

https://dspace.org/

Public engagement throughout the research process in a health and socio-demographic surveillance system study area in rural South Africa

Twine, Rhian

2019
https://hdl.handle.net/10539/27990

Downloaded from a DSpace repository. https://dspace.org/

PUBLIC ENGAGEMENT THROUGHOUT THE RESEARCH PROCESS IN A HEALTH AND SOCIO-DEMOGRAPHIC SURVEILLANCE SYSTEM STUDY AREA IN RURAL SOUTH AFRICA

Rhian Twine

Original published work submitted to the Faculty of Health Sciences,
University of the Witwatersrand, Johannesburg,
in fulfilment of the requirements for the degree of PhD in Public Health

Johannesburg, 4th June 2019

SUPERVISORS

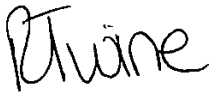
Professor Gillian Lewando Hundt, Warwick Medical School, University of Warwick, UK and Honorary Professor, School of Public Health, University of the Witwatersrand, South Africa

Professor Kathleen Kahn, MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt), School of Public Health, University of the Witwatersrand, South Africa

DECLARATION

Student's contribution to published papers

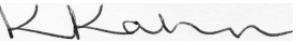
I, Rhian Twine, student number 823551/8, declare that this thesis is my own work and that I contributed adequately towards research findings published in the papers stated below which are included in my thesis.

Signature of Student  **Date** 4th June 2019

Name of Primary Supervisor Gillian Lewando Hundt

Signature of Primary Supervisor  **Date** 4th June 2019

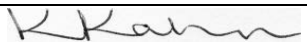
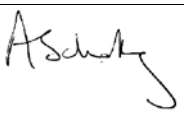
Name of Co-Supervisor Kathleen Kahn

Signature of Co-Supervisor  **Date** 4th June 2019

Agreement by co-authors

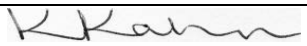
By signing this declaration, the co-authors listed below agree to the use of the papers by Rhian Twine as part of her thesis.

Paper 1:
Twine, R, Kahn, K, Scholtz, A & Norris, SA. (2016). Involvement of stakeholders in determining health priorities of adolescents in rural South Africa. *Global Health Action*. 9(1):1–9. doi.org/10.3402/gha.v9.29162.

Authors	**Name**	**Signature**	**Date**
1st author	Rhian Twine		15/2/2019
2nd author	Kathleen Kahn		15/2/2019
3rd author	Alexandra Scholtz		19/2/2019
4th author	Shane Norris		24/2/2019

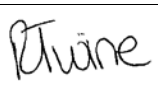
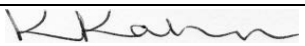
Candidate managed the preparation and implementation of fieldwork and led all three workshops during which analysis of most data occurred. The candidate wrote the first draft of the manuscript, finalised the paper based on co-author comments and managed the process of publication, responding to reviewers and making the necessary adaptations to the paper.

Paper 2:
Twine, R, Lewando Hundt, G & Kahn, K. (2017b). The 'experimental public' in longitudinal health research: views of local leaders and service providers in rural South Africa. *Global Health Research and Policy*. 2(1):26. doi.org/10.1186/s41256-017-0046-7.

Authors	**Name**	**Signature**	**Date**
1st author	Rhian Twine		15/2/2019
2nd author	Gillian Lewando Hundt		15/2/2019
3rd author	Kathleen Kahn		15/2/2019

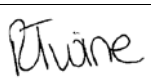
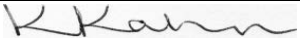
Candidate planned the study together with Lewando Hundt and Kahn. She implemented the study, conducted the analysis and linked the findings to the literature supported by Lewando Hundt. Kahn provided critical revision of the manuscript. Twine managed the process of publication.

Paper 3:
Twine, R, Lewando Hundt, G & Kahn., K. (2019). Dilemmas in Ethics in practice in a Longitudinal Health Surveillance Site: identifying opportunities for widening participation of residents. *Frontiers in Sociology.* 4:33. doi:10.3389/fsoc.2019.00033

Authors	**Name**	**Signature**	**Date**
1st author	Rhian Twine		15/2/2019
2nd author	Gillian Lewando Hundt		15/2/2019
3rd author	Kathleen Kahn		15/2/2019

Candidate planned the study together with Lewando Hundt and Kahn. She implemented the study, conducted the analysis and linked the findings to the literature supported by Lewando Hundt. Kahn provided critical revision of the manuscript. Twine managed the process of publication.

Paper 4:
Twine, R, Kahn, K & Lewando Hundt, G. (2017a). Assessing the effectiveness of a longitudinal knowledge dissemination intervention: Sharing research findings in rural South Africa. *Gateways: International Journal of Community Research and Engagement*. 10:143. doi.org/10.5130/ijcre.v10i1.5111.

Authors	**Name**	**Signature**	**Date**
1st author	Rhian Twine		15/2/2019
2nd author	Kathleen Kahn		15/2/2019
3rd author	Gillian Lewando Hundt		15/2/2019

Candidate planned the study together with Lewando Hundt and Kahn, led the fieldwork that resulted in the practical knowledge dissemination work that was discussed in this study, conducted the analysis and linked the findings to the literature supported by Lewando Hundt. Kahn provided critical revision of the manuscript. Twine managed the process of publication.

ABSTRACT

Background

Research governance in longitudinal health research areas, particularly with vulnerable populations, requires effective public engagement. The overall aim of this thesis is to explore and extend understandings of public engagement in a longitudinal health and demographic surveillance system study area (HDSS) in rural South Africa. The four research papers deal with public engagement throughout the research process: public involvement in research governance including the co-production of knowledge in research protocol development; dilemmas of ethics in practice or ethics in the field; mechanisms for knowledge transfer and translation of research findings to the experimental public; and the views of the experimental public on living within a longitudinal HDSS study area.

Methods

The case study derives from a longitudinal health study area in rural South Africa: the Medical Research Council / Wits University Rural Public Health and Health Transitions Research Unit (Agincourt). This is a mixed methods case study of public engagement throughout the research process. The qualitative mixed methods used were: a modified Delphi exercise; participatory visualisation; ethnographic field notes; individual, natural and focus group interviews with residents, village leaders, and service providers; and responses to critical incident scenarios from researchers who had been involved in nested research projects. Quantitative data were from secondary analysis of reports on village-based dissemination of findings.

Findings

Public engagement is increasingly regarded as an essential component in public health research and research governance. This thesis has extended knowledge on the lived experiences of experimental publics, namely residents in longitudinal health research areas. Firstly, public engagement and involvement in protocol development has the potential to shape research priorities and budgets. Secondly, there is an understanding and acceptance of being part of public health research, but there were concerns about some ethics in practice issues. These included requests for increased researcher

accountability in relation to giving back individual screening results and more effective and targeted dissemination of results. Thirdly public engagement as part of research governance in longitudinal public health research areas has the potential to enhance mutual trust, ethics in practice and science as a public good.

Conclusion

The case study is an original contribution to knowledge on the dynamics, mechanisms and meanings of public engagement in longitudinal public health research, and its importance for ensuring fair benefit for research participants. These research findings on public engagement within the HDSS are generalisable, and relevant in relation to research governance in longitudinal health research areas. A synthesis of models of public engagement and knowledge brokerage were developed into a hub and spokes model of public engagement that could guide longitudinal research organisations to improve public engagement at all stages of the research process. The focus on ethics in practice with an experimental public as part of civic science provides a framework for analysis of public engagement and research governance within public health longitudinal research areas.

DEDICATION

To my ever supportive parents – thank you.

FOREWORD

Without my patient and dedicated supervisor, Prof Gillian Hundt, and her very patient husband Otto's builder's tea and famous breakfasts, meals and hospitality I would not have finished this work.

