitment techniques. This will be explored

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 7: Research Partners: the process of implementing a strategic community engagement method

further in the next chapter, which presents qualitative data from interviews with the Research Partners.

While most Research Partners decided to administer their allotted surveys alone, during work or personal time, there was one notable exception. One Research Partner, Njabulo, decided to organise a community football tournament in collaboration with the research team. This community survey event was originally planned as a one-day event with four teams and became a two-day event with 16 teams. This two-day event resulted in 17.4% of the total completed questionnaires and 19% of the total completed contact sheets during the survey period. Four Research Partners, five *Africa Centre* fieldworkers, and the project research assistant administered the survey to men observing and participating in the tournament.

VII. Conclusions

This chapter focused on the process of the strategic community engagement method to encourage participation in the *Impilo Yamadoda* study. In order to frame this process we began with an overview of how the Research Partner organisations were identified, as well as the training protocol for the individuals who became the *Impilo Yamadoda* Research Partner team.

The cyclical process described as part of the Research Partner organisation identification exercise helped to give as much variability as possible in partner organisation selection. Although this was not necessary as part of the *Impilo Yamadoda* protocol, it was important in order to remain in keeping with the theoretical underpinnings of this strategy: inclusiveness in identifying and approaching partnering organisations was thought to foster good will towards the study within the targeted communities. This was the first formal move towards the iterative creation of the strategic community engagement method utilised in the *Impilo Yamadoda* study.

All organisations that accepted the offer of partnership were invited to send representatives to a formal training meeting at the *Africa Centre* site. Many organisations that

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 7: Research Partners: the process of implementing a strategic community engagement method

accepted the offer of partnering with the *Impilo Yamadoda* study were small community-based organisations (48%). Those that were able to send representatives formally became Research Partner organisations. Most of these (80%) were CBOs, which was initially surprising given larger organisations' prior requests for training and other non-monetary resources from *Africa Centre*.

After an organisational assessment it became clear that most Research Partner organisations and their representatives had very little, if any, experience with research. No volunteer had previous experience of research implementation. To meet the needs of the Research Partners, and to improve the quality of research collected, it was decided that volunteers be directly observed administering the survey with participants prior to being given packets of surveys to implement on their own. The intent of this direct observation was to provide a slow start-up to increase the volunteers' capacity and competence with the work. This shared activity between the Research Partners and the core project team allowed the partnership between researchers and the volunteer team to have meaning, and as such was essential to the strategic community engagement method (206).

In order to better understand the survey uptake data from the phase 2 survey implementation were presented, including recorded returns of the survey questionnaire and contact sheets. While Research Partners were able to recruit large numbers of participants to the *Impilo Yamadoda* survey phase, in comparison to *Africa Centre* fieldworker staff (FWs), the FWs had higher rates of acceptance to both the questionnaire (RPs: 66.3%; FWs: 82.5%) and the contact sheet (RPs: 74%; FWs 91.2%). After analysing these data to uncover potential correlations between acceptance rates and training time and location, no clear correlation with either of these was found.

Despite the higher uptake of survey questionnaires and contact sheets by *Africa Centre* fieldworkers, it is clear that the strategic community engagement method used to involve men in the Hlabisa sub-district to the *Impilo Yamadoda* study encouraged the engagement of men in the

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 7: Research Partners: the process of implementing a strategic community engagement method

survey phase. The next chapter will present and discuss qualitative interviews with a sub-set of the Research Partner volunteer team in order to more fully explore the findings presented here.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 8: Research Partners part 2: qualitative data exploring the process of a strategic community engagement technique

Chapter 8:

Research Partners part 2: qualitative data exploring the process of a strategic community engagement technique

I. Introduction

The decisions the Research Partners made when implementing the *Impilo Yamadoda* survey form one set of data, and how they discuss their involvement form another. Further deepening these data are field notes: a classic ethnographic technique with the researcher as participant observer. While these data are useful to look at independently, when analysed together these data serve to create rich description of an event. The data presented in the previous chapter will help to contextualise the qualitative data presented in this chapter. While the interview data presented here serves more to describe the Research Partners and their organisations, rather than the participants, when looked at empirically participants and Research Partners share many of the same characteristics. This is neither accidental nor incidental: Research Partners were recruited based on their associations with the target community (i.e., Zulu-speaking men aged 18-35). This relates back directly to the theoretical premises described in chapters 3 and 4, and specifically to the theories of Goffman and Goodenough, where the emphasis is on performed behaviour and how it relates to identity, and behaviour change as an activity performed by communities (104, 206).

In chapter 7 we discussed how an essential aspect of the strategic community engagement method was working with small community based organisations which were connected to communities of young men in their communities. In addition, the shared activity of directly observed survey implementation strengthened the feeling of partnership between the *Impilo Yamadoda* research team and the Research Partners. These aspects of the strategic community engagement method are further examined for their importance in their contribution to the engagement of young men in Kwa-Zulu Natal in the *Impilo Yamadoda: Men's Health Study*.

II. Methods

Main themes	Sub themes
Perception of self in relation to others	Work, volunteering & Family life: how spend time
	Same/different than others
Research Literacy (Research Partners)	Perceptions of research
	Experiences with <i>Impilo Yamadoda</i> study
Research engagement (participants)	Barriers to recruitment
	Ideas of how to increase participation in research

Table 8.1: *Main and sub themes across Research Partner interviews*

A grounded theoretical framework shapes this analysis through an examination of the biographical, social, and practical experiences of the Research Partner team, as described in interviews and field notes. The theory used here is rooted in the specific definitions of culture and community discussed in Chapter 4.

Analysis of the qualitative interviews has formed the way this chapter is presented. Field notes from survey implementation events and data from in-depth interviews are compared with the empirical outcomes described in the previous chapter and Research Partners' own reflection of events.

Data from 6 in-depth interviews with Research Partners were conducted. I took all field notes during directly observed survey implementation events and in-depth interviews. In-depth interview transcripts were treated first as individual case studies and then categorised and coded to interpret themes between cases. Field notes were matched to specific Research Partner interviews as a supplemental dataset. After individual interviews and field notes were analysed, transcripts and field notes were re-read and further coded to bring forward similarities and differences running through the entire dataset (see Table 8.1, this page, for list of themes found between cases).

In the main body of this text, Research Partners and whom they represent will be presented through qualitative data consisting of in-depth interviews and field notes collected

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 8: Research Partners part 2: qualitative data exploring the process of a strategic community engagement technique

during participant observation. The resulting qualitative analysis describes the Research Partners' motivations and experiences with the implementation of the *Impilo Yamadoda* project.

All pseudonyms are unique to the individuals they represent; i.e. the Research Partner "Njabulo" quoted here is referring to the same Research Partner "Njabulo" described in the previous chapter.

III. Descriptions of Research Partners

The importance of shared activity to a feeling of community is clear on the individual level when examining Research Partners' self-description of their daily activities. Knowing whom he shared his daily life with and what activities he partook in results in an understanding of the Research Partners' point of reference within his community. It is then of little surprise that data from in-depth interviews uncovered deep descriptions of self. Research Partners wove descriptions of themselves by aligning or opposing themselves to the men in the communities they were researching; personal identity was illustrated by placement of the self into the social sphere.

Many Research Partners who were interviewed choose to explain their own identity by explicitly describing themselves as different, or implicitly as superior, to other men in their communities.

What was striking in Simphiwe's interview was the passion with which he spoke about his role in educating his peers. Simphiwe's story of being orphaned at a young age and subsequently taking on the responsibilities of head of household seems to feed into his narrative of himself as caregiver to the larger community of his peers.

– Field notes, interview with Simphiwe

Research Partners such as Simphiwe, above, clearly delineated themselves as different from their peers, explaining this through a dialogue of not only doing more than others to help their communities, but also through descriptions of what they "do not" do. These men discussed not

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 8: Research Partners part 2: qualitative data exploring the process of a strategic community engagement technique

participating in what they describe as popular but destructive activities, and not understanding the actions and/or motivations that leads their peers to engage in problematic behaviours:

They are not really interested in things that concern their health, they prefer nightlife and going to taverns, I don't know what causes that.

– Simphiwe

You see there was a time when one of the [men I work with] said he wanted to visit me, and then I said, "Besides work, what else would we talk about if you visit me?" Because I know that I do not - I do not drink, I do not smoke...

- Mbongiseni

By placing the behaviours of smoking, drinking and going to taverns in the context of something they do not do, these Research Partners place their own behaviours implicitly as healthy and/or health promoting. Rather than looking at these statements simply as a dialogue of being out of place in the peer group, when looked at with the lens of this specific cultural context in this point in time, they become value-laden descriptions of the participants. In particular Mbongiseni's statement: "I do not drink, I do not smoke..." works to embed meaning into his deeper dialogue later in the interview, in his discussion of why he does not consider himself to have friends:

No, it's not that I feel no need to have a friend or it's just because I'm too busy. Let me say ... at work, you don't have to trust anybody, you see? ... So now, eh, you see sometimes people let you down... for many reasons that are not known to you.

– Mbongiseni

Failing to have a complex support network of extended family and friends is virtually unspoken, yet Mbongiseni is forthright about explaining his lack of friends during his interview.

[The research assistant] seemed shocked by Mbongiseni's declaration that he does not have friends. His inability to hide a reaction to this statement leads me to think that this is something a Zulu man would not normally admit to. At two separate points after this [statement] Mbongiseni again took up the topic of friends, discussing how many people consider him a friend, telling him their troubles, but again he emphasised that he does not share those same feelings for them.

- Field notes, interview with Mbongiseni

When examining his interview further, the emphasis Mbongiseni placed on his status as both married and a waged employee stands out. As explained in the previous chapter, having waged

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 8: Research Partners part 2: qualitative data exploring the process of a strategic community engagement technique

employment placed him in a different and implicitly higher social status than the majority of the survey participants. Describing his peer group as ‘less-than’ explains away his lack of a peer network: one cannot be a peer if one is not equal. Additionally, his self-description as a teetotaler combines with his reference to himself as a member of his church’s elite, both of which are valued cultural currency in this area. All of these combine to form his self-depiction, serve to countermand his lack of friends, and in total place him above other men of his age within his community’s hierarchy.

In contrast to those exemplified above, some Research Partners wove images of themselves as similar to their peers when discussing one topic, and then different in other instances. These interviews illustrate the fluidity of Research Partners’ views of themselves in relation to others, depending on the given social circumstances. These men are depicting their identities as part of a dynamic process within the communities they reside in. If personal identity is internalisation of a reflected social identity, then identity is necessarily fluid; social identity is conditioned on action and those actions are valued in the reflections of the individuals who witness or perform them, (or choose not to) (104, 206). Simphiwe illustrates this dynamic process in his description of his peers as “clueless” and inexplicable in some sections of the interview, while describing these same peers as capable of making rational decisions based on information in other sections.

I saw when I was still at school, the people who were and still are supported by their parents... the majority of them are excessive drinkers and don't like going to school. These people get everything they want, and yet they are wasting their lives on useless things. ... Just looking at what happens, they are clueless about a lot of things.

...

I think if you told them beforehand, how the research will benefit them and their communities, and that it will be passed to the government to help them, then they will be more willing to take part in research programmes.

- Simphiwe

Community members are thus able to take on a multi-dimensional role, much the same as Njabulo describes himself below as both ‘involved/different’ and ‘uninvolved/the same’ at

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 8: Research Partners part 2: qualitative data exploring the process of a strategic community engagement technique

different times with the same social group. In the first excerpt (below), Njabulo describes himself as much the same as his peers:

...because I'm unemployed, I just sit around with the other guys from my neighbourhood, my friends. We just sit around doing nothing much, those are the people that I spend most of my time with.

- Njabulo

In this instance “doing nothing much” is a shared activity. Yet, when pressed to describe his daily activities, we find that Njabulo volunteers in several organisations within his community. He describes multiple attempts to start youth projects, specifically to curb their temptations to turn to crime amidst an atmosphere of boredom and apathy. Njabulo is a local football coach, and while he did not generate the highest approval rating for the survey implementation itself, he did manage to organize a football tournament that generated the most questionnaires and contact sheets of any Research Partner during this phase. In his in-depth interview he describes how he was able to organise this event as well as to have 81% of the men he asked complete the questionnaire and 67% of men asked complete the contact sheet:

...maybe that's why most of the people found it easy to fill in these forms with me, because I'm usually involved with some community project.

- Njabulo

Comparing his reported level of activity with that of the survey participants described in chapter 6, it is clear that he is not the same as many of the men in his community: Njabulo's membership in multiple community groups focused on community development activities sets him apart. Field notes from the football tournament corroborate the disjuncture between his actual activities and his self-description:

Njabulo seems both active and aloof... while he doesn't seem to have a designated job in his role of tournament organiser and coach [his team is not playing], he chooses to mingle with the coaches rather than the Impilo Yamadoda study team, which other Research Partners are doing.

...

Others have chosen to work in teams while Njabulo seems to focus more on the event and the community members as friends rather than as potential survey participants. ... Njabulo disappeared during the closing remarks, even after I had asked him to stand up to acknowledge his role as organiser.

- Field notes at football tournament

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 8: Research Partners part 2: qualitative data exploring the process of a strategic community engagement technique

Regardless of the incongruence between described self-identity and observed social identity, like the rest of the Research Partners, Njabulo's influence within his community is undoubted. The football tournament would not have been a success without Njabulo's knowledge of the men in the community he lives and works in. As Njabulo says, his involvement in community activities itself generates trust in him.

All Research Partners that were interviewed either explicitly or implicitly emphasised their influence in their communities. Several Research Partners highlighted their influence through a dialogue of the importance of being 'known' and trusted in the community to facilitate participant acceptance to the research:

I think what helped, in most cases, to get people to take part in the research, was that they knew us as part of the community ... which made it easier for me to talk to some people, you see?

- Simphiwe

Yes, I saw that I was skilled enough to go out, and also I am used to dealing with and mobilising the youth. So that is why I didn't have any difficulties.

- Sipho

In addition, Research Partners discussed that their role in their organisations facilitated this trust and gave opportunity to recruit men to the survey.

... my bag was always with me because I used to go survey with it at work. So after work my bag also goes with me so... there and there I get the men.

- Richman

Ya, sometimes some of them they go to my office to visit some of the – to ask something, and then we ask about the survey... They go straight to me to ask something, and then in that time I use the chance to ask [if they will participate in the] Impilo Yamadoda survey.

- Armstrong

In these interviews, 'work' is mostly described through descriptions of the survey process as well as through the duties they perform for their organisation, while 'trust' is described as earned through previous work on community development projects.

First of all... if you are working with the community, or you are working with somebody, first they are going to trust you. If they trust you, it is so easy [for them]

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 8: Research Partners part 2: qualitative data exploring the process of a strategic community engagement technique

to do something for you. If they never trust you... then nobody will be a part of what you are doing.

- Armstrong

In the above quote, the concept of shared activity denoting membership in community is deepened to include a sense of trust. According to Goodenough, work in groups creates the sense of trust and shared values that community affiliation is based upon: “By working in groups, even on tasks that require no cooperation, they reinforce in one another the values they individually associate with their work” (206). Conversely, an unknown person is not to be trusted, as his/her motivations cannot be predicted:

I'm just a guy who enjoys talking with different people, because you never know if you'll need help from a person. In Zulu they say unyawo alunankumbulo, which means you can meet up with a person anywhere your feet take you. Since we are men we travel a lot and you never know one day I might end up being your brother in law... and I know that I won't have any problems because we have already met.

- Njabulo

Trust is inherently earned through observable practice; the level of trust achieved in the community does not seem to be contingent on whether the man himself feels different or similar to his peers but rather his actions towards others. These individuals have high potential for influencing social change through their trusted status in their communities, which, in this case translated to creating positive impressions of research within their communities.

If community change comes about partially via individuals with high levels of trust and knowledge of their communities, then the success generated by the Research Partners in survey administration, in retrospect, is expected. However, as we discussed earlier, (chapter 4) trust in individuals alone is not sufficient to create social change (196, 206). We have learned from collaborative community development work that successful collaboration between supporting partners and key community members is necessary to create a dynamic of change within a community (196, 198, 199, 206). In the role of the supporting partner, the research team was tasked with creating a platform for the needs of both the research team and the Research Partner volunteers' needs to be heard and addressed. The way this was done during the *Impilo*

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 8: Research Partners part 2: qualitative data exploring the process of a strategic community engagement technique

Yamadoda project was first through a formalised Research Partner training session, as discussed in the previous chapter.

The lack of experience on the part of Research Partner organisations, particularly small CBOs, was reflected in in-depth interviews; only one Research Partner interviewed discussed previous involvement with an “*Africa Centre* project”. This Research Partner reflected positively on his prior experience and cited it as a reason for his involvement with the *Impilo Yamadoda* study:

Impilo Yamadoda was not the first project which Africa Centre wanted to engage the community in ... Africa Centre ran a project similar to Impilo Yamadoda ...that project concentrated on men who played soccer, you see. ... It taught us about life, and how we should behave ourselves as soccer players, [and taught us about] alcohol, and also about health. So when Impilo Yamadoda started I realised that this project was similar to the previous one I had done, and so I was interested in continuing being a part of it.

– Njabulo

However, the project that is mentioned above was not actually a research project but a project that *Africa Centre* has run as part of the institutions’ core community engagement programming.

As can be shown from the example above, Research Partners held varied understandings of research. The dual aims of the *Impilo Yamadoda* study: to learn more about men’s interest and motivations for engaging in research as well as young men’s health interests, were discussed with both Research Partners and potential participants. However, the difference between research and direct service provision was particularly difficult for Research Partners to distinguish. Research Partners were told during training sessions, and in printed materials, that the main aim of the study was to inform researchers about what aspect of health research encouraged young men to become involved in health research. Yet this was clearly translated by Research Partners to be an interest in how to improve the health of men in the community; the line between interest in improving research practice and interest in improving service provision was blurred.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 8: Research Partners part 2: qualitative data exploring the process of a strategic community engagement technique

Although the *Impilo Yamadoda* study was a research project with the aim of improving participant engagement with research, this study shares important similarities with participatory research in that a central goal is to understand a practice in order to improve upon it (182, 221, 224). This is underlined by the knowledge that Research Partners, in their role as research administrators, share the belief that their involvement with the project improves the health of their communities. Thus the line between research and service provision is blurred. While seen as disparate during topic guide construction, the theme of research literacy was informed by a discussion of the expectations Research Partners had of outcomes of the *Impilo Yamadoda* study. Few Research Partners could clearly articulate the process of how research would help to improve their communities yet all expressed a certainty that it would do so.

...I think this research is very helpful to people, especially the men, since it teaches them about life and how they must live it positively.

- Richman

Ok, from working with Impilo Yamadoda and seeing what the project is about I've discovered that the main reason behind it is to help men, you see? ...they are the ones who infect women with HIV. ... We at the [CBO] are left with their kids, which we need to help. The research on the other hand is able to help educate this man, and if he is informed about his health and HIV he will also protect his wife, and this will, in the long run, prevent having children left without parents. Those orphans will now be [the CBO's] responsibility.

- Simphiwe

This concept was further developed through questioning what methods Research Partners suggested could be used to increase the engagement of potential male participants to the study:

I think if you told them beforehand how the research will benefit them and their communities, that it will be passed to the government to help them, then they will be more willing to take part in the research programmes.

- Simphiwe

The definitions of research above have imbedded deeper meanings of the purpose of research, and this purpose is directly linked to a definition of service provision.

This relationship can be seen as complex when exploring data from the IDIs; Research Partners who were situated within the *Africa Centre* Demographic Surveillance Area

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 8: Research Partners part 2: qualitative data exploring the process of a strategic community engagement technique

(DSA) reported potential participants' reluctance to take part in an *Africa Centre* research project as a result of their previous experiences with the DSS research:

...they didn't like to take part because, I don't know. They don't like doing the research from Africa Centre. ... Um, they say they ask – eh, they don't ask good questions. ... they are not talking about [Impilo Yamadoda] questions, they are talking about the [DSS] research... ya.

- Richman

They just see that you come from Africa Centre and don't want to talk to you. ... I don't think that many of them refused to give their contact details because it was asked by Impilo Yamadoda, because they have no issue with this research.

- Simphwe

In contrast, as seen in the quote from the Research Partner below, potential participants outside the DSA were reported to view the *Africa Centre* favourably:

Research Assistant: *With people knowing that the research was done by Africa Centre... how do people in your community feel about Africa Centre?*

Research Partner: *They don't have a problem with Africa Centre because they have mobile houses [HIV testing and ART clinics] in the area...*

- Njabulo

The service provision referred to in the above interview excerpt is a joint partnership between the KwaZulu-Natal Department of Health and the *Africa Centre*, called the Hlabisa HIV Treatment and Care Programme. This programme was established in 2004 to aid the South African government initiative in rapidly rolling out ART drugs to eligible individuals. The Hlabisa HIV Treatment and Care Programme is comprehensive throughout the sub-district and so eligible members include people *Impilo Yamadoda* participants know in their communities, and may directly include a portion of our participant base. Because of the very high HIV prevalence in this area, even those that are not infected are affected by HIV; after years of government-led denialism keeping ART treatment from those that needed it [e.g., (49, 52, 53)], the ART programme in the Hlabisa sub-district has reason to be well received. That Research Partners outside of the *Africa Centre* DSA mention this service provision while those within it do not may be due to pure chance, however it is worthy of note that the dialogues chosen by these Research Partners are thus dichotomised.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 8: Research Partners part 2: qualitative data exploring the process of a strategic community engagement technique

No matter what the location of the Research Partner, or the stated barrier they faced, all discussed strategies of how they were able to overcome these barriers, as is seen in the quotes below:

Eh, when they don't want to fill the forms I said, "So you don't want to be a part of this thing" [but] others came and said, "Let's do this." And then if they feel they want to fill the form, they came to me and said, "Hey now I have changed my mind and we want to fill in that thing you were talking about the other day." So they came and said, "Ok", then I say, "Ok let's do it." Even now others are asking, even now...

- Sipho

Yes I do think that there is something I could say to them [to encourage them to take part in research]. ... Just to encourage them to engage themselves in research projects because it involves their lives you see... because I think this research is very helpful to people, especially the men, since it teaches them about life and how they must live it positively.

- Njabulo

... I told them a little, eh, this is the first eh, project that set to talk about men's health. Then [some men] changed their minds and said 'Yes, we will give you a chance, just explain.' And then I explained it to them.

- Richman

The majority of active Research Partners chose to administer research at their leisure, without planning events in collaboration with *Impilo Yamadoda* staff. In-Depth Interviews and informal conversations with Research Partners reveal that many volunteers decided to administer the survey either house-to-house or in the workplace. Several Research Partners implemented the survey in different geographical area types. One Research Partner reported to us that he had spread the word about the survey during the implementation period to the extent where men were coming to his home in order to participate in the research. During his IDI this Research Partner described his survey administration technique:

...I believe if you want to trace or you want to [find] something, you go from house to house... and then if you go house to house you will find out something. ...first I started with the youth, so I [went] to the sports field and then I got the people. And then I went to the church – so then I go to church when my organisation – because I do two things, I will go for Impilo Yamadoda and sometimes I am working with my organisation. When I go to do my duty for my organisation, I will carry the questionnaire of Impilo Yamadoda.

- Armstrong

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 8: Research Partners part 2: qualitative data exploring the process of a strategic community engagement technique

In the above quote we can see that Armstrong used both his personal and organisational connections to recruit potential survey participants. It is with these supports that Armstrong became one of the Research Partners with the highest rates of acceptance to both the questionnaire (adjusted rate: 100%; 37/37) and contact sheet (adjusted rate: 97.30%; 36/37). Research Partner organisational support allowed Research Partners like Armstrong the time and occasionally the physical space, to administer research.

IV. Research Partner motivations to participate

Where the line between research and service provision is blurred, so too is the role of the Research Partner as researcher and participant. As individuals in relation to their respective communities, Research Partners shared the dual role of researcher and participant within the *Impilo Yamadoda* project. They were researchers in the sense that they recruited and then administered a survey to their peers; they were participants inasmuch as they themselves were participating in a research experiment to test the efficacy of this engagement technique. While the Research Partners and the rest of the project team saw this duality, it is unlikely that the men and women within the communities targeted by the research held the same views. As administrators of the survey, Research Partners were seen as affiliated with *Africa Centre* as well as the community:

...so they end up saying, "Eyi you come with this Africa Centre of yours, hey don't do that to me because I don't want to be involved with Africa Centre."

- Siphho

As is beginning to be uncovered, the relationships and beliefs community members hold with *Africa Centre* were variable. Research Partners freely discussed the feelings of trust/mistrust and respect/derision that the institution evokes for potential participants. While it is not appropriate or feasible that the impact of the whole of *Africa Centre* research to the community is explored here, it should not go without mention. Social science studies have discussed the impact of repeated research on the communities being studied; research fatigue, or

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 8: Research Partners part 2: qualitative data exploring the process of a strategic community engagement technique

as the name implies, community members' rejection of research engagement after being repeatedly targeted for investigation, has been explored within vulnerable and minority populations (251).

As was discussed in chapter 3, during the first month of the *Impilo Yamadoda* project (February 2009), *Africa Centre* began a year-long reflective practice exercise to investigate community resistance to the HIV surveillance programme (181). This report discussed the difficulty fieldworkers had in explaining the difference between the HIV surveillance as a research programme and direct service provision. As Cousins notes, it is important to acknowledge that an element of the misunderstanding between service provision and research in this area is a linguistic one: the Zulu term *ucwaningo* can be used for both research and service provision (181). However, while this is important to note, because Zulu is an essentially contextual language if the speaker takes care, specific meanings can be conveyed.

With receipt of HIV testing results being seen as an unacceptable benefit to participants of the *Africa Centre* HIV surveillance research (as discussed in chapter 3), fieldworkers struggled to find acceptable ways to engage participants. Benefits to the *Africa Centre* HIV surveillance research are largely on the population level and concern influence of strategic planning and implementation of health services in the area. However, population-level benefits may be a difficult concept to convey as a benefit received by individuals who are asked to participate in research. Research Partners reported their observations of dissatisfaction with "Africa Centre research;" community members felt that they should receive specific and individual benefits from research participation. In the quote below Simphiwe explains that *Africa Centre* surveillance research participants see the questions asked as a direct and concrete way to improve their circumstances:

So if people from Africa Centre ask some people what they use to cook their food, they immediately assume that they will be provided with electrical stoves, [but instead] Africa Centre staff will return and ask the same questions.

- Simphiwe

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 8: Research Partners part 2: qualitative data exploring the process of a strategic community engagement technique

Akin to these findings, Cousins' report states that *Africa Centre* fieldworkers were voicing community members' feelings of "not getting anything" as a result of their participation in research (181). As a result, fieldworkers felt the need to couch an agreement to participate in research with an improved health outcome on the part of the participant (181).

A complex relationship forms when the decision to participate in research comes from the implicit benefit of service provision. Participant's expectations may have been unrealistic for the research institute to meet; certainly expectations of health service provision, and to a lesser part, comprehensive health education, are unrealistic for a small-scale research project such as *Impilo Yamadoda*. As was discussed above in relation to *Africa Centre* HIV surveillance research, the primary goal of much health research is for long-term benefit to the communities where research takes place, yet the form these benefits take is often intangible and difficult to convey to potential participants. Both *Africa Centre* fieldworkers and Research Partner volunteers conveyed messages stressing the importance of participation in research and the implicit message that this participation would result in improved health outcomes for both individuals and the community:

Ya, I think there is something I told them that help them to agree [to participate]. Like when they – they disagree, I sit down with them and say, "Hey guys in these days people are dying. So what you have to do is to, is to check, you know, know your [HIV] status." And when they are – when he thinks about that, he ends up agreeing.

- Siphso

What comes to mind for investigators when the term 'benefits of engagement' is used is not the same as what is meant by the Research Partners of the *Impilo Yamadoda* study (nor to the larger DSA population, as can be extrapolated from Cousins' report). Research Partners discuss appropriate potential benefits exclusively in non-cash forms: electrical appliances, transport expenses, health services, and health information are all directly discussed as expected benefits to engagement with research. Research Partners' own motivations, directly shaped by *Impilo Yamadoda* study staffs' explanations of how they would benefit, (chiefly in the form of organisational assistance), were also discussed.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 8: Research Partners part 2: qualitative data exploring the process of a strategic community engagement technique

While the research project did eventually give small payments to the Research Partners who administrated the surveys, none were told at the beginning of this exercise that they would receive any monetary benefit. All Research Partners were told they would receive reimbursement in cash for transport expenses if there was need to travel for project related duties. Those that could not outlay their own funds were given the option of having an *Impilo Yamadoda* research associate come to them. Benefits of their engagement were stated at the outset of the project as being principally non-monetary in nature; an on-going dialogue regarding what form of assistance the project could give to the partner organisation would continue throughout the partnership. None of the volunteers or partner organisations asked for remuneration in any tangible way; the most concrete form of exchange asked for by one organisation was to provide plastic sheet protectors for key organisational documents. Because of this it was decided by the principle investigator and me that it was unethical to give nothing back to the Research Partners and their organisations. Therefore, at the end of the survey implementation period Research Partners were reimbursed for their time based on the amount of time they contributed in the survey implementation period. Matching funds were given to the Research Partner's organisation.

After Research Partners and their organisations were given cash reimbursement for their time, the benefit from participation that was most discussed by Research Partners during in-depth interviews was to pass along health education to their peers and others in their communities. The promise of getting assistance: with HIV testing, with material items, or simply with a more detailed knowledge of positive health practice, was noted by Research Partners as instrumental in not only obtaining potential participant acceptance but also to their own motivations for participation. During the topic of personal motivations for volunteering for the research project, knowledge and education gained often came to the fore, as is highlighted in the quotes below.

I decided to work with Africa Centre on Impilo Yamadoda because, as I said, I love to work with the people here. It gives me the knowledge to – how to talk with the people, how to hold [knowledge] which is for the people.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 8: Research Partners part 2: qualitative data exploring the process of a strategic community engagement technique

- Sipho

That is probably one of the reasons I decided to take part in this research, so that men can also start changing and be able to get more information about HIV/AIDS.

- Simphiwe

Ya, I decided to come because what is interesting [for] myself is to see one day the HIV and AIDS needs to be conquered. That is what I want. If somebody says that we are trying prevention of the HIV/AIDS I can't not get in there. Because I am looking sometimes for a new generation without HIV/AIDS.

- Armstrong

Gaining knowledge and spreading education to others should not simply be seen as an aspect of altruism, or be dismissed as an ideal held solely by these individuals. In the specific context of this study, for these communities with very high HIV prevalence, knowledge, and particularly the ability to effectively convey that knowledge to others in the community, can be seen as a way to increase personal social standing, or social status. As social status can be a driver of change (206), for these men social status increases via empowerment from the receipt and subsequent dissemination of knowledge. The Research Partners are trusted and respected men in their communities and, as they self-report, this is based at least partially on their work in community development activities. The social standing of Research Partners in their communities was effectively shown in their ability to influence potential participants to engage in the research project. Affiliation with *Africa Centre* furthers this social standing by giving Research Partners direct access to a source of reliable knowledge to impart to the community. In this way Research Partners see their participation as a way to gain access to an important benefit of research engagement: the knowledge that community members need in order to live healthier lives. This knowledge, along with the proven role of these volunteers as community educators and change agents, served to enhance the Research Partners' social statuses within their communities. In a social setting where attaining status through normative methods, e.g. attaining waged employment and marriage, is increasingly difficult (120, 124), gaining access to alternate methods of social mobility is an attractive benefit of engagement among these participants. Additionally, performing actions for the improvement of others is a culturally acceptable method to increase individual social status in traditional Zulu society. These combine

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 8: Research Partners part 2: qualitative data exploring the process of a strategic community engagement technique

to form an appropriate incentive for young Zulu speaking men to participate as active partners in health research programmes such as *Impilo Yamadoda*.

V. Conclusions

While it is clear that the strategic community engagement method used to involve men in the Hlabisa sub-district to the *Impilo Yamadoda* study was successful in that the target number of men participated in all phases of the study (as seen in the previous chapter), the reasons behind that success are less easily delineated. To analyse the context in which these men volunteered to participate came about, several layers of complexity must be defined. What explicit and implicit expectations participants had for engaging with this health research study must be investigated in relation to the specific context of the target population.

When the philosophy behind a research protocol of community engagement is explicitly focused on practical partnership this informs both the direction of research and the process that will bring it about. In the *Impilo Yamadoda* study, the research protocol was designed long before the key players in its implementation were known. However, the above investigation shows that the flexibility of this design allowed for a process that gave Research Partners an opportunity to provide essential input into project implementation, such as might be used in participatory research models, (i.e., PAR, and participatory research as defined in theoretical chapter 4), without changing the fixed research protocol. This is an important finding in our investigation of if participatory research methods can be used to encourage men's participation in biomedical health research in the global south. The strategic community engagement method may therefore provide a needed middle ground between the flexible participatory research design, and the ad-hoc participant engagement methods that are often used for fixed design research. This potential benefit will continue to be discussed throughout the remaining chapters of this thesis.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 8: Research Partners part 2: qualitative data exploring the process of a strategic community engagement technique

In this chapter we have found that the dialogue between the research team and the Research Partners worked to promote the study with participants and facilitate the data collection process within the research project. The sense of ownership of the research on the part of the target community also correlated with practical implementation of the survey project by the Research Partner team.

Once identified, potential Research Partner organisations, and then individuals within those organisations, largely self-selected into the research study. The simple inclusion criteria in this study relied heavily on self-selection for organisations and individuals within them. It was made explicit from the outset that Research Partner organisations would need to support their volunteer administrators by giving them time, and in some cases, space to administer the research. Volunteers themselves were selected by the organisations; however, the process of attending first training and then in-service training reduced the number of men who would eventually implement the survey. In this way a very specific group of men were brought forward, men who were shown to have the support of their host organisations, the motivation, and time, to implement the survey. It is likely that the process of identifying the Research Partner organisations, which in turn identified individual volunteers, was a key factor in the success of the strategic community engagement method.

In addition, data indicate that individual Research Partners, either personally or as proxy representatives of their organisations, held high enough status and trust within their communities to effectively convey good will towards *Impilo Yamadoda* research. Analysis of process outcomes and IDIs show that it is likely that the location of implementation and level of training were less important to potential participants' decision to engage with the survey than who the men implementing the survey were. Interestingly, Research Partners who met with potential participants' feelings of negativity towards the host institution were able to overcome this obstacle by focusing on their own trusted status and relationships with members of the target community.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 8: Research Partners part 2: qualitative data exploring the process of a strategic community engagement technique

The individual motivations Research Partners held for engaging in the *Impilo Yamadoda* study are then examined. While trusted and respected in their communities, by comparing descriptions of their daily lives with the demographic data gathered from survey participants, we see that the Research Partners are also part of this group of largely disenfranchised men. Research Partner motivations for increasing their social standing in their communities through improving the health knowledge of their peers can easily be seen as a mutually beneficial relationship. Analysis of individual interviews with Research Partners, along with a contextual understanding of the cultural mores of this society, provides insight into this dynamic process. In a community where mutual reciprocity is implicit, engaging in ‘something for nothing’ is unacceptable. This investigation shows that creating a research environment where reciprocity is integral involves implementing a flexible design allowing for continual dialogue with the target communities. Through this direct community member engagement with the research process, the trust necessary to gain access to the participant base is achieved.

Chapter 9:

Participant recruitment to the *Impilo Yamadoda* experimental phase

I. Introduction

This chapter explores implementation of the strategic community engagement technique as it was applied to engage young Zulu-speaking men in the biomedical HIV prevention intervention phase of the *Impilo Yamadoda* study. Outcomes from the implementation of phase 4 recruitment are derived from participant recruitment logs, participant observation, and attrition logs from the intervention and randomisation events.

The analysis presented here will assist our understanding of the acceptability of the participant recruitment practices of the experimental phase of the *Impilo Yamadoda* study. As this phase of the study is modelled after a RCT research design, the analysis presented in this chapter will continue in our investigation of our second research question: “Can participatory research methods be used to encourage men’s participation in biomedical health research in the global south?”

In addition, these data will be used to contextualise the participants’ self-reported motivations to participate in *Impilo Yamadoda* presented in the next chapter and thus will enable us to further understand the factors that contributed to the engagement of young men in Kwa-Zulu Natal in the *Impilo Yamadoda: Men’s Health Study*.

II. Outcomes from the phase 4 experiment recruitment and enrolment

In the phase 4 experiment of the *Impilo Yamadoda* study it was expected that approximately 300 ≥ 18 to ≤ 35 Zulu-speaking men would need to enrol at baseline to reach the recruitment goal of N=200. This figure assumed an approximate 30% attrition rate between baseline and enrolment completion for a total of N=200 participants. Recruitment to phase 4 baseline was scheduled to take place 30 July – 30 September 2010, inclusive.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 9: Participant recruitment to the *Impilo Yamadoda* experimental phase

As was discussed in the methodological chapter, a main source of recruitment for the phase 4 experiment was via participants electing to leave contact information during the phase 2 survey. These potential participants were only contacted if they were age-eligible to enrol in the experiment, therefore the same criteria for eligibility in the phase 3 qualitative component were used: all Zulu-speaking male contact sheet respondents ≥ 18 to ≤ 35 who had valid telephone contact information were informed of phase 4 community enrolment events. These eligible potential participants were called by the lead research assistant to be informed about the start of the experiment and were given information on how to enrol.

Research Partners who elected to continue their involvement with the study were also asked to help advertise the start of the experiment. These Research Partners were given basic information about the procedures and goals of the experiment, and enrolment eligibility requirements were emphasised. Research Partners then promoted the start of the experimental phase within their communities via word of mouth, in the ways that they best saw fit. Most Research Partners told us that they promoted the experimental phase either informally, i.e. when they saw a peer or potential eligible participant that they knew in passing, or formally, i.e. in announcement at church service or at their organisations' meeting. In addition, posters and flyers were distributed to Research Partners for them to post in shops and community organisations. These promotional materials detailed the dates, times, and locations of the events and included basic study information in Zulu (see English versions, Appendices 5.1 and 5.2). We expected that the Research Partners' communications to potential participants by word of mouth together with the printed information they were given would assist in pre-screening potential participants for the enrolment events.