My work colleagues – who are more like family – Kathleen Kahn (also my supervisor whose edits, comments and dedicated support were phenomenal), Steve Tollman, Simon Khoza, Audrey Khosa and Jeffrey Tibane in particular - but very dangerous to mention names as you all know how much you mean – from admin to our workaholic gardener, thank you for your support. I also thank Jocelyn Watkins, Violet Ndlovu and Meriam Maritse who assisted with data collection and transcription.

Having spent 30 years living and working in rural Bushbuckridge, which is my home, I love this public. I thank them for teaching me so much about research, engagement, and for embracing our differences. People like the study participant who, when I asked her a question about a research project, remembered all the many projects she had participated in, as well as the names of the fieldworkers who had administered the questionnaires. When I asked her what she thought of all this research she said "Rhian, Wits has been part of my life since I was 15!" May we never take advantage of your generosity of spirit and time, and of our special relationship of trust and respect.

And Wayne, Sammy, Robby – we do well, don't we?!

ACKNOWLEDGEMENTS

Without the participation of the people living and working in the Agincourt HDSS study area, none of this work would be possible.

This project was supported by the University of the Witwatersrand, the South African Medical Research Council, the South African National Research Foundation through their Community Engagement Funding Instrument (grant 767 93314), the EU Marie Curie Improving Population Health Through Research Exchanges' (IPHTRE) grant and the Wellcome Trust (grants 058893/Z/99/A; 069683/Z/02/Z; 085477/Z/08/Z; 085477/B/08/Z) that supported the health and socio-demographic surveillance system.

LIST OF FIGURES

Figure 1: Conceptual framework 6

Figure 2: The structure of a health and demographic surveillance system (Ye et al., 2012:4).....10

Figure 3: INDEPTH-affiliated health and demographic surveillance system study areas 2018 (www.indepth-network.org/about_us) 11

Figure 4: Civic science in relation to the civic domain and democracy (Garlick and Levine, 2017:693) 14

Figure 5: Location of the MRC/Wits-Agincourt Unit HDSS study area in rural north east South Africa and details of the study area 35

Figure 6: Overview of study design for process of consultation during protocol development (Twine et al., 2016).....43

Figure 7: Difference between questions asked in original vs new village, 2014 61

Figure 8: Information attendees at village-based feedback meetings found most useful, 2001-2015.....73

Figure 9: Trends in categories of questions asked at village-based meetings, 2002-2015 (Twine, Kahn and Lewando Hundt, 2017a:152).....74

Figure 10: Reported activities undertaken subsequent to the previous year's KDI (Twine, Kahn and Lewando Hundt, 2017a: Figure 6 p153). 77

Figure 11: Proportion of population over 18 years attending village-based meetings, 2001-2015 (Twine, Kahn and Lewando Hundt, 2017a:155).....78

Figure 12: Current and previous positions of the longitudinal health research study area in the field of civic science. Adapted version of Figure 1, p.6 from Garlick and Levine (2017).....81

Figure 13: The hub and spokes model of public engagement in longitudinal health and demographic surveillance study areas.....83

LIST OF TABLES

Table 1: 10 dimensions of knowledge brokerage adapted from Bornbaum et al (5:2015) 33

Table 2: Methods and data analysis of case study 41

Table 3: Selection of participants from each of the two selected villages (n=12 per village) 45

Table 4: Total number of residents interviewed in the 2 villages 45

Table 5: Sample size and criteria for participant selection of local village leaders and service providers (Twine, Lewando Hundt and Kahn, 2017b) 47

Table 6: Critical incident scenarios (Twine, Lewando Hundt, Kahn 2019) 49

Table 7: Number and location of principal investigators and research managers responding to critical incidents ‘researchers’ (Twine, Kahn and Lewando Hundt, 2019) 50

Table 8: Annual village meetings: number of reports and questionnaires 2001-2015 51

Table 9: Public engagement throughout the research process in a health and socio-demographic surveillance system in rural South Africa 56

Table 10: Number of participants at each stage of the Delphi process (Twine et al., 2016:7) 59

KEYWORDS

Civic science
Consent and confidentiality
Co-production of knowledge
Ethics in practice
Fair benefit
Health and demographic surveillance system (HDSS)
Human biological samples
Knowledge brokerage
Knowledge dissemination, translation and transfer
Knowledge dissemination intervention (KDI)
Longitudinal health and demographic surveillance health research study areas
Participatory parity
Public engagement
Weak and strong publics

ABBREVIATIONS

ARVs- Anti-retrovirals

CAB – Community Advisory Board

CAG – Community Advisory Group

CDF – Community Development Forum

CIOMS - Council for International Organisations of Medical Sciences

FGD – Focus group discussion

HBC – Home based care

HDSS – Health and demographic surveillance system

ICH-GCP – International Committee on Harmonisation – Good clinical practice

INDEPTH - International Network for the Demographic Evaluation of Populations and Their Health

KDI – Knowledge dissemination intervention

MRC – Medical Research Council

NGOs – Non-governmental organisations

NIHR UK – National Institute of Health Research United Kingdom

PAR – Participatory action research

PEO – Public Engagement Office

RAG – Research Advisory Group

RCT - Randomised controlled trial

WHO – World Health Organization

LIST OF PAPERS

Paper 1: Twine, R, Kahn, K, Scholtz A and Norris, S. (2016). Involvement of stakeholders in determining health priorities of adolescents in rural South Africa. *Global Health Action.* 9(1):1-9. doi: 10.3402/gha.v9.29162

Paper 2: Twine, R, Lewando Hundt, G. and Kahn, K. (2017b). The 'experimental public' in longitudinal health research: views of local leaders and service providers in rural South Africa. *Global Health Research and Policy.* 2(1):26. doi.org/10.1186/s41256-017-0046-7.

Paper 3: Twine, R, Lewando Hundt, G, and Kahn, K. (2019). Dilemmas of ethics in practice in longitudinal health research: identifying opportunities for widening participation of residents. *Frontiers in Sociology.* 4:33. doi:10.3389/fsoc.2019.00033.

Paper 4: Twine, R, Kahn, K and Lewando Hundt, G. (2017a). Assessing the effectiveness of a longitudinal knowledge dissemination intervention: Sharing research findings in rural South Africa. *Gateways: International Journal of Community Research and Engagement.* 10:143-63. doi:10.1186/s41256-017-0046-7.

The papers are all published under creative commons attribution licences, which permits their reproduction in this thesis. They are referred to by their corresponding Arabic numerals throughout this text

TABLE OF CONTENTS

DECLARATION iii

ABSTRACT vii
Background vii
Methods vii
Findings vii
Conclusion viii

DEDICATION ix
FOREWORD x
ACKNOWLEDGEMENTS xi

LIST OF FIGURES xii
LIST OF TABLES xiii
KEYWORDS xiv
ABBREVIATIONS xv
LIST OF PAPERS xvi
TABLE OF CONTENTS 1

CHAPTER 1: INTRODUCTION 4
1.1. Research questions 5
1.2. Conceptual framework 5

CHAPTER 2: BACKGROUND AND LITERATURE REVIEW 7
2.1. The new South Africa 7
2.2. Health and demographic surveillance systems (HDSS) 9
2.3. Weak and strong publics 11
2.4. Public or community engagement? 12
2.5. Civic science and citizen science 13
2.6. Experimental publics 16

2.7. Public engagement models 16
2.7.1. Public engagement in longitudinal health research 17
2.8. Co-production of knowledge 18
2.9. Ethics, public engagement and international public health research 20
2.10. Ethics in practice 23
2.10.1. Fair benefit 24
2.10.2. Informed consent and confidentiality 25
2.10.3. Collection of human biological samples 27
2.10.4. Study withdrawal 28
2.11. Involving publics in research governance 29
2.12. Public engagement during knowledge brokerage 30

CHAPTER THREE: SETTING AND METHODS 35
3.1. The Agincourt health and demographic surveillance system study area .. 35
3.2. Methods and data analysis 40
3.2.1. Method 1: Modified Delphi technique and participatory visualisation 42
3.2.2. Method 2: Semi-structured individual, focus and natural group interviews 44
3.2.3. Method 3: Ethnographic field notes and critical incident scenarios 48
3.2.4. Method 4: Secondary analysis of village feedback reports and questionnaires 51
3.3. Ethical considerations 51
3.3.1. Positionality and reflexivity 51
3.3.2. Ethical clearance 54

CHAPTER FOUR: RESULTS 55
4.1. To what extent can public engagement in a longitudinal research area foster the co-production of knowledge? 57
4.2. What is distinctive about research ethics in practice in longitudinal health research study areas? 61
4.2.1. Informed consent and confidentiality 62
4.2.2. Giving blood and reporting back individual screening results 67
4.2.3. Study withdrawal 71

4.3. What is the impact of knowledge dissemination, transfer and translation of research findings through public engagement in a longitudinal health research study area? 72
4.3.1. Knowledge acquisition 73
4.3.2. Change in attitudes 74
4.3.3. Changes in practice 76
4.3.4. Reach 77
CHAPTER FIVE: DISCUSSION AND CONCLUSIONS 80
5.1. Civic science 83
5.2. Public engagement and the co-production of knowledge 84
5.3. Ethics in practice in longitudinal health research study areas 87
5.3.1. Informed consent and confidentiality 87
5.3.2. Giving blood and reporting back individual screening results 91
5.3.3. Study withdrawal 93
5.4. Knowledge dissemination, transfer and translation of research findings 94
5.5. Limitations 96
5.6. The way forward 97
5.7. Conclusion 99

REFERENCES 101

APPENDIX A: Topic guides for semi- structured individual, natural and focus group interview 113
APPENDIX B: Ethics certificates 117
APPENDIX C: Published papers 121
Paper 1 121
Paper 2 131
Paper 3 144
Paper 4 157

CHAPTER 1: INTRODUCTION

The overall aim of this thesis is to extend knowledge and understandings of public engagement and ethics in practice in longitudinal Health and Demographic Surveillance System (HDSS) study areas, drawing on empirical and conceptual findings from a case study undertaken in rural South Africa. Findings are generalisable and can guide research governance in longitudinal health research areas globally. The research is framed conceptually within the field of civic science as an analysis of public engagement at different stages of the research process.

The setting is the MRC/Wits-Agincourt Unit's HDSS study area, which started in 1992, and is reasonably typical of HDSS study areas situated across low and middle income countries. This HDSS has been conducting research on a geographically defined population of 116 500 people living in 21 500 households in 27 villages since 1992. Routine data collected include births, deaths, in and out migration as well as scheduled updates of, for example, education status, marital status and socio-economic status. Nested research studies including cohort studies, cross sectional surveys and intervention studies are also regularly conducted. More recently, work has extended to include collection of bio-medical samples such as blood and other human tissues. All work requires appropriate institutional and governmental ethical approval, and individual consent is sought for all studies. This case study is concerned with all research conducted in this study area.

There is a strong rationale for this study as an original contribution to the growing academic debate around the dynamics of public engagement in longitudinal HDSS study areas (Geissler and Molyneux, 2011) – and a growing literature about user and public involvement in health and research, specifically on dynamics of public engagement in longitudinal HDSS study areas. These issues are being debated within a current Wellcome Trust Strategic Award on global health research ethics and community engagement, and will be of interest to the International Network for

the Demographic Evaluation of Populations and Their Health (INDEPTH) which is an umbrella organisation of HDSS study areas across the world (www.indepth-network.org), of which the MRC/Wits-Agincourt Research Unit is a founding member. Much of the literature to-date focuses on procedural ethics, rather than the ethics in practice in longitudinal HDSS study areas, which is an emergent area to which this doctoral research has contributed.

1.1. Research questions

1. To what extent can public engagement in a longitudinal health research area foster the co-production of knowledge?
2. What is distinctive about research ethics in practice in longitudinal health research study areas?
3. What is the impact of knowledge dissemination, transfer and translation of research findings through public engagement in a longitudinal health research study area?

1.2. Conceptual framework

Civic science encourages interaction and debate between researchers and the public, and was used as the conceptual framework (Figure 1) in order to examine public engagement in a longitudinal health research area at different stages of the research process, focusing on co-production of knowledge (Ostrom, 1996 in Filipe et al 2017), weak and strong publics (Gibson, Hundt and Blaxter, 2014), ethics in practice (Guillemin and Gillam, 2004) and knowledge dissemination, transfer and translation (Lavery *et al.*, 2010) .

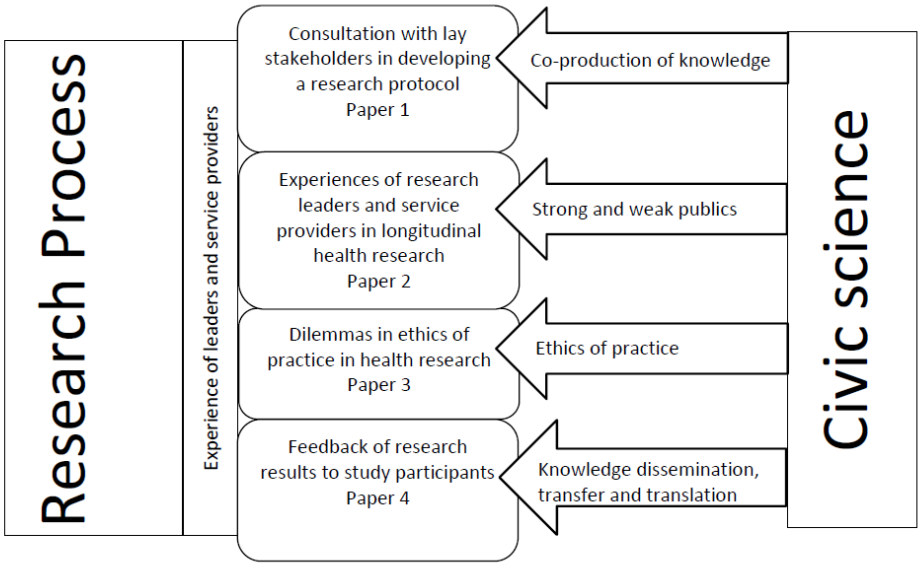


Figure 1: Conceptual framework

CHAPTER 2: BACKGROUND AND LITERATURE REVIEW

This chapter situates the thesis in the South African context and explains the specific research setting within which the data were collected. Public engagement in public health research is positioned at the interface of bioethics, philosophy, social (sociology, anthropology and economics) and political sciences and the literature review draws on concepts and theoretical approaches from these disciplines.

2.1. The new South Africa

South Africa is still struggling with the effects of it's apartheid past and associated socioeconomic injustices. Black people were systematically exploited through providing cheap labour to benefit the white population, economically marginalised and deprived of a good standard of living through being denied access to well-paid work, (Fraser, 1995), and forced to live in 13% of the land, most of which was not arable. Additionally, black people in South Africa suffered from social and cultural injustices, for example not being able to vote and receiving inferior education that aimed to create a poorly educated labour pool. Despite this situation, through a long struggle led by black South Africans, the system of apartheid ended and the country achieved full democracy in 1994.

The right to health care is now enshrined in the Bill of Rights, Chapter 2 of The Constitution of the Republic of South Africa 2006. This states that '*Everyone has the right of access to a) Health care services, including reproductive health care, b) Sufficient food and water, and c) Social security, including, if they are unable to support themselves and their dependants, appropriate social assistance'* (Constitution of the Republic of South Africa, 1996:11).

With the dawn of democratisation and enfranchisement of South African society in 1994, '*South Africa's post-apartheid government needed no convincing of the virtues of participatory governance mechanisms'* (Friedman, 2006:1) with the aim to deepen democracy. Development of policies was to be negotiated, and included grass roots citizens in decision making. Structures such as school governing bodies, hospital boards and clinic committees, and community development forums were meant to ensure greater community representation. However, the struggle against the exclusion of the majority from social justice, including the right to make decisions about their own lives, had been primarily between urban black city dwellers and the white minority (Friedman, 2006). Attention was focussed on urban areas, and yet the poorest and most disenfranchised were living in the rural areas (Tollman, 2008). Conflict in rural areas was mainly focussed on border issues between the various 'homelands' – the 13% of the land allocated to black people during apartheid (Ritchken, 1995). Twenty-five years post democracy, rural development is evident with increased provision of infrastructure such as paved roads, electricity, piped water, housing and improved access to health care and education.