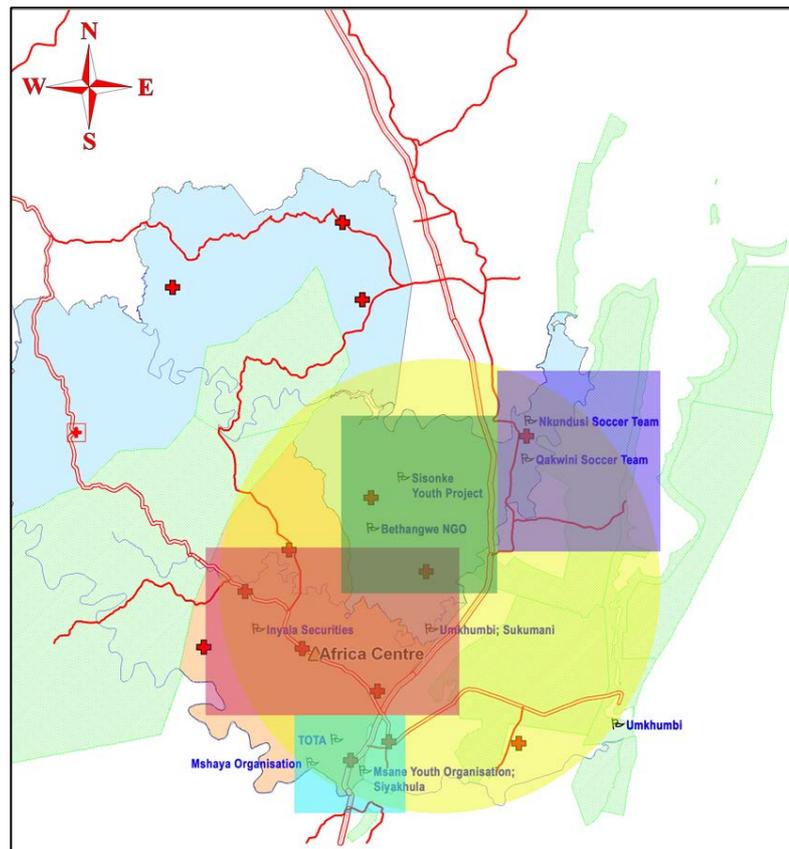


Figure 9.1: Five targeted community enrolment locations (phase 4)

In selecting locations for community enrolment events, five areas were identified that men throughout the sub-district would have access to. Anticipating the possibility that our target number of enrolled participants in this phase ($N=200$) was well below the number of eligible men leaving contact information in phase 2 ($n=430$), and that our target might well be reached before all recruitment events took place, it was necessary to prescribe the order that enrolment events were held. Potential community locations and dates of enrolment events were identified using phase 2 survey participation logs. Community locations were grouped geographically to encompass all phase 2 survey administration locations; five geographic areas were identified as potential recruitment sites for the experiment (Figure 9.1, this page). Four of these locations encompassed survey recruitment sites while the fifth was to be held in town, a central location that the majority of the population had easy and regular access to (see yellow area in Figure 9.1, this page). Response rates to the phase 2 survey were seen as potential determinants of phase 4 enrolment interest; areas with higher survey response rate were prioritised to hold enrolment

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 9: Participant recruitment to the *Impilo Yamadoda* experimental phase

events first. The resulting potential enrolment event dates and locations were discussed and agreed upon by the research team prior to contacting Research Partners. These locations and dates were seen as parameters to provide Research Partners with guidance in planning the events: Research Partners planned all specific community locales and times of events and were given information to distribute in their communities advertising the start of the experiment.

Anticipating that participant referral would be key to recruitment of participants, a snowball referral system was set up. Participants who enrolled were given two tickets with a unique number that was linked to their participant ID. Participants could then give these tickets to peers, and if successfully enrolled, this referral would entitle him to an *Impilo Yamadoda* t-shirt. There was a maximum of one t-shirt per participant, so those who referred more than one person who enrolled would not receive any additional incentive. These t-shirts were thought to serve as both an incentive and advertising for the study, allowing links between each phase of the study to become more apparent through study name and logo recognition.

All potential participants, regardless of how they were referred to the study, were given information on the theory, design, and practice of the experimental study before baseline enrolment. It was fully explained to all potential participants that the consent they were considering giving was for their involvement in a study lasting a minimum of nine months, required answering sensitive sexual and health related questions, and provision of blood samples at baseline and multiple follow up points. Randomisation was also explained at this time. In these information sessions potential participants were told that they would be randomly assigned follow-up procedures: they would be allocated to either face-to-face or mobile phone interviews, and their blood would be collected either via micro-capillary in their community or venepuncture at clinic. All willing participants were quizzed on their understanding of the study requirements and ability to consent prior to their enrolment to the phase 4 experiment baseline procedures (see Appendix 5.7 for phase 4 experiment consent form).

While it was explained that participation would necessitate mobile phone use, potential participants were not explicitly told that they would receive a mobile phone during enrolment.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 9: Participant recruitment to the *Impilo Yamadoda* experimental phase

Nevertheless, at one of the enrolment events a potential participant asked if he would be given a phone to use for the research; he was told that all participants would be given a mobile phone to use throughout the study. It is likely that this led to more potential participants knowing that they would be receiving a mobile phone if they were to complete phase 4 enrolment.

Non-cash incentives in the form of local store vouchers were given to participants upon completion of each study procedure. The amount of reimbursement, approximately £8.00⁶ (R100.00), was in line with recommendations of the South African Medical Research Council (179), and ultimately calculated to be equivalent to transport expenses participants in the farthest communities in the study area would incur in a return trip to *Africa Centre*. As monetary reimbursement has been discussed elsewhere as integral in the decision making process for participation in research (252-254), monetary reimbursements given during this phase will be discussed in detail in section V below, which focuses on the role and definition of incentives during this phase of *Impilo Yamadoda* research.

While participants had the option to enrol at baseline in community venues, interestingly, 76% (178/234) of participants who enrolled did so at *Africa Centre*. The chart below (Figure 9.2, page 169) shows the actual number of participants enrolled per day over the recruitment period. The enrolment event referred to above, where the receipt of mobile phones for use in the study was elucidated, was held on 15 August 2010. In the below chart we can see that there is no difference in the pattern of enrolment after this date. The target number of participants was reached on 9 September 2010, which allowed recruitment to end two weeks ahead of schedule.

⁶ Currency exchange rates from <http://www.xe.com>, site accessed 16 December 2011

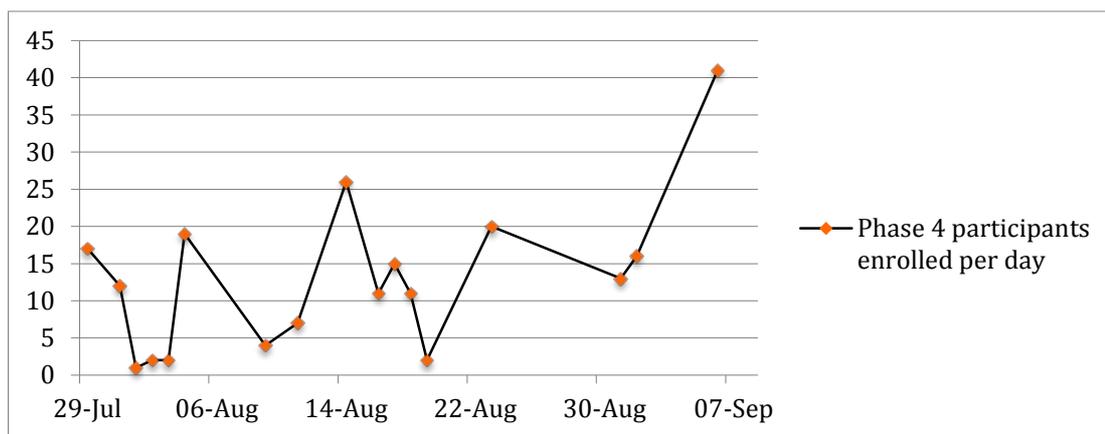


Figure 9.2: Daily participant enrolment in phase 4

It should be noted that the last day of recruitment is not shown on Figure 9.2 (this page). On 7th September 2010 sixty potential participants came to Africa Centre to enrol in the experiment. This number of potential participants was greater than anticipated and therefore not all eligible men could be enrolled that day. Men who could not be enrolled that day were pre-screened for eligibility and then given the option to return to *Africa Centre* to complete enrolment on either 8th or 9th September. As there was no further space for participants beyond those pre-screened on 7th September, and therefore new potential participants were turned away following this date, 7th September can be considered the last official day of recruitment to the *Impilo Yamadoda* experiment. All those who expressed interest in enrolment after this date were placed on a waiting list. There was no sign that recruitment would have slowed had there been capacity to enrol more participants.

Recruitment was held in two stages in order to correctly estimate the number of participants necessary to fulfil the enrolment target. Approximately 150 participants, or half of the anticipated N=300, were enrolled at baseline and then invited to attend the intervention and randomisation event to complete their enrolment. The first of two intervention and randomisation events was held at the end of the first month of enrolment. After this event a second group of participants was recruited in order to complete the experiment enrolment target.

The first recruitment stage, 30 July – 24 August inclusive, included three community events and 11 days of *Africa Centre* enrolment. A total of 149 participants completed a baseline questionnaire and gave a (micro-capillary) blood sample during this initial enrolment period.

All of these men were invited to the intervention event (‘Men’s Health Fair’) to complete enrolment. As was fully discussed in the methodology chapter of this thesis (chapter 5, section 6 c-e), during the Men’s Health Fair all participants were given information specific to men’s health concerns, randomised to one of four follow-up arms, and given a mobile phone for use throughout the study. Of those invited to the first health fair, 87.25% (130/149) attended.

Using the first health fair attendance rate as a predictive estimate for attendance to the second fair, we concluded that rather than the initially expected 30% attrition we could anticipate approximately 15% attrition. With this in mind, 85 new participants were enrolled. In addition, all participants enrolled at baseline that did not attend the first fair (n=19) were invited to the second health fair. As can be seen from the upward trend in Figure 9.2 (page 169) after 29 August, (the date of the first health fair), interest in the study accelerated. The 85 new participants recruited during the second period enrolled at *Africa Centre* during four recruitment days. In total, 104 participants were invited to the second health fair. Attrition continued to be low at the second health fair, with 89.42% (93/104) of participants attending. Figure 9.3 (this page) shows the number of participants at both Men’s Health Fairs as well as the overall number of participants who attended. In total, 95.3% (223/234) of participants enrolled at baseline attended one of the two health fairs and thus completed enrolment.

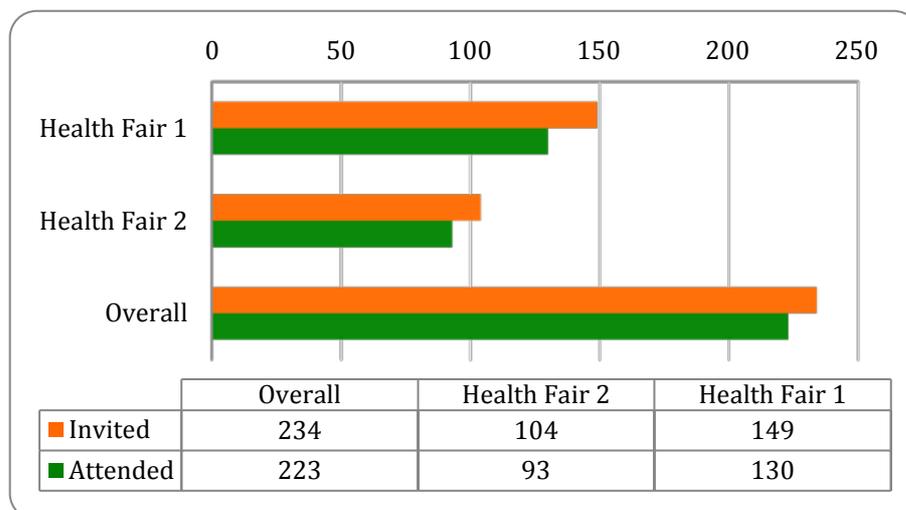


Figure 9.3: *Participation at Men’s Health Fairs*

As phase 4 was modelled after a randomised control trial (RCT) yet was not the same as a full-scale trial, it is important to be clear about what procedures potential participants were expected to adhere to. The flow chart shown in Figure 9.4, (this page) reviews the eligibility requirements and procedures that were required of potential participants in order to completely enrol in the *Impilo Yamadoda* phase 4 experiment.

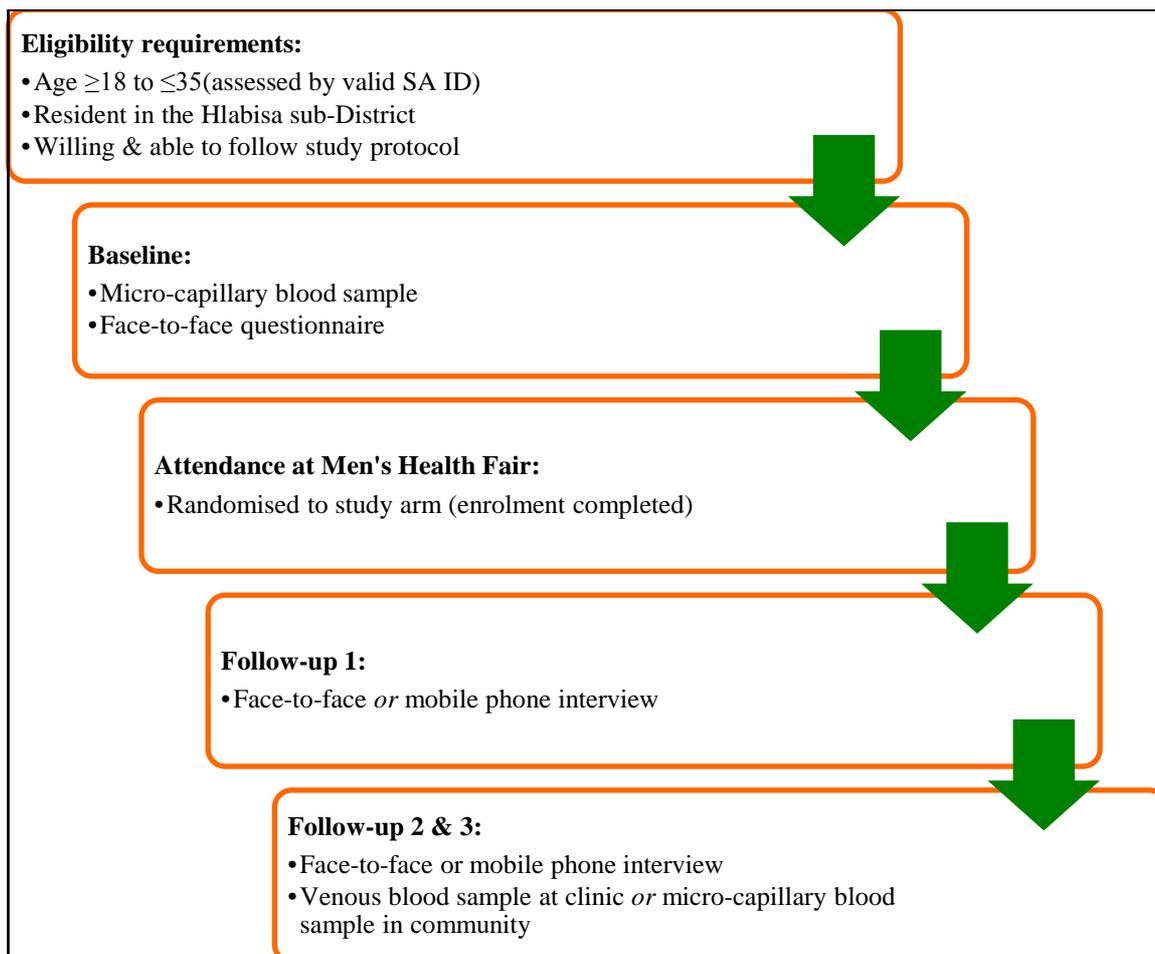


Figure 9.4: Phase 4 participant requirements

All baseline and all follow-up questionnaires contained sensitive sexual and health-related questions. The confidentiality of all participant materials, via use of individual participant ID numbers linking all a participants' materials, as per standard human subjects research procedure, was fully explained at information sessions during baseline enrolment. In addition to this verbal explanation, all phase 4 experiment procedures, including participant

rights and responsibilities, were given to participants in written form in Zulu at baseline enrolment (see Appendix 5.6 for the English version).

Procedures for the experimental study were standardised as much as possible in order to make transparent comparison with similar health research projects involving the collection of blood and behavioural data during multiple follow-ups (154, 155). Figure 9.5 (this page) details the (actual and anticipated) number of participants at the start of each stage of the phase 4 experiment. As this thesis is focused on the initial engagement of men into health research, while the number of participants eligible to participate in each follow-up are given, data for the retention of participants at the completion of the follow-up stages are not given.

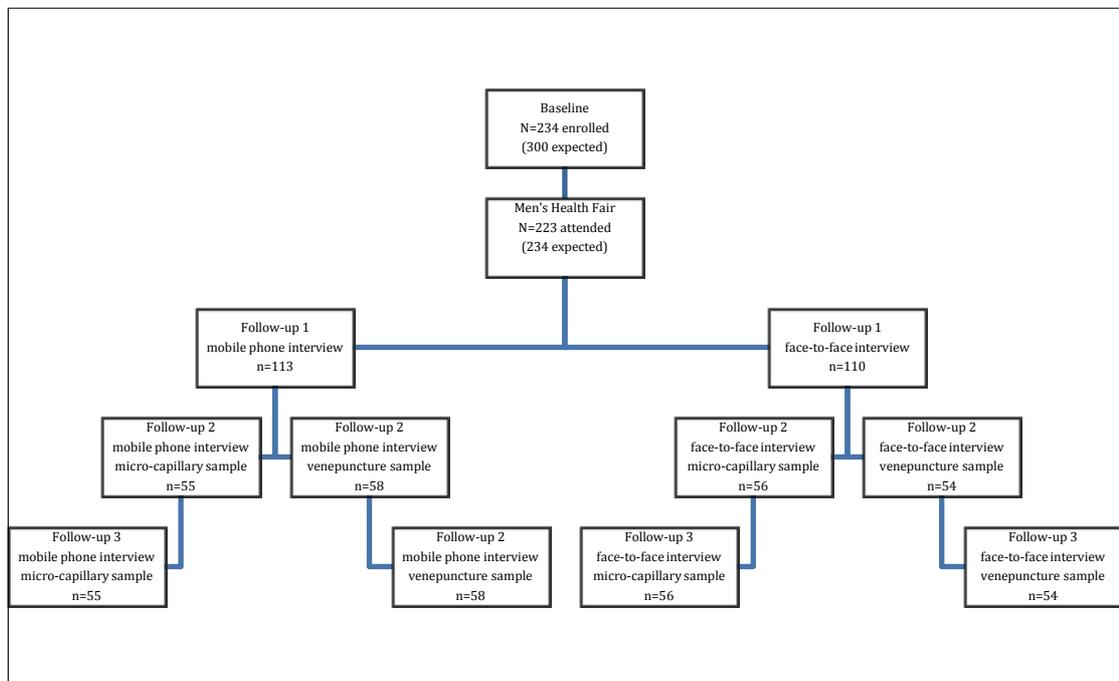


Figure 9.5: Phase 4 experiment design, showing numbers of participants eligible at each stage

It has been shown throughout the last two chapters that the initial phases of the *Impilo Yamadoda* study were acceptable to participants. It is clear from the outcomes presented here that the *Impilo Yamadoda* phase 4 experiment recruitment was not an exception to this trend; in the *Impilo Yamadoda* study we saw high levels of engagement throughout all phases of research.

III. Conclusions

This chapter followed the participation of young men in the *Impilo Yamadoda* study experimental phase. It is clear from the recruitment and enrolment data that young Zulu men found the *Impilo Yamadoda* study experiment acceptable. Recruitment was ended 2 weeks ahead of schedule in phase 4, and more than 95% of those participants completed their enrolment via attendance at the Men's Health Fair intervention and randomisation events. This shows that the strategic community engagement method, which detailed collaboration between the Research Partners and the *Impilo Yamadoda* research team, was able to successfully encourage the target population to enrol in our randomised trial including provision of blood samples and sensitive behavioural information. These data are useful in our investigation of whether participatory research methods can be used to encourage men's participation in biomedical health research in the global south. While we can see that the participatory method used in the *Impilo Yamadoda* study was useful in encouraging participation in the phase 4 experiment, we cannot fully answer this question until all the data are explored. Therefore this question will be fully addressed in the final conclusions of this thesis (chapter 11).

So far we have discovered several factors to further our understanding of what contributed to the engagement of young men in Kwa-Zulu Natal in the *Impilo Yamadoda: Men's Health Study*. In the last several chapters we have seen that the strategic community engagement method relied on collaboration between the Research Partners and the *Impilo Yamadoda* study researchers. Research Partner Organisations and the volunteer team who became Research Partners were identified in phase 1 of the *Impilo Yamadoda* study. Leaders of smaller organisations were more interested in joining in collaboration with the research team. We explored interviews with the men who became Research Partners in the previous chapter. This analysis led us to the understanding that Research Partners may be able to increase their social standing in their communities through improving the health knowledge of their peers via the training in health they accessed as part of their engagement in the *Impilo Yamadoda* study. Meanwhile, the involvement of Research Partners from smaller community-based organisations

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 9: Participant recruitment to the *Impilo Yamadoda* experimental phase

was seen as beneficial to the research study: Research Partners' knowledge of the local community could be transferred to the *Impilo Yamadoda* study researchers.

In addition, we saw that during Phase 1, the Research Partners were given formal and informal training in research methods by *Impilo Yamadoda* researchers. These training sessions allowed for an increase in the understanding of research (research literacy) on the part of Research Partners. This element of knowledge transfer was important in facilitating the competent collection of survey questionnaire data. Through the analysis of survey data presented in chapter 6, we have seen that this was successfully accomplished. However, what was important to the implementation of the strategic community engagement method was that the shared activity of these training exercises (at both *Africa Centre* and in the local communities) may have led to an increased sense of ownership of the research study on the part of the Research Partners. Through the previous chapter we saw that Research Partners saw *Impilo Yamadoda* as distinct from other *Africa Centre* research studies. The Research Partners also discussed how they portrayed the *Impilo Yamadoda* study as different than other *Africa Centre* studies. In the next chapter we will explore how the *Impilo Yamadoda* participants view themselves and their prospective participation in the phase 4 experiment, through an analysis of in-depth interviews and focus groups collected in phase 3.

Chapter 10: Qualitative analysis of participant motives for research engagement

I. Introduction

Throughout this thesis we have explored the findings of the *Impilo Yamadoda: Men's Health Study* in order to answer two research questions: 1. What factors contributed to the engagement of young men in Kwa-Zulu Natal in the *Impilo Yamadoda: Men's Health Study*?, and 2. Can participatory research methods be used to encourage men's participation in biomedical health research in the global south? In this chapter, we will examine the thoughts and motivations young men in the Hlabisa sub-district have when deciding to participate in biomedical HIV prevention research. Here men's self-reported motivations for their prospective decisions to engage with biomedical research are analysed and compared with the actual process of enrolment of men in the experimental phase of the study reported on in the previous chapter.

Data from this chapter are largely drawn from qualitative individual in-depth interviews and focus group discussions collected as part of the *Impilo Yamadoda* phase 3 qualitative study. These interviews and focus groups were held with a sub-set of *Impilo Yamadoda* phase 2 survey participants. To a lesser extent, field notes I collected are also reported on here. These field notes were taken during informal interviews with staff during enrolment events and invited guests at the intervention.

Analysis of qualitative interviews has formed the way this chapter is presented. Field notes compiled from experimental phase recruitment events and in-depth interviews are compared with the empirical outcomes presented in the previous chapter. In-depth interview and focus group discussion transcripts were transcribed, translated, and checked for accuracy prior to analysis (please see chapter 5, section 7 for the full discussion of data preparation methods). After the data were prepared, transcripts were re-read and further thematically coded to bring forward similarities and differences running through the entire dataset. As these interviews were used in analysis for the *Impilo Yamadoda* research objectives as well as for this study, there were several common themes found that were not seen to be of relevance to this investigation,

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 10: Qualitative analysis of participant motives for research engagement

and so were not followed up in this discussion. For the full list of themes found in the phase 3 participant IDI and FGD dataset please see Appendix 4.7.

The link between the phases of the *Impilo Yamadoda* study allow analysis between an exploration of what phase 3 participants discussed as their motivations for participating and actual participation in the phase 4 experimental phase. In addition, due to the methodological decisions made in recruiting participants, it is highly likely that many of the men who elected to participate in phase 4 had participated in earlier stages of the study. This chapter will contribute to our understanding of the factors that contributed to the engagement of young men in Kwa-Zulu Natal in the *Impilo Yamadoda: Men's Health Study* by presenting an in-depth analysis of what the young men involved in phase 3 in-depth interviews and focus group discussions stated as their motivations for joining the study.

II. *Umahlalela*, (if you are just sitting): self-descriptions and daily life

A total of 81 men took part in 20 individual in-depth interviews and 8 focus group discussions in the third phase of the *Impilo Yamadoda* study. These men described themselves through personal experience and in relation to their family, friends, and larger community. Personal philosophies and everyday experiences were described via explicit and implicit explanations of common versus ideal behaviours. Participants' social position and identity came through clearly in explanations of expectations and feelings of responsibility towards, and inversely, of dependency upon family, friends, and community.

Throughout individual interviews and focus groups participants gave clear description of their concepts of Zulu masculinity. Descriptions of what it meant to be a "right" man, or "how it is to live as a man" were given in dichotomies of expectations: men who are "right" go to clinic yet their peers do not go to clinic; men should be monogamous and use "caution," yet participants' peers are not cautious and have multiple girlfriends; men should "know where they stand" with regard to HIV status, yet their peers are afraid to test for HIV. In the first of two

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 10: Qualitative analysis of participant motives for research engagement

interview excerpts below, Jabulani talks about how he feels men behave, whilst in the second section the same participant discusses what beliefs and behaviours he believes young people must adhere to in order to “remain healthy and live for a long time”:

...[men] do many things and usually return home after dark, they sleep around and have many girlfriends, and spread their diseases to every person.

...

I actually [want] to be able give people advice on taking care of themselves and not to engage in sex. ... they must get married first. For girls too, to be disciplined, and attend the Reed Dance and [have their virginity tested]. This will make boys to also look after themselves because that helps them in the long run. They will remain healthy and live for a long time.

- Jabulani, IDI

It is clear to this participant that two dominant concepts of Zulu masculinity: having many girlfriends, and being married and looking after oneself, are at odds and that he feels responsibility for giving “people advice on taking care.” These contradictions of masculinity and feelings of responsibility are echoed throughout participants’ interviews. Ideal concepts of masculinity highlighted in interviews with participants were to get tested for HIV regularly, pay *lobola* and get married, use condoms with non-primary partners, strengthen the homestead through waged employment, and educate their peers on the “right” way to be a man.

...we men are not cautious if we sleep with women. That thing worries me. Especially for those who drink liquor. ... When one is drunk he doesn’t think that life doesn’t end here. ... Forgetting that there is someone left behind and his children watching him. If it was [up to] me, we as men should be listening; should really be listening and do what is being said.

- Mandla, IDI

Ideals of Zulu masculinity that have been found by other researchers, specifically those involving expectations of family and fatherhood, unsurprisingly come through strongly in these accounts as well (117, 119, 124). Unpacking the above quote we see a complex picture of men’s behaviours and responsibilities. “Forgetting that there is someone left behind” refers to a man’s wife or primary partner, and goes on explicitly to state that drinking and lack of “caution” (a term repeatedly referred to in interviews to mean lack of condom use) is worrying behaviour, particularly in light of the perpetrators’ “children watching him.” This “forgetting” is attributed

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 10: Qualitative analysis of participant motives for research engagement

to alcohol use, commonly described through this dataset as an encouragement for men to participate in risk-increasing behaviour, such as unprotected sexual intercourse with casual partners. “If it was [up to] me, we as men should be listening; should really be listening and do what is being said,” implicitly refers to both the HIV prevention information that is nearly ubiquitous in this area of very high HIV prevalence, and an acknowledgment that his peers are not following this advice. Also implicit is that Mandla himself is following this advice, or if he is not, that he should be. This telling excerpt portrays the hegemonic view of Zulu masculinity along with all of its obligations and responsibilities.

More surprisingly is the emphasis that these participants made with regard to their commitment to the larger community outside of the family and homestead. Interviewees wove descriptions of themselves and their peers through these two main concepts: a Zulu man must sacrifice his time and material goods for both family and community; through these acts he becomes the respected *baba*. In the following quote, Zakes, a member of focus group discussion 2, comprised of 18-20 year old men from a rural part of the sub-district, reveals the respect that *baba* (“fathers”) have earned by being resourceful and providing for their families.

Ya fathers from my area are doing things, like fishing; I see it as a big thing because we are able to feed ourselves by doing that. ... people from the community, men, they are able to group together, and share ideas... They would group together and talk about maybe getting something to transport what they have planted and take it to the companies, things like sugarcane. They are able to contribute and raise the money to buy their transport that will transport those things. ... they also get money to support their families...

- Zakes, FGD 2

As community affiliation is based on shared activity, practice and discussion of masculinity by the men in this context continues to shape and define those behaviours that are “right” from those that are “not right;” *abafana* (boys) cannot become *amadoda* (men), much less the respected *baba*, except through community acknowledged recognition (104, 107, 196, 200, 206). Throughout the interviews, as the majority of participants described their lives in contrast to the ideal Zulu man, it becomes apparent that the young men engaged in the *Impilo Yamadoda* study feel they are not yet *amadoda*. A defining theme in this dataset is the tension

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 10: Qualitative analysis of participant motives for research engagement

between participants' acknowledgement of their poor social standing and their desire to prove themselves worthy of respect.

The tension between the spoken or explicitly expected behaviour for men versus what men are actually doing is particularly evident during the initial section of the individual interview. Under the first topic of the interview participants were asked how they spend their time and, (if this did not arise spontaneously), were then prompted to speak about income generation, family and friends. During individual interviews, two men discussed holding full-time waged employment, several were full-time students, and the majority were men who described themselves as looking for work. Those who held waged employment or were full-time students described themselves quite differently than those who were not employed or in school. Students described spending their time both at school or revising, and as spending free time helping with family chores and playing football:

During weekdays normally I wake up in the morning and prepare for going to school. Eh, when coming back from school, I do the washing if I have to. If there is any work that needs to be done, I do it, and then I go to the [sports] grounds. I go to play football until the sunset and then come back in the evening to bathe, and do the schoolwork, if there is any. If there is [no school work] I go to study alone and [then] sleep.

- Sithembiso, IDI

Similarly, participants who held waged employment discussed work and social activities. Men who were not employed or enrolled in school spent time in interviews describing their involvement in income generating activity, spending time with family, and socialising with friends. At face value, these activities are not vastly different from the activities students and employed participants described; however, the manner in which their time was spoken about reveals the difference. In the excerpt below, one participant describes his daily life:

Research Assistant: ... *How do you spend most of your time?*

Participant: *Ok, just wait, I'll introduce myself. My name is Jabulani Ndebele from Mtubatuba municipality, and I work at the Hlabisa Municipal Development office.*

- Jabulani, IDI

Jabulani, who held full-time waged employment at the time of interview, literally defined himself through a statement of his location and activities. In contrast, the unemployed

participant below entered into a long discussion where he described his daily situation as problematic.

Research Assistant: ... *What I want you to tell me right now, please tell me about your normal day, how is it like, from the morning you wake up, what are the things you become busy with till sunset?*

Participant: *Most of the time I stay at home, but it sometimes differs, in that when I wake up in the morning I sometimes have a problem as to where to go, in the first instance... Yes. If it happens that my friends are there... I maybe go out or walk around by the road and see who can I get and how. ... It can also happen that others come as well; also the ones who are like me, who are lonely.*

- Bongi, IDI

While Jabulani and Bongi both define themselves through their activities, the participant who is unemployed signifies that he is not in an ideal situation. Additionally, Bongi's acknowledgment of "others," "the ones that are like me," gives the interviewer information that his situation is not unique. By telling us that there are others like him, his problem of where to go or what to do with his time expands to include a group of "lonely" peers and allows us contextualisation of the situation on a larger level. Bongi's problem then can be seen as a problem within the community, or a systemic issue. Not only is the tone of this interview in contrast with the excerpt from the employed participant, the unemployed participant defines himself in relation to the problem of unemployment within his community rather than as an individual, as was shown in the first excerpt from Jabulani, above. The employed participant describes himself as an individual through his actions, while the unemployed participant describes lack of action and his social group.

Many unemployed participants discussed income generation as a process rather than a set activity. The process of generating income was described as cyclical and seemingly without end: community projects fail when key people are offered steady employment; work such as selling foodstuff and charcoal by the side of road is dependent on season and weather; and piecework repairing neighbours houses, cars, and/or cell phones, does not guarantee direct monetary compensation. Steady employment was depicted as ideal but ephemeral, a good time between the times "when there are no jobs [and] things go badly." Self-directed or self-

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 10: Qualitative analysis of participant motives for research engagement

organised employment was more prevalent among participants; small projects were described as keeping men busy and sometimes even generated cash or in-kind income.

... We had a poultry project where we were buying chicks, raising and selling them. That's the job I was keeping myself busy with all the time. So as time went on the situation changes. ... It then ended; our project wasn't going anywhere and we had a halt, you see? It is something I was keeping myself busy with.

- Philani, IDI

... If there are no opportunities we make employment opportunities. ... So right now we have a garden we usually take the members to. We have it because we are not working and we just stay even during the weekdays [doing nothing]. It is better that we work in the garden, and what we get [from the garden] we sell it to get what we can eat.

- Dumisani, IDI

Keeping busy can be seen as essential in forming the line between social activity towards an idealised masculinity and sitting around without responsibilities.

Umahlalela, or literally from the Zulu, “if you are just sitting,” describes being stuck in the liminal space between boyhood and manhood. *Umahlalela* is an on-going state of inactivity; people who are *amahlalela* (plural) are seen as not only unemployed but also unemployable, and akin to the concept of *umnqolo* South African anthropologist Mark Hunter describes as “an unmasculine rural man so timid he won't even herd cattle” (120). In vernacular, to call someone *umahlalela* is an insult, connoting that this person holds limited respect due to laziness and questionable intellect. As a theoretical category, *umahlalela* can be seen as useful in describing the struggle many of our participants faced on a daily basis. The difficulty to gain respect without a source of income leaves Zulu men struggling against being seen as *amahlalela*. Interview narratives, specifically individual interviews, show this struggle acutely as men alternately weave descriptions of themselves in congruence and opposition to those who are *amahlalela*. The below set of quotes are taken from Philani's individual in-depth interview and show the struggle between his circumstance and his struggle against becoming *umahlalela*. In the first excerpt the participant is responding to what he does during weekdays, while in the second he is being prompted to discuss what he does to earn money:

Eh, for me, as someone who is always at home, I would put it like, that as someone not working, I usually wake up and do what I can, like household chores. ... If

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 10: Qualitative analysis of participant motives for research engagement

there is nothing to be done there, sometimes I help by accompanying [my] child to school.

Right now I would say I just do anything that is at home. Whatever needs doing at home. Or with my other brothers, it can be friends or people we live with, just help with that. It is just helping one another, we usually help one another when someone asks, like asking me to help when building a house; I usually do that freely.

- Philani, IDI

The expectation from the community towards able-bodied young men is that upon request they will use their time to do housework or anything to assist family, friends, and neighbours. It is in this act of “keeping busy” or, as the participant above puts it, “I just do anything,” that allows these men to differentiate themselves from *amahlalela*. Below, Vusimuzi describes his activities during the week as different from the weekend, not incidentally describing his schedule akin to that of a waged employee.

What I normally wake up to during weekdays, as someone who is not employed... I stay at home, you see? I take the working tool, spades, picks, I do the flower garden and remove the grass from the premises. I do that from Monday till Friday, and during weekends I'm able to stretch my legs by visiting friends, you see, and go to see people in town.

- Vusimuzi, IDI

The negative impact unemployment or underemployment has on men's social standing is richly described in these interviews. One participant discusses how his economic dependence on others destroyed the respect his family members had for him:

It is not as it was... I once worked. It is not the same; I used to see things happening. I was taken as the big brother before but now I am just like everyone there: all [of us are] children in the household.

- Bongi, IDI

The path from boyhood to manhood in traditional Zulu culture is via socially recognised actions (72, 121, 123, 124). A boy becomes a man through his daily actions, showing his responsibility towards himself, his family, friends, and larger community. Masculinity is performed by an individual and assessed by the community. In the economic sphere, underemployment has limited the viability of performing status-increasing actions in rural KwaZulu-Natal. Men struggle as they gain years without work, marriage, or legitimate children (124). As outlined in the literature review of this thesis (Chapter 3, section 3), much has been written about the effects of economic conditions on modern Zulu men, such as discussions on the impact of

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 10: Qualitative analysis of participant motives for research engagement

lobola on social recognition and internalisation of masculinity (128). These concepts are essential in framing this discussion, yet there has been little investigation to date of the impact of these on participation outside of the family and sexuality. As we turn to examine what these men have said motivates them to participate in research, it will be essential to keep in mind the underlying concept of *umahlalela* and the importance of performing actions connoting social responsibility.

III. Self-reported motivations for study engagement

Participants in individual and focus group interviews were asked about their views and interest in health research. The questions men were asked varied from asking about their actual decision to participate in *Impilo Yamadoda*, to presentation of a vignette where a fictitious potential participant was asked to enrol in a biomedical health research study. Vignettes were given in interviews in order to allow men who were not comfortable discussing their personal opinions of research within a research context. By placing their own opinions as those of the fictional protagonist, participants would ostensibly feel at liberty to discuss potential barriers to research engagement (228). With that said, nearly all participants indicated they felt free to discuss their personal feelings about health research participation; while the vignettes provided important context to participants whereby they could discuss the polemic, participants were articulate in indicating where they agreed or disagreed with the protagonists' choices and what choices they themselves would make. The following set of excerpts was taken from focus group 6, 21-24 year old men from the same area. Prior to these comments the research assistant read aloud one of the two vignettes and asked men if what they would do if they were placed in a similar situation to the protagonist (Thabani) who was offered short-term employment in Johannesburg whilst he was enrolled in a long-term research study. It was implied that choosing the job could mean discontinuing participation in the study while choosing the study meant Thabani's *lobola* payment could be delayed.

Xolani: Personally, for me, I would have to [decide] just how important it is for me to be part of this research. Also [I must] look at the difficulties I'll come across once this research is over, and if I see that it will benefit me, then I'll continue. If I don't see the importance of being in the research I must then go to Johannesburg for the job.

Lucky: Personally the one that I see as most important is to continue with the research.

Zakhele: I also think that it's important for [Thabani] to pay lobola except if the researchers will give him enough vouchers to pay his lobola. If in the end he will get [no money] for taking part then I think it's only right that goes for the job before he loses it.

- FGD 6

As is exemplified above, participants were comfortable talking about the reasons they would or would not continue with research when faced with other options. It is important to keep the openness exemplified by these participants in mind as we move forward with this analysis.

During the code generation stage of analysis it was determined that one of the main themes in this dataset was “research”. Eight individual sub-themes fell under this heading: study compliance, research interest, importance of incentives, form of incentive, value of participation, expectations from research participation (non-monetary), research involvement, and, willingness to provide blood (as part of research participation). It is largely from these sub-themes that the analysis below is based (for the full list of themes and sub-themes please see Appendix 4.7).

In interviews and focus groups, participants discussed what their reasons for participating in research were: interest in the topic of health, gathering together with other men, and being involved in something positive for the community.

I can say that what I like in the Impilo Yamadoda study is, it is where we share health knowledge among men. And another thing is that I like to volunteer in taking part in the community that I love and live in.

- Lungani, FGD 7

...I had a look and saw that maybe sometimes you take things for granted but it might happen that this is the opportunity ... that one day you [can] work with people and will be able to tell them about something that you see as a problem. Maybe one day ... you will find yourself in front of the people explaining to them about the problem of this disease.

- Sifiso, IDI

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 10: Qualitative analysis of participant motives for research engagement

Research Assistant: ...*what made you end up deciding to enrol in the Impilo Yamadoda study?*

Participant: ...*the brother who was asking me questions, the way he asked the questions, I saw that it is important to me and to my area community. Eh, it seems as if my area community is - I could say that they need health awareness very much.*

- Sithembiso, IDI

Incentives to join research, and the form that these take, were discussed as part of the probed topics prescribed in the interview guide but were not expanded on by participants who generally stated they were secondary to their decision making process. The majority of men stated their belief that participation in the *Impilo Yamadoda* study would help to improve their lives and the lives of others in the community, and importantly, that this was central in their decision to participate.