However development has been somewhat hampered by patrimonialism, employment of cadres (former anti-apartheid activists) and corruption within the ruling party (Beresford, 2015). Beresford describes how 'gatekeeper politics' ensures that those in power stay in power, and in rural areas these are predominantly elected ward councillors with access to state spoils – eroding resources available for development. The mechanisms by which the voices of the rural poor were supposed to have been heard should have borne the fruit of participatory governance. However, these very mechanisms are biased towards those already in positions of power – those who could bring their concerns to the government in any case (Beresford, 2015). Grassroots organisations may not believe that these mechanisms are open to them, nor that their voices will actually be taken into consideration (Friedman, 2006). The planned participatory mechanisms have not enabled the authorities to understand, nor act on, the needs of the poor. There is also a lack of distinction between different groups of poor

people, including rural, female, unemployed and non-documented (Friedman, 2006). These most disenfranchised are turning to old struggle actions, such as service delivery strikes. According to Friedman, the most effective way for this situation to be remedied is through better communication and direct contact between government officials and its citizens. Information about policies and practices and the choices available can then be discussed and the voices of citizens taken seriously.

2.2. Health and demographic surveillance systems (HDSS)

There is a general lack of vital registration data across low and middle-income countries. A global response to this problem was the spread of longitudinal HDSSs across the Global South (Ye et al., 2012). HDSSs are designed for longitudinal research, collecting epidemiological data including risks, exposures and outcomes. They operate in geographically defined areas, self-selected owing to the lack of data (Sankoh and Byass, 2012). Most longitudinal HDSS study areas are located in sub-Saharan Africa and Asia, and are generally situated in rural, resource-poor settings. HDSSs collect population data including births, deaths, in-migrations and out-migrations. Many HDSSs also collect health and socio-economic data, such as migration, marital status, education levels and socio-economic status indicators, frequently household assets. Following the baseline census of a defined geographic area, data are collected through regular update rounds during which household and individual characteristics are updated as shown in Figure 2. An HDSS can also be used to create samples for additional surveys and cohort studies, adding to the richness of evidence that can be used for planning (Ye *et al.*, 2012).

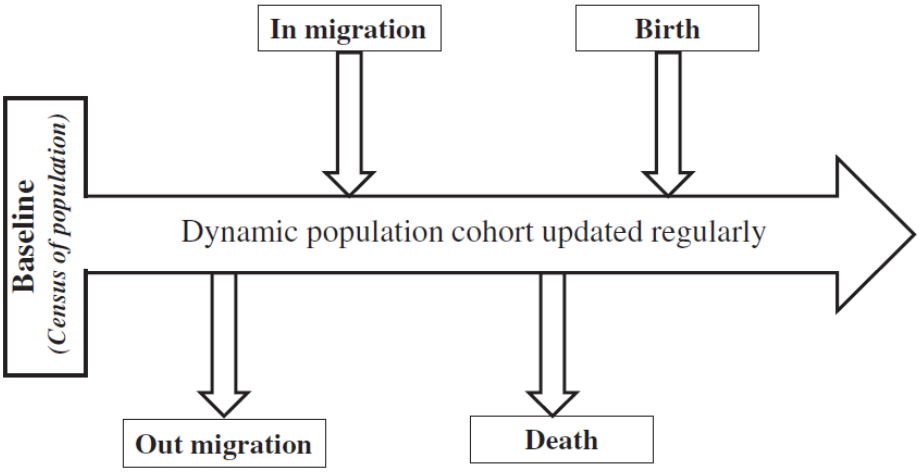


Figure 2: The structure of a health and demographic surveillance system (Ye et al., 2012:4)

Most longitudinal HDSS study areas are members of the International Network for the Demographic Evaluation of Populations and Their Health (INDEPTH). Formed in 1998, INDEPTH aims to facilitate collaborative, multicentre research involving longitudinal HDSS study areas, share data and practices and assist new HDSS study areas in order to address the lack of vital data in LMICs. Additionally, INDEPTH aims to assist countries in the Global South, currently lacking human capacity, to make use of these rich population datasets (Sankoh and Byass, 2012). In 2018, there were 48 INDEPTH-affiliated longitudinal HDSS study areas operating in 19 countries across the world (http://www.indepth-network.org/) (Figure 3).

Longitudinal study designs, such as cohort studies and HDSSs, involve long-term involvement of both the experimental public they create and researchers. Often these studies are situated in rural, resource-poor settings where there are inequities in power and information between researchers, research participants and those who use research information (Nuffield Council on Bioethics, 2005). Unlike a time-limited cross-sectional study, longitudinal health research in geographically defined areas involves study participants, users of research information, university researchers, and service providers such as municipalities,

Departments of Health and Education, in ongoing and continuing relationships. Public engagement by research institutions with participants, policy makers and the wider public can help to address inequities.

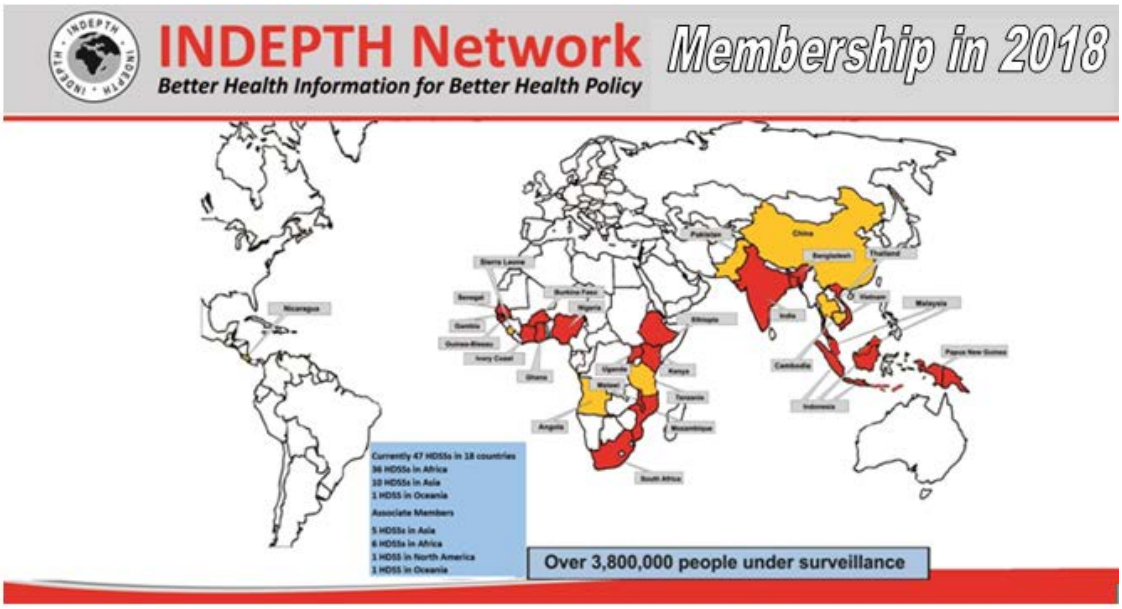


Figure 3: INDEPTH-affiliated health and demographic surveillance system study areas 2018 (www.indepth-network.org/about_us)

The value of longitudinal research is cumulative, and as such relations between the various groups involved needs to build on trust and respect, with mutual understanding of the benefits and burdens of research (Molyneux *et al.*, 2009). In a few countries, including the UK since the 1990s, patient and public involvement (PPI) has been a focus of health delivery and research in the National Health Service (Gibson, Hundt and Blaxter, 2014). However, it is only more recently that such engagement has been promoted in more traditional, non- participatory research.