I would have participated even if the [store] voucher was not there, because I would have got some knowledge which I can share with my community, I would have found what I don't know and go back to my community and plough that back.

- Thulani, IDI

I can say to number one, maybe so that the community gets educated I must first come forward. Me first, so that the community will be able to be educated as well... besides that, I wouldn't want to get the community educated whereas I am busy being scared...

- Mdu, FDG 7

Specifically how participation in research would benefit their communities was explored in individual interviews and focus groups. The majority of participants discussed how “knowledge” gained from health research participation would be the main benefit they would gain.

Research Assistant: *Eh, do you think it has some impact on you to know that you are going to get [a store voucher]?*

Participant: *Eh, I would say it didn't have any impact on me because for me coming here, I came just to discuss about men's health. I didn't know that maybe [the voucher] might come up.*

Research Assistant: *Um, by the time you heard that [the voucher] might come up, is there any difference it made to your mind or it just became the same as the time you left home not knowing that you might get something?*

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 10: Qualitative analysis of participant motives for research engagement

Participant: *Yeah, it [was] the same because the things that I wanted to - of importance to me is that I will make it [here], to know about life and discuss about men's health.*

- Nkululeko, IDI (Emphasis, mine)

The process of gaining knowledge, or more specifically, positive health and life skills for men, and “ploughing that back” to the community was the most often mentioned incentive to join health research. Precisely how knowledge would help the community was sometimes not understood by participants, yet the sense that it would help was still strong. However, the majority of participants stated clear links between knowledge acquisitions via research engagement, bringing the information they would learn to their larger peer group, and the result of an educated community that has the ability to lead healthier lives.

What is important is knowledge and empowering your mind and knowing about health, especially as we are talking about health here. Do you see that health is important? If you are going to leave [research], we won't know many things, we will lose it and find ourselves getting into a big problem while if we knew, no, this would not have happened. ... I think the community can benefit with information so that it can be able to educate the kids, imparting knowledge to those still growing up so as to have a healthy nation, healthy generations to come, not a sick generation.

- Philani, IDI

I saw that by joining [Impilo Yamadoda] I might play a role in changing people's lives. The HIV statistics are high and because at the end of the day someone can be helped by the knowledge that I have, which I may also pass to them.

- Ayanda, IDI

The process of gaining knowledge from research involvement is seen as important not only in allowing the participant to engage in healthier behaviours on an individual level, but also as it allows the participant to become a community educator. Becoming a community educator is seen as another pathway towards performing actions connoting social responsibility in the community.

An important aspect of this process is that participants see themselves as not only given valuable information on how to live as a man that they can then pass on to others, but as given this knowledge from a legitimate source. While HIV prevention education is ubiquitous the

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 10: Qualitative analysis of participant motives for research engagement

quality of that education is questionable; misinformation and feelings of conspiracy around HIV infection were common throughout the interviews.

Can I ask brother, is it true that [you can prevent HIV] even if you sleep with another positive person maybe with a condom or if you don't use it but maybe [make] sure if you are done you quickly go for washing?

- Phila, FGD 1

And the condom as well, it happens that you go there, but the condom is broken... ehm, it really happens, I have proven this. ... I do not know what causes this, just open it and pour water inside. You see those found in the clinic...? I am [one of those] who does not use them.

- Mandoza, FGD 6

As has been shown in chapter 8 (section 3) in regard to motivations of the Research Partners to participate, while the role and expectations of *Africa Centre* in the communities it works within is complex, the institution is nonetheless thought of as a source of reliable and important health knowledge. It is with this validated knowledge gained from *Africa Centre* that the research participant is able to educate his peers:

If we are sitting chatting I tell them some things saying, "hey guys do you know how this happened?" They would be able to listen to me. Why? Because they always see me, maybe, they know that I go regularly to Africa Centre.

- Innocent, IDI

IV. The role of incentives and reimbursements

As was mentioned above, non-cash reimbursements, in the form of store vouchers and mobile phone airtime credit, were given to participants for their time and transport expenses. Non-cash reimbursements were used in lieu of cash primarily for the safety of research staff and participants; research staff carrying large amounts of cash for distribution to participants was seen to be a safety risk for participants and researchers alike in this high-crime area (255, 256). In the above analysis the importance of voucher reimbursements was noted as secondary to participant motivations to engage in the *Impilo Yamadoda* study. As was noted above, during interviews the research assistant posed hypothetical situations (vignettes) that might influence participants to engage in biomedical health research or not, and voucher reimbursement was a

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 10: Qualitative analysis of participant motives for research engagement

part of this discussion. All participants in individual and focus group interviews discussed the importance of voucher reimbursement for expenses incurred as a result of their participation. Interestingly, the majority of participants stated that zero personal cost for participation was of more importance to them than material gain. Many participants, such as those quoted below, explained how they had to borrow money for transport to get to the interview, and that reducing this “burden” for others, or alleviating this situation all together, was the main importance in receiving voucher reimbursement for participation.

Yes I see that there is [a difference] for me. Because I am not working just staying at home, so I even requested the transport fee from my mother. ... So if I tell her that there is a little that I got to take transport back home, I think that reduces the burden from her.

- Sifiso, IDI

It will be difficult [to participate without reimbursement] but you can do it ... But it may be limited by that maybe you'd like to go there but you don't have time or you don't have the transport fee to get there. ...it is easy to sacrifice your time because you are helping the community, not because there is a benefit you want to get. It is that everyone must end up knowing about this research or be part that this thing he wishes for his locality.

- Dumisani, IDI

However, when asked how much importance their peers might place on receiving a voucher reimbursement, many participants stated that this would help to encourage men to engage with the research:

No, [the voucher] is just to put pressure to the people, you see, for them to be courageous [and participate in research].

- Vusimuzi, IDI

Eh, discontinuation of the voucher sometimes hinders one who wants information. Let me make an example, just like me, as I am not working, you find that I don't have money but am really interested to meet with people. According to my opinion I think that, I would say that ... if there is no voucher - the voucher is also important because as I am here, I have learnt a lot that I will be able to tell someone.

- Mandla, IDI

Some participants explained that potential participants would be more encouraged to join a research project with monetary reimbursement versus one without it, because people should not be expected to work without earning something:

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 10: Qualitative analysis of participant motives for research engagement

I think [men would rather join research] that is giving the reimbursement because sometimes people like to work and earn. So now if they do not earn, some ... say you work backward like a chicken you see. So sometimes they want to look at, "what am I getting at the end of the day?"

- Sakhile, IDI

In the above quote Sakhile references a Zulu saying where “working backward like a chicken” discusses a person who scratches in the dirt to get little or no reward. Sakhile seems to contradict the participants above who play down the importance of voucher reimbursement; however, if looked at from a view of reciprocation the meaning this participant places on reimbursement can be better understood. As is literally expressed above, reciprocity for work separates humans from lower level animals; the importance of reciprocation should not be understated in this context. As has been discussed throughout in this thesis, providing something for nothing is anathema. However, monetary gain is one of a variety of reimbursements that is of value here. If reimbursement is looked at from these men’s perspectives we can see that while monetary gain is important, it is not the only or even the usual method of reimbursement for ones time.

In the section above, we have seen that majority of men interviewed are happy to invest their time in any activity that will set themselves apart from those of their peers who are *amahlalala*. It is this combination of community expectations towards self-motivated work and lack of opportunity that makes volunteering one’s time so appealing. When discussing income-generating activities, the participant below discussed why he finds odd jobs helping neighbours as it is often without the expectation of direct payment:

Sometimes it is just helping one another, seeing that I am not doing anything, sometimes you need to move your body rather than not doing anything. I also just help not expecting to get [money] in return.

- Philani, IDI

While payment is not expected *quid pro quo*, there is an expectation of generalised reciprocity, in other words, Philani believed that his actions will be reciprocated or appropriately reimbursed in the future (218). In the excerpt below, Philani continues, explaining that payment for his work was gaining knowledge as well as a small monetary token:

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 10: Qualitative analysis of participant motives for research engagement

I just say, “no, what I am doing I know it helps me somewhere, it empowers and educates me with certain things because I am also growing,” you see? ... What I also get, it would be that someone saw that because of what we did for him, “just take this little thing for yourself,” without me saying that I want money or I want something for doing this job.

- Philani, IDI

Central to Philani’s statement is that he is being educated about new things which he feels will be helpful to him in the future; while he does not expect payment *per se* he does expect that he will learn something through his efforts. Another participant made the connection between research engagement and his participation in community-building activities. In the quote below Bongi discusses why he does not expect monetary reimbursement for his participation in research:

...like football, just like me because I have a team I’m the coach of, I don’t get anything, I also don’t get even a cent, it is just that I like football. Also in research, even if I don’t get any [money] - but somewhere I will benefit if I don’t have the virus.

- Bongi, IDI

By participating in these activities for very little (if any) monetary gain, these men are able to continue to gain new knowledge believing that it will protect them from HIV, and have an acceptable place within the community, rather than be seen in the perpetual state of just sitting.

V. Conclusions

In order to make sense of what participants are discussing as their motivations to participate in the study, it is essential to place these data within a specific context. The male participants of the *Impilo Yamadoda* study are largely disenfranchised and see themselves as having few opportunities to change their social and economic position. Participants struggle to place themselves apart from their peers who are considered *umahlalela*, in a continuing state of social and economic disenfranchisement.

Africa Centre for Health and Population Studies is a well-known institution in the community; what *Africa Centre* is known for however, is highly dependent on the direct

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 10: Qualitative analysis of participant motives for research engagement

experiences the particular individual has with the institution and the resulting overall community views. The dynamic shown in the chapter 8 (section 3) in regard to Research Partner engagement, where affiliation with *Africa Centre* was rife with complexity, was not as strong a theme in this dataset. Several participants acknowledged that as *Impilo Yamadoda* was an *Africa Centre* project this might be a potential barrier to their peers' engagement. More prevalent was that participants expressed that their own engagement with research was an opportunity to receive essential information that will help to bring forward "a healthy generation" in their communities.

Participants discuss the importance of knowledge, a non-cash benefit to participation, as being more important than material gain. Understanding this in the study's context, education is seen as an appropriate reciprocation for participation, on the same par as other community-engaged activities such as football coaching and assisting neighbours with small jobs. Participants saw receipt of knowledge, made legitimate by affiliation with the research institute, as a pathway towards peer health education, an activity important for individual and community development. Voucher reimbursement was seen as important as an encouragement for potential participants as well as to enable the engagement of men who cannot afford transport costs associated with research participation.

The importance of research participation as a legitimate community development activity is explained through the expectations of reciprocation within this context. Reciprocation is not expected *quid pro quo* but rather as a process of developing the self and community through shared knowledge and experience. It is essential that the research institute, and by extension the research programme, be seen by the target communities as a part of this reciprocal exchange. The development and use of appropriate incentives in the *Impilo Yamadoda* study is an important contributing factor in the engagement of young men in Kwa-Zulu Natal in the *Impilo Yamadoda: Men's Health Study*.

In the next and final chapter of this thesis the findings from this chapter, as well as the previous results chapters (6-10) will be brought together to fully answer our research questions.

Chapter 11: Conclusions and implications

I. Introduction

Throughout this thesis we have investigated how the young men engaged in the *Impilo Yamadoda: Men's Health Study* viewed and experienced participation in the research in order to investigate two research questions:

1. Can participatory research methods be used to encourage men's participation in biomedical health research in the global south?
2. What factors contributed to the engagement of young men in Kwa-Zulu Natal in the *Impilo Yamadoda: Men's Health Study*?

This chapter will summarise key results from this investigation and examine the resulting analyses towards provision of pragmatic suggestions for future researchers in similar settings.

II. Contextualising methods of collaborative community engagement

In chapters 2, 3, and 4 it was posited that situating this investigation within what is already known about the setting in which it takes place provides important contextual insight to our outcomes. This investigation took place in South Africa, which is known to be one of the countries in the world with the highest prevalence of HIV infection (1). The epidemic in South Africa is considered to be a generalised one, where infection is primarily through heterosexual sex (1).

Further, the study area itself, the Hlabisa sub-district of rural KwaZulu-Natal, is an area that is known to have a population with very high HIV prevalence (91). HIV prevalence rates are known in this population as a result of the *Africa Centre for Health and Population Studies* longitudinal HIV surveillance of a small section of the *Impilo Yamadoda* study area (88). *Africa Centre* is a well-established research institute with a pre-existing community advisory board,

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 11: Conclusions and implications

among other important structural elements that allow research to progress along a cost-effective timeline. In addition, demographic surveillance shows that the need for development of new modalities of HIV prevention is pressing in this area (91). These factors situate the *Impilo Yamadoda* study area as one that is ideal for a biomedical HIV prevention intervention study: structural capacity and the demonstrated need for new prevention technologies are key factors in biomedical HIV prevention trial site selection (257). However, it is of equal importance to select a research site where community acceptability of HIV prevention intervention research is high, and thus a base of potential participants can be reached (257).

In our further investigation of this area, we have seen that this area of South Africa has a unique history; from early ethnographic accounts “before the White man” to the more recent history of the rise and eventual fall of the apartheid government, KwaZulu-Natal and the Zulu people have a rich and extensively documented history (52, 72, 121). Zulu men in particular have been the subjects of research focused primarily on the family and sexuality; several of these studies have shown that violence has become a dominant form of sexual expression among men (97, 112, 258, 259). Several studies have hypothesised that the place of Zulu men in society has been undergoing change related to the difficult social and economic trials of the twentieth and twenty-first centuries (48, 120, 124, 125, 129). For example, long term and recent economic privation has been linked to a social shift in Zulu men’s ability to achieve a traditional ideal of Zulu masculinity (124).

Looking at the historical context of South Africa and specifically Zulu men, we can see that there may be specific concerns related to engaging with this population. However, through a review of clinical trial and men’s health research literature we find that it is not well understood how to best engage men in resource-poor settings in biomedical HIV prevention research. When reviewing the literature on published biomedical HIV prevention trials specifically engaging men, such as the literature on circumcision, we find that little has been reported on the engagement methods used or the development of appropriate engagement methods (168, 169, 172, 175). What can be learned from this literature is focused on specific

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 11: Conclusions and implications

techniques that can be used in pragmatic ways, such as placing emphasis in trial promotion materials of the potential benefits and harm that might be experienced as part of research participation (176). These findings allow researchers to better communicate the aims of the investigation to potential participants, and may increase the good will of members of the target communities towards the trial (171, 176).

In a somewhat parallel exercise, there is a large literature on participatory methods of research implementation. Yet these methods have very different aims: the willingness to participate studies in biomedical research direct researchers to investigate potential participant facilitators and barriers for enrolling and adhering to a fixed protocol, whilst participatory research methods work with members of the community to define methods of investigation that are feasible and acceptable within that specific context (182, 220). From theories of individual, community, and cultural change we can recognise it is essential to understand the context that one is working within (104, 107, 187, 196, 206, 207).

The theoretical basis for this investigation required a thorough understanding of cultural, community and individual paradigms. In the theory this investigation moved forward with, individual identity is based on communal identity (104). This dynamic process of change works on both the individual and collective level as there is no personal identity without community; it is through the community that individuals create identity. Identity is necessarily fluid, as how we see ourselves in relation to others changes when we perceive how others see us (104). It is the *doing* of identity that forms identity; personal identity is never static (104, 206). Change is a natural part of the dynamic process of individual and communal identity formation. If we think of culture as a macro version of community, cultures are also formed through this process of reflexivity. The geographic (e.g., land), structural (e.g., political structures), and temporal elements, combined with the complex imaginings and identities of the people who share it, form cultures (206, 211, 213). Culture and community are thus essential elements of the fluid process of individual identity formation. Individual identification with the community is enhanced through collaborative action (104, 206). Collaborative action helps to promote not only

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 11: Conclusions and implications

identification (or, ownership), with a community, but ownership of the action itself (196, 199, 206). In other words, when we work collectively we form bonds with the people we are working amongst (shared identities), the place we are working in (communities), and the project we are working towards (change). This process then has the potential for sustainability, as identity with and ownership of the project has been formed on multiple levels. When we view culture and community as an essential part of individual identity we can begin to understand why programmes focused on the individual level are rarely sufficient to create change (196, 206).

This thesis focuses on what happens when we apply this theory of community change to a community-based engagement strategy in rural KwaZulu-Natal, South Africa.

III. Theory of the strategic community engagement method

This investigation takes into account social science theory and methodology as well as empirical public health evaluation science. Drawn from the gaps in the biomedical evaluation research literature, and incorporating the fluid methods of participatory research, the strategic community engagement method encouraged participation in the *Impilo Yamadoda* study through collaborative work with community-based volunteers from existing local organisations.

Grassroots collaborative community development theory informed the initial step in the strategic community engagement method, that of identifying existing local organisations who might be interested in partnering with the research study. While the research team did not necessarily approach a representative group of all organisations in the area, attempt was made to contact all listed employer, community, non-governmental, and faith based organisations that worked with men in the Hlabisa sub-district. This was thought to foster inclusiveness (rather than exclusiveness) and allow the research programme to be seen as a collaborative effort with (rather than for) the community. Collaborative community development theories posit that collaboration creates a support structure that fosters behaviour change (196, 206).

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 11: Conclusions and implications

Although the focus of the *Impilo Yamadoda* study was predetermined, the exact structure and mechanisms of the strategic community engagement method were not. The theory behind the engagement method encouraged active collaboration between *Impilo Yamadoda* researchers, and members of the community (206, 223). In addition, gatekeeper organisations, such as governmental bodies and regulating officials were consulted to allow for a further three-way partnership as suggested by community development theorists (196, 198). The essential elements of “active collaboration,” especially between Research Partners and *Impilo Yamadoda* researchers were delineated as: communication throughout the project, and continuous work on shared activities (196, 206).

What the Research Partners and partnering organisations received as a result of their participation was not decided beforehand. In other words, organisations were told that *Africa Centre* would assist in non-monetary ways to develop their organisation or members in their organisations. While the *Impilo Yamadoda* study’s scope to provide assistance was somewhat limited, organisations were supplied with examples of how this could be done. *Africa Centre* provided parameters to the *Impilo Yamadoda* study researchers at the start of the study. Examples of potential assistance included: computer classes, HIV education seminars, and, assistance with grant applications. This (although limited) level of agency Research Partner organisations had for determining the direction of their partnership with the research was theorised to create a sense of interdependency (rather than dependency) and create links with *Africa Centre* as an institution to foster strength within the Research Partner organisations (196).

Training Research Partner volunteers to implement the survey with members of their communities was theorised as participatory research practice. This aspect of the strategic community engagement method was thought to encourage identification with the research, first amongst the Research Partners, and then by diffusion, to the potential participants in the research. The theoretical background for this aspect of the method comes from the theory that participatory action creates investment (ownership) in the project undertaken (196, 199, 206).

The final step was then to encourage community members who were not Research Partners to take part in the study. This was thought to create a ‘diffusion effect’. It was theorised that if community members (in this case, potential participants), saw their community leaders (Research Partners) and local organisations (Research Partner organisations) invest in the project (i.e., *Impilo Yamadoda*) they would be more likely to want to take part themselves.

The next section will discuss what the main findings from this investigation were, as a summary of chapters 6-10 of this thesis. It is only after this discussion that we can fully understand the benefits and drawbacks of use of the strategic community engagement method described here.

IV. Study findings

The young Zulu-speaking male participants of the *Impilo Yamadoda* study were first described in chapter 6 through a statistical analysis of their demographic profile and responses to a brief men’s health survey. Somewhat unsurprisingly, we found that this group of survey participants’ demographic indicators were fairly homogeneous. After adjusting for potential confounders, participants in the *Impilo Yamadoda* survey were less likely to be employed than men of similar ages in the *Africa Centre* Demographic Surveillance Area (DSA); the percentage of survey participants employed was 20.27% while *Africa Centre* Household Socio-Economic Surveillance (HSE) data from the same time period reports 32.60% employment. The majority of survey participants were unmarried (93.27% 679/728), and had completed grade 7 or above (90.86% 646/711). Our understanding of this group of semi-educated, unmarried, unemployed or under-employed men was furthered through additional survey data specifying social group membership. The majority of survey participants (56.33%) were involved in sports groups, and logistic regression confirms that this was strongly correlated with those survey participants who were eligible for the phase 4 experiment (men 18-35 years inclusive). Social group membership and marital status, alongside indicators of economic disenfranchisement, was hypothesised as

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 11: Conclusions and implications

correlating with the majority of these participants' indication of willingness to participate in future HIV prevention research (60.95%; 448/735). Interestingly, health education interest was linked to participants' willingness to take part in HIV research through the strong associations found in the Likert-type scale analysis between willingness to participate and perceived individual and community level benefits.

The analysis of individual interviews and focus groups with *Impilo Yamadoda* phase 3 participants presented in chapter 10 furthered our understanding of the participants. As found in analysis of the survey questionnaire, participants in individual interviews and focus groups also indicated willingness to participate in future biomedical HIV prevention research. When presented with vignettes describing a hypothetical research study including the collection of blood samples (see Appendices 4.3 and 4.4 for vignettes), participants were overwhelmingly positive about their potential participation. In addition, process data from the actual recruitment of similar participants (and possibly in some cases, the same participants) to the *Impilo Yamadoda* phase 4 experiment support these reports of willingness to provide blood samples as part of research; the enrolment target for the experiment was reached two weeks ahead of schedule.

Why these men decided to participate in the study was analysed using in-depth interviews and focus groups with *Impilo Yamadoda* phase 3 qualitative study participants. In partial answer to this question participants reported that receipt of health education, and specific interest in receipt of men's health and HIV prevention education, was the most important benefit they could receive for their health research participation. Participants spontaneously indicated their desire to distribute the benefits from research to their communities via peer education. Further analysis of these data point to participants' new role as peer educators as an important individual-level benefit to their engagement with research. Interestingly, as these men reported their desire to become peer educators, their self-descriptions included low levels of participation in activities they saw as beneficial to themselves or their larger community.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 11: Conclusions and implications

To answer why Research Partners participated, individual interviews with a purposive sub-set of volunteer Research Partners were analysed. In contrast to interviews with participants, individual interviews with Research Partners portray this group as involved with the community via the organisations they represent. As representatives of local community-based organisations, or to a lesser extent, employer organisations, these men reported a sense of inclusiveness in their communities. This is unsurprising as the volunteers were recruited by their host organisations (or in some cases volunteered themselves) precisely because of their inclusion within the community of men they live and/or work amongst. Pragmatically, Research Partner volunteers worked primarily as a bridge between the *Africa Centre* researchers and members of target communities. Potential participants were introduced to the *Impilo Yamadoda* study during the phase 2 survey by the Research Partner volunteer team. In addition, Research Partners saw themselves as both representatives and participants in the study. Striking a balance between participant and researcher allowed Research Partners to be seen as both trusted community members via their association with their parent organisation and holding legitimate knowledge via their association with *Africa Centre*. Research Partners, as examples of responsible men in their communities, portrayed participation in the *Impilo Yamadoda* study as a way for their peers to be involved in something that would help the health and development of their communities. As represented by the return of more than double the amount of questionnaires and contact sheets expected in the phase 2 survey, this peer education effect was highly influential in engaging young men with the *Impilo Yamadoda* study during its initial phases.

Just as in-depth interviews with Research Partners began to unpack the reasons behind their success in engaging participants, individual and focus group interviews with survey participants brought forward the reasons for their enthusiasm for the study. During analysis of in-depth interviews with a sub-set of survey participants, social status once again came to the fore via analysis of participants' decision to engage with *Impilo Yamadoda* research. Participants in individual interviews and focus groups expressed their struggle against the label

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 11: Conclusions and implications

of *umahlalela*, or the continuous state of “just sitting,” by describing their willingness to “keep busy” with anything that was seen as helpful to themselves or their communities. Among the range of activities these men were eager to partake in was the *Impilo Yamadoda: Men’s Health Study*.

Motivations for willingness to participate in the study only became clear when related back to the specific context of this investigation: lack of opportunity and disenfranchisement combined with the belief that their participation would enable them to contribute to the community motivated men to engage with the study. Individual gain from participation in *Impilo Yamadoda* was reported by participants to be weighted towards receipt of knowledge rather than monetary reimbursements. This was explained through examination of systems of reciprocity that participants described being involved with: piecework for family, friends, and other community members was not reimbursed *quid pro quo* but rather through receipt of new knowledge (via learning a new trade or practicing a known one) and secondary to this, a small monetary payment. In addition, the receipt of HIV prevention knowledge from *Africa Centre* allowed information gained via research engagement to be legitimised. As holders of this valuable knowledge the participants were thus enabled to become peer educators, a far cry from the do-nothing *umahlalela*. With the increase in social status via their new role as community educators these participants move away from their *umahlalela* peers and closer to the respected status of *baba*, a father and provider in the community.

V. Study findings in relation to the main research questions

Can participatory research methods be used to encourage men's participation in biomedical health research in the global south?		
Findings	Feasibility/ Acceptability	Chapter in thesis
Validation of data through survey analysis indicates good quality of the data	<i>Feasibility of preclinical research method</i>	Chapter 6
The return of more than double the amount of questionnaires and contact sheets expected in the phase 2 survey	<i>Acceptability of preclinical phase recruitment and implementation method</i>	Chapter 7
Analysis of the survey process indicates that collaborative work with the Research Partner team was sufficient to recruit participants to the survey phase in the allotted time.	<i>Feasibility of preclinical research method</i>	Chapter 7
Phase 3 qualitative study participants indicate (prospective) interest in taking part in HIV prevention intervention research including provision of blood samples	<i>Acceptability of blood-taking for biomedical research</i>	Chapter 10
Phase 4 enrolment target reached two weeks ahead of schedule indicates participants' willingness to provide blood samples as part of research	<i>Acceptability of biomedical research: blood-taking and recruitment methods</i>	Chapter 9
95.3% (223/234) of participants enrolled at baseline attended one of the two health fairs (completed enrolment)	<i>Acceptability of randomisation in biomedical research</i>	Chapter 9

Table 11.1: *Feasibility and acceptability of elements of the strategic community engagement method*

Our first research question explores elements of the strategic community engagement method used in the *Impilo Yamadoda* study in order to better understand their potential feasibility and acceptability for use in future research studies in the global south. Table 11.1 (this page), lists each of the elements of the strategic community engagement method, their feasibility and acceptability, and where these findings are discussed in the thesis.

In chapter 6, we found through validation of elements within the dataset that the data that Research Partners collected through their implementation of the phase 2 survey was of a good standard. This indicates that it is feasible to work collaboratively with lay community volunteers to implement unnamed survey research among their community members, despite the limited time and scope of the formal Research Partner training programme. In chapter 7 we found that not only was the quality of the data collected good, but also that the Research Partners were able to gather more questionnaires and contact sheets than was originally anticipated. This high rate of returns indicates that Research Partners were effective in engaging young men in the *Impilo Yamadoda* study to the survey phase.

In chapter 10 we learned that phase 3 qualitative study participants indicated interest in taking part in HIV prevention intervention research including provision of blood samples. The interviews and focus groups with phase 3 participants was prospective to their enrolment in the study, however, these data were confirmed in chapter 9, where the recruitment of participants to the *Impilo Yamadoda* phase 4 experiment was presented. In chapter 9 we found that the phase 4 enrolment target was reached two weeks ahead of schedule. Together these reports indicate participants' acceptability of provision of micro-capillary blood samples as part of the *Impilo Yamadoda* experimental phase. In chapter 9 we also found that 95.3% (223/234) of participants that enrolled at baseline also completed their enrolment by attending one of the two "Men's Health Fairs". As these health fairs were also randomisation events, this indicates *Impilo Yamadoda* experimental phase participants' acceptability of randomisation to one of the three study arms.

While these data indicate the feasibility and acceptability of use of the strategic community engagement method to encourage participation in biomedical research in the global south, there are some important limitations of this research. Importantly, as was shown in chapter 3 (section 6), there are specific concerns potential participants may have when deciding to enrol in biomedical HIV prevention intervention research. For example, not all of the elements of a full scale biomedical trial were tested in this study: there was no administration of experimental medicines in any of the study arms, no participants received their HIV test results during any phase of the research, and randomisation did not mean postponement of treatments or allocation of a placebo. The *Impilo Yamadoda* study experimental phase randomised participants to two different modalities of blood taking (venepuncture at clinic versus micro-capillary sample in a community setting), and two different types of follow-up method (mobile phone interview versus face-to-face). Randomisation may thus have been more acceptable than might be during a full-scale biomedical trial.

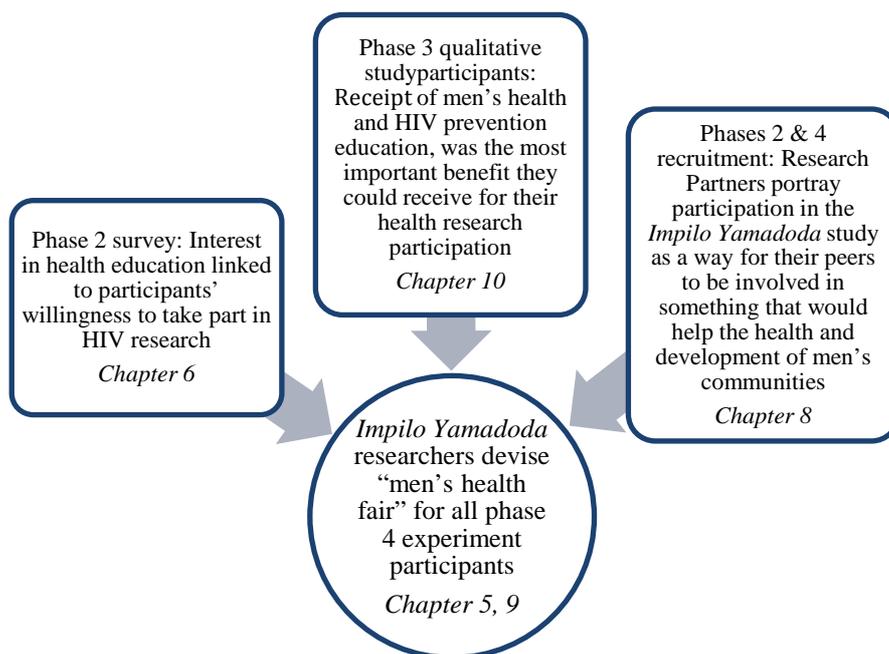


Figure 11.1: Findings from investigation of main research question and the effect on the phase 4 biomedical experiment design

The main study findings in response to our second research question and how they affected the design of the *Impilo Yamadoda* experimental phase can be seen in Figure 11.1,(this page). In chapter 6 we found that men indicated interest in participating in HIV prevention research. Through further analysis we found that this interest was linked to participants' interest in health education. During individual interviews and focus group discussions with a subset of survey participants we found a strong theme of health education as the most important benefit participants' could receive from their involvement in health research. Directly related to this was the finding during in-depth interviews with Research Partners, who believed that participation in the *Impilo Yamadoda* study would lead to "healthier communities." We found that Research Partners also described this as an important incentive to participation in the *Impilo Yamadoda* study. While this did not allow us to understand the complex dynamics around participation in the research study, we felt that this evidence was sufficient to justify assuring that an element of the phase 4 experiment include health education. Although a "health fair" was part of the original protocol design, when the importance of this as a benefit to participation was seen we decided to give men more than the informational sessions planned; stakeholder

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 11: Conclusions and implications

partners (i.e., Hlabisa hospital and the Department of Social Development) were consulted in collaboration with Research Partner organisations in the design and implementation of the “Men’s Health Fair” held during the phase 4 biomedical experiment randomisation event.

The section below will further our understanding of the usefulness of the strategic community engagement method by focusing on specific benefits and drawbacks of the strategic community engagement method.

VI. Benefits and drawbacks of the strategic community engagement method

From this analysis we have seen that the strategic community engagement method developed for use in the *Impilo Yamadoda: Men’s Health Study* was a feasible and acceptable tool to encourage young Zulu-speaking men to take part in all phases of the study. Moving beyond feasibility and acceptability in this specific context, this section will discuss the potential benefits and drawbacks of using the strategic community engagement method.

Working collaboratively with the Research Partner volunteers allowed for identification of common goals for the research team and potential participants of the *Impilo Yamadoda* study. When we examine this further we can see that the most important common goal identified in the initial collaborative process between the research and Research Partner team was to work towards better health for young men in the sub-district. However, better health for men was not a primary goal of the *Impilo Yamadoda* study. While understanding how to best engage potential participants in a large-scale HIV prevention intervention study can be seen as a long-term effect resulting in better health, particularly if the methods identified can be generalised to other settings, the short-term gains by the individuals within this study (both Research Partners and participants) was minimal. After the goal of better health for men was determined, the Research Partner team was given information on basic HIV prevention by the *Impilo Yamadoda* team as part of their research training. The study participants’ HIV prevention and health-increasing education was limited to the ‘interventions’ at the Men’s Health Fair (*Impilo*

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 11: Conclusions and implications

Yamadoda experimental phase). Yet participants and Research Partners alike agreed that they had been given valuable health information that could be passed on to others, and this was seen as a main incentive to their continued participation in *Impilo Yamadoda*. Participants and Research Partners reported that speaking one-on-one to study staff and having increased opportunities to speak with their peers about men's health and HIV prevention was a valuable way to increase both their health education and their social standing. This was most apparent among focus group participants; however, the theme of "coming together in groups" to talk about sex, health, and disease was prevalent throughout qualitative data collected from participants and Research Partners.

Direct involvement of the Research Partners from the initial stages of the study allowed potential participants to view engagement with the *Impilo Yamadoda* study as potentially positive for the community. Analysing interviews with Research Partners we can see that this was likely due to the way they encouraged participation in the study. As discussed in chapter 8, Research Partners told participants that *Impilo Yamadoda* was a research study to encourage men's health:

I think if you told them beforehand, how the research will benefit them and their communities, and that it will be passed to the government to help them, then they will be more willing to take part in research programmes.

- Simphiwe (Research Partner)

The above quote is instructive not only to see how Research Partners described *Impilo Yamadoda* to participants, but as insight into how the structure of change is understood. If following the theoretical guidelines of a collaborative community development project, or that of a participatory action research study, there would necessarily be a component of this method that encouraged sustainable change (184, 196, 199). Taylor-Ide's theory of sustainable change creation includes a three-way partnership for top-down, bottom-up, and outside-in collaboration. We can see that in this engagement method, *Africa Centre* can be seen as the 'outside-in', and the Research Partners' the 'bottom-up', but the top-down element was limited to consultation with stakeholder organisations during the Research Partner organisation

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 11: Conclusions and implications

identification period (early phase 1) and the planning and implementation of the “Men’s Health Fair” (prior to phase 4 randomisation). Simphiwe discusses the role of government in creation of sustainable change, yet there is only a token element of how sustainable change could be produced in the strategic community engagement method: reports and publications arising from this research will be funnelled to individuals in government agencies that decide on the structure and function of the health education programmes in the area. This model may thus suffer from the lack of a true three-way partnership.

Yet there were benefits of the strategic community engagement method that might be considered sustainable. The Research Partner training programme, including the direct practice of administering the phase 2 survey, increased research literacy on the part of the Research Partners. Increased research literacy on the part of these community-based volunteers can be seen as an important long-term effect of this collaboration: the Research Partner organisations identified in this process have continued to volunteer their time with *Africa Centre* and are providing important insight and collaborative direction in community engagement with the upcoming Treatment as Prevention (TasP) study in the sub-district⁷ (260). In this way the Research Partner team has moved beyond a consultancy position, such as in the standard Community Advisory Boards that are often research institutes’ main point of community contact, to an active role in the research planning and implementation process. This is an important element in the sustainability of the strategic community engagement method, particularly in areas where there are on-going studies (i.e., demographic surveillance), and other sites where large-scale biomedical research is likely to take place.

To further the sustainability of the lessons learned in this investigation, please see Appendix 6 for suggestions for Principle Investigators, Project Leaders, and Trial Coordinators to use in the design and implementation of community-based HIV prevention intervention research in the global south.

⁷ Personal correspondence, John Imrie, Assistant Director and Social Science Lead, *Africa Centre for Health and Population Studies*, 2012.

VII. Implications

We have seen throughout this thesis that the participants of the *Impilo Yamadoda* study based their decision to enrol on factors that had not been considered as being influential by the research team during the study design period. Receipt of knowledge about “men’s health” including HIV prevention, and increased social standing on the part of the participant, were seen to be more influential to participant willingness to engage with *Impilo Yamadoda* than material reimbursements such as store vouchers. That these incentives were discussed as early on as during the Research Partner training programme shows that this method was effective at identifying the wants and needs of potential participants in the *Impilo Yamadoda* study. This was later confirmed through in-depth interviews and focus groups with participants, and thus shows one of the values of using this collaborative approach to participant engagement in research.

HIV service provision in the developing world is undergoing an ideological shift towards an interdependent view of how to tackle the epidemic: treatment, testing, care and support are being seen as parts of a whole package in preventing new infections and care for the infected (261). This change in planning for service provision necessitates an important shift in viewing people not only as vulnerable but also as actively engaged with the world; individuals’ adherence to treatment is now seen to be based on a variety of individual and social factors (261). It is currently acknowledged that variables that may not be readily and empirically measurable in their direct impact on behaviour, such as social and economic capital, are essential considerations when designing service provision (215, 216). HIV research is likewise shifting; since 2005 there has been a growing literature towards understanding the impact that community dynamics and economic statuses of target populations have on participant engagement with biomedical research (173, 174).

In chapter 4 (section 2) of this thesis it was posited that while researchers are increasingly looking to new ways to engage potential participants in research, rarely are community engagement methods based on robust social science findings (180, 194). When looking at

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Chapter 11: Conclusions and implications

biomedical health research participant engagement programmes and early top-down models of community development a similarity can be found: in these top down models of development, a problem is identified by professionals outside of the community who then import resources to “solve” that problem (195, 196). These models of development perpetuate existing power imbalances rather than shape positive community change (198-200), a dynamic that can be seen as influencing the past failures of biomedical trials to engage communities in research (173, 174).