2.3. Weak and strong publics

Linked to the concept of civic science is the work of Nancy Fraser who writes about the politics of redistribution and recognition, as well as the concepts of weak and strong publics, and subaltern publics. Weak or strong publics are defined according

to the degree to which all members of the public sphere who are affected by an issue participate in communication about the issue with 'participatory parity.' This is measured by the effectiveness of the decisions through assessing which actions are taken, and the degree to which those responsible are held accountable by members of the public sphere. An analysis of public engagement and user involvement can be framed using the concepts of weak and strong publics (Gibson, Hundt and Blaxter, 2014). The population living within a longitudinal health surveillance area form a subaltern public as they are objects of study by the researchers. Historical research has recently become more concerned with accounts of events from not only the points of view of leading social actors such as rulers, officers, prosperous landowners and gentry, but also of those who have less status and visibility such as maidservants, slaves and enlisted men. These are often accessed through diaries, correspondence and oral histories. This research elicits subaltern voices of the population in a longitudinal health and demographic surveillance system research area on research governance and the research process that they are part of (Dutta, 2004).

2.4. Public or community engagement?

The literature acknowledges that there are numerous ways to define the public worked with during research activities (Tindana *et al.*, 2007). Additionally, different authors use the terms public engagement or community engagement interchangeably. For example, in their definition of community, Pratt and De Vries (2018) include research information users such as policy makers and health care service providers, as well as research beneficiaries, including participants, their families and the communities from which they come. The Council for International Organisations of Medical Sciences defines the community as any sector of society that has a stake in the research (CIOMS, 2016). In this thesis, the term public engagement is used throughout rather than community engagement for two reasons. Public, rather than community, is used since the work focusses on public health research, and thus the research is important to both those directly affected by or involved in the research as well as a broader audience, since public health

aims to improve global health. Secondly, the residents living within the longitudinal HDSS study area come from different villages and wards, and the boundary of the HDSS is not congruent with other political, regional and administrative boundaries in the area. The residents within the HDSS boundary are an experimental public, defined through research, rather than a single community.

2.5. Civic science and citizen science

Civic Science is a concept that has emerged fairly recently in the field of Civic Studies (Bäckstrand, 2003; Levine, 2011) and is related to ideas of participatory democracy. Civic science (Bäckstrand, 2003) can be a way of conceptualising public engagement activities in longitudinal health research areas. The body of work of the recently deceased Economics Nobel prize winner, Elinor Ostrom (2005) was concerned with how 'human groups manage public goods and common-pool resources' (Levine, 2011:5) of which health and research are examples. She was interested in the community ownership of these public goods, and in the workings of participatory governance. This is an approach that moves away from the idea that resources are either publicly or privately owned and managed, and looks at civic society and community ownership of public goods.

Garlick and Levine (2017) further described the capacity of civic science to link science researchers with civic society in democratic action in order to encourage science to be recognised, and practiced as a public good (Figure 4). Scientific knowledge, if paired with democratic responsibilities and civic action, could translate into meaningful policy and practice changes addressing societies' most pressing problems (Garlick and Levine, 2017). Thus, facts, values and strategies could be combined to lead to positive collective action (Levine, 2011).

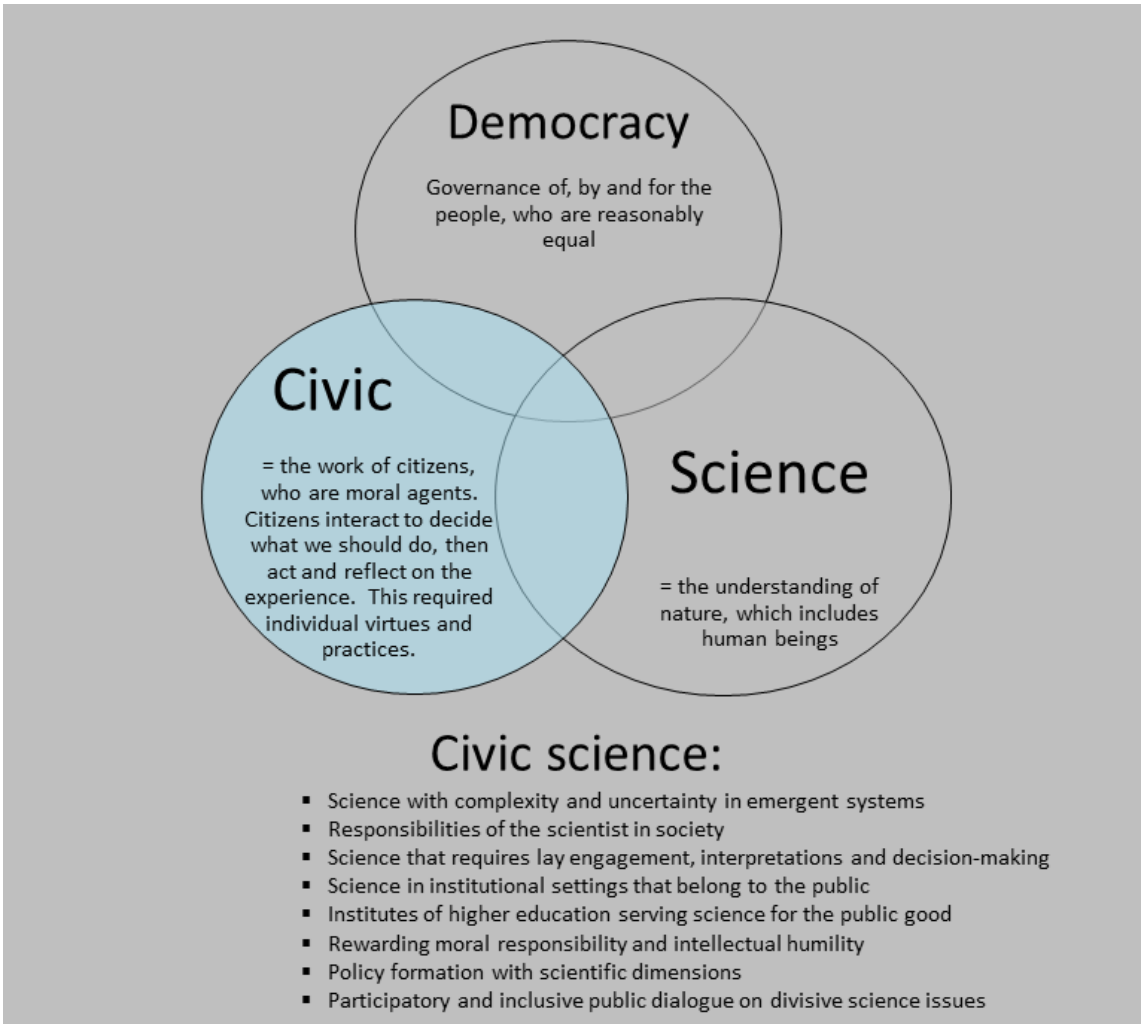


Figure 4: Civic science in relation to the civic domain and democracy (Garlick and Levine, 2017:693)

These are ambitious aims, and can be divided into three interconnected areas: participation, representation and democratisation (Bäckstrand, 2003). In relation to participation, and based on Elinor Ostrom's concepts of participatory governance, civic science focusses on 'participatory paradigms of science' – with debate between researchers, policymakers and the wider public, and with research seen as a global public good (Bäckstrand, 2003; Boyte, 2011).

Bäckstrand argues that civic science can potentially enhance representation of citizens within the area under study, making it more of a democratic enterprise. Boyte also explores the role that civic science can play in fostering democratic action and political change (Boyte, 2011). Public engagement within a longitudinal

health and demographic surveillance system (HDSS) study area can be viewed through the lens of civic science. Conceptually this is a way of framing public engagement within the research process and research governance.

The growing 'citizen science' movement, currently mainly used within environmental research, can be applied to a number of activities that involve the public in science. It can involve volunteers in gathering data, analysing data, using information communication technologies and fundraising for science, for example through crowdfunding, by presenting research as an opportunity for investment. In genomics, customers may pay for personalised genetic data but also voluntarily fill in questionnaires and agree that their data can be used for research purposes within biobanks (Woolley *et al.*, 2016).

Both civic science and citizen science are linked to the democratisation of science and society. However, civic science has a different paradigm, focusing not only on involving citizens in research activities, but considering scientific activities and outputs as mechanisms to increase public engagement, enhance the democratisation of science, and influence political and policy change using research evidence (Levine, 2007; Garlick and Levine, 2017). The view of scientific knowledge in this paradigm is that it is an unbounded commons and a public good (Hess and Ostrom, 2007).

This is where the published papers of this PhD are positioned within civic science, arguing that increasingly meaningful public engagement in longitudinal health surveillance study areas can be achieved by a) mechanisms for increasing user and public involvement throughout the research process, including the generation of research topics (Paper 1: Twine *et al.*, 2016), b) ways of encouraging the co-production of knowledge through the recognition of lay as well as professional expertise at different stages of the research process (Paper 1: Twine *et al.*, 2016; Paper 2: Twine, Lewando Hundt and Kahn, 2017b), c) awareness of particular issues of ethics in practice that arise during longitudinal research (Paper 2: Twine, Lewando Hundt and Kahn, 2017b; Paper 3: Twine, Kahn and Lewando Hundt,

2019), d) improving strategies for including publics in the governance of research projects (Paper 3: Twine, Kahn and Hundt, 2019), and d) knowledge brokerage activities aimed at effective knowledge dissemination and use (Paper 4: Twine, Kahn and Lewando Hundt, 2017a).

2.6. Experimental publics

The publics of public health in Africa have recently come under discussion (Kelly, MacGregor and Montgomery, 2017). Rather than defining publics, Kelly et al (2017) note that there are multiple publics, engagement with the public is not static, and that shifting relations that occur between society, the state and researchers influence public engagement. Publics can also make dynamic shifts according to time and place, as well as owing to cultural, political and economic influences. These influences themselves create a politics of inclusion and exclusion in public health research (Kelly, MacGregor and Montgomery, 2017).

Montgomery and Pool (2017) have proposed the concept of 'experimental publics' to describe the participants involved in clinical trials. Echoing Kelly et al (2017), their rationale is that the term 'community' has been used uncritically, while in reality, 'trial communities are socially constructed with geographic, demographic and health related inclusion and exclusion criteria' (Kelly, MacGregor and Montgomery, 2017; Montgomery and Pool, 2017; Twine, Lewando Hundt and Kahn, 2017b, p2). In this thesis, and the four published papers, the terms public engagement and experimental publics are used, drawing on this recent debate.

2.7. Public engagement models

Terms such as 'stakeholder' or 'user involvement' are often used to characterise aspects of public engagement in research. Still commonly used is Arnstein's ladder of citizen participation which identifies eight levels from manipulation by researchers to citizen control (Arnstein, 1969). Her focus is on identifying the modalities and degrees of power, influence and participation of citizens through

public engagement. She is clear that the eight levels of citizen participation is a simplification and that there may be many more.

Kirkby (2004) divides engagement into three categories: consultation, collaboration and stakeholder-controlled research (Kirkby, 1999). More recently, Tritter and McCallum suggest that these ladders and classifications do not take into account the diversity of possible stakeholders, political and social influences, and quality of stakeholder involvement (Tritter and McCallum, 2006). They suggest that public engagement needs a model represented by a mosaic of tiles, representing different interactions between the diverse stakeholders and researchers with different engagement aims emanating from the various stages of the research process. In this model, public engagement in research is not linear and hierarchical, but rather multipronged and dynamic, and lay experts themselves need to be involved in developing the process. This thesis including the published papers adopts the Tritter and McCallum approach (2006) of conceptualising public engagement as complex, non-linear and dynamic. In longitudinal health research, public engagement is particularly multi-layered as it occurs over time and with the same experimental public, unlike cross-sectional research.

2.7.1. Public engagement in longitudinal health research

In longitudinal HDSS study areas, there are regular updates of individual and household demographic and health data of the entire population, detailed Geographic Information System (GIS) maps of villages, and 'nested' research studies involving specified samples from the full HDSS (Ye *et al.*, 2012). Consideration of ethical issues when working with experimental publics in these settings is critical so that vital processes of research governance which consider and include the participation and views of local residents are routinised (Nuffield Council on Bioethics, 2005; Kamuya, Marsh, *et al.*, 2013; MacQueen *et al.*, 2015).

Information generated through the regular data rounds conducted in HDSS study areas have contributed to population health interventions such as distribution of

insecticide treated bed nets to prevent malaria, use of oral rehydration fluid, laws regulating salt content in bread and other foods (Bertram *et al.*, 2012) and links between cessation of breastfeeding and malnutrition in infants (Tollman and Zwi, 2000; Carrel and Rennie, 2008). Since research activities in HDSSs are longitudinal and the publics living in these small, geographically defined study areas are intensely monitored, their potential to contribute to global health equity needs to be balanced against the ethical considerations for the individuals and publics living and working in these areas (Carrel and Rennie, 2008).

While there is an increased focus on the ethics of biomedical research and the need for public engagement to enable both relevance and benefit from research for research participants (Nuffield Council on Bioethics, 2005), literature focusing on public engagement in longitudinal HDSS study areas is an emergent area (Carrel and Rennie, 2008; Hyder *et al.*, 2012; Mondain, 2013). Kamuya, Marsh and Molyneux have published liberally on ethics and public engagement in the Kilifi HDSS study area in Kenya (Marsh *et al.*, 2008, 2011, Molyneux *et al.*, 2009, 2013; Kamuya, Theobald, *et al.*, 2013; Kamuya *et al.*, 2015), and Tindana on the same topics in Navronga in Ghana (Tindana *et al.*, 2007, 2011). Nakibinge et al (2009) mention that working with more stable, homogenous rural populations might have facilitated the effectiveness of their public engagement activities over 20 years in Uganda. Challenges in their study area included participation fatigue and ensuring sustainability of services offered through research activities as also reported by Mondain (2013). Public engagement in longitudinal health surveillance systems is key to maintaining trust and understanding between the researchers and the experimental public. This thesis and its four papers focuses on the complexities of public engagement in one such setting. One concept that is relevant to public engagement is the co-production knowledge.

2.8. Co-production of knowledge

Elinor Ostrom was one of the first to use the term co-production of knowledge when discussing contributions from ‘individuals who are not ‘in’ the same

organisation being transformed into goods and services' (Ostrom, 1996 in Filipe et al 2017;1) There is a recent move towards 'revolutionising' health care and health research through co-production of knowledge. In the UK, co-production of knowledge has been said to be the most radical of National Health Service approaches, and aims to create user-led, people-centred health care services, and could be called co-production of value and services in health care (Filipe, Renedo and Marston, 2017). In health research, the co-production of knowledge aims to create people centred research, and is an iterative process that brings together various values and social relations within public engagement in research activities. Co-production of knowledge aims to encourage public participation in research, and values lay perspectives and knowledge as essential in order to produce knowledge that can be translated into practice (NIHR UK, 2015).

An awareness of the importance and relevance of the knowledge and experiences of people other than researchers, often referred to as lay experts or stakeholders, in determining the relevance and effectiveness of research and its results is increasing: '*if research in the field of public health is to develop more robust and holistic explanations for patterns of health and illness in contemporary society, then it must utilize and build on lay knowledge – the meanings health, illness, disability, and risk have for people'* (Popay and Williams, 1996:760). As Tritter and McCallum (2006) point out, engagement between diverse groups of lay experts and either health care providers or researchers can lead to the co-production of knowledge. This includes working together to share experiences and acknowledge differences, as well as determining the relevance of the research, through understanding the data and working towards uptake of results (Elliott and Popay, 2000; Tritter and McCallum, 2006; Fortmann, 2011). This may assist in improving the quality of research data, since if participant populations understand the relevance of research to themselves and feel that they have co-produced the knowledge, they may be more willing to participate and spend time providing accurate data (Marsh *et al.*, 2011).