The recommendation that target communities be consulted prior to biomedical HIV prevention research implementation is not new; social scientists and ethicists agree that community involvement is essential to the success of a research study (170, 171, 179, 192, 204). Yet while researchers attempt to identify and liaise with leaders of the communities affected by research prior to study implementation (170, 171, 179, 204, 205), community engagement is rarely directed by evidence or robust theory (17, 180). Although encouraging high levels of research engagement among target populations is essentially a behaviour change activity, community change theories have not yet been considered in relation to creation of community engagement methods for biomedical research in the global south. The results of this investigation suggest that community-based engagement methods can be constructed using theories of participatory research and collaborative community development to encourage participant engagement in HIV prevention intervention research in the global south. Additionally, the application of this practice may further target communities’ good will towards biomedical HIV prevention research, improving research results for both participants and researchers alike.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

References cited

References cited

1. UNAIDS. World AIDS day report. [n.p.]: Joint United Nations Programme of HIV/AIDS 2011.
2. UNAIDS. Global report: UNAIDS report on the global AIDS epidemic 2010. [n.p.]: Joint United Nations Programme of HIV/AIDS 2010.
3. Mbizvo, MT, Bassett, MT. Reproductive health and AIDS prevention in sub-Saharan Africa: the case for increased male participation. *Health Policy and Planning*. 1996; 11 (1): 84-92.
4. Dunkle, Kirsin L, Jewkes, Rachel. Effective HIV prevention requires gender-transformative work with men. *Sex Transm Infect*. 2009; 83: 173-174.
5. Brown, Sally. What makes men talk about health? *J Gend Stud*. 2001; 10(2): 187-196.
6. Banks, Ian. No man's land: men, illness, and the NHS. *BMJ*. 2001; 323: 1058-1060.
7. Ramjee, Gita, Shattock, Robin, et al., editors. Short Report: Microbicides 2006 Conference. *Microbicides Conference*; 2006; Cape Town, South Africa: AIDS Research and Therapy; 2006.
8. Ditlopo, Prudence, Mullick, Saiqa, et al. Testing the effectiveness of the Men as Partners program in Soweto, South Africa: *Frontiers in Reproductive Health Program (FRONTIERS)*, Population Council, 2007 June 2009.
9. Jewkes, Rachel. Impact of Stepping Stones on incidence of HIV and HSV-2 and sexual behaviour in rural South Africa: cluster randomised control trial. *BMJ*. 2008; 337 (a506): 391-395.
10. Mantell, Joanne E., Dworkin, Shari L., et al. The promises and limitations of female-initiated methods of HIV/STI protection. *Social Science & Medicine*. 2006; 63: 1998-2009.
11. Smith, Robert J, Magnet, Shoshana. The introduction of vaginal microbicides must also target men. *J Mens Health Gend*. 2007; 4 (1): 81-84.
12. Peacock, Dean, Levack, Andrew. The Men as Partners program in South Africa: reaching men to end gender-based violence and promote sexual and reproductive health. *Int J Mens Health*. 2004; 3 (3): 173-188.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

References cited

13. Arend, Elizabeth, editor. For men only: a case study of male-centred, community-based VCT. Southern African AIDS Conference; 2009; Durban.
14. Becker, Ruth, editor. Count on me: men talking to men about PMTCT. Southern African AIDS Conference; 2009; Durban.
15. Struthers, Helen, editor. Reviewing the situation: men's perceptions of HIV and health services in Soweto, South Africa. Southern African AIDS Conference; 2009; Durban.
16. Schaik, Nienke Van, editor. Mobile testing improves testing in men and those who are well. Southern African AIDS Conference; 2009; Durban.
17. Staley, Kristina. Exploring impact: public involvement in NHS, public health and social care research. Eastleigh: INVOLVE 2009.
18. Imrie, John, Newell, Marie-Louise. Impilo Yamadoda: Men's Health Study protocol: an exploratory study of issues in men's health and mechanisms to increase participation and retention of male participants in community-based HIV prevention research. [Unpublished]. 2009: 1-15.
19. Qualitative Research Practice. Ritchie, Jane, Lewis, Jane, editors. London: Sage Publications; 2003.
20. Pitts, Margaret Jane, Miller-Day, Michelle. Upward turning points and positive rapport-development across time in researcher-participant relationships. *Qualitative Research*. 2007; 7 (177).
21. Wallerstein, Nina. Power between evaluator and community: research relationships within New Mexico's healthier communities. *Soc Sci Med*. 1999; 49: 39-53.
22. UNAIDS. Report on the global HIV/AIDS epidemic 2008: executive summary. [n.p]: Joint United Nations Programme of HIV/AIDS 2008.
23. Asamoah-Odei, Emil, Calleja, Jesus M Garcia, et al. HIV prevalence and trends in sub-Saharan Africa: no decline and large subregional differences. *Lancet*. 2004; 364: 35-40.
24. USAID. HIV/AIDS health profile: sub-Saharan Africa. [n.p.]: United States Agency for International Development 2011 March 2011.
25. Chopra, Michey, Lawn, Joy E, et al. Achieving the health Millennium Development Goals for South Africa: challenges and priorities. *Lancet*. 2009; 374: 1023-31.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

References cited

26. UNAIDS. Country situation: South Africa, July 2008. [n.p]: Joint United Nations Programme of HIV/AIDS 2008.
27. Mooney, Gavin, Gilson, Lucy. The economic situation in South Africa and health inequities. *Lancet*. 2009; 374 (9693): 858-859.
28. (CIA), Central Intelligence Agency. CIA - The World Factbook - Country Comparison : Unemployment Rate. 2009 [cited 2009 13 October]; Available from: <http://www.cia.gov/library/publications/the-world-factbook/rankorder/2129rank.html?countryName=South Africa&countryCode=sf®ionCode=af&rank=171%23sf - sf>.
29. Schwabe, Craig. Fact Sheet: poverty in South Africa. Human Sciences Research Council; South African Regional Poverty Network; 2004 [06 January 2012]; Available from: <http://www.sarpn.org.za/documents/d0000990/>.
30. (CIA), Central Intelligence Agency. CIA - The World Factbook - Country Comparison : Distribution of family income - Gini index. 2009 [updated biweekly; cited 2009 14 October]; Available from: <http://www.cia.gov/library/publications/the-world-factbook/rankorder/2172rank.html>.
31. Motsoaledi, PA. Country progress report on the declaration of commitment on HIV/AIDS: South African Ministry of Health 2010.
32. (UN), United Nations. World Economic Situation and Prospects 2009: Update as of mid-2009. World Economic Situation and Prospects [serial on the Internet]. Available from: <http://www.un.org/esa/policy/wess/wesp2009files/wesp09update.pdf>
33. World economic outlook update: an update of the key WEO projections: International Monetary Fund 2011.
34. Arieff, Alexis, Weiss, Martin A, et al. The global economic crisis: impact on sub-Saharan Africa and global policy responses. Washington, DC: Congressional Research Service 2009.
35. The Lancet South Africa Series Executive Summary Core Group, Lawn, JE, et al. Health in South Africa: Executive Summary for the Series. *Lancet*. [Executive summary]. 2009 August.
36. Map of South Africa, with provinces, neighbouring countries and oceans labelled in English. 22 April 2011 ed: Wikipedia; 2011.
37. Fassin, Didier. When bodies remember: experience and politics of AIDS in South Africa: University of California Press; 2007.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

References cited

38. Marmot, Michael. Social determinants of health inequalities. *Lancet*. 2005; 365 (9464): 1099-1104.
39. Jong-wook, Lee. Public health is a social issue. *Lancet*. 2005; 365 (9464): 1005-1006.
40. Farmer, Paul. *Pathologies of power: health, human rights and the new war on the poor*: University of California Press; 2005.
41. Pisani, Elizabeth. *The wisdom of whores: bureaucrats, brothels, and the business of AIDS*. London: Granta Publications; 2008.
42. Farmer, Paul E, Nizeye, Bruce, et al. Structural violence and clinical medicine. *PLoS Med*. 2006; 3 (10): 1686-1691.
43. Porter, Dorothy. How did social medicine evolve, and where is it heading? *PLoS Med*. 2006; 3 (10): 1667-1672.
44. PLoS Medicine Editors, Stonington, Scott, et al. Social Medicine in the twenty-first century. *PLoS Med*. 2006; 3 (10): 1661-1662.
45. Kleinman, Arthur, Benson, Peter. Anthropology in the clinic: the problem of cultural competency and how to fix it. *PLoS Med*. 2006; 3 (10): e294.
46. Holtz, Timothy H, Holmes, Seth, et al. Health is still social: contemporary examples in the age of the genome. *PLoS Med*. 2006; 3 (10): e419.
47. Parkhurst, Justin O. The Uganda success story? Evidence and claims of HIV-1 prevention. *Lancet*. 2002; 360 (9326): 78-80.
48. Hunter, Mark. The changing political economy of sex in South Africa: the significance of unemployment and inequalities to the scale of the AIDS pandemic. *Soc Sci Med*. 2007; 64: 689-700.
49. Mangcu, Xolela. *To the brink: the state of democracy in South Africa*. Pietermaritzburg: University of KwaZulu-Natal Press; 2008.
50. Cohen, Jon. South Africa's new enemy. *Science*. 2000; 288 (5474): 2168-2170.
51. Mandela, Nelson. *Long walk to freedom*. Great Britain: Abacus; 1994.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

References cited

52. Meredith, Martin. *The state of Africa: a history of fifty years of independence*. Johannesburg: Jonathan Ball Publishers; 2006.
53. Cullinan, Kerry, Thom, Anso. *The virus, vitamins and vegetables*: Jacana Media (Pty) Ltd; 2009.
54. BBC News. Aids experts condemn SA minister. BBC News.co.uk; 2006 [cited 2009 18th August]; [online newspaper]. Available from: <http://news.bbc.co.uk/1/hi/world/africa/5319680.stm>.
55. The Economist. Beetroot but no blushes. Johannesburg August 24, 2006 [cited 2009 18th August]; [online newspaper]. Available from: http://www.economist.com/displayStory.cfm?story_id=7843324.
56. Baleta, Adele. "Dr Beetroot" sidelined in South Africa. Lancet. [newsdesk]. 2006 October 2006; 6.
57. Cohen, Jon. AIDS researchers decry Mbeki's views on HIV. Science. 2000; 288 (5466): 590-591.
58. Paton, Alan. *Cry, the beloved country*. New York: Scribner; 1948.
59. Mathabane, Mark. *Kafir boy: the true story of a black youth's coming of age in apartheid South Africa*: Simon & Schuster; 2006.
60. Forsyth, Brian, Vandormael, Alain, et al. The political context of AIDS-related stigma and knowledge in a South African township community. *Journal of Social Aspects of HIV/AIDS*. 2008; 5 (2): 74-82.
61. Phillips, Mark, Coleman, Colin. Another kind of war: strategies for transition in the era of negotiation. *Transformation*. 1989: 1-30.
62. Pembrey, Graham. HIV & AIDS in South Africa. [webpage]: avert.org; 2009 [updated 28th July 2009; cited 2009 19th August]; Available from: <http://www.avert.org/aidssouthafrica.htm>.
63. Coovadia, Hoosen, Jewkes, Rachel, et al. The health and health system of South Africa: historical roots of current public health challenges. *Lancet*. 2009; 374: 817-34.
64. South African Department of Health. *Health sector strategic framework 1999-2004*. 1999 [cited 2009 19th August]; Available from: <http://www.doh.gov.za/docs/policy/framework/chap01.html>.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

References cited

65. South African Department of Health. White paper for the transformation of the health system in South Africa. Pietermaritzburg: Ministry of Health. 1997.
66. Govender, Pregs. Love, courage, insubordination and HIV/AIDS denialism. In: Cullinan, Kerry, Thom, Anso, editors. *The virus, vitamins and vegetables: the South African HIV/AIDS mystery*. Auckland Park: Jacana; 2009. p. 36-57.
67. Cherry, Michael. The president's panel. In: Cullinan, Kerry, Thom, Anso, editors. *The virus, vitamins and vegetables: the South African HIV/AIDS mystery*. Auckland Park: Jacana; 2009. p. 16-35.
68. McGregor, Liz. Garlic, olive oil, lemons and beetroot. In: Cullinan, Kerry, Thom, Anso, editors. *The virus, vitamins and vegetables: the South African HIV/AIDS mystery*. Auckland Park: Jacana; 2009. p. 130-142.
69. Sidley, Pat. Clouding the AIDS issue. *BMJ*. [Press]. 2000; 320 (7240): 1016.
70. Steinberg, Jonny. *Three letter plague: a young man's journey through a great epidemic*. London: Vintage Books; 2009.
71. Ndaki, Kanya. Traditional alternatives? In: Cullinan, Kerry, Thom, Anso, editors. *The virus, vitamins and vegetables: the South African HIV/AIDS mystery*. Auckland Park: Jacana; 2009. p. 143-156.
72. Bryant, AT. *The Zulu people: as they were before the White man came*. Pietermaritzburg: Shuter and Shooter; 1967.
73. Kale, Rejandra. South Africa's health: traditional healers in South Africa: a parallel health care system. *BMJ*. 1995; 310: 1182-1185.
74. Wilkinson, D., Wilkinson, N. HIV infection among patients with sexually transmitted diseases in rural South Africa. *Int J STD AIDS*. 1998; 9 (12): 736-769.
75. King, Rachel. Collaborating with traditional healers for HIV prevention and care in sub-Saharan Africa: suggestions for programme managers and field workers: UNAIDS 2006.
76. Population Council and Health Systems Trust. *Understanding barriers to community participation in HIV and AIDS services: Report on research results dissemination meetings*. Johannesburg: The Population Council 2006.
77. Ministry of Health. *HIV/AIDS and STD strategic plan for South Africa 2000-2005*. Cape Town: Government of South Africa. 2000.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

References cited

78. Peltzer, Karl, Mngqundaniso, Nolwandle. Patients consulting traditional health practioners in the context of HIV/AIDS in urban areas in KwaZulu-Natal, South Africa. *Afr J Traditional, Complementary and Alternative Medicines*. 2008; 5(4): 370-379.
79. Stephen, Janine. "Saints and sinners": the Treatment Action Campaign In: Cullinan, Kerry, Thom, Anso, editors. *The virus, vitamins and vegetables: the South African AIDS mystery*. Auckland Park: Jacana; 2009. p. 157-174.
80. Treatment Action Campaign. *Campaigning for the rights of people with HIV/AIDS! | Treatment Action Campaign*. Creative Commons Attribution Share Alike 3.0 Unported License; 2009 [cited 2009 15 October]; Available from: <http://www.tac.org.za/>.
81. Khan, Haider Ali. *The political economy of sanctions against apartheid*. Boulder & London: Lynne Rienner Publishers; 1989.
82. Marshall, Sarah Jane. South Africa unveils national HIV/AIDS treatment programme. *Bulletin of the World Health Organization*. [News]. 2004; 82 (1): 73-74.
83. Geissler, PW, Pool, R. Editorial: Popular concerns about medical research projects in sub-Saharan Africa - a critical voice in debates about medical research ethics. *Trop Med Int Health*. 2006; 11(7): 975-982.
84. Networks, UN Integrated Regional Information. South Africa: men falling through the cracks. 2005 [cited 2009 24 August]; Available from: <http://www.aegis.com/news/irin/2005/IR050766.html>.
85. Africa Centre for Health and Population Studies. *ACDIS fieldwork manual*. [unpublished]; 2008.
86. South African Department of Health. *Based on the Mid-year estimates by Stats SA In Health*. Pietermaritzburg: 2006.
87. *State of the Population of KwaZulu-Natal: Demographic Profile and Development Indicators*: School of Development Studies, University of KwaZulu-Natal 2010.
88. Tanser, Frank, Hosegood, Victoria, et al. Cohort profile: Africa Centre Demographic Information System (ACDIS) and population-based HIV survey. *Int J Epidemiol*. 2007; 37 (5): 956-962.
89. Hosegood, Victoria, McGrath, Nuala, et al. The impact of adult mortality on household dissolution and migration in rural South Africa. *AIDS*. 2004; 18: 1585-1590.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

References cited

90. Shisana, O, Rehle, T, et al. South African national HIV prevalence, incidence, behaviour and communication survey 2008: a turning tide among teenagers? Cape Town 2009.
91. Welz, Tanya, Hosegood, Victoria, et al. Continued very high prevalence of HIV infection in rural KwaZulu-Natal, South Africa: a population-based longitudinal study. *AIDS*. 2007; 21: 1467-1472.
92. Cameron, Elaine, Bernardes, Jon. Gender and disadvantage in health: men's health for a change. *Sociology of Health & Illness*. 1998; 20 (5): 673-693.
93. White, Alan. Men's health: the challenges ahead. *J Mens Health Gend*. 2004; 1(4): 296-299.
94. O'Brien, Rosaleen, Hunt, Kate, et al. "It's caveman stuff, but that is to a certain extent how guys still operate:" men's accounts of masculinity and help seeking. *Soc Sci Med*. 2005; 61: 503-516.
95. Robertson, Lynn M, Douglas, Flora, et al. What works with men? A systematic review of health promoting interventions targeting men. *BMC Health Services Research*. 2008; 8 (141): 816-823.
96. Varga, Christine A. How gender roles influence sexual and reproductive health among South African adolescents. *Stud Fam Plann*. 2003; 34 (3): 160-172.
97. Wood, Katherine, Jewkes, Rachel. Violence, rape, and sexual coercion: everyday love in a South African township. *Gend Dev*. 1997; 5 (2): 41-46.
98. Varga, Christine A. The forgotten fifty per cent: a review of sexual and reproductive health research and programs focused on boys and young men in sub-Saharan Africa. *Afr J Reprod Health*. 2001; 5(3): 175-195.
99. Sternberg, Peter, Hubley, John. Evaluating men's involvement as a strategy in sexual and reproductive health promotion. *Health Promot Int*. 2004; 19 (3): 389-396.
100. Hawkes, Sarah, Hart, Graham. Men's sexual health matters: promoting reproductive health in an international context. *Trop Med Int Health*. 2000 Jul; 5 (7): A37-44.
101. Hibbard, J. H., Pope, C.R. Gender roles, illness orientation and use of medical services. *Social Science Medicine*. 1983; 17 (3): 129-37.
102. Morrell, Robert. Fathers, fatherhood and masculinity in South Africa. In: Morrell, Robert, Ritcher, Linda, editors. *Baba: men and fatherhood in South Africa*. Cape Town: HSRC Press; 2006.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

References cited

103. Rousseau, Nathan. *Self, symbols, and society: classic readings in social psychology*: Rowman & Littlefield Publishers; 2002.
104. Goffman, Erving. *The presentation of self in everyday life*: Penguin books; 1959.
105. Courtenay, Will H. Constructions of masculinity and their influence on men's well-being: a theory of gender and health. *Soc Sci Med*. 2000; 1385-1401.
106. Galdas, Paul M., Cheater, Francine, et al. Men and health help-seeking behaviour: literature review. *Integrative Literature Reviews and Meta-Analyses*. 2005; 49 (6): 616-623.
107. Gramsci, Antonio. *Selections from the prison notebooks of Antonio Gramsci*. Hoare, Quintin, Smith, Geoffrey Nowell, editors. New York: International Publishers; 1971.
108. Family Health International, HIV Prevention Trials Network. *Community Involvement in International Research: Lessons Learned from the HIV Prevention Trials Network*, Network, HIV Prevention Trials; 2006.
109. Johnson, WD, Hedges, LV, et al. Interventions to modify sexual risk behaviors for preventing HIV infection in men who have sex with men (review). *Cochrane Database of Systematic Reviews*. 2003; 4 (1): CD001230.
110. Herbst, Jeffrey H, Sherba, R Thomas, et al. A meta-analytic review of HIV behavioral interventions for reducing sexual risk behavior of men who have sex with men. *Acquir Immune Defic Syndr*. 2005; 39 (2): 228-241.
111. Villarruel, Antonia, III, Jolm B Jemmott, et al. A randomized controlled trial testing an HIV prevention intervention for Latino youth. *Arch Pediatr Adolesc Med*. 2006; 160: 772-777.
112. Jewkes, Rachel, Sikeyiya, Yandisa, et al. *Understanding men's health and use of violence: interface of rape and HIV in South Africa*. Pretoria: Gender and Health Research Unit, Medical Research Council 2009.
113. Mills, Edward J, Ford, Nathan, et al. Expanding HIV care in Africa: making men matter. *Lancet*. [Comment]. 2009 July 25, 2009; 374: 275-276.
114. Sternberg, Peter, White, Alan, et al. Damned if they do, damned if they don't: tensions in Nicaraguan masculinities as barriers to sexual and reproductive health promotion. *Men Masc*. 2007; 10 (5): 538-556.
115. myjoyonline.com. *Health Minister Wants Men to Bear Pregnancy*. 2006.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

References cited

116. Collumbien, Martine, Hawkes, Sarah. Missing men's messages: does the reproductive health approach respond to men's sexual health needs? *Cult Health Sex.* 2000; 2 (2): 135-150.
117. Montgomery, Catherine, Hosegood, Victoria, et al. Men's involvement in the South African family: engendering change in the AIDS era. *Soc Sci Med.* 2006; 62 (62): 2411-2419.
118. Olin, John, Kokolamami, Jacques, et al. Community preparedness for HIV vaccine trials in the Democratic Republic of Congo. *Cult Health Sex.* 2006; 8 (6): 529-544.
119. Fitzgerald, Molly, Collumbien, Martine, et al. "No one can ask me 'Why do you take that stuff?': men's experiences of antiretroviral treatment in South Africa. *AIDS Care.* 2010 22 (3): 355-60.
120. Hunter, Mark. *Love in the time of AIDS: inequality, gender, and rights in South Africa.* Bloomington and Indianapolis: Indiana University Press; 2010.
121. Krige, Eileen Jensen. *The social system of the Zulus.* 4th ed: Shuter & Shooter; 1962.
122. Bryant, AT. *Zulu medicine and medicine men: Centaur;* 1966.
123. Hunter, Mark. Cultural politics and masculinities: multiple-partners in historical perspective in KwaZulu-Natal. *Cult Health Sex.* 2005; 7(4): 389-403.
124. Hunter, Mark. Fathers without amandla: Zulu-speaking men and fatherhood. In: Ritchter, Linda, Morrell, Robert, editors. *Baba: Men and Fatherhood in South Africa.* Cape Town: HSRC Press; 2006. p. 99-107.
125. Morrell, Robert, Ritcher, Linda. Introduction. In: Morrell, Robert, Ritcher, Linda, editors. *Baba: men and fatherhood in South Africa.* Cape Town: HSRC Press; 2006.
126. Carton, Benedict. *Blood from your children: the colonial origins of generational conflict in South Africa: The University Press of Virginia;* 2000.
127. *Baba: men and fatherhood in South Africa.* Ritcher, Linda, Morrell, Robert, editors. Cape Town: HSRC Press; 2006.
128. Marcus, Tessa. Virginty testing: a backward-looking response to sexual regulation in the HIV/AIDS crisis. In: Carton, Benedict, Laband, John, et al., editors. *Zulu identities: being Zulu, past and present.* Pietermaritzburg: University of KwaZulu-Natal Press; 2008. p. 536-544.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

References cited

129. Hunter, Mark. AIDS and the changing political economy of sex in South Africa: from apartheid to neo-liberalism: University of KwaZulu-Natal. Available from: <http://scnc.ukzn.ac.za>.
130. Rabe, Maria Elizabeth. Black mineworkers' conceptualisations of fatherhood: a sociological exploration in the South African goldmining industry: University of South Africa; 2006.
131. Campbell, Catherine. Learning to kill? Masculinity, the family and violence in Natal. *J South Afr Stud.* [Special issue: political violence in southern Africa]. 1992; 18 (3): 614-628.
132. Khanyile, Nyanda, Godana, Patrick, editors. Engaging men to reduce children's vulnerability to HIV/AIDS and gender-based violence. 4th South African AIDS Conference; 2009; Durban: SA AIDS.
133. Justice, Snoke Gender. Snoke Gender Justice. Snoke Gender Justice; 2009 [cited 2009 15 October]; One Man Can Campaign]. Available from: <http://www.genderjustice.org.za/onemancan/>
134. Monakisi, Jeffrey, editor. Masculinity and prevention. 4th South African AIDS Conference; 2008; Durban.
135. Hussain-Gambles, Mahvash, Atkin, Karl, et al. Why ethnic minority groups are under-represented in clinical trials: a review of the literature. *Health and Social Care in the Community.* 2004; 12 (5): 382-388.
136. Killien, Marcia, Bigby, Judy Ann, et al. Involving minority and underrepresented women in clinical trials: the National Centers of Excellence in Women's Health. *J Womens Health Gend Based Med.* 2000; 9 (10): 1061-1070.
137. Sheikh, Aziz. Why are ethnic minorities under-represented in US research studies? *PLoS Med.* 2006; 3 (2e49): 0166-0167.
138. Shavers-Hornaday, Vicky L, Lynch, Charles F, et al. Why are Africa Americans under-represented in medical research studies? Impediments to participation. *Ethn Health.* 1997; 2 (1-2): 31-45.
139. Corbie-Smith, Giselle, Thomas, Stephen B, et al. Attitudes and beliefs of African Americans toward participation in medical research. *Journal of General Medicine.* 2001; 14 (9): 537-546.
140. Wendler, David, Kington, Raynard, et al. Are racial and ethnic minorities less willing to participate in health research? *PLoS Med.* 2006; 3 (2e19): 0201-0210.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

References cited

141. Corbie-Smith, Giselle. The continuing legacy of the Tuskegee syphilis study: considerations for clinical investigation. *American Journal of the Medical Sciences* 1999; 317 (1): 5-8.
142. Freimuth, Vicki S, Quinn, Sandra Crouse, et al. African American's views on research and the Tuskegee syphilis study. *Soc Sci Med.* 2001; 52: 797-808.
143. Gamble, Vanessa Northington. Under the shadow of Tuskegee: African Americans and health care. *Am J Public Health.* 1997; 87 (11): 1773-1778.
144. Bates, Benjamin R, Harris, Tina M. The Tuskegee study of untreated Syphilis and public perceptions of biomedical research: a focus group study. *J Natl Med Assoc.* 2004; 96 (8): 1051-1064.
145. Meinert, Curtis L. Redesign of trials under different enrolment mixes. *Stat Med.* 1999; 18: 241-251.
146. Geller, Nancy L. Commentary on 'Redisgn of trials under different enrolment mixes' by Curtis L Meinert. *Stat Med.* 1999; 18: 253-254.
147. Freedman, Laurence S, Simon, Richard, et al. Inclusion of women and minorities in clinical trials and the NIH Revitalization Act of 1993 - the perspective of NIH clinical trialists. *Control Clin Trials.* 1995; 16: 277-285.
148. United States National Institutes of Health. NIH Revitalization Act, Subtitle B, Part 1, Sec 131-133 [n.p.]: United States National Institutes of Health. 1993.
149. Woolson, Robert F, Jones, Martha F, et al. Discussion of "Inclusion of women and minorities in clinical trials and the NIH Revitalization Act of 1993 - the perspective of NIH clinical trialists". *Control Clin Trials.* 1995; 16: 301-303.
150. Taylor, Holly A. Inclusion of women, minorities, and children in clinical trials: opinions of Research Ethics Board administrators. *Journal of Empirical Research on Human Research Ethics: an International Journal.* 2009; 4 (2): 65-73.
151. Stewart, D, Wilson, R, et al. Patient and public involvement. *Ann Oncol.* 2011; Suppl 7: vii54-vii56.
152. INVOLVE. [cited 2013 10 August]; [homepage online]. Available from: <http://www.invo.org.uk/>.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

References cited

153. Donovan, Jenny, Milla, Nicola, et al. Quality improvement report: Improving design and conduct of randomised trials by embedding them in qualitative research: Protect (prostate testing for cancer and treatment) study. *BMJ*. 2002; 325 (7367): 766-769.
154. Friedman, Lawrence M, Furberg, Curt, et al. *Fundamentals of clinical trials*. New York: Springer-Verlag; 1998.
155. Bowling, Ann. *Research methods in health*. Third ed. Berkshire: McGraw Hill Open University Press; 2009.
156. Sanson-Fisher, Roberto William, Bonevski, Billie, et al. Limitations of the Randomised Controlled Trial in evaluating population-based health interventions. *Am J Prev Med*. 2007; 33 (2): 155-161.
157. Victoria, Cesar G, Habicht, Jean-Pierre, et al. Evidence-based public health: moving beyond randomized trials. *American Journal of Public Health*. 2004; 94 (3): 400-405.
158. Strauss, Ronald P, Sengupta, Sohini, et al. Willingness to volunteer in future preventative HIV vaccine trials: issues and perspectives from three US communities. *JAIDS*. 2001; 26 (1): 63-71.
159. Hays, Robert B, Kegeles, Susan. Factors related to the willingness of young gay men to participate in preventative HIV vaccine trial. *J Acquir Immune Defic Syndr Hum Retrovirol*. 1999; 20: 164-171.
160. Info, AIDS. What is an HIV/AIDS clinical trial? 2005 [cited 2013 17 August]; Available from: http://aidsinfo.nih.gov/contentfiles/WhatIsAClinicalTrial_FS_en.pdf.
161. Network, HIV Vaccine Trials. Volunteer FAQs. [cited 2013 17 August]; Available from: <http://www.hvtn.org/science/volunteerfaqs.html>.
162. Pool, Robert, Montgomery, Catherine M, et al. A mixed methods and triangulation model for increasing the accuracy of adherence and sexual behaviour data: the Microbicides Development Programme. *PLoS One*. 2010; 5 (7 (e11600)): 1-8.
163. Allen, Louisa. Managing masculinity: young men's identity work in focus groups. *Qualitative Research*. 2005; 5 (1): 35-58.
164. Pini, Barbara. Interviewing men: gender and the collection and interpretation of qualitative data. *Journal of Sociology*. 2005; 41(2): 201-216.
165. Oliffe, John, Bottorff, Joan L. Innovative practice: ethnography and men's health research. *J Mens Health Gen*. 2006; 3 (1): 104-108.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

References cited

166. Schwalbe, Michael, Wolkomir, Michelle. The masculine self as problem and resource in interview studies of men. *Men Masc.* 2001; 4 (1): 90-93.
167. Robiner, William N, Yozwiak, John A, et al. Barriers to clinical research participation in a diabetes randomized clinical trial. *Soc Sci Med.* 2009; 68: 1069-1074.
168. Scott, BE, Weiss, HA, et al. The acceptability of male circumcision as an HIV intervention among a rural Zulu population, KwaZulu-Natal, South Africa. *AIDS Care.* 2005; 17 (3): 304-313.
169. Auvert, Bertran, Taljaard, Dirk, et al. Randomized, controlled intervention trial of male circumcision for reduction of HIV infection risk: the ANRS 1265 trial. *PLoS Med.* 2005; 2 (11): 1112-1122.
170. Joint United Nations Programme on HIV/AIDS. Ethical considerations in biomedical HIV prevention trials. Geneva: UNAIDS 2007.
171. AVAC. Good participatory practice: guidelines for biomedical HIV prevention trials 2011. Geneva: Joint United Nations Programme of HIV/AIDS 2011.
172. Westercamp, N, Bailey, RC. Acceptability of male circumcision for prevention of HIV/AIDS in sub-Saharan Africa: a review. *AIDS Behav.* 2007; 11: 341-355.
173. McGrory, E, Irvin, A, et al. Research rashomon: lessons from the Cameroon pre-exposure prophylaxis trial site. Washington DC: Global Campaign for Microbicides at PATH 2009.
174. Page-Shafer, Kimberly, Saphonn, Vonthanak, et al. HIV prevention research in a resource-limited setting: the experience of planning a trial in Cambodia. *Lancet.* 2005; 366.
175. Bailey, Robert C, Moses, Stephen, et al. Male circumcision for HIV prevention in young men in Kisumu, Kenya: a randomised controlled trial. *Lancet.* 2007; 369: 643-56.
176. Dhalla, S., Nelson, K., et al. HIV vaccine preparedness studies in the non-organization for economic co-operation and development (non-OCED) countries. *AIDS Care.* 2009; 21 (3).
177. Grant, Robert M, Lama, Javier R, et al. Preexposure chemoprophylaxis for HIV prevention in men who have sex with men. *N Engl J Med.* 2010; 363 (27): 2587-2599.
178. Office of the President. Non-Profit Organisations Act, 1997. Cape Town: Government Gazette. 1997.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

References cited

179. South African Medical Research Council. Guidelines on ethics for medical research: HIV preventive vaccine research 2003.
180. Newman, Peter A. Towards a science of community engagement. *Lancet*. [Correspondence]. 2006; 367 (9507): 302.
181. Cousins, Thomas. Report on reflective practice: internal process reflection on participation rates in HIV surveillance in the DSA. [Unpublished internal report]. 2009.
182. Cornwall, Andrea, Jewkes, Rachel. What is participatory research? *Soc Sci Med*. 1995; 41 (12): 1667-1676.
183. Penzhorn, Cecilia. Participatory research: Opportunities and challenges for research with women in South Africa. *Womens Stud Int Forum*. 2005; 28: 343-354.
184. Hall, Budd L. From margins to center? The development and purpose of participatory research. *Am Sociol*. 1992; 23 (4): 15-28.
185. Reason, Peter, Bardbury, Hilary, editors. *The Sage handbook of action research: participative inquiry and practice*. Second edition: Sage Publications; 2008.
186. Whyte, William F. Advancing scientific knowledge through participatory action research. *Sociological Forum*. 1989; 4(3): 367-385.
187. Whyte, William F, editor. *Participatory action research*: Sage publications; 1991.
188. Mosavel, Maghboeba, Simon, Christian, et al. Community-based participatory research (CBPR) in South Africa: engaging multiple constituents to shape the research question. *Soc Sci Med*. 2005; 61: 2577-2587.
189. Ansari, W El, Phillips, CJ, et al. Narrowing the gap between academic professional wisdom and community lay knowledge: preceptions from partnerships. *Public Health*. 2002; 116: 151-159.
190. Ansari, W El. Collaborative research partnerships with disadvantaged communities: challenges and potential solutions. *Public Health*. 2005; 119: 758-770.
191. Central Intelligence Agency. *The world factbook - country comparison: distribution of family income - gini index*. CIA; 2012 [updated biweekly 15 January 2012]; [electronic report]. Available from: <https://http://www.cia.gov/library/publications/the-world-factbook/rankorder/2172rank.html>.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

References cited

192. UNAIDS. Good participatory practice: guidelines for biomedical HIV prevention trials. [n.p.]: Joint United Nations Programme of HIV/AIDS; 2007.
193. Newman, Peter A, Duan, Naihua, et al. HIV vaccine acceptability among communities at risk: the impact of vaccine characteristics. *Vaccine*. 2006; 24: 2094-2101.
194. MacQueen, Kathleen M. Framing the social in biomedical HIV prevention trials: a 20-year perspective. *JAIDS*. 2011; 14 (suppl 2) (S3): 1-8.
195. McKnight, John L, Kretzman, John P. Mapping community capacity. In: Minkler, Meredith, editor. *Community organizing and community building for health*. 2nd ed. New Brunswick, New Jersey and London: Rutgers University Press; 2007.
196. Taylor-Ide, Daniel, Taylor, Carl E. *Just and lasting change: The Johns Hopkins University Press*; 2002.
197. Campbell, Catherine, Jovchelovitch, Sandra. Heath, community and development: towards a social psychology of participation. *J Community Appl Soc Psychol*. 2000; 10 (4): 255-270.
198. Labonte, Ronald. Community, community development, and the forming of authentic partnerships: Some critical reflections. In: Minkler, Meredith, editor. *Community Organizing and Community Building for Health*. New Brunswick, NJ: Rutgers University Press; 1997. p. 88-101.
199. Freire, Paulo. *Pedagogy of the oppressed*. New revised 20th anniversary ed. New York: The Continuum Publishing Company; 1995.
200. Minkler, Meredith, Pies, Cheri. Ethical issues and practical dilemmas in community organization and community participation. In: Minkler, Meredith, editor. *Community organizing and community building for health*. 2nd ed. New Brunswick, New Jersey and London: Rutgers University Press; 2007.
201. Song, Miri, Parker, David. Commonality, difference and the dynamics of disclosure in in-depth interviewing. *Sociology* 1995; 29 (2): 241-256.
202. Lewis, Diane. Anthropology and colonialism. *Current Anthropology*. 1973; 14 (5): 581-602.
203. Merriam, Sharan B, Johnson-Bailey, Juanita, et al. Power and positionality: negotiating insider/outsider status within and across cultures. *International Journal of Lifelong Education*. 2001; 20 (5): 405-416.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

References cited

204. Essack, Zaynab, Koen, Jennifer, et al. Stakeholder perspectives on ethical challenges in HIV vaccine trials in South Africa. *Dev World Bioeth.* 2010; 10 (1): 11-21.
205. Barry, Michele. Ethical considerations of human investigation in developing countries. *N Engl J Med.* 1988; 319 (16): 1083-1086.
206. Goodenough, Ward Hunt. *Cooperation in change: an anthropological approach to community development.* 5th ed. New York: Russell Sage Foundation; 1963.
207. Walter, Cheryl L. Community building practice: a conceptual framework. In: Minkler, Meredith, editor. *Community organizing and community building for health.* 2nd ed. New Brunswick, New Jersey and London: Rutgers University Press; 2007.
208. Barnard, Alan. *History and theory in anthropology.* Cambridge: Cambridge University Press; 2000.
209. Crisp, Richard J, turner, Rhiannon N. *Essential social psychology.* 2nd ed. London: Sage Publications Ltd.; 2010.
210. Hayes, Nick, Orrell, Sue. *Psychology: an introduction.* 3rd ed. Essex: Longman Group UK Ltd.; 1998.
211. Holland, Dorothy, Jr, William Lachicotte, et al. *Identity and agency in cultural worlds:* Harvard University Press; 1998.
212. Campbell, Catherine, MacPhail, Catherine. Peer education, gender and the development of critical consciousness: participatory HIV prevention by South African youth. *Soc Sci Med.* 2002; 55: 331-345.
213. Dlamini, Jacob. *Native nostalgia:* CTP Book Printers; 2009.
214. Moletsane, Relebohile, editor. *Cultural nostalgia in the age of AIDS in South Africa: swimming against the tide?* Southern African AIDS Conference; 2009; Durban.
215. Campbell, Catherine, Gillies, Pamela. Conceptualizing 'social capital' for health promotion in small communities: a micro-qualitative study. *J Community Appl Soc Psychol.* 2001; 11: 329-346.
216. Hawe, Penelope, Shiell, Alan. Social capital and health promotion: a review. *Soc Sci Med.* 2000; 51 (2000): 871-885.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

References cited

217. Campbell, Catherine. Embracing complexity: towards more nuanced understandings of social capital and health. *Glob Health Action*. 2011; 4 (5964).
218. Putnam, Robert D. *Bowling alone: the collapse and revival of American community*. New York: Simon & Schuster; 2000.
219. Whitehead, Margaret, Diderichsen, Finn. Social capital and health: tip-toeing through the minefield of evidence. *Lancet*. [Commentary]. 2001; 358: 165-166.
220. Berg, Bruce L. *Qualitative research methods for the social sciences*. Fifth ed. Boston: Pearson Education Inc.; 2004.
221. Whyte, William Foote. Encounters with participatory action research. *Qualitative Sociology*. 1995; 18 (3): 289-299.
222. Greenwood, Davydd J, Whyte, William Foote, et al. Participatory action research as a process and as a goal. *Human Relations*. 1993; 46 (2): 175.
223. Minkler, Meredith, editor. *Community organizing and community building for health*. 2nd ed. New Brunswick, New Jersey and London: Rutgers University Press; 2007.
224. Robson, Colin. *Real world research*. Second ed. Malden, MA; Oxford, UK; Victoria, Australia: Blackwell Publishing; 2002.
225. Sieber, Sam D. The intergration of fieldwork and survey methods. *The American Journal of Sociology*. 1973; 78 (6): 1335-1359.
226. Zagumny, Matthew J., Brady, D. Brian. Development of the AIDS Health Belief Scale (AHBS). *AIDS Educ Prev*. 1998; 10 (2): 173-179.
227. Charmaz, Kathy. *Constructing grounded theory: a practical guide through qualitative analysis*. London: Sage Publications; 2006.
228. Barter, Christine, Renold, Emma. The use of vignettes in qualitative research. *Social Research Update* [serial on the Internet]. 1999; (25): Available from: <http://sru.soc.surrey.ac.uk/SRU25.html>.
229. Price, Neil, Hawkins, Kirstan. Researching sexual and reproductive behaviour: a peer ethnographic approach. *Soc Sci Med*. 2002; 55: 1325-1336.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

References cited

230. Dawson, Susan, Manderson, Lenore, et al. A manual for the use of focus groups: methods for social research in disease. Boston, MA, USA: International Nutrition Foundation for Developing Countries 1993.
231. Ritchie, Jane, Lewis, Jane, editors. Qualitative research practice. London: Sage Publications; 2003.
232. Starace, F, Wagner, T M, et al. Knowledge and attitudes regarding preventative HIV vaccine clinical trials in Italy: results of a national survey. *AIDS Care*. 2006; 18 (1): 66-72.
233. Mills, Edward, Cooper, Curtis, et al. Barriers to participating in an HIV vaccine trial: a systematic review. *AIDS*. 2004; 18: 2235-2242.
234. Jenkins, Richard A, Chinaworapong, Suchada, et al. Motivation, recruitment, and screening of volunteers for a phase I/II HIV preventive vaccine trial in Thailand. *J Acquir Immune Defic Syndr Hum Retrovirol*. 1998; 18 (2): 171-177.
235. Middlekoop, Keren, Myer, Landon, et al. Adolescent and adult participation in an HIV vaccine trial preparedness cohort in South Africa. *J Adolesc Health*. 2008; 43: 8-14.
236. Newell, Colin. Africa Centre Demographic Information System (ACDIS) analytical dataset documentation. HSE7 2010, 2009.
237. Mid-year population estimates 2011. Pretoria: Statistics South Africa 2012.
238. Ministerial committee on learner retention in the South African schooling system. Progress report to the Minister of Education 2007.
239. Department of basic education South Africa. Education statistics in South Africa 2009. [n.p.]: Department of basic education, South Africa 2010.
240. Bhorat, Haroon, Kanbur, Ravi. Poverty and policy in post apartheid South Africa. [n.p.]: HSRC Press 2006.
241. Peltzer, Karl. Traditional health practitioners in South Africa. *Lancet*. 2009; 374 (09): 956-957.
242. Shisana, O, Rehle, T, et al. South African national HIV prevalence, HIV incidence, behaviour and communication survey, 2005. Cape Town: Nelson Mandela Foundation 2005.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

References cited

243. Snow, R C, Madalane, M, et al. Are men testing? Sex differentials in HIV testing in Mpumalanga province, South Africa. *AIDS Care*. 2010; 22 (9): 1060-1065.
244. Community involvement in international research: lessons learned from the HIV Prevention Trials Network: Family Health International, HIV Prevention Trials Network 2006.
245. Dodds, Julie P, Mercer, Catherine H, et al. Men who have sex with men: a comparison of a probability sample survey and a community based study. *Sex Transm Infect*. 2006; 82 (1): 86-87.
246. Hennekens, Charles H, Buring, Julie E. *Epidemiology in medicine*. Mayrent, Sherry L, editor. Philadelphia: Lippincott Williams & Wilkins; 1987.
247. Alegi, Peter. The sport of Zuluness: masculinity, class and cultural identity in twentieth century Black soccer. In: Carton, Benedict, Laband, John, et al., editors. *Zulu Identities: Being Zulu, Past and Present*. Pietermaritzburg: UKZN Press; 2008. p. 273-280.
248. Ganguli, M, Lytle, ME, et al. Random versus volunteer selection for a community-based study *Journals of Gerontology Series A-Biological Sciences and Medical Sciences*. 1998; 53 (1): M39-M46.
249. Peil, Margaret. *Social science research methods: an African handbook*. London: Hodder & Stoughton; 1982.
250. Garmaise, David, Avdeeva, Yana, et al. *Community involvement in HIV vaccine research: making it work*. [n.p.]: International Council of AIDS Service Organizations 2006.
251. Clark, Tom. 'We're over-researched here!': Exploring accounts of research fatigue within qualitative research engagements. *Sociology*. 2008; 42 (5): 953-970.
252. Bentley, JP, Thacker, PG. The influence of risk and monetary payment on the research participation decision making process. *J Med Ethics*. 2004; 30: 293-298.
253. Cryder, Cynthia E, London, Alex John, et al. Informative inducement: study payment as a signal of risk. *Soc Sci Med*. 2010; 70: 455-464.
254. Kwagala, Betty, Wassenaar, Douglas, et al. Payment and direct benefits in HIV/AIDS related research projects in Uganda. *Ethics & Behavior*. 2010; 20 (2): 95-109.
255. SAPA. Murder rates highest in rural areas. *News 24* [newspaper article online]. 2011 [cited 2011 19 January]: Available from:

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

References cited

<http://www.news24.com/SouthAfrica/News/Murder-rates-highest-in-rural-areas-20110119>.

256. South African Police Service. Crime in Hlabisa (KZN) for April to March 2003/2004 - 2010/2011. [n.p.] 2011.
257. Plescia, Carolyn. Clinical trial site capacity catalogue: a project of the microbicide donors committee quick working group. Silver Spring, Maryland: Alliance for Microbicide Development 2008.
258. Jewkes, Rachel K, Levin, Jonathan B, et al. Gender inequalities, intimate partner violence and HIV prevention practices: findings of a South African cross-sectional study. *Soc Sci Med.* 2003; 56 (2003): 125-134.
259. Wood, Katherine, Maforah, Fidelia, et al. "He forced me to love him:" putting violence on adolescent sexual health agendas. *Soc Sci Med.* 1998; 47 (2): 233-242.
260. Africa Centre for Health and Population Studies. Preparing communities for a trial of early treatment as prevention. [10 March 2012]; Available from: <http://www.africacentre.ac.za/Default.aspx?tabid=261>.
261. Smith, Jackie, Setswe, Geoffrey, et al., editors. Track 4: social and economic sciences report back. Southern African AIDS conference; 2011; Durban.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Appendix 1: Ethical review board approvals

Appendix 1: Ethical review board approvals

1.1 University College London Ethical Review Board approval

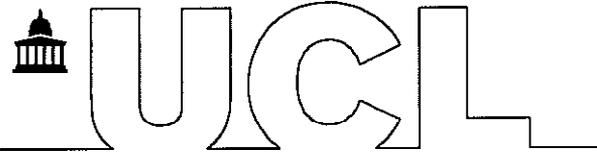
1.2 University College London Ethical Review Board continuing approval

1.3 University of KwaZulu-Natal Humanities and Social Science Ethical Review Board approval

1.4 University College London Ethical Review Board amendment approval

1.5 University of KwaZulu-Natal Humanities and Social Science Ethical Review Board amendment approval

1.6 University of KwaZulu-Natal Biomedical Ethics Review Board approval



Professor Marie-Louise Newell
Department of Paediatric Epidemiology
UCL Institute of Child Health
30 Guilford Street
London

27 July 2009

Dear Professor Newell

Notification of Ethical Approval

Ethics Application: 1934/001: Impilo Yamadoda: Men's Health Survey

I am pleased to confirm that further to your satisfactory responses to the committee's comments, your study has been approved by the UCL Research Ethics Committee for the duration of the project, i.e. until August 2010.

Approval is subject to the following conditions:

1. You must seek Chair's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form'.

The form identified above can be accessed by logging on to the ethics website homepage: <http://www.grad.ucl.ac.uk/ethics/> and clicking on the button marked 'Key Responsibilities of the Researcher Following Approval'.

2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. Both non-serious and serious adverse events must be reported.

Reporting Non-Serious Adverse Events.

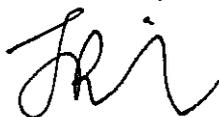
For non-serious adverse events you will need to inform Ms Helen Dougal, Ethics Committee Administrator (h.dougal@ucl.ac.uk), within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair of the Ethics Committee will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Reporting Serious Adverse Events

The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.

On completion of the research you must submit a brief report (a maximum of two sides of A4) of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

Yours sincerely



Sir John Birch
Chair of the UCL Research Ethics Committee

Cc: Sebastian Fuller



Annual Continuing Review Approval Form

It is a requirement of the UCL Research Ethics Committee that research projects which have received ethical approval by the Committee are monitored annually. Therefore, this form must be completed and returned **PRIOR** to the date that the current approval expires. If your project has ceased or was never initiated, it is still important that you complete this form so that we can ensure that our records are updated accordingly.

1	ID Number: Application 1855/004 1934/001	Principal Investigator: Prof. Marie-Louise Newell
2	Project Title: Impilo Yamadoda: Men's Health Study	
3	Current Approval Expires: 1 August 2010	
4	Project Status: (please tick relevant box) <input checked="" type="checkbox"/> Active <input type="checkbox"/> Terminated	
5	Current Status of Human Participant Use: Beginning date: 1/09/09 Date completed (if applicable): Total Number enrolled to date: 720	
6	Human participants will no longer be used. Please explain:	
7	If funded study, please indicate: Agency: European and Developing Countries Clinical Trial Partnership Project Period: Agency Award Number:	
8	Number of participants who withdrew from the project: NONE Please provide reasons for withdrawal: N/A	

9 Have you modified your research since your last review? Yes No

If so, you are required to submit a revised application form to the Committee for review.

10 Please provide with this form a brief report describing the progress of your study thus far.

Include a description of any **adverse or unforeseen circumstances** arising out of the research project (e.g. a complaint by a participant, an incident endangering a research worker taking a questionnaire out to a population study, etc) together with a summary of any recent literature, findings, or other relevant information associated with your study.

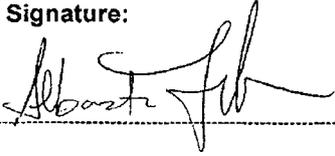
There have been no adverse events in this research project.

In the initial phase of the project we completed identification of volunteers ('Research Partners') to administer a short survey to men over 16 years of age in their home or work communities. Survey data collection exceeded expectations (n=300 expected) with 978 men approached and 696 agreeing to take part. Of those men who agreed to complete the survey 543 consented to leave their contact information with us for participation in later stages of data collection. This survey phase ended 1st February 2010. All survey data are currently being analysed and once completed, will be reported back to the community and stakeholders via survey administrators and Africa Centre Community Advisory Board updates.

Survey participants consenting to survey follow-up were purposively sampled by age and location to participate in either an individual In-Depth Interview (IDI) or a Focus Group Discussion (FGD). 20 IDIs and eight FGDs were undertaken from November 2009 to June 2010. Data from this qualitative phase is currently being prepared for analysis.

All Research Partners agreed to be contacted for follow-up using IDI; 12 were identified as suitable to represent the sample of 24. Six IDIs of survey administrators took place in March 2010. We are currently completing a primary analysis of this data before completing the 6 outstanding interviews, which follows the grounded theory analysis technique detailed in our application.

We expect to terminate the project following the collection of the remaining IDIs with survey administrators, which is expected to be early September 2010.

Print Name: Sebastian S Fuller	Signature: 	Date: 8 July 2010
--	--	-----------------------------

FOR OFFICE USE ONLY:

Approval

The continuing monitoring of this protocol has been reviewed and approved by the Committee. The re-approval date is 01/08/2010 and is valid for 1 year from this date, until 01/10/2010

Signed: Angela Fuller (Secretary of the UCL REC)

Please return completed form to:

03/08/2010

Secretary of the UCL Research Ethics Committee
Graduate School
North Cloisters, Wilkins Building
Gower Street
London
WC1E 6BT

RESEARCH OFFICE (GOVAN MBEKI CENTRE)
WESTVILLE CAMPUS
TELEPHONE NO.: 031 – 2603587
EMAIL : ximbap@ukzn.ac.za

20 OCTOBER 2009

MR. SS FULLER
CENTRE FOR SEXUAL HEALTH & HIV RESEARCH
(AFRICA CENTRE FOR HEALTH & POPULATION STUDIES)

Dear Mr. Fuller

ETHICAL CLEARANCE APPROVAL NUMBER: HSS/0252/09

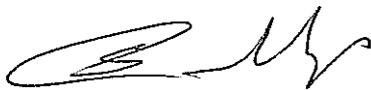
I wish to inform you that your application for ethical clearance has been granted full approval for the following project:

“Impilo Yamadoda (Men's Health)”

PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully



.....
PROFESSOR STEVEN COLLINGS (CHAIR)
HUMANITIES & SOCIAL SCIENCES ETHICS COMMITTEE

cc. Prof. M Newell
cc. Prof. J Imrie
cc. Prof. G Hart
cc. Ms. S Grobler

Mr Sebastian Fuller
Research Department of Infection & Population Health
Centre for Sexual Health & HIV Research
Mortimer Market
Capper Street
London
WC1E 6JB

16 February 2010

Dear Mr Fuller

Re: Ethics Application: 1934/001: Impilo Yamadoda: Men's Health Study

Further to your email of 3 February, I am pleased to confirm that the Vice-Chair has approved your request to include an additional set of in-depth interviews with community leaders who have been involved in the research project as organisers and survey administrators to the above study.

As always, please notify the Administrator of the Ethics Committee if you propose to make any further amendments.

It is also your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others.

On completion of the research you must submit a brief report (a maximum of two sides of A4) of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

With best wishes

Yours sincerely

Sir John Birch
Chair of the UCL Research Ethics Committee

Cc. Professor Marie-Louise Newell
Professor Graham Hart

UCL Research Ethics Committee
c/o Graduate School
North Cloisters
Wilkins Building
Gower Street
London WC1E 6BT

Tel: 020 7679 7844
Fax: 020 7679 7043
Email: ethics@ucl.ac.uk

RESEARCH OFFICE (GOVAN MBEKI CENTRE)
WESTVILLE CAMPUS
TELEPHONE NO.: 031 – 2603587
EMAIL : sshrec@ukzn.ac.za

9 DECEMBER 2009

**MR. SS FULLER
CENTRE FOR SEXUAL HEALTH & HIV RESEARCH
AFRICA CENTRE FOR HEALTH & POPULATION STUDIES**

Dear Mr. Fuller

PROTOCOL REFERENCE NUMBER: HSS/0252/09
PROJECT TITLE: "IMPILO YAMODDA (MEN'S HEALTH STUDY)"

FULL APPROVAL NOTIFICATION – AMENDMENT

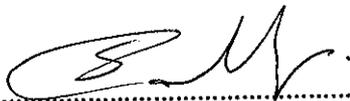
This letter serves to notify you that your application for an amendment has been granted full approval through an expedited review procedure:

Any alterations to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study must be reviewed and approved through an amendment /modification prior to its implementation. Please quote the above reference number for all queries relating to this study.

PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years

Best wishes for the successful completion of your research protocol.

Yours faithfully



.....
**PROFESSOR STEVEN COLLINGS (CHAIR)
SOCIAL SCIENCES & HUMANITIES RESEARCH ETHICS COMMITTEE**

cc. Newell M Prof.
cc. Imrie J Prof.
cc. Hart G Prof.
cc. Grobler S Ms.



RESEARCH OFFICE
Biomedical Research Ethics Administration
Westville Campus, Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za
Website: <http://research.ukzn.ac.za/ResearchEthics/BiomedicalResearchEthics.aspx>

27 July 2010

Prof. J Imrie
Africa Centre for Health and Population Studies
Mtubatuba
3935
KwaZulu- Natal

Dear Prof Imrie

PROTOCOL: Impilo Yamadoda: Men's Health Study. REF: BE057/010

EXPEDITED APPLICATION

A sub-committee of the Biomedical Research Ethics Committee has considered and noted your application dated 08 March 2010.

The study was approved pending appropriate responses to queries raised. Your responses dated 19 June 2010 to queries raised on 20 May 2010 have been noted by a sub-committee of the Biomedical Research Ethics Committee. The conditions have now been met and the study is given full ethics approval and may begin as from 27 July 2010.

This approval is valid for one year from **27 July 2010**. To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2004), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements

as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at <http://research.ukzn.ac.za/ResearchEthics11415.aspx>.

BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

The sub-committee's decision will be **RATIFIED** at a full sitting of the Biomedical Research Ethics Committee meeting to be held on **10 August 2010**.

We wish you well with this study. We would appreciate receiving copies of all publications arising out of this study.

Yours sincerely

A handwritten signature in black ink, appearing to read 'D.R. Wassenaar', written in a cursive style.

Professor D.R Wassenaar
Chair: Biomedical Research Ethics Committee

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Appendix 2: Phase 2 survey

Appendix 2: Phase 2 survey

2.1 Phase 2 survey: Information Sheet

2.2 Phase 2 survey: Questionnaire

2.3 Phase 2 survey: Contact Sheet

2.4 Phase 2 survey: Participation rate log

Impilo Yamadoda: Survey Information Sheet

What is this study about?

Africa Centre researchers have gathered a great deal of information about the lives and living conditions of people and households in the Hlabisa sub-district. In a number of other studies we have also learned a great deal about HIV/AIDS and women and children. However, over the years, very little has been recorded about the health needs, beliefs, and practices of Zulu men in the Hlabisa sub-district. Africa Centre researchers are currently conducting a study in this area that is specifically focused on men to try to gain an understanding from Zulu men about your own views on health needs and practices. By increasing our understanding of men's health needs and beliefs we can make the prospect of participating in health research an attractive one for you.

If more men participate in health research, researchers are able to understand how to ensure health care improvement initiatives specifically include men. We believe that if there are better health opportunities for men, then men will become more engaged, and that positively engaged men will be able to live healthier lives. When men are healthier it helps to create a healthier community overall.

What is my role in the study?

We would like you to complete a short **anonymous survey questionnaire**. The survey asks you about where you spend your time, if you have access to a cell phone, your employment status and membership in community groups/organisations, your general health and HIV specific health concerns, attitudes to HIV prevention, and your interest in various parts of health research. There are **no** elements to this phase where we will ask you to provide biological specimens (such as blood).

Once you have finished the survey we will ask you if you are interested in helping us further with our research by participating in an individual interview or a group discussion. In these discussions we would like to ask you in a bit more detail about your own or your community's health beliefs and concerns and why men do or do not participate in HIV related research. In order to participate further in the study you will need to provide us with some contact information so we can get in touch and arrange a time to meet again. You are under **no obligation** to give us your contact information, even if you decide to complete the survey questionnaire. If you do decide to give us your contact information you are under **no obligation** to continue with the research and may withdraw from the study at any time. If you change your mind after completing the contact sheet and no longer wish to be involved please inform our study representatives (named below) and we will cease future contact with you. There will be no negative consequence to you if you decide not to give your contact information or if you withdraw your involvement in future research at a later date.

How will my confidentiality be protected?

This survey is anonymous; there is nowhere on this form where your name or contact information will be recorded.

Submission of a completed questionnaire implies consent to participate. As participation is anonymous it will not be possible for us to withdraw your completed questionnaire once you have returned it to us.

If you choose to keep in contact with us please complete the contact form with the person administering your questionnaire. Your *Impilo Yamadoda* research representative should keep your questionnaire and contact form in separate envelopes once they have been completed. If you have any questions or concerns about this process please contact the study staff using the contact information below.

Sebastian Fuller, Project Leader; **Contact number: 035 550 7670; Cell: 076 408 8160**
Nkululeko Mngomezulu, Research Assistant; **Contact number: 035 550 7614; Cell: 079 851 1427**

If you would like to speak to someone outside the research team for any reason relating to your participation in this project, please contact: **Mduduzi Mahlinza**, Community Liaison Office; **Contact number: 035 550 7500**

Physical address: Africa Centre for Health & Population Studies, R618 en route to Hlabisa, Somkhele.

*The University KwaZulu-Natal Human & Social Sciences Ethics Board has approved this study
This study has been approved by the University College London Ethics Board Project ID# 1934/001*



Impilo Yamadoda: Men's Health Survey Questionnaire

Administrator read aloud: Thank you for agreeing to take part in this important research on men's health. This survey is anonymous, which means that we will not collect your name or contact details on this form. Please answer the questions as honestly as possible.

You do not have to provide contact information in order to take part in this survey. However, if you would like to be involved with further research conducted by Africa Centre you can provide us with your contact details after the interview is completed. Your contact details will be kept separate from your completed questionnaire in order to make sure that your identity is not matched to your answers to these questions.

I. Demographics

1. What is your current age? _____ Years
2. What is your current marital status?
 - Married
 - Engaged/not yet married
 - Single
 - Widowed
 - Divorced
3. How many people are **current residents** of your household? (*Interviewer - Current residents are people that live in your house at this time.*) _____
4. What is the highest education grade you have completed? _____

II. Cell Phone Data

5. Do you own a cell phone?
 - Yes → Q. 6
 - No → Q. 9
6. Do you share this cell phone with anyone else? [*Interviewer - By sharing a phone we mean that you and one or more other people use the phone at different times as a main source of telephone contact.*]
 - Yes
 - No → Q. 9
7. Do you share your cell phone number with anyone? [*Interviewer - By sharing a number we mean that you and one or more other people use the same number at different times as a main source of telephone contact.*]
 - Yes
 - No → Q. 9
8. Who do you share your cell phone number with?
Tick all that apply
 - Wife
 - Girlfriend
 - Brother/sister
 - Children
 - Friend
 - Other (name relationship) _____

III. Daily Activities, Work, and Community Involvement

9. Are you currently employed?
 - Yes → Q. 10
 - No → Q. 15



10. In a typical working day, how many hours do you work? _____ Hours

11. In a typical working week how many days do you work? _____ Days

12. What mode of transport do you use to get to work?

Tick all that apply

- Taxi
- Driving own car
- Carpool/ Lift club [joining a car with others going to the same place]
- Car lift from employer
- Bicycle
- Walking/By foot
- Other _____
- None [for example: working at home]

13. How long does it take you to travel **to** work each day (*one way*)? _____ Minutes _____ Hours

14. When you have completed work where do you spend your time?

_____ → Q. 16

15. If you are **currently unemployed**, what do you do in the time that others are working?

16. Do you belong to any of the following organizations?

Tick all that apply

- Burial Society
- Community garden group
- Farmer's Association
- Sports group (indicate which sport) _____
- Study group
- Choir or music group
- Youth group
- Informal trader's group
- Men's association
- Church group
- Stokvel
- School committee
- Water committee
- Policing forum
- Development committee
- Tribal authority (chief, induna, councillor)
- Community health worker
- Other (*please indicate*) _____

IV. (General) Health/ Health Interests:

17. How would you describe your general health at present?

- Excellent/ Very good/ Good
- Fair
- Poor



18. We are interested in knowing what aspects of health are of concern to men. Please indicate if you are interested in learning about the following: *Tick all that apply*

- Diabetes
- Blood pressure
- Heart disease
- HIV/AIDS
- Sexually transmitted infections (other than HIV)
- Men's nutrition & fitness
- Mental health issues
- Alcohol use
- Tobacco use
- Male circumcision
- Using traditional medicines and Western medicines together
- Violence
- Physical or sexual abuse
- Vehicle Safety
- Other (*please indicate*) _____

V. HIV/AIDS specific:

19. Do you know anyone who has tested for HIV?

- Yes
- No
- Don't know

20. Have you ever requested and had an HIV test?

- Yes
- No
- Don't know

VI. Health Research

21. We are interested in developing programmes that give information to men on the different ways that help to prevent the spread of HIV. Would you be willing to be a research participant in a HIV prevention education programme for men?

- Yes
- No → Q. 24
- Don't know/Undecided

22. If the following programmes to learn about HIV prevention were to take place, which would you be willing to participate in?

Tick all that apply

- Condom use education
- Men's discussion group on health & sexuality
- Circumcision education
- Other (*indicate which*) _____

23. In a future part of the *Impilo Yamadoda* study we will be asking men if they will give us a blood sample, so we can estimate how many men that participate in *Impilo Yamadoda* have HIV. The person taking the blood samples will not be able to tell if a man has HIV, they will not do a test for HIV or be able give you a test result. The blood samples will go to a laboratory where they are checked to see if any are HIV-positive. This will be done by someone with special training, who will also not be able to tell who the blood samples belong to. To be clear, this is not an HIV test where you can find out the result and learn if you have HIV. We are not asking you to give a sample now. However, if you would like to know where you can get an HIV test and learn the result (VCT), we can tell you places to go after this interview.

Knowing this, would you be willing to give a blood sample as part of research to help identify more effective HIV interventions for men?

- Yes
- No
- Undecided



Administrator Instructions for questions 23-34:

Read the statement and also read the options to the respondent so that he will know the way in which he has to answer the questions (i.e. "I do not have a problem with my daughter dating an immigrant. Do you strongly agree, agree, neutral, disagree, or strongly disagree?") **Tick only one box per question.**

Read aloud to participant:

The rest of this survey is a series of statements that you may or may not agree with. These statements are opinions (not facts). Please respond to the following statements on a scale from strongly agree to strongly disagree, depending on how you feel about the statement.

24. My participation in HIV prevention research helps to improve the health of my community
 Strongly agree Agree Neutral Disagree Strongly Disagree
25. I am more likely to participate in HIV prevention research if I am paid for my participation
 Strongly agree Agree Neutral Disagree Strongly Disagree
26. I am more likely to participate in HIV prevention research if I receive information about how to maintain good health as part of my participation
 Strongly agree Agree Neutral Disagree Strongly Disagree
27. I am more likely to participate in HIV prevention research if I receive health care as part of my participation
 Strongly agree Agree Neutral Disagree Strongly Disagree
28. I am too busy to take part in HIV prevention research
 Strongly agree Agree Neutral Disagree Strongly Disagree
29. I do not know other men who participate in HIV prevention research
 Strongly agree Agree Neutral Disagree Strongly Disagree
30. I think I will enjoy participating in HIV prevention research
 Strongly agree Agree Neutral Disagree Strongly Disagree
31. There are ways to prevent becoming infected with HIV
 Strongly agree Agree Neutral Disagree Strongly Disagree
32. If I participate in HIV prevention research it is possible that people will think I have HIV.
 Strongly agree Agree Neutral Disagree Strongly Disagree
33. People in my community would like it if I participated in HIV prevention research
 Strongly agree Agree Neutral Disagree Strongly Disagree
34. Some people claim that giving a blood sample as part of research can give you HIV. I believe this is true.
 Strongly agree Agree Neutral Disagree Strongly Disagree
35. I believe that only traditional medicine can effectively prevent HIV
 Strongly agree Agree Neutral Disagree Strongly Disagree

Survey Participant Contact Sheet

Rec. Loc code _____

Administrator read aloud: *By giving us the information on this contact sheet you agree to have employees from the Africa Centre attempt to contact you for the purpose of inviting you to participate in further research. You do not need to provide us with any information you do not wish to. There are no negative consequences if you choose not to provide us with this information. Your contact information will be kept confidential (will not be shown to the public) and will only be used for the purpose of Africa Centre research projects. You are under no obligation to participate in further research by providing this information and may ask us to stop contacting you at any time without any negative consequences.*

1. Are You willing for us to contact you for further research, if need be by calling any of the numbers you provide or visiting you at the location you list here? Yes No (If 'NO' do not continue form.)

2a. First Name(s): _____ 2b. Surname(s): _____

2c. Any other name(s) you are commonly known as: _____

3. What is your current age? _____ yrs

4a. Do you have a phone number we can contact you with? Yes No Refused

4b. Main Phone number: _____ (check that there are **ten digits** to the number)

4c. Best time to call: _____ (day of week) _____ (time of day)

4d. Whose phone number is this?

Own Partner Family Member Other , specify relationship: _____

4e. May we leave a message here? (tick all that apply): SMS Voice Refused

5a. If you have another phone number we can call in order to reach you we can collect this number here. We will ask for you by name and say we are calling from the Africa Centre.

Do you have another phone number we can contact you with? Yes No Refused

5b. Secondary Phone number: _____ (check that there are **ten digits** to the number)

5c. Whose phone number is this?

Own Partner Family Member Other , specify relationship: _____

5e. May we leave a message here? (tick all that apply): SMS Voice Refused

6a. Is there any place that we may visit to be able to find you (social or community group, taxi rank, church, etc.)? Yes No Refused

Location (name and/or type: ex, shop, church) _____

6b. Area (of location): _____

6c. Directions (note where directions start, any major roads and landmarks like large trees, or stores, note colour of buildings, anything that will help to direct us to the location):

6d. Best time to visit: _____ (day of week) _____ (time of day)

6e. If we do not find you here may we ask for you by name? (We will identify ourselves as Africa Centre employees.) Yes No

*Thank you for agreeing to provide us with your contact details!
An Impilo Yamadoda researcher will be in contact with you soon for an opportunity to involve you
in future research.*

Signature of Administrator:	Date of signature:
Print name and surname:	

*The University KwaZulu-Natal Human & Social Sciences Ethics Board has approved this study
This study has been approved by the University College London Ethics Board Project ID# 1934/001*

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Appendix 3: Research Partner involvement

Appendix 3: Research Partner involvement

3.1 Research Partner organisation assessment

3.2 Research Partner survey administration training feedback form

3.3 Research Partner interview purposive sampling framework

3.4 Research Partner interview consent form

3.5 Research Partner interview information sheet

3.6 Research Partner interview topic guide

Community Organisation Research Partnership Assessment Guidelines

I. Organisation details

1. Name of organisation _____
2. Organisation location _____
3. Primary contact member details
 - a. Name (first, last) _____
 - b. Title _____
 - c. Tel. number (primary) _____
 - d. Tel number (secondary) _____
 - e. Best mode of contact _____
 - f. Best time to contact _____
4. How many people are employed/members of this organisation? _____
5. What is the (approximate) ratio of men to women in this organisation? _____% M _____% F
6. What is the average age of employees/members in this organisation? _____ years
7. What are the normal hours of work/meeting here? _____ Time _____ Day(s) per week (ex: *every Monday; every second Tuesday and Friday; M-F every week*)

II. Community & Partnership Experience

8. Has this organisation ever partnered with another agency before?

If yes, please answer question 6, if not skip to question 7

- Yes
- No
- Don't know

9. Is the above partnership still in effect?

- Yes
- No
- Don't know

10. Has this organisation ever hosted a community event?

- Yes
- No
- Don't Know

III. Research Knowledge & Experience

11. Has this organisation been involved with any research projects before?

- Yes
- No
- Don't Know

a. If yes, please list all names & topics

12. Are you aware of any health research projects currently going on in this area?

- Yes
- No

a. If yes, please list all names & topics

IV. Interest

Please answer as a representative of your organisation.

13. As we have spoken about, the first project we are working on is a survey project. We would like our partner organisations to help us with this by distributing and implementing a short survey questionnaire with men in your organisation. Would you be willing to be involved with the survey project as a research administrator yourself?

- Very interested
- Interested
- Indifferent
- Somewhat interested
- Not interested

14. Do you know other men in this organisation who would be willing to be involved with the survey project?

- Yes
- Not sure/Maybe
- No

a. If yes, can we have the contact details of this man?

- Yes
- Not sure/Maybe
- No

b. Secondary contact member details:

1. Name (first, last) _____
2. Title _____
3. Tel. number (primary) _____
4. Tel number (secondary) _____
5. Best mode of contact _____
6. Best time to contact _____

Survey administration training - *Impilo Yamadoda*

Date of Training: _____

Topic of the training

Content: _____

Trainer: _____

Circle a number from 1 to 5 below that best describes the training today, where 1=not at all and 5=definitely

Did the training session meet your training needs?

1 2 3 4 5

Was the content understandable?

1 2 3 4 5

Was the delivery of the training appropriate?

1 2 3 4 5

Answer the questions below:

What was the most important thing you learnt from this training?

What was the least important thing you learnt from this training?

How could the training have been improved?

Do you feel any of the content of the training today needs to be repeated or clarified further? If so what, how and when?

Research Partner	Organisation Type	Questionnaires response rate	No. Q returned	Contact Sheet Response	No. CS returned	Selection for Interview		Q mean=67.36 (62.36 - 72.36)	CS mean=74.22 (69.22 - 79.22)
						Y/N	Interview status		
RP1	FBO	100.00%	37	81.08%	30	N	NA	above	above
RP2	CBO	80.70%	46	67.39%	31	Y	29/03/2010	above	below
RP3	Private employer	71.43%	20	70.00%	14	Y	Did not schedule	average	average
RP4	CBO	49.18%	60	70.00%	42	Y	18/03/2010	below	average
RP5	FBO	42.27%	41	65.85%	27	Y	Did not schedule	below	below
RP6	CBO	84.93%	62	85.45%	53	Y	Not available	above	above
RP7	CBO	41.13%	51	66.67%	34	Y	Not available	below	below
RP8	CBO	66.67%	54	25.93%	14	Y	24/03/2010	average	below
RP9	CBO	100.00%	34	97.06%	33	Y	15/03/2010	above	above
RP10	CBO	79.37%	50	98.00%	49	Y	23/03/2010	above	above
RP11	Private employer	100.00%	50	100.00%	50	N	NA	above	above
RP12	CBO	55.00%	11	100.00%	11	N	No longer RP	below	above
RP13	FBO	84.62%	22	25.93%	10	Y	Did not schedule	above	below
RP14	CBO	NA	NA	NA	NA	N	Unreliable data	NA	NA
RP15	Public employer	0		0		Y	26/03/2010	0	0
RP16	CBO	0		0		Y	No Show (2)	0	0
RP17	Private employer	0		0		N	NA	0	0
RP18	CBO	0		0		N	NA	0	0
RP19	Private employer	0		0		N	NA	0	0
RP20	CBO	0		0		N	NA	0	0
RP21	FBO	0		0		N	NA	0	0
RP22	CBO	0		0		N	NA	0	0

Impilo Yamadoda: Informed Consent Individual In-Depth Interview

Impilo Yamadoda is a health research study conducted by the Africa Centre for Health and Population Studies concerning men's health and HIV/AIDS.

Administrator: This consent form quiz is meant to be an assurance that the participant has a good understanding of the research study and their role in it. Only after the information sheet has been **fully explained** to the participant is this form to be completed. If the participant has any remaining questions or cannot answer this sheet correctly the information **must be clarified before** the interview begins.

Please read all questions carefully and tick as appropriate	True	False
1. The information sheet about the <i>Impilo Yamadoda</i> study and my part in it has been read to me.		
2. Some of the topics of this interview are about my experiences as a Research Partner.		
3. For my participation in this interview I will be given a ZAR100.00 voucher for either store credit or cell phone airtime.		
4. No one can become upset as a result of this interview.		
5. I cannot refuse to speak about any of the topics discussed once the interview has begun.		
6. I can withdraw from this research study at any time without negative consequence.		
7. This interview will be audio-recorded and transcribed into a written account.		
8. My name will be used in reports and publications from this study, and any identifying information will not be removed from written transcripts.		
9. All audio recordings and written transcripts resulting from this interview will be kept on password-protected computers that only authorised research staff have access to.		
10. This consent form, which has both my name and study identification code, will be kept in a locked file cabinet only accessible to authorized <i>Africa Centre</i> research staff.		
11. If I become upset as a result of this interview there is a counsellor I can speak to.		
12. I agree to participate in this interview of my own free will.		

Signature of volunteer:	Date of signature
Print name and surname	

Time of Signature (24 hour clock): ____:____

Signature of Study Staff taking consent	Date of signature
Print name and surname:	

_____ Participant Study Identification Code

_____ Voucher #

_____ Receipt #

Impilo Yamadoda: Research Partner In-Depth Interview Information Sheet

What is this interview about?

You were asked to take part in this interview as a result of your role as Research Partner and survey administrator with the *Impilo Yamadoda* project. Your contribution to this project has been very valuable to us. As part of understanding how we can engage with young men in health research we would like to ask you some questions about your views of how the research process has gone. Some of the topics we will discuss with you will be personal because we would like to know some more about what your life is like outside of being a research partner. Finally, we will be asking you to speak freely during the interview about what it is you recommend health research with young men be like in the communities you are involved with. There are no right or wrong answers to the topics that we will discuss; this interview is about you.

This interview is part of a qualitative **social science study**. This involves taking part in an individual in-depth interview. There are **no** elements to this phase where we will ask you to provide biological specimens (such as blood).

We expect your individual interview to be about one hour in duration. We will audiotape your interview so that we can be sure to accurately describe your thoughts later on. A written transcript of your interview will also be produced for the same purpose.

How will my confidentiality be protected?

If you agree to participate in this interview, instead of recording your name you will be given a number code (study identification code) that is unique to you. The audio recording and transcript of your interview will be identified by your study identification code in order to keep your identity confidential. All names (your own or any one else's) referred to during the interview will be deleted to protect your confidentiality.

The audio recording and written transcripts of your interview will be kept on password-protected computers that only the researchers involved in this study have access to. Consent forms with your name, signature, and study identification code will be kept at the *Africa Centre for Health and Population Studies*, in a locked file cabinet that only the researchers involved in this study have access to. All data will be collected and stored in a way that protects your confidentiality.

We may use some of what you say in your interview to give voice to your beliefs or concerns when we write publications about this study. Any publications using your words will not identify you as the speaker. Instead we will use pseudonyms (a made-up name different from your own) and all details that might identify you will be changed in order to protect your confidentiality.

What are my potential risks for participating?

You will also be asked to openly discuss what the value of research is and what motivations you have to participate in research. Discussing this in a research setting may cause you to become uncomfortable or embarrassed.

A few people may become distressed as a result of this interview. If you should become distressed at **any time** during or after your discussion group you may ask to speak to a counsellor who can help you.

If you wish to speak to a counsellor please use the contact information below to contact us so that we may help you access our counsellor.

What are my benefits for participating?

Many people enjoy the opportunity to discuss their lives with others; we hope that you find your experience enjoyable. We will compensate you for your personal costs of attending with an R100.00 Boxer store voucher. Beyond this, we expect that the information we gather will be very helpful in informing our understanding of health beliefs, practices, and the role of health research for Zulu men. With this information the research team intends to make recommendations for and produce health research that is suited to Zulu men's lives.

What are my rights as a research participant?

At any point during the interview you have the right to refuse to answer any question or discontinue the interview entirely and there will be no negative consequence if you choose to do so. You can withdraw your participation in the study up to two weeks after your interview. If you choose to withdraw during this period we will destroy all recordings and any transcripts that have been produced as a result of your interview. If the two-week period has past please understand that we cannot withdraw your interview but that you still have the right to refuse to be contacted further by our study staff.

Thank you for taking the time to read this!

Sebastian Fuller, Project Leader; **Contact number: 035 550 7670; Cell: 076 408 8160**
Mlungisi Zungu, Research Assistant; **Contact number: 035 550 7614; Cell: 079 851 1427**

Physical address: Africa Centre for Health and Population Studies, R618 en route to Hlabisa, Somkhele. Contact number: 035 550 7500

If you would like to speak to someone outside the research team for any reason relating to your participation in this project, please contact:

Mduduzi Mahlinza, Community Liaison Office; **Contact number: 035 550 7500**

*The University KwaZulu-Natal Human & Social Sciences Ethics Board has approved this study
This study has been approved by the University College London Ethics Board Project ID# 1934/001*

Individual In-Depth Interview – Research Partners Topic Guide

I. Warm up & framing

First, I want to ask you some questions about yourself:

- A. What is a **normal weekday** for you? Please describe a typical weekday from the time you get up in the morning until you go to sleep in the evening.
- B. Is a typical **weekend day** different that a day during the week? What are the different things you do on the weekend?

Probes:

- What do you do to get money?
- Are you in school?
- When do you spend time with family? Friends?
- What community groups do you spend time with?

II. Initial involvement with the project

Now that we have some understanding of who you are, I'd like to ask some questions about your experiences with the research project:

- A. In relation to your role on the IY project, which organisation(s) are you affiliated with?
- B. How did you come to work with us on the *Impilo Yamadoda* project?
 - Who contacted you about the project?
- C. Please tell me **what made you decide** to become a research partner for IY.
 - What is it that made you decide to come to the first meeting we had?
 - What is it that helped you decide to continue to be involved with the project?

III. Survey recruitment & participation rate

A. For those who were active:

How did you **recruit men to the survey**?

- Were there specific places you went to find men?

What was the reaction to the **questionnaire**?

How did you feel about asking men to leave their **contact information** with us?

- Any things you did that worked? Did not work?

What did you find the most **unexpected** about administering the survey?

B. *For those that were NOT active:*

Have you spoken to people about the research project? If yes, what was their response?

What do you feel was your biggest barrier in taking a larger part in this project?

IV. Research Literacy

What do **you** think is the difference between a research study (eg Impilo Yamadoda) and a community development project (like your NGO/community group)?

Do you think men in your community share this view?