Public engagement in research – which can transform weak publics into stronger publics, enhance public involvement in research governance and engage the public in all stages of the research process – contributes towards co-production of knowledge. There has been recognition that diverse stakeholders need to be involved in all stages of the research process (Entwistle *et al.*, 1998; Tritter and McCallum, 2006; Filipe, Renedo and Marston, 2017). Co-production of knowledge through public engagement is an iterative process, and different engagement strategies may have different aims for their co-production of knowledge processes.

Co-production of knowledge can have positive impacts on all stages of the research process, including developing user focused objectives, questions, information, user friendly questionnaires and interview guidelines, assisting with more appropriate recruitment strategies, enhancing consumer focused interpretation of data and more appropriate knowledge dissemination interventions (Brett *et al.*, 2014). For example, Allotey et al (2014) state that the ultimate goal of their public engagement process in a recently established HDSS would 'evolve from investigator driven questions to joint and community directed research priorities' (Allotey et al 2014:2), and the National Institute of Health Research-UK aims to include the public as partners in everything they do by 2025 ((NIHR UK, 2015). There may be reservations on the part of researchers, despite the more obvious benefits listed by Brett et al (2014), including whether there are sufficient resources available, concerns about impact on scientific integrity, and lack of confidence in the knowledge base of lay experts. In this thesis, the co-production of knowledge is considered to be part of public engagement and to be relevant at all stages of the research process and to research governance in the MRC/Wits-Agincourt HDSS, and that it strengthens the ethical conduct of research.

2.9. Ethics, public engagement and international public health research

Following a long history of health research funded by the Global North and carried out in Africa, there has in recent years been an increase in the amount of funding

major international agencies such as the United States National Institutes of Health, the UK Wellcome Trust and the Bill and Melinda Gates Foundation are giving for health related research in the Global South (Tindana *et al.*, 2007). Health research funded by the Global North and conducted in the Global South has contributed significantly to understandings of health and disease, and the improvement of health services globally (Nuffield Council on Bioethics, 2005). However, conducting research in resource poor areas raises complex ethical concerns. There is a growing focus on how public engagement in research can help to improve the ethics of research funded and often led from the Global North and carried out in the Global South (Nuffield Council on Bioethics, 2005; Emanuel *et al.*, 2004; Marsh *et al.*, 2011). The same international funders who fund the research itself, are increasingly funding public engagement activities as well making them mandatory (MacQueen *et al.*, 2015; Pratt and de Vries, 2018).

There is a small but growing body of literature focussing on how the three ethical principles included in the 1979 Belmont Report: respect for persons, beneficence and justice (The National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, 1979; Kass *et al.*, 2014) apply to public health research in countries in the Global South (Emanuel *et al.*, 2004; Lavery *et al.*, 2010; Hyder *et al.*, 2012; Kass *et al.*, 2014; Koen, Wassenaar and Mamotte, 2017). Specifically the more recent ethical guidelines for international research developed by the Council for International Organizations of Medical Sciences (CIOMS, 2016) and the Nuffield Council of Bioethics report (Nuffield Council on Bioethics, 2005) are relevant.

As stated in the Nuffield Council on Bioethics report (2005), countries in the Global South sorely need research to identify how to deal with their specific disease burden, but frequently have to rely on external funding, usually from the Global North. Implicit in this situation is inequality between the researchers, sponsors, service providers, policy makers and research participants. The Nuffield report focusses on four principles in an effort to ensure justice: ‘the duty to alleviate suffering; the duty to show respect for persons; the duty to be sensitive to cultural

differences and the duty not to exploit the vulnerable' (Nuffield Council on Bioethics, 2005). This growing awareness of the potential for harming participants, and assumptions about political, economic and cultural situations have highlighted the need for public engagement in research, especially in the Global South (Emanuel *et al.*, 2004; Geissler and Pool, 2006; Tindana *et al.*, 2007; Molyneux *et al.*, 2009; Lavery *et al.*, 2010; Twine and Hunter, 2011; Marsh *et al.*, 2011; Kamuya, Marsh, *et al.*, 2013; Kass *et al.*, 2014; MacQueen *et al.*, 2015; Pratt and de Vries, 2018; Reynolds and Sariola, 2018). The role that participants and the communities that they live in have in health research, particularly with regards to ethical decision making and potential benefits, is increasingly under discussion (Jentsch and Pilley, 2003; Lavery *et al.*, 2010; MacQueen *et al.*, 2015). It has been noted that the success of such research is dependent on successful engagement with those who will be directly affected (Tindana *et al.*, 2007).

Increasingly, there are calls for public engagement to occur at all stages of the research process (South African Department of Health, 2007; UNAIDS/WHO, 2007; Hosegood and Madhavan, 2010; UK National Institute for Health Research, 2014), including project start-up, data collection, analysis and dissemination of findings. Although there is a growing literature on public engagement in public health research (Madhavan *et al.*, 2007; Tindana *et al.*, 2007; Molyneux *et al.*, 2012; Molyneux and Bull, 2013; Allotey *et al.*, 2014; Simwinga *et al.*, 2016), there is still a need for literature describing how to do this effectively, and the impact of engagement strategies (Tindana *et al.*, 2007; Nakibinge *et al.*, 2009; Lavery *et al.*, 2010; Allotey *et al.*, 2014; Brett *et al.*, 2014).

Public engagement in research has the potential to strengthen ethical practice, through empowering and strengthening the protection of participants, enhancing the level of trust and respect between researchers and research participants, as well as ensuring the relevance of the research to local communities (Marshall and Rotimi, 2001; Tindana *et al.*, 2007; Marsh *et al.*, 2011). A lack of clarity regarding the scope and range of public engagement has been identified, and can *'be broadly divided into those that are more instrumental, such as engaging*

communities to improve the quality of the research (or simply satisfying funders), and those that are more intrinsic such as engaging communities to show respect or to ensure a sense of inclusion' (Molyneux and Bull, 2013:9). This integrating narrative and the four published papers explore both of these dimensions of public engagement.

2.10. Ethics in practice

Not all situations that occur during fieldwork can be dealt with using procedural institutional ethical codes of conduct. In order to enhance ethical research practice, Guillemin and Gillam (2004) have suggested that 'ethics in practice', or dealing with ethical dilemmas that occur during field research, are also of key importance. Ethics in practice has also been referred to as 'situational ethics', as 'relational ethics' (Ellis, 2007) or as 'practical ethics' (Paradis and Varpio, 2018). Guillemin and Gillam refer to 'ethically important moments' (Guillemin and Gillam, 2004:266). Ethics in practice involves '*critical reflection both on the kind of knowledge produced from research and how that knowledge is generated*' in order to deal with these moments (Guillemin and Gillam, 2004:274), requiring reflective practice or reflexivity of the research team. Reflexivity is '*critical reflection both on the kind of knowledge produced from research and how that knowledge is generated*' (Guillemin and Gillam 2004:274). Reflexive researchers consider the different cultural and social world views between participants and themselves (Doumbo, 2005; Kamuya, Theobald, *et al.*, 2013; Molyneux and Bull, 2013). Actions taken to alleviate these situations can lead to more nuanced and enlightened ethical practices in research (Guillemin and Gillam 2004). The focus of this thesis is dilemmas of ethics in practice rather than procedural ethics, and the work makes contributions to this area. Within the field of bioethics, whether procedural or in practice, four areas were identified as key during empirical work in the study setting: fair benefit, informed consent and confidentiality, collection of human biological samples and study withdrawal.