What do you suggest researchers do in order to involve more young men in research?

Now I'd like to give you some time to talk about anything you think is important for us to understand about young (Zulu) men and health research. Please speak use this opportunity to speak freely.

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Appendix 4: Phase 3 qualitative interviews with participants

Appendix 4: Phase 3 qualitative interviews with participants

4.1 Phase 3 IDI information sheet

4.2 Phase 3 FGD information sheet

4.3 Phase 3 IDI consent form

4.4 Phase 3 FGD consent form

4.5 Phase 3 IDI topic guide

4.6 Phase 3 FGD topic guide

4.7 Phase 3 IDI and FGD thematic chart



Impilo Yamadoda: In-Depth Interview Information Sheet

What is this study about?

Africa Centre researchers have gathered a great deal of information about the lives and living conditions of people and households in the Hlabisa sub-district. In a number of other studies we have also learned a great deal about HIV/AIDS and women and children. However, over the years, very little has been recorded about the health needs, beliefs, and practices of Zulu men in the Hlabisa sub-district. Africa Centre researchers are currently conducting a study in this area that is specifically focused on Zulu men to gain an understanding about your own views on health needs and practices. By increasing our understanding of men's health needs and beliefs we can make the prospect of participating in health research an attractive one for you.

If more men participate in health research, researchers are able to understand how to ensure health care improvement initiatives specifically include men. We believe that if there are better health opportunities for men, then men will become more engaged, and that positively engaged men will be able to live healthier lives. When men are healthier it helps to create a healthier community overall.

What is my role in the study?

The phase of the research study *Impilo Yamadoda* that you have been invited to become involved with is a qualitative **social science study**. This involves taking part in an individual in-depth interview. There are **no** elements to this phase where we will ask you to provide biological specimens (such as blood).

There are no right or wrong answers to the topics that we will discuss; this interview is about you. Some of the topics we will discuss with you will be personal, and on the topic of your health and cultural beliefs about health and health care. While we will not ask you to disclose any specific illnesses to us we will be asking about your personal health in general terms. We will also be talking about the attitudes you have about Western and traditional medical care and HIV/AIDS specifically. Another topic is based on how health, and HIV research in specific, is conducted. We will discuss the benefits and drawbacks to being a part of HIV prevention research. As part of the interview we will be exploring new ideas of what may motivate men like you to become involved – and stay involved – with health research. It is important that you feel comfortable in discussing these topics as honestly as possible.

We expect your individual interview to be about one hour in duration.

We will audiotape your interview so that we can be sure to accurately describe your thoughts later on. A written transcript of your interview will also be produced for the same purpose.

How will my confidentiality be protected?

If you agree to participate in this interview, instead of recording your name you will be given a number code (study identification code) that is unique to you. The audio recording and transcript of your interview will be identified by your study identification code in order to keep your identity confidential. All names (your own or any one else's) referred to during the interview will be deleted to protect your confidentiality.

The audio recording and written transcripts of your interview will be kept on password-protected computers that only the researchers involved in this study have access to. Consent forms with your name, signature, and study identification code will be kept at the *Africa Centre for Health and Population Studies*, in a locked file cabinet that only the researchers involved in this study have access to. All data will be collected and stored in accordance with the Data Protection Act 1998.

We may use some of what you say in your interview to give voice to your beliefs or concerns when we write publications about this study. Any publications using your words will not identify you as the speaker. Instead we will use pseudonyms (a made-up name different from your own) and all details that might identify you will be changed in order to protect your confidentiality.

What are my potential risks for participating?

The interview you have been invited to participate in has been designed in part to increase understanding of your health needs, beliefs, and practices. To this end, you will be asked some personal questions on the topic of your cultural health beliefs and practices that may cause you to feel uncomfortable or embarrassed. You will also be asked to openly discuss what the value of research is and what motivations you have to participate in research. Discussing this in a research setting may cause you to become uncomfortable.

A few people may become distressed as a result of discussing the topics of this interview. If you should become distressed at **any time** during or after your discussion group you may ask to speak to a counsellor who can help you. If you wish to speak to a counsellor please use the contact information below to contact us so that we may help you access our counsellor.

What are my benefits for participating?

Many people enjoy the opportunity to discuss their lives with others; we hope that you find your experience enjoyable. We will compensate you for your personal costs of attending with your choice of either store vouchers (Boxer) or cell phone airtime to the value of ZAR100.00. Beyond this, we expect that the information we gather will be very helpful in informing our understanding of health beliefs, practices, and the role of health research for Zulu men. With this information the research team intends to: make recommendations to health professionals about the types of health care the men in this area need; create health research that is suited to Zulu men's lives.

What are my rights as a research participant?

At any point during the interview you have the right to refuse to answer any question or discontinue the interview entirely and there will be no negative consequence if you choose to do so. You can withdraw your participation in the study up to two weeks after your interview. If you choose to withdraw during this period we will destroy all recordings and any transcripts that have been produced as a result of your interview. If the two-week period has past please understand that we cannot withdraw your interview but that you still have the right to refuse to be contacted further by our study staff.

Thank you for taking the time to read this!

Sebastian Fuller, Project Leader; **Contact number: 035 550 7670; Cell: 076 408 8160**

Nkululeko Mngomezulu, Research Assistant; **Contact number: 035 550 7614; Cell: 079 851 1427**

Physical address: Africa Centre for Health and Population Studies, R618 en route to Hlabisa, Somkhele.
Contact number: 035 550 7500

If you would like to speak to someone outside the research team for any reason relating to your participation in this project, please contact:

Mduduzi Mahlinza, Community Liaison Office; **Contact number: 035 550 7500**

*The University KwaZulu-Natal Human & Social Sciences Ethics Board has approved this study
This study has been approved by the University College London Ethics Board Project ID# 1934/001*

Impilo Yamadoda: Focus Group Discussion Information Sheet

What is this study about?

Africa Centre researchers have gathered a great deal of information about the lives and living conditions of people and households in the Hlabisa sub-district. In a number of other studies we have also learned a great deal about HIV/AIDS and women and children. However, over the years, very little has been recorded about the health needs, beliefs, and practices of Zulu men in the Hlabisa sub-district. Africa Centre researchers are currently conducting a study in this area that is specifically focused on men to try to gain an understanding from Zulu men about your own views on health needs and practices. By increasing our understanding of men's health needs and beliefs we can make the prospect of participating in health research an attractive one for you.

If more men participate in health research, researchers are able to understand how to ensure health care improvement initiatives specifically include men. We believe that if there are better health opportunities for men, then men will become more engaged, and that positively engaged men will be able to live healthier lives. When men are healthier it helps to create a healthier community overall.

What is my role in the study?

The phase of the research study *Impilo Yamadoda* that we would like to invite you to become involved with is a qualitative **social science study**. This involves taking part in a focus group discussion. There are **no** elements to this phase where we will ask you to provide biological specimens (such as blood).

Some of the topics we will discuss with you will be personal, and on the topic of men's health and your cultural beliefs about health and health care. We will be talking about the attitudes men have about Western and traditional medical care and HIV/AIDS specifically. Another topic is based on how health, and HIV research in specific, is conducted. We will discuss the benefits and drawbacks to being a part of HIV prevention research. As part of the group discussion we will be exploring new ideas of what may motivate men to become involved – and stay involved – with health research.

There are no right or wrong answers to the topics that we will discuss; this discussion group is about you and your community. Some of the men who speak up may have different opinions about what is going on in the community. While you may disagree with some group members please remember that in this discussion all viewpoints are valuable. It is very important that everyone taking part feel comfortable speaking about these topics as honestly as possible.

We expect your focus group discussion to be between 1 and 2 hours in duration.

We will audiotape your discussion group so that we can be sure to accurately describe your thoughts later on. A written transcript of your group discussion will also be produced for the same purpose.

How will my confidentiality be protected?

If you agree to participate in this focus group discussion, instead of recording your name your group will be given a number code (study identification code) that is unique to the group you participate in. The audio recording and written record of your discussion group will be identified by your study identification code in order to keep your identity confidential. All names (your own or any one else's) referred to during the discussion group will be deleted. Individuals in the group will be assigned a letter code (for example: "Person A", "Person B") and not by name.

The audio recording and written transcripts of your discussion group will be kept on password-protected computers that only the researchers involved in this study have access to. Consent forms with your name,

signature, and study identification code will be kept at the *Africa Centre for Health and Population Studies*, in a locked file cabinet that only the researchers involved in this study have access to. All data will be collected and stored in accordance with the UK Data Protection Act, 1998.

We may use some of what you say in your discussion group to give voice to your ideas, beliefs, or concerns when we write publications about this study. Any publications using your words will not identify you as the speaker. Instead we will use pseudonyms (a made-up name different from your own) and all details that might identify you will be changed in order to protect your confidentiality.

What are my potential risks for participating?

The discussion group you have been invited to participate in has been designed in part to increase understanding of your health needs, beliefs, and practices. To this end, you will be asked some personal questions on the topic of your cultural health beliefs and practices that may cause you to feel uncomfortable or embarrassed. You will also be asked to openly discuss what the value of research is and what motivations men have to participate in research. Discussing this in a research setting may cause you to become uncomfortable.

A few people may become distressed as a result of discussing the topics of this focus group discussion. If you should become distressed at **any time** during or after your discussion group you may ask to speak to a counsellor who can help you. If you wish to speak to a counsellor please use the contact information below to contact us so that we may help you access our counsellor.

What are my benefits for participating?

We expect that you will find this discussion group informative; many people enjoy the opportunity to discuss their community with others. We will compensate you for your personal costs of attending with your choice of either store vouchers (Boxer) or cell phone airtime to the value of ZAR100.00. Beyond this, we expect that the information we gather will be very helpful in informing our understanding of health beliefs, practices, and the role of health research for Zulu men. With this information the research team intends to: make recommendations to health professionals about the types of health care the men in this area need; create health research that is suited to Zulu men's lives.

What are my rights as a research participant?

At any point during the discussion group you have the right to refuse to answer any question or discontinue your involvement entirely and there will be no negative consequence if you choose to do so. Please note that once you agree to participate in a discussion group we cannot withdraw your taped involvement afterward but that you still have the right to refuse to answer any questions, to leave the group, and to not be contacted further by our study staff once you have requested this.

Thank you for taking the time to read this!

Sebastian Fuller, Project Leader; **Contact number: 035 550 7670**

Nkululeko Mngomezulu, Research Assistant; **Contact number: 035 550 7614**

Physical address: Africa Centre for Health and Population Studies, R618 en route to Hlabisa, Somkhele.
Contact number: 035 550 7500

If you would like to speak to someone outside the research team for any reason relating to your participation in this project, please contact:

Mduduzi Mahlinza, Community Liaison Office; **Contact number: 035 550 7500**

*The University KwaZulu-Natal Human & Social Sciences Ethics Board has approved this study
This study has been approved by the University College London Ethics Board Project ID# 1934/001*

Impilo Yamadoda: Informed Consent Individual In-Depth Interview

Impilo Yamadoda is a health research study conducted by the Africa Centre for Health and Population Studies concerning men's health and HIV/AIDS.

Administrator: This consent form quiz is meant to be an assurance that the participant has a good understanding of the research study and their role in it. Only after the information sheet has been **fully explained** to the participant is this form to be completed. If the participant has any remaining questions or cannot answer this sheet correctly the information **must be clarified before** the interview begins.

Please read all questions carefully and tick as appropriate	True	False
1. The information sheet about the <i>Impilo Yamadoda</i> study and my part in it has been read to me.		
2. Some of the topics of this interview are on the topic of health and sexuality.		
3. For my participation in this interview I will be given a ZAR100.00 voucher for either store credit or cell phone airtime.		
4. No one can become upset as a result of this interview.		
5. I cannot refuse to speak about any of the topics discussed once the interview has begun.		
6. I can withdraw from this research study at any time without negative consequence.		
7. This interview will be audio-recorded and transcribed into a written account.		
8. My name will be used in reports and publications from this study, and any identifying information will not be removed from written transcripts.		
9. All audio recordings and written transcripts resulting from this interview will be kept on password-protected computers that only authorised research staff have access to.		
10. This consent form, which has both my name and study identification code, will be kept in a locked file cabinet only accessible to authorized <i>Africa Centre</i> research staff.		
11. If I become upset as a result of this interview there is a counsellor I can speak to.		
12. I agree to participate in this interview of my own free will.		

Signature/Thumbprint of volunteer:	Date of signature
Print name and surname	

Time of Signature or thumb print (24 hour clock): __: __

Signature of Study Staff taking consent	Date of signature
Print name and surname:	

_____ Participant Study Identification Code

_____ Voucher #

_____ Receipt #

Impilo Yamadoda: Informed Consent **Focus Group Discussion**

Impilo Yamadoda is a health research study conducted by the Africa Centre for Health and Population Studies concerning men's health and HIV/AIDS.

Administrator: This consent form quiz is meant to be an assurance that the participant has a good understanding of the research study and their role in it. Only after the information sheet has been **fully explained** to the participant is this form to be completed. If the participant has any remaining questions or cannot answer this sheet correctly the information **must be clarified before** the focus group discussion begins.

Please read all questions carefully and tick as appropriate	True	False
1. The information sheet about the <i>Impilo Yamadoda</i> study and my part in it has been read to me.		
2. Some of the topics of this focus group discussion are on the topic of health and sexuality.		
3. For my participation in this focus group discussion I will be given a ZAR100.00 voucher for either store credit or cell phone airtime.		
4. No one can become upset as a result of this focus group discussion.		
5. I cannot refuse to speak about any of the topics discussed once the focus group discussion has begun.		
6. I can withdraw from this research study at any time without negative consequence.		
7. This focus group discussion will be audio-recorded and transcribed into a written account.		
8. My name will be used in any reports and publications from this study, and any identifying information will not be removed from written transcripts.		
9. All audio recordings and written transcripts resulting from this focus group discussion will be kept on password-protected computers that only authorised research staff have access to.		
10. This consent form, which has both my name and study identification code, will be kept in a locked file cabinet only accessible to authorized <i>Africa Centre</i> research staff.		
11. If I become upset as a result of this focus group discussion there is a counsellor I can speak to.		
12. I agree to participate in this focus group discussion of my own free will.		

Signature/Thumbprint of volunteer:	Date of signature
Print name and surname	

Time of Signature or thumb print (24 hour clock): __: __

Signature of Study Staff taking consent	Date of signature
Print name and surname:	

_____ Participant Study Identification Code

_____ Voucher #

_____ Receipt #

Individual In-Depth Interview Topic Guide

Daily Activities, Work, and Community Involvement

Please describe to me how a **typical weekday** goes for you; tell me the details of where you go, what you do, and the people you may see from when you wake up in the morning to when you go to sleep.

Now, please describe a **typical weekend day**, again, please go into detail of what you do, who you meet, etc, from when you wake up in the morning to when you go to sleep. Also, describe the difference between Saturday and Sunday, if any.

Probes:

What do you do to **get money**? (Formal jobs, informal jobs, pension, etc)

Are there any **activities/organisations in the community** you belong to? If so, what are they?

How often do you spend time on these activities?

Are you in **school**? If so, how much time do you spend in school?

How much time do you spend with **family**? When do you get time to spend with family?

General Health/Health History

While the following topics we will be discussing in this section relate to your personal health history, you are not being asked to disclose any diagnosis of illness here. If you choose to disclose personal medical information you are welcome to do so, and all such information will be kept in confidence (accessible only to study staff). However, you may discuss your history of health and/or illness without disclosure of medical diagnosis.

Please describe how **your health** has been throughout your life.

Probes:

Have you ever been very sick? How old were you at that time?

Do you consider yourself to have had a healthy childhood?

Were you healthy as a young adult?

How would you describe your health currently?

Please discuss any **health related concerns** you have (eg., HIV, heart disease, epilepsy, diabetes). This includes illness that you may not have but are concerned you may have in the future.

If you were **offered any information** or education on the health concern you mentioned above, would you be interested to receive such information?

What would be the **best way** for you to become educated on your health concerns? (For example, would you be willing to go to a discussion group made up of other men your age and doctors?)

Health beliefs and practices

Have you ever been to your **area hospital**? If so, please describe a situation where you sought help from the hospital (for yourself or someone else). If you have not been, what is the reason?

Probes:

How do you feel about your area hospital (positive, negative, indifferent)?

How was the cure you were seeking helped (or not) by your visit to the hospital?

Have you ever been to your **local clinic**? If so, please describe a situation where you sought help from the clinic (for yourself or someone else). If you have not been, what is the reason?

Probes:

How do you feel about your local clinic (positive, negative, indifferent)?

How was the cure you were seeking helped (or not) by your visit to the clinic?

Sometimes people would rather seek a traditional cure than Western medicine. Please describe a situation when you have sought help from a **traditional healer**.

Probes:

How do you feel about visiting a traditional healer or herbalist?

What was the cure you were seeking? How was this helped by the healer/herbalist?

HIV/AIDS

*The next topic we will discuss is about HIV and AIDS specifically. Understand that you are **not** being asked to disclose your HIV status to us. Although we believe your input is very important to this study, as with the rest of the interview, you can choose not to answer any question you are not comfortable with.*

Have you **ever tested** for HIV?

If yes: Please describe to me the **last time you tested** for HIV: what type of place did you test at (hospital, clinic, mobile test site, etc), how did you feel going for the test, how long did it take, etc.?

We understand that not everyone wants to be tested for HIV. What was it about this time or setting (place) that made you want to test for HIV?

Did you receive your test results?

Probes:

If you did not receive your test results, what is the reason?

Did you feel fear about obtaining your results?

If never tested: Have you been given the **opportunity** to test for HIV?

If yes: Please describe to me **a situation** when you were offered an HIV test and **refused**.

Please describe a situation where you feel your life has been **impacted by HIV/AIDS**.

Probes:

Do you know anyone who has died from AIDS related illness?

Have you cared for anyone living with HIV/AIDS?

Do you fear yourself or a loved one may become infected with HIV?

Blood Sample as part of Research

In the next phase of the *Impilo Yamadoda* study we will be asking men if they will give us a blood sample, so we can estimate how many men that participate in *Impilo Yamadoda* have HIV. The person taking the blood samples will not be able to tell if a man has HIV, they will not do a test for HIV or be able give you a test result. The blood samples will go to a laboratory where they are checked to see if any are HIV-positive. This will be done by someone with special training, who will also not be able to tell who the blood samples belong to. To be clear, this is not an HIV test where you can find out the result and learn if you have HIV. We are not asking you to give a sample now. However, if you would like to know where you can get an HIV test and learn the result (VCT), we can tell you places to go after this interview.

Knowing this, **describe how you would feel** if you were asked to give a **blood sample** as part of research to help identify more effective HIV interventions for men?

Health Research Interest

Why did you decide to be involved with the *Impilo Yamadoda* study?

Probes:

Does the **subject matter** of this research study interest you?

Would you be interested in **similar studies in the future**?

Would you have chosen to participate if this research was not **specifically for men**?
Would you have chosen to participate in the study if it was not on the **subject of health**?

Researchers try and make sure that the people who participate in research projects are **compensated** in various ways for their participation. Before you agreed to participate you engaged in a discussion about what benefits you would receive by taking part in this research. As you may recall one of the benefits you will receive as reimbursement for your time and expense is a ZAR100.00 voucher. Please discuss what impact knowing that you would receive this voucher had on your decision to participate.

Probes:

Would you have decided to participate in this interview if you were not compensated in this way?
Do you feel that the voucher is something that encourages men to participate?
If the voucher was for ZAR50.00 would you have still decided to participate?

Some of the **benefits** that participants receive when they take part in health research are not material and/or short term but long term and/or educational. Examples of short term or material benefits are the vouchers for cell airtime that we just discussed. An example of a long term or educational benefit is when participants take part in a discussion group that is designed to teach people how to prevent HIV. What are some **long term or educational benefits** you might be interested in receiving as part of participation in health research?

Probes:

Are the examples you mentioned something you think **other men** might be interested in?

Some health research studies are short term, for example, a short questionnaire that we ask participants to complete, or a single interview, like this one. Other health research projects are long term, meaning that researchers ask participants to keep in contact with us every few months over a period of a year or longer. The following story is an example of a man who has chosen to participate in such a project.

Several months ago Thabani enrolled in a one year HIV prevention research study. As part of his participation requirement he must keep in touch with the research team every four months for an interview and take a blood test for HIV. Thabani understands that if he misses his appointments he can no longer participate. He is interested in the study and has so far kept all of his appointments; Thabani feels that the benefits to remaining involved are good. He believes that the information sessions he took part in gave him good health information, and while he is still not sure which ways of prevention are right for him he feels that talking in the interviews has helped him to think about the ways he can protect himself from HIV, and now looks forward to the sessions. Recently Thabani has had a change in his situation whereby his uncle has found him work in Johannesburg for two months. Thabani has been saving for lobola for some time and until now has not been able to collect enough; with this short-term job in Johannesburg he would have enough to pay. Thabani also believes that if he is away during this time he will miss his appointment and have to drop out of the project.

What are some **challenges** Thabani faces as part of participating in a long-term research project such as the one that was discussed? What are the **benefits**?

What, if anything, could the research team do to keep Thabani involved?

Probes:

Would it be easier for someone like Thabani to use **SMS** to keep in touch with the researchers than to come in for face-to-face interviews? Would this be something that might be helpful to you?

Recruitment & Retention Recommendations

There are many different reasons why people decide if they want to **take part in** health research or not. The following story is an example of a situation that one man is in while he decides if he wants to be a participant in a health research study.

Njabulo is a father of three and lives with his partner, the mother of his children. He and his partner also care for the young child of his recently deceased sister. He is unemployed but does odd jobs in order to get money. Sometimes Njabulo finds work as far as Richard's Bay, and in order to save money he stays with some family in Empangeni while he is working in that area. He doesn't enjoy being away from his household, but if an opportunity comes for work he feels he must go. Recently Njabulo was approached by a friend of his who is active in his church, asking if he was interested in participating in a new research study that looks at how to prevent spread of HIV. He is interested in the information on HIV prevention because he is worried that his sister, whose child he now cares for, was HIV infected, so he decides to call the research team to find out more. When Njabulo calls the study team he learns that his participation in the research visits to a local clinic every four months for a year in order to take part in a one-on-one interview and get a health check-up. While the research tells him that his participation will not be shared by anyone but the research team, the health check-up includes taking an HIV test and the interview is very personal, asking questions about his sex life and relationship with his partner. The researcher also tells Njabulo that it is important that he go to every appointment and so if he misses one appointment he can no longer be a part of the study. He also learns that he will be given a small amount of money for his participation, reimbursement for his travel cost to clinic, free health check-ups for the year and a chance to get his HIV test results as well, if he would like them.

Please discuss if this type of research project is something **you would be interested in** participating in.

Probes:

What do you think makes men like Njabulo want to be involved in health research (benefits)?

What discouraged Njabulo from being involved in health research?

What do you feel Njabulo feels is the purpose of health research? Do you agree with Njabulo?

What value does health research hold for you personally?

In what ways do you think Njabulo's community would benefit from his participation in health research? Is Njabulo's community similar to yours?

We understand that different men have different interests and priorities in their lives. Some men may like to join sports teams and some men may like to join political groups while others would rather stay at home with family. We have spent some time today discussing the reasons why men might want to take part in health research studies. Now I would like to discuss where we may find these men who would like a chance to participate in health research.

Where would you suggest we **find men who might be interested in participating in health research?**

Probes:

Do you think that men who are involved in other community activities may want to participate in health research?

Do you think there are certain characteristics/traits of men who want to take part in health research? If so, what are those characteristics?

Focus Group Discussion Topic Guide

Some of the topics that we will discuss today are very personal. Please understand that in discussion you are requested to talk about how you feel the community of men you belong to sees these issues. If you would like to answer from your personal experience or share personal stories you are welcome to do so, however, please understand that you are not required to share your own personal experiences in order to participate in this discussion group.

Daily Activities, Work and Community Involvement

What do most of the men you know for **work or some type of activity to get money**? This may include formal or informal jobs.

What do men your age do **during the day**/work time if they are **not working** or trying to get money?

How do you **know your male** friends?

Probes:

Did you grow up together (same location)?

Did you attend the same school(s)?

Does your family (brother, sister, mother, father, etc) know each other?

Do you belong to the same community groups (church, other social groups, etc)?

Do you frequent the same shops, restaurants, shebeens, etc.?

Health beliefs and practices

What is the **difference** between seeking help from a **doctor at hospital and a doctor at clinic**?

Probes:

When does one go to each? **How often**?

Tell me some examples of illness that might bring you to hospital.

What is the difference between seeking help from a **Western doctor and a traditional healer or herbalist**?

Probes:

Tell me an example of a time you would choose to seek help from a Western doctor.

What is an example of a time you would choose to visit a traditional healer (or herbalist)?

Is there a **difference in cost** between going to a hospital, clinic, and traditional healer/herbalist?

Probes:

Tell me what the cost is for each. Do you think the cost determines when men seek help from these places/people?

HIV/AIDS & VCT

How has HIV/AIDS affected your **community**?

Probes:

Have you **seen people die** of AIDS related causes?

How can you know if someone is infected with HIV/AIDS?

Probes:

Is it clear/obvious to you **who is infected** with HIV/AIDS by **looking at them**?

Are there **rumours** of who is infected in your community?

What does it mean for a (Zulu) man to get **tested for HIV**?

Probes:

How will the community view a man who gets tested for HIV?

Please describe the **positive and negative effects from** being tested for HIV.

What are some reasons a man would go to get tested for HIV?

Blood Sample as part of Research

In the next phase of the *Impilo Yamadoda* study we will be asking men if they will give us a blood sample, so we can estimate how many men that participate in *Impilo Yamadoda* have HIV. The person taking the blood samples will not be able to tell if a man has HIV, they will not do a test for HIV or be able give you a test result. The blood samples will go to a laboratory where they are checked to see if any are HIV-positive. This will be done by someone with special training, who will also not be able to tell who the blood samples belong to. To be clear, this is not an HIV test where you can find out the result and learn if you have HIV. We are not asking you to give a sample now. However, if you would like to know where you can get an HIV test and learn the result (VCT), we can tell you places to go after this interview.

Knowing this, **describe how you would feel** if you were asked to give a **blood sample** as part of research to help identify more effective HIV interventions for men?

Health Research Interest

Why do you think men might decide to be involved with the *Impilo Yamadoda* study?

Probes:

Does the **subject matter** of this research study interest men?

Do you think men might be interested in **similar studies in the future**?

Do you think men might like to participate because this research is **specifically for men**?

Do you think men might like to participate because this research is on the **subject of health**?

Researchers try and make sure that the people who participate in research projects are **compensated** in various ways for their participation. Before you all agreed to participate we engaged in a discussion about what benefits you would receive by taking part in this research. As you may recall one of the benefits you will receive as reimbursement for your time and expense is a ZAR100.00 voucher.

Please discuss what you think that the impact knowing that men would receive this type of compensation might have on their decision to participate.

Probes:

Do you think men might decide to participate in groups like this one if they were not compensated in this way?

If the voucher was for ZAR50.00 do you think men would still like to participate?

Some of the **benefits** that participants receive when they take part in health research are not material and/or short term but long term and/or educational. Examples of short term or material benefits are the vouchers for cell airtime that we just discussed. An example of a long term or educational benefit is when participants take part in a training group that is designed to teach people how to prevent

HIV. What are some **long term or educational benefits** you think men might be interested in receiving as part of participation in health research?

Probes:

For example, might men be interested in learning about nutrition and fitness?

Would men be more interested in taking basic computer education classes?

What are some other educational benefits might men be interested in receiving?

Some health research studies are short term, for example, a short questionnaire that we ask participants to complete, or a single focus group discussion, like this one. Other health research projects are long term, meaning that researchers ask participants to keep in contact with us every few months over a period of a year or longer. The following story is an example of a man who has decided to participate in such a project.

Several months ago Thabani enrolled in a one year HIV prevention research study. As part of his participation requirement he must keep in touch with the research team every four months for an interview and take a blood test for HIV. Thabani understands that if he misses his appointments he can no longer participate. He is interested in the study and has so far kept all of his appointments; Thabani feels that the benefits to remaining involved are good. He believes that the information sessions he took part in gave him good health information, and while he is still not sure which ways of prevention are right for him he feels that talking in the interviews has helped him to think about the ways he can protect himself from HIV, and now looks forward to the sessions. Recently Thabani has had a change in his situation whereby his uncle has found him work in Johannesburg for two months. Thabani has been saving for lobola for some time and until now has not been able to collect enough; with this short-term job in Johannesburg he would have enough to pay. Thabani also believes that if he is away during this time he will miss his appointment and have to drop out of the project.

What are some **challenges** Thabani faces as part of participating in a long-term research project such as the one that was discussed?

What are the **benefits** for participating in a project such as this?

What, if anything, could the research team do to keep Thabani involved?

Probes: Would it be easier for someone like Thabani to use **SMS** to keep in touch with the researchers than to come in for face-to-face interviews? Would this be something that men you know might be interested in?

Recruitment & Retention Recommendations

There are many different reasons why people decide if they want to **take part in** health research or not. The following story is an example of a situation that one man is in while he decides if he wants to be a participant in a health research study.

Njabulo is a father of three and lives with his partner, the mother of his children. He and his partner also care for the young child of his recently deceased sister. He is unemployed but does odd jobs in order to get money. Sometimes Njabulo finds work as far as Richard's Bay, and in order to save money he stays with some family in Empangeni while he is working in that area. He doesn't enjoy being away from his household, but if an opportunity comes for work he feels he must go. Recently Njabulo was approached by a friend of his who is active in his church, asking if he was interested in participating in a new research study that looks at how to prevent spread of HIV. He is interested in the information on HIV prevention because he is worried that his sister, whose child he now cares for, was HIV infected, so he decides to call the research team to find out more. When Njabulo calls the study team he learns that his participation in the research visits to a local clinic every four months for a year in order to take part in a one-on-one interview and get a health check-up. While the research tells him that his participation will not be shared by anyone but the research team, the health check-up includes taking an HIV test and the interview is very personal, asking questions

about his sex life and relationship with his partner. The researcher also tells Njabulo that it is important that he go to every appointment and so if he misses one appointment he can no longer be a part of the study. He also learns that he will be given a small amount of money for his participation, reimbursement for his travel cost to clinic, free health check-ups for the year and a chance to get his HIV test results as well, if he would like them.

Please discuss if this type of research project is something **you think men like you would be interested in** participating in.

Probes:

What do you think makes young men like Njabulo want to be involved in health research (benefits)?

What discouraged Njabulo from being involved in health research?

What do you feel Njabulo feels is the purpose of health research? Do you feel most men would agree with Njabulo?

In what ways do you think Njabulo's community would benefit from his participation in health research? Is Njabulo's community similar to yours?

We understand that different men have different interests and priorities in their lives. Some men may like to join sports teams and some men may like to join political groups while others would rather stay at home with family. We have spent some time today discussing the reasons why men might want to take part in health research studies. Now I would like to discuss where we might find these men who would like a chance to participate in health research.

Where would you suggest we find men who might be interested in participating in health research?

Probes:

Do you think that men who are involved in other community activities may want to participate in health research?

Do you think there are certain characteristics/traits of men who want to take part in health research?

If so, what are those characteristics?

Impilo Yamadoda (phase 3) participant IDI & FGD main and sub-themes:

Main theme	IDI Sub-themes	FGD sub-themes
Background	<ol style="list-style-type: none"> 1. Income generation 2. Living conditions 3. Educational experience 4. Housing 5. Family structure 	<ol style="list-style-type: none"> 1. Living conditions (own) 2. Living conditions (others) 3. Family structure 4. Friendships 5. How men generate income
Health history (personal)	<ol style="list-style-type: none"> 1. Visit to traditional healers 2. Visit to clinic 3. Visit to hospital 4. Visit to private healthcare 5. Health general 	<ol style="list-style-type: none"> 1. Visit to traditional healers 2. Visit to clinic 3. Visit to hospital
Health Beliefs and practices	<ol style="list-style-type: none"> 1. Diseases of concern 2. Illness severity 3. Reasons to seek traditional medicine 4. Manifestations of illness 5. What it is to be healthy 6. What is illness 7. Treatment pathways 8. Men in caring roles 	<ol style="list-style-type: none"> 1. Diseases of concern 2. Illness severity 3. Reasons to seek traditional medicine 4. What it is to be healthy 5. What is illness 6. Barriers to treatment 7. Treatment pathways 8. Men in caring roles
Social position and identity	<ol style="list-style-type: none"> 1. Socialising 2. Community involvement 3. Expectations and community 4. Expectations of masculinity 5. Expectations to family 6. Feelings of responsibility 7. Dependency 8. <i>Umahlalela</i> 9. Personal identity 	<ol style="list-style-type: none"> 1. Socialising 2. Community involvement 3. Expectations of masculinity 4. Expectations to family 5. Feelings of responsibility 6. Dependency/government grants 7. <i>Umahlalela</i> 8. Thieves, robbery, and theft
HIV (not prevention)	<ol style="list-style-type: none"> 1. Getting test results 2. HIV status disclosure 3. Experiences of HIV/proximity 4. HIV knowledge 5. Experiences of caring /death due to HIV 6. HIV testing 	<ol style="list-style-type: none"> 1. HIV status disclosure 2. Experiences of HIV/proximity 3. How you know someone is HIV+
Research	<ol style="list-style-type: none"> 1. Study compliance 2. Research interest 3. Importance of incentives 4. Forms of incentives 5. Value of participation 6. Non-monetary research incentives 7. Research involvement (personal) 	<ol style="list-style-type: none"> 1. Research interest 2. Importance of incentives 3. Forms of incentives 4. Value of participation 5. Non-monetary research incentives 6. Willingness to provide blood

	<ul style="list-style-type: none"> 8. Willingness to provide blood 9. Myths in research literature 	
Prevention	<ul style="list-style-type: none"> 1. Condom use/no condom use 2. Sexual behaviour 3. HIV prevention 4. Sexual partnerships 5. General illness prevention (not HIV) 6. Expectations of sexuality 7. Expectations of HIV prevention 	<ul style="list-style-type: none"> 1. Condom use/no condom use 2. Sexual behaviour 3. HIV prevention 4. Expectations of sexuality 5. Expectations of HIV prevention
Education	<ul style="list-style-type: none"> 1. Peer education 2. Community education 3. Attitudes toward education 4. Community participation 5. Role of community educator 	<ul style="list-style-type: none"> 1. Attitudes toward education 2. Discussion group as educational forum 3. Knowledge dissemination

Sebastian S Fuller

Engaging young men in biomedical HIV prevention research: lessons from a community-based study in rural KwaZulu-Natal, South Africa

Appendix 5: Phase 4 experiment

Appendix 5: Phase 4 experiment

5.1 Phase 4 tri-fold promotional brochure

5.2 Phase 4 baseline enrolment SOP

5.3 Phase 4 intervention and randomisation SOP

5.4 Phase 4 micro-capillary collection SOP

5.5 Phase 4 temporary storage and processing of micro-capillary specimen SOP

5.6 Phase 4 baseline information sheet

5.7 Phase 4 baseline consent form

5.8 Phase 4 baseline questionnaire

5.9 Phase 4 barcode and study ID card

5.10 Phase 4 snowball referral ticket

5.11 Phase 4 information sheet: study arm A

5.12 Phase 4 information sheet: study arm B

5.13 Phase 4 information sheet: study arm C

5.14 Phase 4 information sheet: study arm D

Check with your Impilo Yamadoda representative or contact the study staff to find out where we will be next!



Mlungisi Zungu, Research Assistant

Office: 035 550 7614

Cell: 079 851 1427



Lungani Masinga, Research Assistant

Office: 035 550 7612

Cell: 072 379 7265



Ntombikayise Mncwango,
Community Liaison Officer

Office: 035 550 7601

Cell: 082 640 4046



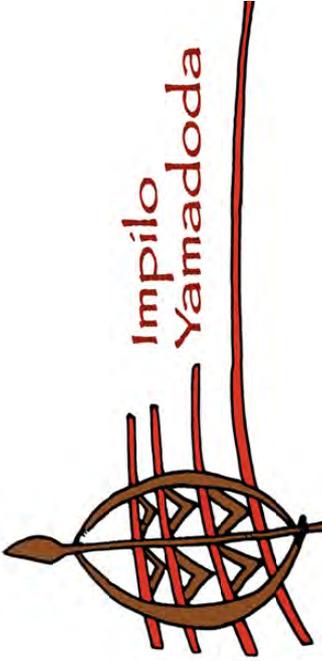
Sebastian Fuller, Project Leader

Office: 035 550 7601

Cell: 072 379 7383



Prof. John Imrie, Principle Investigator
Office: 035 550 7640



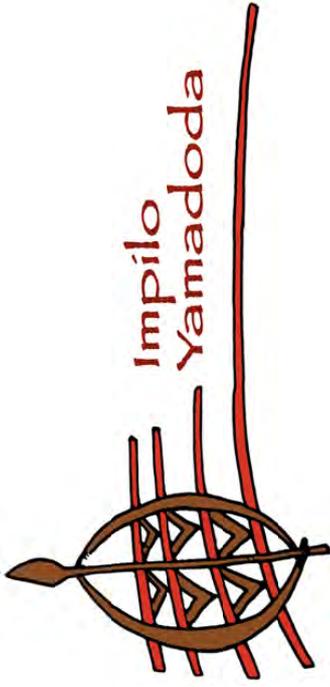
Men's Health Study



If you would like to speak to someone outside the research team for any reason relating to your participation in this project, please contact:

Mduduzi Mahlinza, Community Liaison

Office; Contact number: 035 550 7500



Men's Health Study



What is the research about?

You may have heard about the *Impilo Yamadoda* study in your community: this research study is designed for men in order to learn about men's health needs and find out what makes it easier for men to participate in health research. This winter we will begin the last phase of the *Impilo Yamadoda* study. In this phase of the study we will look at some different ways to do health research with men.

Am I eligible?

You are eligible to enrol if you are:

- ★ Male
- ★ Between 18 - 35 years of age
- ★ Resident in the Hlabisa health sub-District
- ★ Willing to participate in the study for at least six months
- ★ Have a valid South African Identity Booklet (SA ID)

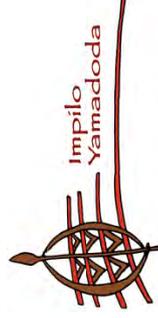
Impilo Yamadoda will be having information and enrolment sessions here:

★ Qakwini Sport Grounds (next to Qakwini clinic)

Sunday, 1st August 9am - 1pm

★ Zaba Community Hall, Ophondweni

Thursday, 5th August 9am - 1pm



Ngingathola kuphi kabanzi?

Impilo Yamadoda is coming to an area near you! We will be holding information sessions where men will find out more about the trial, and if they like, can enrol. If you think that you might like to enrol please bring your SA ID with you - you cannot enrol without an SA ID. We can only enrol up to the first 300 men that are interested so be sure to come to one of the information sessions listed here!

What can I do if I am not eligible?

While we can only enrol men between 18 - 35 years of age in this study, we know that women and men of all ages have important roles in the health of their communities. If you cannot take part yourself we encourage you to speak to the eligible men you know about how they can be involved. Please feel free to contact us for more information about the study no matter your age or gender!

Impilo Yamadoda Trial SOP: Enrolment event protocol for fieldworkers

Purpose: To outline protocol of implementation of recruitment events for AfrEVacc *Impilo Yamadoda* experimental trial field staff

Scope: Enrolment events for AfrEVacc *Impilo Yamadoda* experimental trial

Goal: 5 events over 2 months; recruit (average) 30 ppl/event = minimum total 150 participants.

Africa Centre staff involved: Five Fieldworkers (FW); Two Research Assistants (MZ & LM); Community Liaison Officer (NM); Project Coordinator (PC)

1. During recruitment event

- 1.1. PC and/or RP will record attendance on the participation rate log throughout the event
- 1.2. MZ will give all participants an isiZulu version of the IY P4 information sheet
- 1.3. MZ leads short information session to the group of men assembled.
- 1.4. After info session, participants that are interested will be directed to a FW/LM for enrolment
- 1.5. LM/FW will pre-screen participant for eligibility:
 - 1.5.1. LM/FW will ask to see participant's SA ID book and check he is male between 18-35 years old
 - 1.5.2. LM/FW will ask participant if he lives in the Hlabisa sub-district
 - 1.5.2.1. If the participant is unsure, LM/FW will ask the participant where he lives (ward/area, etc) to confirm he is a resident of the Hlabisa sub-district
 - 1.5.3. LM/FW will ask participant if he is willing and able to provide consent to 6-8 months of study participation
 - 1.5.4. If a participant is not eligible to participate he is told he is ineligible and thanked for his time. **Do not continue to enrol participant**
- 1.6. After pre-screening criteria is met, eligible participants will be asked to provide consent
- 1.7. LM/FW will read aloud consent form quiz: participant must place an X in the box corresponding to the answer they believe is correct
- 1.8. All incorrect answers must be gone over with participant by LM/FW until LM/FW believes the participant understand the correct response **or** feels he cannot understand
 - 1.8.1. If there is any question that the participant has the ability to consent, the PC will make the final determination if a participant will be enrolled.
 - 1.8.2. If a participant is not eligible to participate he is told he is ineligible and thanked for his time. **Do not continue to enrol participant**
- 1.9. If participant is eligible to participate then participant and LM/FW must sign consent form in duplicate
- 1.10. The **participant copy** of consent form is given to participant
- 1.11. LM/FW records SA ID number from participants' SA ID in marked area on the back of **IY study copy of consent form**
- 1.12. LM/FW records Study ID number from questionnaire onto participant ticket
- 1.13. LM/FW places barcode sticker on top of questionnaire
- 1.14. LM/FW records Study ID from questionnaire on the marked space on the back of the **IY study copy of consent form**
- 1.15. LM/FW places study copy of consent form in plastic envelope 'completed consent forms'
- 1.16. LM/FW administers questionnaire orally in isiZulu to participant.

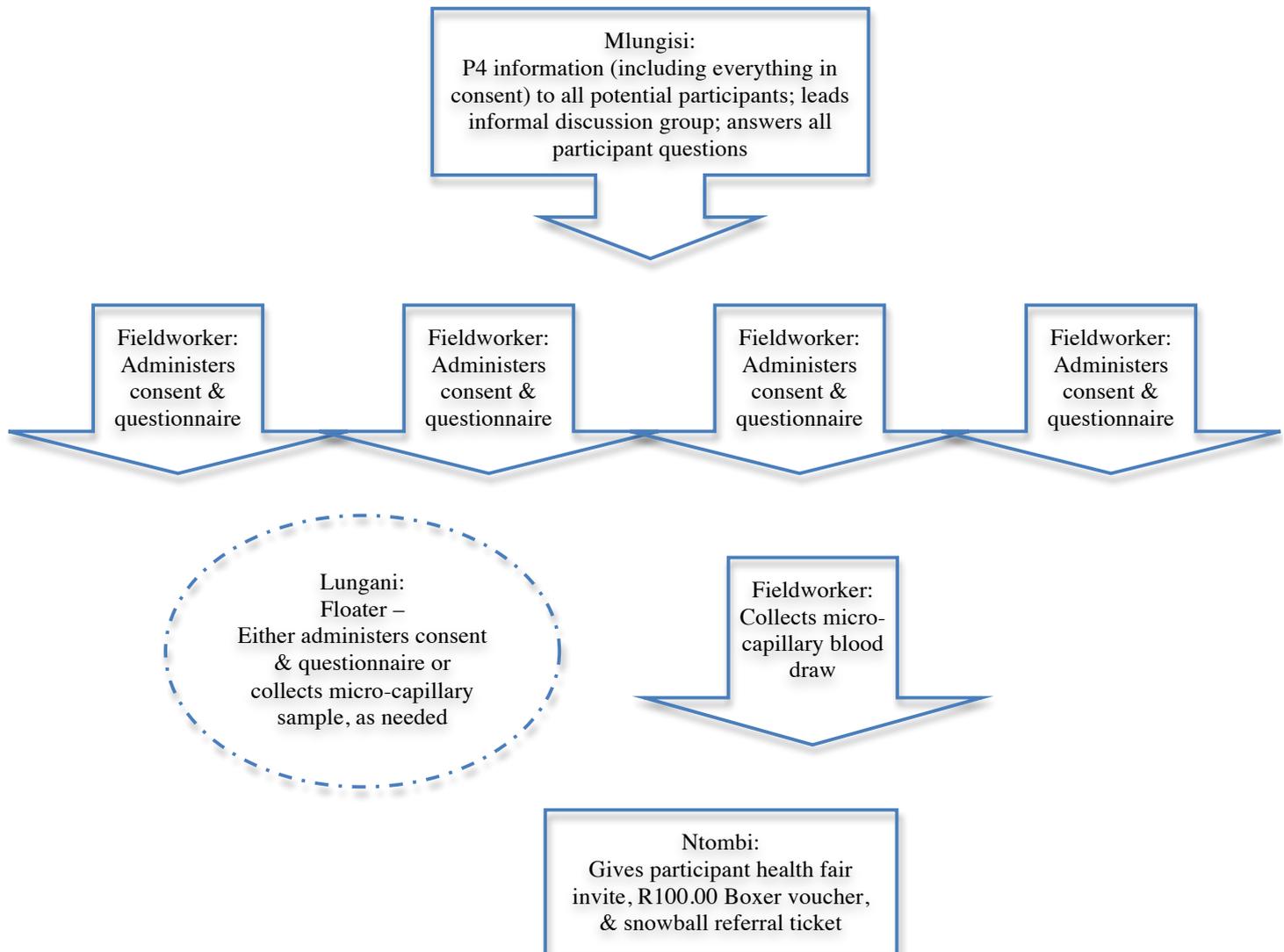
- 1.17. After questionnaire is complete LM/FW places barcode on 'registry of completed questionnaires' form & records Study ID number in the relevant space
- 1.18. LM/FW places study copy of consent form in plastic envelope 'completed questionnaires'
- 1.19. After questionnaire is complete LM/FW checks that the participant now has **participant copy** of consent form, one information sheet and one participant ticket
 - 1.19.1. If a participant is missing a form LM/FW will supply him with one.
- 1.20. LM/FW places completed questionnaire in marked folder ("completed questionnaires") and then directs participant to micro-capillary collection table
- 1.21. LM/FW at micro-capillary sample table takes participant ticket from participant
- 1.22. LM/FW at micro-capillary sample table captures blood sample from participant (**see SOP for baseline micro-capillary blood collection**)
- 1.23. LM/FW at micro-capillary sample table places barcode from participant ticket on micro-capillary sample
- 1.24. LM/FW at micro-capillary sample table places barcode from participant ticket on micro-capillary sample envelope
- 1.25. LM/FW at micro-capillary sample table places envelope with micro-capillary sample into ziplock bag in the cooler (there can be up to
- 1.26. LM/FW at micro-capillary sample table places barcode on 'completed micro-capillary' form
- 1.27. LM/FW at micro-capillary sample gives participant back his participant ticket
- 1.28. LM/FW at micro-capillary sample table directs participant to NM for their reimbursement and health fair invitation
 - 1.28.1. NM takes the participant's participant ticket & checks to make sure there are only **5 barcodes remaining on the card**
 - 1.28.2. If there are more than 5 barcodes remaining on the card NM will direct participant to micro-capillary blood sample table. **No reimbursement is given at this time.**
 - 1.28.3. If the participant refuses to give a blood sample he will no longer be eligible to participate in the study. The participant will not be given a Boxer voucher or a Health Fair invitation.
- 1.29. If 3 barcodes are remaining on the card, NM places barcode and records participant ID# from participant ticket on 'reimbursement log' form
- 1.30. Participant is given R100.00 Boxer voucher
- 1.31. Participant must sign next to his barcode on 'reimbursement form' log
- 1.32. Participant is read and then given invitation to health fair by NM
 - 1.32.1. NM will point out date and time for fair
 - 1.32.2. NM will emphasise importance of bringing ID book and participant ticket to fair
 - 1.32.3. NM will tell participant that health fair is an invitation only event so they must not invite other people
 - 1.32.4. NM will point out rapid named HIV test referral information
- 1.33. NM places one barcode each on two snowball referral tickets
- 1.34. NM gives participant 2 snowball referral tickets
- 1.35. NM explains the referral process to the participant:
 - 1.35.1. If a participant refers someone who **completes enrolment** the man who referred him will receive an IY t-shirt at the health fair
 - 1.35.2. Men who are referred by the participant must give the referral ticket to the fieldworker who enrolls them
 - 1.35.3. Men who are referred must complete enrolment in the IY project
 - 1.35.4. All t-shirts will be given out at the health fair
- 1.36. NM tears referral ticket in half and discards the half where the barcodes were.
- 1.37. NM gives remaining half of participant ticket back to participant
- 1.38. NM checks that participant has his participant ticket, information sheet and consent form copy
 - 1.38.1. If participant is missing any forms NM will supply them

- 1.39. Participant is thanked for his time
- 1.40. PC will be on hand to supervise/coordinate event & answer participant questions
- 1.41. If a participant loses his ticket between any of these stages, staff must notify PC

2. After Enrolment event

- 2.1. MZ collects all completed forms and all other supplies from fieldworkers (unused forms & micro-capillary collection supplies; pens, clipboards & other supplies)
- 2.2. LM will collect micro-capillary blood sample coolers from fieldworkers at the event site
- 2.3. All fieldworkers fill out the time schedule sheet for the day, sign it (record of overtime), and give it to MZ
- 2.4. LM gives research partners any extra fliers to hand out in the community
- 2.5. Upon return to Africa Centre LM processes micro-capillary samples following the correct micro-capillary handling SOP
- 2.6. Upon return to Africa Centre MZ will be responsible for correctly filing and entering the data into the databases set up for this purpose (further outlined in the P4 data management SOP)

Flowchart and layout



Impilo Yamadoda Trial SOP: Health Fair Protocol

Purpose: To outline protocol during intervention and randomisation events for volunteers, project and field staff

Scope: Health Fair events for AfrEVacc *Impilo Yamadoda* experimental trial

Africa Centre staff involved: Five Fieldworkers (FW); Two Research Assistants (MZ & LM); Community Liaison Officer (NM); Project Coordinator (PC)

1. Procedure at entrance to Health Fair

- 1.1. Participant shows up at event, shows his ID to attendant who checks his name and ID number against a list.
- 1.2. If he is on the list, attendant ticks a box on the check-in sheet to register his arrival.
- 1.3. Attendant gives the participant a wrist band which he must not take off until he leaves the event
- 1.4. Attendant tells participant to see the next attendant
- 1.5. Next attendant gives the man a sealed envelope with a playing card inside and tells the man to open the envelope, discards the envelope and keeps the playing card
- 1.6. Attendant tells the participant to immediately proceed to queue for randomisation table with the matching suit shown on his playing card.

2. Procedure at Randomisation Table

- 2.1. Participant queues for the randomisation table where the sign matches the suit on his playing card (i.e., queen of clubs for the clubs table, two of diamonds for the diamonds table, etc)
- 2.2. At randomisation table the participant shows the attendant his playing card, participant ticket and his (SA) ID
- 2.3. Attendant checks participant's Study ID number and/or (SA) ID number against the randomisation table list.
- 2.4. **If** participant is listed to get a t-shirt attendant will give him an IY t-shirt.
- 2.5. Attendant writes card suit and number on the list next to participants details
- 2.6. Attendant takes a plastic envelope from the bin and checks to make sure the suit corresponds to the playing card the participant has given him.
- 2.7. Attendant writes Study Group letter (shown on the letters inside the envelope) on the list next to participants details
- 2.8. Attendant writes study ID number on the sticker on envelope,
- 2.9. Attendant takes a new cell phone voucher from the stack of vouchers and writes study ID number on the voucher for cell phone.
- 2.10. Attendant puts the playing card and cell phone voucher in the participant's plastic envelope.
- 2.11. Attendant then gives the participant the plastic envelope. This packet **must** include a cell phone voucher, lunch ticket, playing card, study group information sheet, cell phone instructions, (and for groups C & D), cell phone interview instructions.
- 2.12. **Attendant has participant sign that he has received his packet**
- 2.13. Attendant tells participant he **must** keep the playing card and cell voucher or he will **not** get his cell phone
- 2.14. Attendant tells the participant to pick up his cell phone **before 14:00**.

3. Procedure at Cell Phone Tent

- 3.1. Participant queues to see attendant at the cell phone table
- 3.2. Once at cell phone table participant hands playing card, cell phone voucher, and his SA ID to one of two attendants seated there.
- 3.3. Attendant checks that the name on the SA ID matches his study number.
- 3.4. After attendant checks, he will take a new cell phone from the bin.
- 3.5. Attendant will open the box, and show the participant the phone, phone number card and charger.
- 3.6. Attendant will dial *100# on the cell phone and show the participant the R50.00 balance and then puts the phone, charger and phone number card back in the box and hands the box to the participant.
- 3.7. Attendant will record handset number (AFR number), playing card number and suit on sheet next to participant's Study ID number and name.
- 3.8. Attendant rips playing card and cell phone voucher in half and puts it in the box next to him
- 3.9. Attendant tells participant to sign for receipt of the cell phone.
- 3.10. Attendant shows the participant the charger and the card with the cell number on it
- 3.11. Attendant tells participant to go to the group table corresponding to his study group (as shown on his folder) where expectations for his participation are explained in further detail.
- 3.12. At the study group table, once finished explaining the study group participation, attendant will tell the participant to proceed to the intervention tables, queue for lunch or watch the presentation, whichever is most appropriate.



Standard Operating Procedure (SOP) for Preparation, Collection, Handling and Transport of Micro-capillary Blood Collection for P4 baseline

PURPOSE:

The purpose of this SOP is to provide guidelines for proper and safe collection and handling of capillary blood specimens, collected into micro-capillary blood tubes, in order to prevent occupational hazard exposure and to maintain optimal specimen integrity.

SCOPE:

This SOP applies to **baseline** micro-capillary blood specimen collection for Phase 4 of AfrEVacc *Impilo Yamadoda*: Men's Health Study. This applies to micro-capillary blood collection during enrolment events and during individual enrolment at Africa Centre.

POLICY AND PROCEDURE: Drawing blood for micro-capillary specimens

1. Safety

- 1.1. Wear a new pair of hand-gloves, and ensure that the gloves fit well and have no holes. Never re-use gloves.
- 1.2. Ensure that you have a sharps bucket for disposal of sharp waste (lancet) and a red bag for disposal of other non-sharp waste (cotton wool, alcohol swabs, tissues)

2. Specimen and form labeling

- 2.1. Always ensure that a new barcode is used for each individual. Specimen barcodes must be unique identifiers for the individual giving the specimen. One barcode number should be used per individual and no two individuals should ever share a barcode.
- 2.2. Place a barcode on the micro-capillary blood tube. Barcodes should be put lengthwise i.e. along the tube, and not across.
- 2.3. Place a matching barcode on the micro-capillary envelope
- 2.4. Each person collecting blood must write a number on the micro-capillary envelope (if it is the first specimen of the day collected you will number it '1', the second would be numbered '2', etc.)
- 2.5. Place another matching barcode on the Received Specimens Log
- 2.6. Write a number matching the one written on the micro-capillary envelope on the Received Specimens Log
- 2.7. Once this is done you are ready to collect the blood sample

3. Blood collection

- 3.1. It is preferable to use the middle finger but if the participant is not willing then use the participant's preferred finger.
- 3.2. Clean the top part of the finger by wiping with an alcohol swab. Always ensure that the finger is clean and allow the alcohol to completely evaporate before pricking the finger.
- 3.3. Ensure that the lancet you are about to use is new and has not been used before.
- 3.4. Remove the cap on the lancet and firmly place the lancet on the cleaned tip of the finger.
- 3.5. The activation button should be facing upwards and the needle side in contact with the finger.
- 3.6. Press down the activation button on the lancet while keeping the lancet firmly pressed onto the finger as you press.
- 3.7. Do not lift the lancet as you press the activation button because this will make the prick unsuccessful.
- 3.8. On pressing, the lancet will automatically prick the finger and blood will start flowing.
- 3.9. Position the tube such that the tip/scoop is next to the prick and blood can easily flow from

the finger prick site into the tube.

- 3.10. Ensure that the finger is pointing downwards to the ground as you collect the blood drops into the micro-capillary tube. This will ensure easy flow of the blood into the tube.
- 3.11. Fill the participant's first labeled tube and when full lift the finger up to reduce blood flow and close the tube.
- 3.12. Give the participant a cotton wool swab to stop the flow while you close the tube.
- 3.13. To close the tube, simply press down the tube caps. The tube makes a click sound indicating that it's firmly closed.
- 3.14. **Ensure that the tube is firmly closed. Never put down a tube without closing it.**
- 3.15. Shake/invert the tubes gently and put the tube in the envelope with matching barcode.
- 3.16. Seal the envelope and place it in a zip-lock bag.
- 3.17. You can place up to 10 envelopes in one zip-lock bag but only one tube per participant should be in one envelope
- 3.18. Place the zip-lock bag in a cooler bag with ice blocks. Always ensure that the cooler stays closed at all times to reduce risk of specimens getting lost or too hot/spoiling.
- 3.19. Dispose of the lancet in the sharps bucket, the alcohol swab, cotton wool, and the used gloves in the red bag. Hazardous waste disposal should be in compliance with the Africa Centre SOP for waste disposal.

4. Submission of Specimens during enrolment events

- 4.1. LM will collect all blood samples and Received Specimens Logs from all fieldworkers assigned to blood collection
- 4.2. LM will add all the barcodes on the Received Specimens Logs together to get a total number of specimens received, being careful not to mix up which Received Specimens Log goes with which cooler (this will help with further reconciliation in step 5.4).
- 4.3. LM will take the total number of specimens received to MZ to check if the total numbers match. If they match they are reconciled. If they do not match, follow procedures in the SOP for *Receipt and Recording of Questionnaires P4 Baseline* for reconciliation of specimens and questionnaires.
- 4.4. Once this is done LM will take Received Specimens Logs and place each Log in a ziplock bag in the cooler that the specimens belong to.
- 4.5. LM will be responsible for ensuring the safe delivery of all coolers, blood specimens and Logs to Africa Centre.

5. Quality Control of Specimens collected during enrolment events

- 5.1. Once back at Africa Centre LM will take the coolers with the Received Specimens Logs to be reconciled with the questionnaires
- 5.2. One at a time accepted specimens are to be taken out of the ziplock bag and brown envelope to check to ensure barcodes on blood specimen tubes and blood specimen envelopes match.
- 5.3. If barcodes match, the specimen is successfully reconciled and must be accepted.
- 5.4. Check that the matching barcodes on specimen and envelope match a corresponding barcode on the Received Specimen Log. Make a tick next to the barcode on the Log.
 - 5.4.1. If the barcode is not found on the Log **carefully** write the number in a new line on the Log
- 5.5. Tick box next to barcode under the 'reconciled' heading of the Received Specimen Log
- 5.6. Place the specimen on the tube rack

- 5.7. Repeat steps 5.1 – 5.4 until all specimens are reconciled
 - 5.8. Return ice blocks used in the field to the freezer and place new, frozen ice blocks in the coolers
 - 5.9. Place tube rack with the newly collected & recorded micro-capillary samples in the transport cooler box and firmly shut the lid
 - 5.10. Continue to step 7
- 6. Submission & Quality Control of Specimens collected at Africa Centre**
- 6.1. Follow protocol in steps 1 -3; **do not follow steps 4 & 5 as they are only for specimens collected during enrolment events.**
 - 6.2. After participant has left, ensure barcode on specimen matches barcode on Received Specimen log
 - 6.3. If barcodes match, the specimen is successfully reconciled and must be accepted.
 - 6.4. Tick box next to barcode under the ‘reconciled’ heading of the Received Specimen Log
 - 6.5. Place the specimen on the tube rack
 - 6.6. Place newly frozen ice blocks in the transport cooler box
 - 6.7. Place the tube rack in the transport cooler box and firmly shut the lid
 - 6.8. Continue to step 7
- 7. Processing Blood Specimens before Shipping**
- 7.1. All questionnaires with matching blood specimen must be entered into STAR database. To do this you must scan all barcodes that have been reconciled from the Received Specimen Log
 - 7.2. Once barcode is scanned tick box next to barcode under ‘scanned’ on Received Specimen Log
 - 7.3. Blood specimens must be transported to Durban Lab every evening via the AC Durban shuttle, except when the field team is working *late afternoon schedule* or a *Saturday schedule*. Details of how to handle and transport specimens when the field team are working *late afternoon* and *Saturday schedules* are contained in the SOP for Temporary Storage and Processing of Micro-capillary specimen tubes
 - 7.4. Specimens must always be placed on racks that are in turn placed in cooler boxes/bags with ice until received in the lab.
- 8. Specimen Transportation to Durban AC Virology Lab**
- 8.1. Place the cooler box with the newly reconciled and recorded specimens in the Durban shuttle
 - 8.2. Tell the shuttle driver that you have given him a cooler box with blood specimens in it for delivery to the Durban lab.
 - 8.3. Except for Specimens collected during a *late afternoon* or *Saturday schedule*, place an “N” under the ‘Processed at AC’ heading on the Received Specimen Log next to all the barcodes of the specimens in the cooler box on the shuttle. NOTE: this is only for specimens that **not been spun/processed!**
 - 8.4. Except for Specimens collected during a *late afternoon* or *Saturday schedule* all specimens must be send to Durban AC Virology Lab on the day they are collected from participants
 - 8.5. Specimens are transported to Durban AC Virology Lab by the daily shuttle, which must not leave the centre until specimens are fully prepared for transportation.



Standard Operating Procedure (SOP) for Temporary Storage and Processing of Capillary Blood Specimens (late afternoon & evening collection)

PURPOSE

This document details the procedures for preparing and storing specimens that cannot be sent to the Africa Centre Virology laboratory on the day of collection. It documents how the specimens should be prepared and the storage temperature requirements including the maximum duration of storage. This SOP ONLY APPLIES to specimens that are collected late or during the weekend. Every effort should be made to ensure that all specimens collected during normal working hours are sent to the AC Virology laboratory on the day that they are collected.

SCOPE

This SOP applies to ONLY those specimens collected late in the field and cannot be sent to the AC virology laboratory on the day of collection. It applies to all specimen reception room- based specimen preparation activities

1. Specimen quality control

- 1.1. Specimens should be checked as documented in the SOP for Preparation, Handling and Processing of Capillary Blood Specimens to ensure that details on the specimens match details on the specimen envelope.
- 1.2. There should be 1 micro-capillary blood specimen tube for each participant in each envelope.
- 1.3. Once this is checked scan barcodes into Impilo Yamadoda STAR database
- 1.4. Once this is done, specimens are now ready for preparation.

2. Safety

- 2.1. Always ensure that you are wearing a laboratory coat and gloves before you start preparing specimens.

3. Specimen preparation of Yellow top microcapillary tubes (SST)

- 3.1. Place all tubes on a rack. Ensure that all tubes are tightly closed. DO NOT open blood tubes, (tube tops/caps close by pressing them down until you hear a click sound).
- 3.2. Open the centrifuge and check to see that the reading is set at 3750 rates per minute (rpm).
- 3.3. Set the time to 10 minutes
- 3.4. Ensure that you have at least 5 empty micro-capillary tubes next to the centrifuge.
- 3.5. Put the tubes inside the specimen tube holders/holes in the centrifuge. The tube holders/holes appear as round holes inside the centrifuge.
- 3.6. All specimen holders/holes should be filled with micro-capillary tubes.
- 3.7. If the tubes are not enough to fill the holders then the empty micro-capillary tubes that you have placed next to the centrifuge should be filled with water. Use these tubes with water to fill in the holders that do not have anything.
- 3.8. **PLEASE NOTE: IT IS DANGEROUS TO SPIN THE CENTRIFUGE WITH EMPTY TUBE HOLDERS- THE MICROCAPILLARY BLOOD TUBES INSIDE MAY BURST OPEN OR THE CENTRIFUGE MAY OPEN AND SPILL BLOOD ALL OVER!!!!!!**
- 3.9. Close the centrifuge tightly. *If the centrifuge is not closed properly it will not spin!*
- 3.10. Press start on the centrifuge.
- 3.11. The centrifuge will spin until 10 minutes is over then it will stop. Do not open the centrifuge until it has written 0. This shows that it is no longer spinning and the pressure has gone down to zero.

3.12. NEVER OPEN THE CENTRIFUGE WHILE IT IS SPINNING!

3.13. When the centrifuge has stopped press the open button.

3.14. Take out all the micro-capillary tubes and place only the ones with blood specimens on a rack.

3.15. Place this rack inside the fridge. Make sure the rack is safe and secure and is sitting flat on the fridge shelf surface.

3.16. Leave the specimens in the fridge until the following day when they will be sent to AC virology laboratory with the rest of that day's specimens.

3.17. Micro-capillary tubes should be transported to AC virology laboratory on the rack, inside a cooler bag with ice.

4. Notes

4.1. Micro-capillary blood specimens should only be prepared if the specimens are not going to the AC virology laboratory on the day of collection.

4.2. All specimens prepared should be sent to the AC virology laboratory the following day, together with the specimens for that day.

4.3. Each day before sending blood specimens check that there are no specimens in the fridge or on the specimen counter from the previous day.

4.4. Specimens prepared over the weekend should be sent to AC virology laboratory on Monday.

4.5. **ALWAYS REMEMBER:** if specimens are kept for too long before they are processed in the laboratory, they will lose cells and cannot be tested. Thus specimens should not be forgotten in the specimen reception room.

Impilo Yamadoda: Trial Information Sheet

What is this trial about?

The *Impilo Yamadoda* trial is a research project where we are interested in learning more about men and men's health needs and finding out what makes it easier for men to participate in health research. Some of the questions we will ask you are about your health, while others will ask very personal questions about sex and sexuality. These personal questions will help us to make suggestions to researchers, funding bodies, and health agencies, for what types of health and research programmes men need in this area. We will also hope to find different ways to help men stay involved in health research; we can find this out by trying out different ways of doing interviews, giving reimbursement, and keeping in touch with the men in this study.

About random allocation

The *Impilo Yamadoda* trial is a research project that will explore different ways of achieving the same goal. One of the things we are interested in is how men respond to different methods of keeping in touch with researchers during a long-term study. Another thing we are looking at is how men respond to different ways of collecting blood within a research study. Because we want to find out the difference between these things, not everyone who participates will participate in exactly the same way. For example, some men who participate in the trial will be using cell phones to interview, and some will have face-to-face interviews. Everyone who participates in the health fair will be assigned to a study group by chance; no one, not even the research team, knows in advance which group you will belong to. It is important to understand that you cannot change your assigned study group for any reason.

What are the differences between the study groups?

Some men will be doing interviews over a cell phone while other men will have that same interview face-to-face. Some men will be asked to provide a blood sample via a finger-prick in their community while some men will have their blood sample collected by a nurse in a clinic. Another difference is that men who participate may receive a Boxer voucher, or cell airtime for participation reimbursement. There is no way of knowing which study group you will be in, so it is important to understand that if you agree to be in the study you are agreeing to take part in which ever part of the research you are assigned to.

What is the same among the study groups?

All of the men in the trial will first take part in an interview and have a finger-prick blood sample taken. Then everyone will be asked to come to a special Men's Health Fair. At this fair you will get information on men's health topics including HIV, general health, and safety. During the fair you will be asked to select a blank sealed envelope, which will have your study group assignment. After receiving your study group assignment everyone who takes part in the study will receive a cell phone with R50.00 airtime credit. After the fair everyone will be asked to follow-up with us again in 3 months for an interview, and then 3 months after that (in six months time) for an interview and a second blood sample collection. Whichever study group men are allocated, everyone will receive a reimbursement to the value of R100.00 in the form of a Boxer voucher or airtime for participation during each follow-up visit.

More about blood collection

There are two types of blood collection methods in this study: micro-capillary blood collection and venepuncture blood draw.

- **Micropillary blood collection** is where you will have your finger pricked with a special sterile lancet to draw a small amount of blood. The Research Assistant will then place the blood into a small tube. The tube of blood will be placed into a container with a label to show that it comes from the *Impilo Yamadoda* study. This box will be sent to a special laboratory with other blood samples.
- A **venepuncture blood draw** is when a qualified nurse uses a sterile needle to draw a small amount of blood from a vein in your arm. This blood will be collected in a vial with a label on it that says it comes from the *Impilo Yamadoda* study. Directly after your blood is drawn, and in your presence, the nurse will give the vial of your blood to the Research Assistant. The Research Assistant will bring it to storage until it is sent to a special laboratory with other blood samples.

While the collection methods are different, both types of blood collection will be treated in the **same way** for this trial: the Research Assistants will never know your HIV status; the blood that is collected will **not** be given a rapid HIV test so both you and the Research Assistant will **not** be able to know if you have HIV. If you would like to have a HIV test where you learn the result the Research Assistant will tell you where and when you can access an HIV test.

What are my potential risks for participating?

The trial you have been invited to participate in has been designed in part to increase understanding of your health and sexuality. To this end, you will be asked some personal questions on the topic of your health and sexual practices that may cause you to feel uncomfortable or embarrassed. While we believe that the answers you give will be helpful, you are **not** required to answer questions that you do not wish to.

A few people may become distressed as a result of participating in this trial. If you should become distressed at **any time** during or after your participation in this trial you may ask to speak to a counsellor who can help you. If you wish to speak to a counsellor please use the contact information below to contact us so that we may help you access our counsellor.

What are the responsibilities of the research staff to participants?

Anyone can stop participating in the *Impilo Yamadoda* study **at any time** without any negative consequence. It is the responsibility of the *Impilo Yamadoda* research staff to make sure that if participants who wish to end their time in the trial are able to do so quickly and easily. Once you leave the study you will no longer receive any contact or further reimbursements from the project or study team. If a participant wishes to withdraw his interview from the study must do so within two weeks of the interview. Once this period has passed while it is possible to stop participation in further aspect of the study, please understand that we cannot withdraw interviews you have done. Blood samples cannot be withdrawn after they are taken because we have no way of linking you to the sample once it has been taken.

Participants have the right to receive their benefits of participation in a timely manner, and it is the responsibility of the research staff that this happens. If, for any reason, you have not received your compensation as detailed here please contact us so that we can correct the problem.

The research staff will protect participants' confidentiality. After participants have been issued a study identification number this will be the way that individual information for participants is identified. This keeps your name separate from your interview and blood sample data. The form participants sign agreeing to be a part of the study has both name and study number, and so are kept in a locked file cabinet that only authorised *Impilo Yamadoda* trial staff have access to.

It is important to us that you understand your rights as a participant in this research. If you have questions about anything here or anything else about the *Impilo Yamadoda* trial please do not hesitate to contact the staff using the below information.

Thank you for taking the time to read this!

Professor John Imrie, Principal Investigator; **Contact number: 035 550 7640**
Sebastian Fuller, Project Leader; **Contact number: 035 550 7670**
Mlungisi Zungu, Research Assistant; **Contact number: 035 550 7614; Cell: 079 851 1427**
Lungani Masinga, Research Assistant; **Contact number: 035 550 7612; 072 379 7265**
Ntombikayise E. Mncwango, Community Liaison Officer; **Contact number: 035 550 7601**

If you would like to speak to someone outside the research team for any reason relating to your participation in this project, please contact: **Mduduzi Mahlinza**, Community Liaison Office; **Contact number: 035 550 7500**

Physical address: Africa Centre for Health & Population Studies, R618 en route to Hlabisa, Somkhele.

If you have any complaints about this study, or problems with the way that your rights are being protected please contact:

Biomedical Research Ethics, Research Office, UKZN, Private Bag X54001, Durban 4000

Telephone: 031 260 4769 or 031 260 1074 Fax: 031 260 2384

Administrator: Ms P Ngwenya Email: ngwenyap@ukzn.ac.za

Chair: Prof D R Wassenaar Email: c/o ngwenyap@ukzn.ac.za

The University KwaZulu-Natal Human Biomedical Research Ethics Board has approved this study

Impilo Yamadoda Trial: Informed Consent

Administrator: This consent form is meant to be an assurance that the participant has a good understanding of the research study and their role in it. Only after the information sheet has been **fully explained** to the participant is this form to be completed. If the participant has any remaining questions or does not answer **all the questions** on this sheet correctly the information **must be** clarified **before** enrolment.

Please read all questions carefully and tick as appropriate	True	False
1. The information sheet about the <i>Impilo Yamadoda</i> trial and my part in it has been read to me.		
2. Participation on this day will enrol me in the <i>Impilo Yamadoda</i> trial for at least the next six months.		
3. After the interview and blood sample collection today I will be given a R100.00 Boxer voucher.		
4. After every time I participate in this research study I will be given reimbursement to the value of R100.00 in store and/or airtime vouchers, and/or food parcels.		
5. Once I am assigned to a study group I can switch to another group if I choose.		
6. Some of the topics of this interview are on the topic of health and sexuality.		
7. Once I enrol in the <i>Impilo Yamadoda</i> trial I cannot leave the study.		
8. The blood sample collected from me will not be used for a rapid HIV test.		
9. No one will know my HIV status as a result of my participation in this research.		
10. No one can become upset as a result of his participation.		
11. This consent form, which has both my name and study identification code, will be kept in a locked file cabinet only accessible to authorized <i>Impilo Yamadoda</i> study staff.		
12. If I become upset as a result of my participation there is a counsellor I can speak to.		
13. I agree to participate in the <i>Impilo Yamadoda</i> trial of my own free will.		
14. I agree to provide a blood specimen today as part of the <i>Impilo Yamadoda</i> trial.		

You have been invited to participate in the *Impilo Yamadoda* trial. *Impilo Yamadoda* is a research project that is seeking to understand the beliefs, needs, and motivations of men to become involved in health and health research. We are enrolling about 200 men in the Hlabisa sub-district to be a part of this phase of the *Impilo Yamadoda* study.

Mlungisi Zungu, Research Assistant, has informed you fully about this study and your responsibilities and rights as a research participant.

All men who agree and are eligible to participate will complete interviews with a trained study researcher and provide us with a blood sample on two separate occasions. All men who are part of the study will also be invited to an *Impilo Yamadoda* Fair, which will include information on men's health. The study involves all men who participate to keep in contact with the research team over a period of 6-8 months.

If you become upset as a result of your participation, you may contact the below study staff in order to receive free counselling services at any time.

You may contact the study team or **Biomedical Research Ethics Office** on **031-260 4769 or 260 1074** if you have questions about your rights as a research participant.

Your participation in this research is voluntary, and you will not be penalized or lose benefits if you refuse to participate or decide to stop at any time.

If you agree to participate, you will be given a signed copy of this document and the participant information sheet which is a written summary of the research.

The research study, including the above information, has been described to me orally. I understand what my involvement in the study means and I voluntarily agree to participate. I have been given an opportunity to ask any questions that I might have about participation in the study.

Signature/Thumbprint of volunteer:	Date of signature
Print name and surname	

Time of Signature or thumb print (24 hour clock): ____:____

Signature of Study Staff taking consent	Date of signature
Print name and surname:	
Signature of witness	Witness: printed name and surname:

_____ Participant Study Identification Code _____ SA ID#

_____ Voucher # _____ Receipt #



Participant ID _____

Administrator read aloud: *The following questions are about your health and sexuality. Some of the questions are very personal. Although we believe these questions are important, I want to remind you can refuse to answer some or all of the questions here. If you become uncomfortable as a result of this interview please let me know and I will refer you to a counsellor. Once we have finished the interview I will ask you how you are to make sure that you feel comfortable with your interview.*

Do you still agree to take part in this interview? Yes No → **stop interview**

I. Demographics

Q. No.	Question & Response
1.	What is your current age? ____ Years <input type="radio"/> Refused
2.	What is your current marital status? <input type="radio"/> Married <input type="radio"/> Engaged/not yet married <input type="radio"/> Single → go to Q. 3 <input type="radio"/> Widowed → go to Q. 3 <input type="radio"/> Divorced → go to Q. 3 <input type="radio"/> Refused → go to Q. 3
2b.	Are you currently living in the same house as your partner? <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Refused
3.	How many people, in total, are current residents of your household? _____ <i>(Interviewer – current residents are people that live in the same house/bounded structure at this time.)</i> <input type="radio"/> Refused → go to Q. 4
3b.	Of these current residents, how many are children (below 18 years of age)? _____ <input type="radio"/> Refused
4.	What is the highest education grade you have completed in school? _____ Grade (1-12) <input type="radio"/> Less than 1 year → go to Q. 6 <input type="radio"/> Never went to school → go to Q. 6 <input type="radio"/> Refused → go to Q. 6
5.	What is the highest grade of education that you completed after school? <input type="radio"/> Certificate <input type="radio"/> Diploma <input type="radio"/> Advanced diploma <input type="radio"/> Bachelor's Degree <input type="radio"/> Honours, Masters. Or Higher <input type="radio"/> None <input type="radio"/> Refused
6.	Are you currently in full-time or part-time education? <input type="radio"/> Yes, full-time <input type="radio"/> Yes, part-time <input type="radio"/> No <input type="radio"/> Refused

7.		Are you currently employed? <input type="radio"/> Yes, full-time <input type="radio"/> Yes, part-time <input type="radio"/> No → go to Q. 8 <input type="radio"/> Refused → go to Q. 8
	7b.	Are you self-employed or an employee? <input type="radio"/> Self-employed <input type="radio"/> Employee <input type="radio"/> Refused

II. General Health

Part A.

8.		How would you describe your general health at present? <input type="radio"/> Very good/Good <input type="radio"/> Fair <input type="radio"/> Poor <input type="radio"/> Refused
9.		Do you have any long-standing illness, disability or infirmity? <input type="radio"/> Yes <input type="radio"/> No → go to Q. 10 <input type="radio"/> Refused → go to Q. 10
	9b.	Does your long-standing illness, disability, or infirmity, limit your activity in any way? <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Refused
10.		Are you receiving a government disability grant? <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Refused
11.		In the past 12 months/year , have you received treatment for any of the following medical conditions? <i>Tick all that apply</i> <input type="checkbox"/> High Blood Pressure <input type="checkbox"/> Diabetes <input type="checkbox"/> Tuberculosis/TB <input type="checkbox"/> Heart Disease <input type="checkbox"/> Other → specify which _____ <input type="checkbox"/> None → go to Q.12 <input type="checkbox"/> Refused → go to Q.12
	11b.	Where have you gone to seek treatment for this condition? <i>Tick all that apply</i> <input type="checkbox"/> Government clinic/hospital <input type="checkbox"/> Private clinic/hospital <input type="checkbox"/> Inyanga/Traditional Healer <input type="checkbox"/> Refused
12.		In the past three months , has there been any change in your health? <input type="radio"/> Yes, improved <input type="radio"/> No, same <input type="radio"/> Yes, worsened <input type="radio"/> Refused

13.	Have you been newly diagnosed with any of the following medical conditions in the past three months ? <i>Tick all that apply</i> <ul style="list-style-type: none"> <input type="checkbox"/> High Blood Pressure <input type="checkbox"/> Diabetes <input type="checkbox"/> Tuberculosis/TB <input type="checkbox"/> Heart Disease <input type="checkbox"/> Other → <i>specify which</i> _____ <input type="checkbox"/> None <input type="checkbox"/> Refused
14.	Are you currently receiving treatments for any of the following medical conditions? (<i>Include treatments that started long ago.</i>) <i>Tick all that apply</i> <ul style="list-style-type: none"> <input type="checkbox"/> High Blood Pressure <input type="checkbox"/> Diabetes <input type="checkbox"/> Tuberculosis/TB <input type="checkbox"/> Heart Disease <input type="checkbox"/> Epilepsy <input type="checkbox"/> None <input type="checkbox"/> Refused
Administrator: for the following section please mark the box under the respondent's response with an X	

	Do you agree, disagree or not have an opinion about the following statements:	AGREE	NEUTRAL	DISAGREE
15.	When I am sick I normally go to clinic			
16.	I advise my family (partner, children, etc) and friends to go to clinic when they are sick			
17.	I often visit friends and family at clinic when they are ill			
18.	Hospital is for people that are very ill			
19.	When I am ill, I prefer to go to a traditional healer rather than to clinic			

II. Part B - Circumcision

20.	Have you ever been circumcised? <ul style="list-style-type: none"> <input type="radio"/> Yes <input type="radio"/> No → <i>go to Q. 21</i> <input type="radio"/> Don't know → <i>go to Q. 22</i> <input type="radio"/> Refused → <i>go to Q. 22</i> 		
	20b.	If you have been circumcised, where was this conducted? <ul style="list-style-type: none"> <input type="radio"/> Government hospital <input type="radio"/> Private clinic/hospital <input type="radio"/> Inyanga/Traditional Healer <input type="radio"/> Other → <i>specify which</i> _____ <input type="radio"/> Don't know <input type="radio"/> Refused 	
	20c.	For what reason(s) were you circumcised? <i>Tick all that apply</i> <ul style="list-style-type: none"> <input type="checkbox"/> Cultural reasons <input type="checkbox"/> Health reasons <input type="checkbox"/> Other → <i>specify which</i> _____ <input type="checkbox"/> Don't know <input type="checkbox"/> Refused 	

21.	If you have not been circumcised, would you consider being circumcised in the future? <input type="radio"/> Yes <input type="radio"/> No → go to Q 22 <input type="radio"/> Don't know → go to Q 22 <input type="radio"/> Refused → go to Q 22	
	21b.	For what reasons would you agree to become circumcised? <i>Tick all that apply</i> <input type="checkbox"/> Cultural reasons <input type="checkbox"/> Health reasons <input type="checkbox"/> Other → specify which _____ <input type="checkbox"/> Don't know <input type="checkbox"/> Refused

III. HIV Knowledge and Beliefs

22.	Where have you learned about how to protect yourself from HIV infection? <i>Tick all that apply</i> <input type="checkbox"/> School <input type="checkbox"/> Workplace <input type="checkbox"/> Clinic <input type="checkbox"/> Hospital <input type="checkbox"/> Friends <input type="checkbox"/> Family <input type="checkbox"/> NGO or Community group (sporting group, men's association, etc) <input type="checkbox"/> Church <input type="checkbox"/> Other → specify which _____ <input type="checkbox"/> None/Never heard about how to protect myself from HIV infection <input type="checkbox"/> Refused	
23.	Do you think that your everyday behaviour puts you at risk for HIV infection? <input type="radio"/> Yes, I think my behaviour puts me at risk <input type="radio"/> No, I do not think my behaviour puts me at risk <input type="radio"/> I don't know/I am not sure <input type="radio"/> Refused	

IV. Sexual Behaviour

[Administrator: for this section define sex as either: vaginal sex (*when a man puts his penis into his partner's vagina*), anal sex (*when a man puts his penis into his partner's rectum*), thigh sex (*when a man puts his penis between his partner's thighs*), or oral sex (*when a person sexually stimulates their partner's genitals using their mouth*)

24.	Have you ever had sex? <input type="radio"/> Yes <input type="radio"/> No → go to Q. 37 <input type="radio"/> Refused → go to Q. 37	
25.	How old were you when you first had sex? ____ Age (in years) <input type="radio"/> Don't remember <input type="radio"/> Refused	
26.	The first time you had sex, how old was your partner? ____ Age (in years) <input type="radio"/> Don't remember <input type="radio"/> Refused	

27.	<p>How did you meet the person you first had sex with? <i>Tick all that apply</i></p> <p><input type="checkbox"/> We met through a friend of the family</p> <p><input type="checkbox"/> We live in the same area/isigodi</p> <p><input type="checkbox"/> We work at the same job</p> <p><input type="checkbox"/> We met at school</p> <p><input type="checkbox"/> We met through a mutual friend</p> <p><input type="checkbox"/> We met at a party/bash</p> <p><input type="checkbox"/> Other → <i>specify which</i> _____</p> <p><input type="checkbox"/> Refused</p>
28.	<p>When you had sex for the first time, which one of these descriptions best applies to you and the person you had sex with?</p> <p><input type="radio"/> We had just met for the first time</p> <p><input type="radio"/> We had recently met</p> <p><input type="radio"/> We had known each other for a while but were not in a steady relationship</p> <p><input type="radio"/> We used to be in a steady relationship but were not at the time</p> <p><input type="radio"/> We were in a steady relationship</p> <p><input type="radio"/> We were living together as a couple and/or married at the time</p> <p><input type="radio"/> Other → <i>specify which</i> _____</p> <p><input type="radio"/> Refused</p>
29.	<p>Have you ever used a condom during sex?</p> <p><input type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Refused</p>
30.	<p>Have you ever given money or possessions in exchange for sex?</p> <p><input type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Refused</p>
31.	<p>Have you ever received money or possessions in exchange for sex?</p> <p><input type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Refused</p>
32.	<p>How many sexual partners, in total, have you had in the past three months? Please include any casual partners as well as regular partners. <i>If you don't know the exact number please answer with your best estimation.</i></p> <p>_____ Number of sexual partners</p> <p><input type="radio"/> 0/None → go to Q. 37</p> <p><input type="radio"/> Refused</p>
33.	<p>Of your total number of sexual partners in the last three months, how many did you have sex with one time only? <i>If you don't know the exact number please answer with your best estimation.</i></p> <p>_____ Number of one-time only partners</p> <p><input type="radio"/> 0/None → go to Q. 35</p> <p><input type="radio"/> Refused</p>
33b.	<p>What type of sex did you engage in with these one-time only partners during the last three months? <i>Tick all that apply</i></p> <p><input type="checkbox"/> Vaginal sex (<i>when a man puts his penis into his partner's vagina</i>)</p> <p><input type="checkbox"/> Anal sex (<i>when a man puts his penis into his partner's rectum</i>)</p> <p><input type="checkbox"/> Thigh sex (<i>when a man puts his penis between his partner's thighs</i>)</p> <p><input type="checkbox"/> Oral sex (<i>when a person sexually stimulates their partner's genitals using their mouth</i>)</p> <p><input type="checkbox"/> Other sex → <i>specify which</i> _____</p> <p><input type="checkbox"/> Refused</p>

33c.	<p>In the last three months, how many of these one-time only sexual partners did you use condoms with? <i>If you don't remember the exact number please answer with your best estimation.</i></p> <p>_____ Number of partners used condoms with</p> <p><input type="radio"/> Refused</p>
34.	<p>Did you use a condom the most recent time you had sex with a one-time only partner?</p> <p><input type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Don't remember</p> <p><input type="radio"/> Refused</p>
35.	<p>Sometimes people have more than one relationship at the same time. How many sexual relationships do you consider yourself involved in at the moment?</p> <p>_____ Number of sexual relationships</p> <p><input type="radio"/> 0/None → go to Q. 37</p> <p><input type="radio"/> Refused</p>
35b.	<p>In the last three months, what types of sex have you had with the partner(s) you are in a relationship with?</p> <p><i>Tick all that apply</i></p> <p><input type="checkbox"/> Vaginal sex (<i>when a man puts his penis into his partner's vagina</i>)</p> <p><input type="checkbox"/> Anal sex (<i>when a man puts his penis into his partner's rectum</i>)</p> <p><input type="checkbox"/> Thigh sex (<i>when a man puts his penis between his partner's thighs</i>)</p> <p><input type="checkbox"/> Oral sex (<i>when a person sexually stimulates their partner's genitals using their mouth</i>)</p> <p><input type="checkbox"/> Other sex → specify which _____</p> <p><input type="checkbox"/> Refused</p>
35c.	<p>In the last three months, how often have you used condoms with the person/people you consider yourself to be in a sexual relationship with?</p> <p><input type="radio"/> Always/Every time</p> <p><input type="radio"/> Usually/More than half the time</p> <p><input type="radio"/> Sometimes/Less than half the time</p> <p><input type="radio"/> Never</p> <p><input type="radio"/> Refused</p>
36.	<p>Did you use a condom the most recent time you had sex with someone you consider yourself to be in a relationship with?</p> <p><input type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Don't remember</p> <p><input type="radio"/> Refused</p>
37.	<p>Have you ever had sex with a man? [Administrator: define sex as either: anal sex (<i>when a man puts his penis into his partner's rectum</i>), thigh sex (<i>when a man puts his penis between his partner's thighs</i>), or oral sex (<i>when a person sexually stimulates their partner's genitals using their mouth</i>)]</p> <p><input type="radio"/> Yes</p> <p><input type="radio"/> No → go to Q. 38</p> <p><input type="radio"/> Refused → go to Q. 38</p>
37b.	<p>Have you had sex with a man in the last three months?</p> <p><input type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Refused</p>

38.	<p>Have you ever had sex with someone when you did not want to? [Administrator: define sex as either: vaginal sex (when a man puts his penis into his partner's vagina), anal sex (when a man puts his penis into his partner's rectum), thigh sex (when a man puts his penis between his partner's thighs), or oral sex (when a person sexually stimulates their partner's genitals using their mouth)]</p> <p> <input type="radio"/> Yes <input type="radio"/> No → go to Q. 39 <input type="radio"/> Refused → go to Q. 39 </p>
38b.	<p>In the last three months, have you had sex with someone when you did not want to?</p> <p> <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Refused </p>

IV. Condom Access

39.	<p>Where have you ever obtained condoms?</p> <p><i>Tick all that apply</i></p> <p> <input type="checkbox"/> Clinic/Local health care centre <input type="checkbox"/> Hospital <input type="checkbox"/> NGO/Community-based organisation <input type="checkbox"/> Home-based care nurse <input type="checkbox"/> Chemist/Beauty supply shop (e.g., Clicks) <input type="checkbox"/> Friend <input type="checkbox"/> Family member <input type="checkbox"/> Person I have sex with <input type="checkbox"/> Other → specify which _____ <input type="checkbox"/> Never obtained condoms → go to Q. 40 <input type="checkbox"/> Refused → go to Q. 40 </p>																								
39b.	<p>Where do you go most often to get condoms?</p> <p> <input type="radio"/> Clinic/Local health care centre <input type="radio"/> Hospital <input type="radio"/> NGO/Community-based organisation <input type="radio"/> Home-based care nurse <input type="radio"/> Chemist/Beauty supply shop (e.g., Clicks) <input type="radio"/> Friend <input type="radio"/> Family member <input type="radio"/> Person I have sex with <input type="radio"/> Other → specify which _____ <input type="radio"/> Refused </p>																								
<p><i>Administrator: for the following section please mark the box under the respondent's response with an X</i></p>																									
	<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 60%;"></th> <th style="width: 10%; text-align: center;">AGREE</th> <th style="width: 10%; text-align: center;">NEUTRAL</th> <th style="width: 10%; text-align: center;">DISAGREE</th> </tr> </thead> <tbody> <tr> <td style="text-align: center;">40.</td> <td colspan="3">I believe using a condom during sex is an effective way to prevent HIV infection</td> </tr> <tr> <td style="text-align: center;">41.</td> <td colspan="3">If I was asked by my partner to use condoms during sex I would agree</td> </tr> <tr> <td style="text-align: center;">42.</td> <td colspan="3">I use condoms every time I have sex</td> </tr> <tr> <td style="text-align: center;">43.</td> <td colspan="3">I use condoms with every sexual partner</td> </tr> <tr> <td style="text-align: center;">44.</td> <td colspan="3">I sometimes have difficulty putting a condom on</td> </tr> </tbody> </table>		AGREE	NEUTRAL	DISAGREE	40.	I believe using a condom during sex is an effective way to prevent HIV infection			41.	If I was asked by my partner to use condoms during sex I would agree			42.	I use condoms every time I have sex			43.	I use condoms with every sexual partner			44.	I sometimes have difficulty putting a condom on		
	AGREE	NEUTRAL	DISAGREE																						
40.	I believe using a condom during sex is an effective way to prevent HIV infection																								
41.	If I was asked by my partner to use condoms during sex I would agree																								
42.	I use condoms every time I have sex																								
43.	I use condoms with every sexual partner																								
44.	I sometimes have difficulty putting a condom on																								

V. HIV Testing

45.	<p>There are many places to get an HIV test. Which is the best place for you to get tested?</p> <ul style="list-style-type: none"> <input type="radio"/> At home <input type="radio"/> Counselling centre <input type="radio"/> At the clinic <input type="radio"/> Mobile testing unit <input type="radio"/> At the hospital <input type="radio"/> Private Doctor <input type="radio"/> Other → <i>specify which</i> _____ <input type="radio"/> Don't know <input type="radio"/> Refused
46.	<p>Do you know your HIV status?</p> <ul style="list-style-type: none"> <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Refused
47.	<p>Have you ever requested and received an HIV test (VCT)?</p> <ul style="list-style-type: none"> <input type="radio"/> Yes <input type="radio"/> No → <i>go to Q 48</i> <input type="radio"/> Refused → <i>go to Q48</i>
47b.	<p>If you have ever requested and received an HIV test (VCT) where did you receive this?</p> <p><i>Tick all that apply</i></p> <ul style="list-style-type: none"> <input type="checkbox"/> At home <input type="checkbox"/> Counselling centre <input type="checkbox"/> At the clinic <input type="checkbox"/> Mobile testing unit <input type="checkbox"/> At the hospital <input type="checkbox"/> Private Doctor <input type="checkbox"/> Other → <i>specify which</i> _____ <input type="checkbox"/> Don't know <input type="checkbox"/> Refused
47c.	<p>Have you requested and received an HIV test (VCT) in the last three months?</p> <ul style="list-style-type: none"> <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Refused

<i>Administrator: for the following section please mark the box under the respondent's response with an X</i>				
	Do you agree, disagree or not have an opinion about the following statements:	AGREE	NEUTRAL	DISAGREE
48.	It is important to me to know my HIV status			
49.	There is medicine to help people who are HIV positive live long lives			
50.	I encourage my (sexual) partner(s) to have an HIV test			
51.	There is medicine to prevent an HIV infected mother from passing the virus to her child			
52.	If I get tested for HIV I will be able to control who knows the result of my test			

VI. Research

53.	Where did you find out about the <i>Impilo Yamadoda</i> trial? <input type="radio"/> I was given a referral ticket from someone <input type="radio"/> I heard about it from someone in my community <input type="radio"/> I heard about it from the Traditional or Municipal Authorities <input type="radio"/> I heard about it in clinic/hospital <input type="radio"/> Other → indicate which _____ <input type="radio"/> Refused			
<i>Administrator: for the following section please mark the box under the respondent's response with an X</i>				
	Do you agree, disagree or not have an opinion about the following statements:	AGREE	NEUTRAL	DISAGREE
54.	My participation in HIV prevention research helps to improve the health of my community			
55.	I am more likely to participate in HIV prevention research if I am paid for my participation			
56.	I am more likely to participate in HIV prevention research if I receive information about how to maintain good health as part of my participation			
57.	I am more likely to participate in HIV prevention research if I receive health care as part of my participation			
58.	I believe that what I say in a research setting will remain confidential (between the research staff and me)			
59.	People in my community would like it if I participated in HIV prevention research			

VII. Check-in and follow-up

Administrator read aloud: *Thank you for taking part in this interview. I hope that this was an enjoyable experience for you. Before we go over the paperwork for your reimbursement, I just want to ask you if you are feeling ok or if you would like me to refer you to a counselor:*

Would you like to speak to a counsellor? Yes No

Before we started the interview I explained that we would like you to continue with this project for 6-8 months. I will be giving you an invitation to the men's health fair, which is the next time we are to see each other.

Do you agree for me to contact you for follow-up in this research? Yes No → end interview

Primary Cell number: _____

May we leave a message here? (tick all that apply): Yes, SMS Yes, Voice No

Secondary Cell Number: _____

May we leave a message here? (tick all that apply): Yes, SMS Yes, Voice No

Fieldworker, complete this section:

Date	Location
Print Name	Signature

P4 - PARTICIPANT ENROLLMENT
BARCODE CARD



AFRICA CENTRE
FOR HEALTH AND POPULATION STUDIES



Impilo Yamadoda

Study ID#

Kumele uphathe lefihikithi kanye nomazisi wakho wase ningizimu Africa embukisweni wezimpilo yamadoda

Ukuxhumana nesitofu se-Impilo Yamadoda, sicela ufone noma uthumele umlayezo ku:

- **Mlungisi Zungu**, Research Assistant: **035 550 7614; Cell: 079 851 1427**
- **Ntombikayise E. Mncwango**, Community Liaison Officer: **035 550 7601; Cell: 082 640 4046**
- **Sebastian Fuller**, Project Coordinator: **035 550 7670**

OUTSIDE REVERSE (4)

OUTSIDE FRONT (1)

Ukuthola ukutholwa ukuze wazi isimo sakho se HIV sicela wakashalele umtholampilo wakho noma eyodwa kalezizikhungo zokuhlola iHIV:

Indawo yokululekelwa iHIV kanye nokuhlola e Mtubatuba

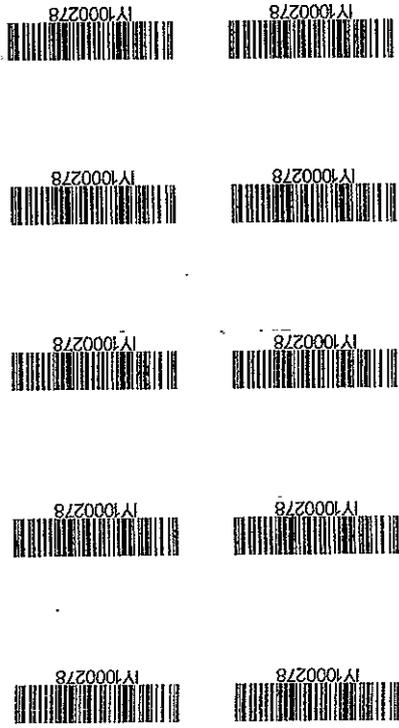
Shop Number 12, Vianchos Centre, (eduze kwaJukebox)
Monday – Friday 8:00 – 16:30; Saturday 8:00 – 13:00
Cell: 0723638607; Office: 035 550 1300

Indawo yokululekelwa iHIV kanye nokuhlola kwaHlabisa

Omahamba nedlwana bokuhlola iHIV ngemurva kwesakhiwo sikamasipala, eduze kwase ABSA bank

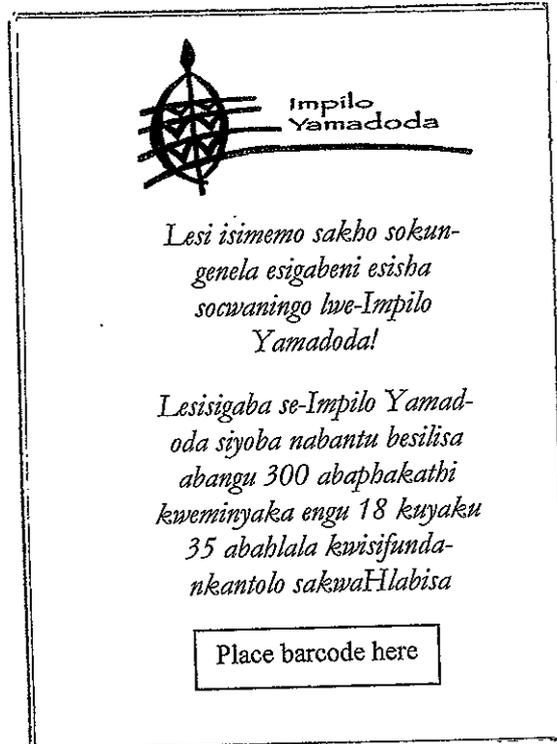
Monday – Friday 8:00 – 16:30

IY1000278



INSIDE LEFT (2)

INSIDE RIGHT (3)



FRONT



REVERSE

P4 Snowball Referral Ticket
English text

FRONT:

This is your invitation to enrol in the newest phase of *Impilo Yamadoda*: Men's Health Study! This phase of *Impilo Yamadoda* will include up to 300 men between the ages of 18-35 who live in the Hlabisa sub-District.

BACK:

If you are eligible and join the study the friend that gave you this card will receive a free t-shirt – just bring this card with you when you enrol!

To set up your appointment to come to Africa Centre and enrol in the *Impilo Yamadoda*: Men's Health Study, call, send an SMS, or send a 'please call me' to:

Mlungisi Zungu, Research Assistant, 035 550 7614; Cell: 079 851 1427
Lungani Masinga, Research Assistant, 035 550 7612; Cell: 072 379 7265



You have been assigned to study group A

You will have your follow-up interviews **face-to-face** with an *Impilo Yamadoda* researcher.

When it is time for your first follow-up interview you will be called on your *Impilo Yamadoda* cell phone by the research assistant to arrange a time and place for your interview. This interview will be held three months after you enrolled in *Impilo Yamadoda*. Your interview will not last more than 30 minutes. When the interview is finished you will receive a R100.00 Boxer voucher to thank you for your time.

For your second follow-up interview, six months after you enrolled in *Impilo Yamadoda*, you will be called to arrange a time to meet for another face-to-face interview with the Research Assistant. At the time of your interview you will also be asked to give a second blood sample. The blood sample collection method is **micro-capillary**, which is the same way we collected your blood for enrolment in this study. You will receive one R100.00 Boxer voucher after completing your interview and one R100.00 Boxer voucher after completing your blood collection.

For more information on blood collection, your face-to-face interview, the way you will be reimbursed for participation, or anything else related to this study please refer to your study information sheet or contact the research team.





Your *Impilo Yamadoda* cell phone

Important information: Please keep this information sheet in a safe place!

How can I use my cell phone to contact the research team?

You can always use your *Impilo Yamadoda* issued cell phone to contact the study team by calling directly or sending an SMS. Please do not use missed calls to contact the research team if you are out of airtime, rather use the free 'please call me' SMS. To send a free 'please call me' SMS to the Research Assistant please enter the following code into your *Impilo Yamadoda* issued cell phone: *140*0798511427# and then press 'send'.

If you wish to send a free message to the Research Assistant you can change your 'please call me' SMS message to a message of your choice by entering the following code into your *Impilo Yamadoda* issued cell phone: *140# pressing send and choosing 'answer' then 'option 4'. The option will then be given for you to change your 'please call me' message to one of your choosing. This new message will remain your default 'please call me' message for one month or until you change it again.

Do **not** use any other cell phone number to contact the study team unless you are calling to report your phone lost or stolen.

What do I do if my *Impilo Yamadoda* cell is lost or stolen?

You must report a lost or stolen *Impilo Yamadoda* cell phone to the research team immediately. To report your cell lost or stolen, please call the study team directly or send a 'please call me' SMS to (the **Project Leader**): 072 379 7383. If this is not possible, please come to the Africa Centre and ask reception to see an *Impilo Yamadoda* staff member. You will receive instructions on what to do next when you contact the study team.

Important numbers

Impilo Yamadoda study staff:

- ❖ Professor John Imrie, Principal Investigator: 035 550 7640
- ❖ Sebastian Fuller, Project Leader: 035 550 7670; Cell: 072 379 7383
- ❖ Mlungisi Zungu, Research Assistant: 035 550 7614; Cell: 079 851 1427
- ❖ Ntombikayise E. Mncwango, Community Liaison Officer: 035 550 7601; Cell: 082 640 4046

If you would like to speak to someone outside of the study team for any reason relating to your participation in this project, please contact:

- ❖ Mduduzi Mahlinza, Community Liaison Office: 035 550 7500

If you have any complaints about this study, or problems with the way that your rights are being protected please contact:

Biomedical Research Ethics, Research Office, UKZN

Private Bag X54001, Durban 4000

Telephone: 031 260 4769 or 031 260 1074

Fax: 031 260 2384

Administrator: Ms P Ngwenya

Email: ngwenyap@ukzn.ac.za

Chair: Prof D R Wassenaar

Email: c/o ngwenyap@ukzn.ac.za





You have been assigned to study group B

You will have your follow-up interviews **face-to-face** with an *Impilo Yamadoda* researcher.

When it is time for your first follow-up interview you will be called on your *Impilo Yamadoda* study cell phone by the research assistant to arrange a time and place for your interview. This interview will be held three months after you enrolled in *Impilo Yamadoda*. Your interview will not last more than 30 minutes. When the interview is finished you will receive a R100.00 Boxer voucher to thank you for your time.

For your second follow-up interview, six months after you enrolled in *Impilo Yamadoda*, you will be called to arrange a time to meet for another face-to-face interview with the Research Assistant. When you arrange your interview you will also be asked to arrange to go to clinic for a second blood sample. The blood sample collection method is **venepuncture**, which must be collected from a nurse at **clinic**. You will receive one R100.00 Boxer voucher after completing your interview and R100.00 airtime credit to your *Impilo Yamadoda* study cell phone after completing your blood collection.

For more information on blood collection, your face-to-face interview, the way you will be reimbursed for participation, or anything else related to this study please refer to your study information sheet or contact the research team.





Your *Impilo Yamadoda* cell phone

Important information: Please keep this information sheet in a safe place!

How can I use my cell phone to contact the research team?

You can always use your *Impilo Yamadoda* issued cell phone to contact the study team by calling directly or sending an SMS. Please do not use missed calls to contact the research team if you are out of airtime, rather use the free 'please call me' SMS. To send a free 'please call me' SMS to the Research Assistant please enter the following code into your *Impilo Yamadoda* issued cell phone: *140*0798511427# and then press 'send'.

If you wish to send a free message to the Research Assistant you can change your 'please call me' SMS message to a message of your choice by entering the following code into your *Impilo Yamadoda* issued cell phone: *140# pressing send and choosing 'answer' then 'option 4'. The option will then be given for you to change your 'please call me' message to one of your choosing. This new message will remain your default 'please call me' message for one month or until you change it again.

Do **not** use any other cell phone number to contact the study team unless you are calling to report your phone lost or stolen.

What do I do if my *Impilo Yamadoda* cell is lost or stolen?

You must report a lost or stolen *Impilo Yamadoda* cell phone to the research team immediately. To report your cell lost or stolen, please call the study team directly or send a 'please call me' SMS to (the **Project Leader**): 072 379 7383. If this is not possible, please come to the Africa Centre and ask reception to see an *Impilo Yamadoda* staff member. You will receive instructions on what to do next when you contact the study team.

Important numbers

Impilo Yamadoda study staff:

- ❖ Professor John Imrie, Principal Investigator: 035 550 7640
- ❖ Sebastian Fuller, Project Leader: 035 550 7670; Cell: 072 379 7383
- ❖ Mlungisi Zungu, Research Assistant: 035 550 7614; Cell: 079 851 1427
- ❖ Ntombikayise E. Mncwango, Community Liaison Officer: 035 550 7601; Cell: 082 640 4046

If you would like to speak to someone outside of the study team for any reason relating to your participation in this project, please contact:

- ❖ Mduduzi Mahlinza, Community Liaison Office: 035 550 7500

If you have any complaints about this study, or problems with the way that your rights are being protected please contact:

Biomedical Research Ethics, Research Office, UKZN

Private Bag X54001, Durban 4000

Telephone: 031 260 4769 or 031 260 1074

Fax: 031 260 2384

Administrator: Ms P Ngwenya

Email: ngwenyap@ukzn.ac.za

Chair: Prof D R Wassenaar

Email: c/o ngwenyap@ukzn.ac.za





You have been assigned to study group C

You will have your follow-up interviews with an *Impilo Yamadoda* researcher using your *Impilo Yamadoda* cell phone.

When it is time for your first follow-up interview the research assistant will call you on your *Impilo Yamadoda* study cell phone to arrange a time for your interview. This interview will be held three months after you enrolled in *Impilo Yamadoda*. Your interview will not last more than 30 minutes. When the interview is finished you will receive R100.00 airtime credit.

For your second follow-up interview, six months after you enrolled in *Impilo Yamadoda*, you will be called to arrange a time for another cell phone interview with the Research Assistant. When you arrange your interview you will also be asked to arrange a time and place to meet with the Research Assistant for a second blood sample. The blood sample collection method is **micro-capillary**, which is the same way we collected your blood for enrolment in this study. You will receive R100.00 airtime credit to your *Impilo Yamadoda* study cell phone after completing your cell phone interview and one R100.00 Boxer voucher after completing your blood collection.

For more information on blood collection, your face-to-face interview, the way you will be reimbursed for participation, or anything else related to this study please refer to your study information sheet or contact the research team.





Your *Impilo Yamadoda* cell phone

Important information: Please keep this information sheet in a safe place!

How can I use my cell phone to contact the research team?

You can always use your *Impilo Yamadoda* issued cell phone to contact the study team by calling directly or sending an SMS. Please do not use missed calls to contact the research team if you are out of airtime, rather use the free 'please call me' SMS. To send a free 'please call me' SMS to the Research Assistant please enter the following code into your *Impilo Yamadoda* issued cell phone: *140*0798511427# and then press 'send'.

If you wish to send a free message to the Research Assistant you can change your 'please call me' SMS message to a message of your choice by entering the following code into your *Impilo Yamadoda* issued cell phone: *140# pressing send and choosing 'answer' then 'option 4'. The option will then be given for you to change your 'please call me' message to one of your choosing. This new message will remain your default 'please call me' message for one month or until you change it again.

Do **not** use any other cell phone number to contact the study team unless you are calling to report your phone lost or stolen.

What do I do if my *Impilo Yamadoda* cell is lost or stolen?

You must report a lost or stolen *Impilo Yamadoda* cell phone to the research team immediately. To report your cell lost or stolen, please call the study team directly or send a 'please call me' SMS to (the **Project Leader**): 072 379 7383. If this is not possible, please come to the Africa Centre and ask reception to see an *Impilo Yamadoda* staff member. You will receive instructions on what to do next when you contact the study team.

Important numbers

Impilo Yamadoda study staff:

- ❖ Professor John Imrie, Principal Investigator: 035 550 7640
- ❖ Sebastian Fuller, Project Leader: 035 550 7670; Cell: 072 379 7383
- ❖ Mlungisi Zungu, Research Assistant: 035 550 7614; Cell: 079 851 1427
- ❖ Ntombikayise E. Mncwango, Community Liaison Officer: 035 550 7601; Cell: 082 640 4046

If you would like to speak to someone outside of the study team for any reason relating to your participation in this project, please contact:

- ❖ Mduduzi Mahlinza, Community Liaison Office: 035 550 7500

If you have any complaints about this study, or problems with the way that your rights are being protected please contact:

Biomedical Research Ethics, Research Office, UKZN

Private Bag X54001, Durban 4000

Telephone: 031 260 4769 or 031 260 1074

Fax: 031 260 2384

Administrator: Ms P Ngwenya

Email: ngwenyap@ukzn.ac.za

Chair: Prof D R Wassenaar

Email: c/o ngwenyap@ukzn.ac.za





Groups C & D: Instructions for cell phone interviews

Before you start your phone interview it is important that you check:

1. **Your cell phone must be fully charged.** This will prevent your interview from being interrupted.
2. You must be in a **quiet place** where you do not think you will be disturbed by anyone for the entire time of your interview (approx 30 minutes). This will insure that the Research Assistant understands you correctly and that you have time to consider your answers.
3. The place you have chosen to talk to the Research Assistant must be **private**. You are in control of your privacy in this type of interview: please make sure that you are not putting yourself into a situation where others can overhear your responses.





You have been assigned to study group D

You will have your follow-up interviews with an *Impilo Yamadoda* researcher using your *Impilo Yamadoda* cell phone.

When it is time for your first follow-up interview the research assistant will call you on your *Impilo Yamadoda* study cell phone to arrange a time for your interview. This interview will be held three months after you enrolled in *Impilo Yamadoda*. Your interview will not last more than 30 minutes. When the interview is finished you will receive R100.00 airtime credit.

For your second follow-up interview, six months after you enrolled in *Impilo Yamadoda*, you will be called to arrange a time for another cell phone interview with the Research Assistant. When you arrange your interview you will also be asked to arrange a time to go to clinic for a second blood sample. The blood sample collection method is **venepuncture**, which must be collected from a nurse at **clinic**. You will receive R100.00 airtime to your *Impilo Yamadoda* study cell phone after completing your interview and R100.00 airtime credit to your *Impilo Yamadoda* study cell phone after completing your blood collection.

For more information on blood collection, your face-to-face interview, the way you will be reimbursed for participation, or anything else related to this study please refer to your study information sheet or contact the research team.





Your *Impilo Yamadoda* cell phone

Important information: Please keep this information sheet in a safe place!

How can I use my cell phone to contact the research team?

You can always use your *Impilo Yamadoda* issued cell phone to contact the study team by calling directly or sending an SMS. Please do not use missed calls to contact the research team if you are out of airtime, rather use the free 'please call me' SMS. To send a free 'please call me' SMS to the Research Assistant please enter the following code into your *Impilo Yamadoda* issued cell phone: *140*0798511427# and then press 'send'.

If you wish to send a free message to the Research Assistant you can change your 'please call me' SMS message to a message of your choice by entering the following code into your *Impilo Yamadoda* issued cell phone: *140# pressing send and choosing 'answer' then 'option 4'. The option will then be given for you to change your 'please call me' message to one of your choosing. This new message will remain your default 'please call me' message for one month or until you change it again.

Do **not** use any other cell phone number to contact the study team unless you are calling to report your phone lost or stolen.

What do I do if my *Impilo Yamadoda* cell is lost or stolen?

You must report a lost or stolen *Impilo Yamadoda* cell phone to the research team immediately. To report your cell lost or stolen, please call the study team directly or send a 'please call me' SMS to (the **Project Leader**): 072 379 7383. If this is not possible, please come to the Africa Centre and ask reception to see an *Impilo Yamadoda* staff member. You will receive instructions on what to do next when you contact the study team.

Important numbers

Impilo Yamadoda study staff:

- ❖ Professor John Imrie, Principal Investigator: 035 550 7640
- ❖ Sebastian Fuller, Project Leader: 035 550 7670; Cell: 072 379 7383
- ❖ Mlungisi Zungu, Research Assistant: 035 550 7614; Cell: 079 851 1427
- ❖ Ntombikayise E. Mncwango, Community Liaison Officer: 035 550 7601; Cell: 082 640 4046

If you would like to speak to someone outside of the study team for any reason relating to your participation in this project, please contact:

- ❖ Mduduzi Mahlinza, Community Liaison Office: 035 550 7500

If you have any complaints about this study, or problems with the way that your rights are being protected please contact:

Biomedical Research Ethics, Research Office, UKZN

Private Bag X54001, Durban 4000

Telephone: 031 260 4769 or 031 260 1074

Fax: 031 260 2384

Administrator: Ms P Ngwenya

Email: ngwenyap@ukzn.ac.za

Chair: Prof D R Wassenaar

Email: c/o ngwenyap@ukzn.ac.za





Groups C & D: Instructions for cell phone interviews

Before you start your phone interview it is important that you check:

1. **Your cell phone must be fully charged.** This will prevent your interview from being interrupted.
2. You must be in a **quiet place** where you do not think you will be disturbed by anyone for the entire time of your interview (approx 30 minutes). This will insure that the Research Assistant understands you correctly and that you have time to consider your answers.
3. The place you have chosen to talk to the Research Assistant must be **private**. You are in control of your privacy in this type of interview: please make sure that you are not putting yourself into a situation where others can overhear your responses.



Five steps to support strategic community engagement in research

1. Iterative community consultation:

Community consultation in research must go beyond the formation and use of a Community Advisory Board (CAB). The CAB is a good starting point, however, the findings discussed in this thesis suggests that community involvement in research requires an iterative process, where the CAB is the starting point and not an end in itself. Our experience with *Impilo Yamadoda* showed that as the CAB was presented information about the study, they in turn spoke to and recommended to us other organisations in the community that might wish to be involved. Just as saturation is reached in qualitative research when repetition of the same themes is shown in new interviews, saturation in the iterative involvement process suggested here is reached when no new contacts are suggested. It is also possible to end the consultation recruitment when the capacity for new organisations has been reached, however this has limitations, as it will be likely that there will be interested groups that come forward as the research study becomes visible in the community throughout the implementation process.

2. Self-selected community involvement:

Following on step one, as more groups are approached the more likely it is that those most interested will be reached. Asking for time commitment, such as attendance in meetings or in research-related training activities, allows ample time for those who are less interested or have less time to commit to the research to opt-out of the partnership. In turn, those that are genuinely interested and have the time to commit to the project build investment through these joint research-community partner activities.

3. Transparency:

Transparency of partnership requirements and goals of the research itself is not only essential to meet the requirements of conducting ethical research, but also to build necessary trust in the project. Potential Research Partners must be able to plan for the responsibilities of their

involvement, both personally (in terms of individual time commitments) and organisationally (in terms of organisational resources). While it can be difficult for Research Partners to understand research protocol, for aspects of the study that cannot be changed (i.e., study arm randomisation) repeated discussion of the research using consistent terms will in time build a more complete understanding. For aspects of the study that are more flexible, such as how unblinding takes place, allowing Research Partners input into the mechanisation of those activities will both increase research literacy and build cultural competency into the protocol. The result will not only improve community-based Research Partners' understanding but also uncover gaps or misperceptions of the research on the part of the professional researchers. This collaborative problem-solving process has the added benefit of increasing overall investment in the research and may also produce a more robust and socio-culturally appropriate study.

4. Community partner participation:

Not all research studies can incorporate Research Partner implementation of research. This is especially true of medical research studies, including the collection of biological specimens. It would be inappropriate, for example, to ask lay community members (regardless of research training) to implement research that includes complex questionnaires, highly sensitive questions, or biological specimen collection. While there is debate on the acceptability of lay people such as popular opinion leaders to discuss sensitive issues with participants of health research or public health promotion, it is ethically irresponsible to place the burden of sensitive confidential information on volunteers, especially as this information may involve people they know well. Brief questionnaires containing minimally sensitive questions, such as the questionnaire implemented in Phase 2 of the *Impilo Yamadoda* study, pose little risk of harm in case of accidental disclosure of participant responses. Many major health research studies require a pre-clinical or pilot stage where this type of research would be appropriate to have community Research Partners implement among their social and/or professional network. In

addition, it would be appropriate and advantageous to have community-based research partners lead research information sessions (both informally and formally) in their communities.

Implementing surveys and/or leading community research information sessions both necessitates community Research Partners to be trained in general research techniques, including ethical research practice, and the research study itself. This training will allow research studies to be presented to potential participants in a way that will be understood more readily than if professional researchers attempted this themselves. Expanding local research literacy is a major added benefit of this approach.

5. Continued and consistent dialogue

Dialogue between the research team and the community Research Partners is not something that ends once participant recruitment ends. Continued dialogue sustains the newly created trust between the research team and community Research Partners, as well as between the community Research Partners themselves. This trust is important for sustainability of the researcher-community dialogue, throughout the study implementation process, dissemination of results, and for future research studies.