2.10.1. Fair benefit

With specific reference to research in resource poor communities, within which most HDSS study areas are situated, the International Ethical Guidelines for Biomedical Research Involving Human Subjects states that the researchers and funders must make every effort to ensure that the research is aligned to the priorities and health needs of the community where the research is planned to take place. The guidelines also state that, within reason, any output be made available for The the public in which the research was carried out (CIOMS, 2016). This challenge is receiving increasing attention, and the question being asked is 'what is fair benefit?' Lairumbi et al (2011) reviewed nine African and seven international research ethics guidelines, and found that only half mentioned benefits to participants, experimental publics and to society in general. There was considerable variation between the guidelines regarding how much responsibility researchers should have for giving benefit, as well as what these benefits might be. This lack of consensus could result in different interpretations and practices around ensuring the social value of research (Nuffield Council on Bioethics, 2005; Participants, 2002; Lairumbi *et al.*, 2011; Molyneux *et al.*, 2012).

Since the ultimate aim of longitudinal HDSS study areas is to improve the health of the public through impacting global health, a clear avenue for contributing towards fair benefit is to develop capacity in the local health care systems (Hyder *et al.*, 2012). Some authors are of the opinion, though, that care needs to be taken to ensure that input by researchers does not impede local government efforts to improve health care systems (Hyder *et al.*, 2012) (for example by taking over a training role so that local government no longer includes facilities in the study area in their planned training sessions). Local employment and spending has been noted as a benefit from longitudinal research, as well as being a strategy to improve public perceptions of research (Nakibinge *et al.*, 2009; Hyder *et al.*, 2012).

It could be construed that the longer there is a sustained relationship between an experimental public and the researchers working in the HDSS, there is a

reasonable expectation for more benefit from the researchers than in short term research (Hyder *et al.*, 2012). Conversely, some argue that providing tangible benefits such as health care, or even developing local health care services, may compromise the validity and generalisability of research results (Carrel and Rennie, 2008; Lavery *et al.*, 2010; Hyder *et al.*, 2012). The balance between incentives and over-incentivising participation in research is a fine line, and balancing potential risks and benefits in longitudinal HDSS study areas can be a delicate task (Carrel and Rennie, 2008). Provision of health care could be seen to adversely influence participants' ability to refuse to participate (Hyder *et al.*, 2012) thus incentives and benefits might undermine one of the core ethical principles of research – informed consent (Nakibinge *et al.*, 2009).

2.10.2. Informed consent and confidentiality

Informed consent is widely recognised as a prerequisite of procedural ethics (The National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, 1979). There is a body of literature exploring the complexities of the consenting process in rural African contexts (Molyneux, Peshu and Marsh, 2005; Tekola *et al.*, 2009; Molyneux and Bull, 2013; Kamuya *et al.*, 2015) where the process of informed consent can be complex and influenced by cultural, gender and social norms (Doumbo, 2005; Molyneux and Bull, 2013; Molyneux *et al.*, 2013; Kamuya *et al.*, 2015). Issues that might influence willingness to consent may include: the level of understanding that fieldworkers have of the research; how they explain this to the potential participant; local cultural and social beliefs and; how participants understand the information (Tekola *et al.*, 2009; Kamuya *et al.*, 2015). Participants may agree to participate in the hope that care might be given, even if informed otherwise, especially in poorly resourced areas (Molyneux, Peshu and Marsh, 2005; Hyder *et al.*, 2012).

Emmanuel et al (2004) discuss the different spheres of consent that are required in community-based research. These can include: collective consent from the wider experimental public in which the research is taking place; the household head

depending on the cultural practices in the area; and the sampled individual him or herself. In some situations, public and household head consent needs to be obtained before the researcher can approach the individual for informed consent (Emanuel *et al.*, 2004; Carrel and Rennie, 2008). Particular to HDSSs, is that consent for regular information updates requires household-level consent from one individual for a range of health and socio-demographic related questions about all members of the household, often without a clearly defined research outcome (Allotey *et al.*, 2014). Hyder et al (2012) point out that if individuals have lived their whole life in longitudinal HDSS study areas, they may regard all work carried out by the research institution as legitimate, especially when collective and household head consent has already been given. Individuals may either not feel empowered, or not consider it their right, to refuse to participate (Hyder *et al.*, 2012). Kamuya et al (2015) describe a phenomenon in a longitudinal HDSS study area in rural Kenya which they call 'silent refusals' – 'hesitating to participate without explicitly refusing' (Kamuya *et al.*, 2015:3). Silent refusals illustrate that although ethical principles such as autonomy are universally applied (Nuffield Council on Bioethics, 2005), such principles need to be negotiated in practice within different cultural and social contexts (Tekola *et al.*, 2009; Kamuya *et al.*, 2015).

Ensuring confidentiality and anonymity are also key to both procedural ethics and ethics in practice, and are inherent in informed consent. In longitudinal HDSS study areas, this is essential since often the sample populations are very large, the project teams are also large, and there is an enormous amount of data that is generated over time about individuals (Aquino *et al.*, 2013). Data and information needs to be kept confidential to reduce the possibility of stigmatisation of individuals. Additionally, care needs to be taken to avoid community level stigma where for example one area of the HDSS might have higher levels of poverty than another. Aquino et al (2013) mention the importance of managing these longitudinal datasets in ways to reduce the possibility of identification of individuals when different projects access the data to address different research questions (Aquino *et al.*, 2013).

Since HDSS study areas are geographically defined, publications about data gathered in HDSSs include descriptions of the area within which the experimental public lives, often with maps. There is therefore a possibility that research results, such as HIV prevalence, gender-based violence prevalence, or even more social type results such as social coherence, could be seen to typify only the experimental public in the HDSS study area, and not a larger population (Marshall and Rotimi, 2001; Tindana *et al.*, 2011). Local fieldworkers are often employed to conduct interviews, and this adds another layer to the importance of training fieldworkers about confidentiality (Molyneux *et al.*, 2013).

2.10.3. Collection of human biological samples

Collection of human biological specimens can contribute greatly to advances in health research and thereby contribute to improved health services. Procedural ethics processes cover the more legalistic aspects of collecting, storing and transporting human biological samples, as well as describing best practices with regards to benefit sharing from any profit that comes from analysis of these samples (Upshur, Lavery and Tindana, 2007; Moodley *et al.*, 2014). In relation to ethics in practice, participants may have views regarding the collection of human biological samples including concerns about future use, report back of results, and where the samples will be stored. (Moodley *et al.*, 2014). Issues about collection of human biological samples have been raised by experimental publics for many years as ways to express deeper concerns about the configuration of international health research in Africa. In longitudinal HDSS study areas, there may be trials or nested observational studies that include the collection of blood and other human biological samples. Rumours around blood taking are built through historical experiences and social belief structures, influenced by cultural practices (Geissler, 2005; Geissler and Pool, 2006; Upshur, Lavery and Tindana, 2007; Kelly, MacGregor and Montgomery, 2017). In the context of a microbicide gel trial in South Africa, there were rumours that blood was being sold for cash by the researchers (Stadler and Saethre, 2011). Clinical researchers and service providers involved with the trial saw these stories as exemplifying

misunderstandings, but the authors interpreted these lay explanations as a critique of relations between researchers and local participants, expressions of popular resistance, and related to local ideas of gender and morality.

Reporting back biomedical screening results that might have an impact on the health needs of individual research participants is a controversial topic within the ethics in practice. Reporting back individual biomedical screening results is part of the ethical imperatives of respect for person, reciprocity, beneficence and justice (Shalowitz and Miller, 2005; Bledsoe et al., 2012), and can foster a positive attitude towards health research. Those against reporting individual biomedical screening results argue that human biological samples should be given for the good of science and mankind, and that results might cause harm if they have not been validated, or tracking has not been adequate and the wrong result is returned (Bledsoe et al., 2012). However, in their review of articles published prior to 2005, Shalowitz and Miller (2005) found that there were very few reports of such harm, and most individuals found their biomedical screening test results beneficial. There is also a concern that giving back individual biomedical screening results might lead to 'therapeutic misconception' (Appelbaum et al., 1987). This term alludes to participant's possible confusion between research, where the primary aim is for knowledge acquisition, and medical care where the primary aim of the activity is considered for the benefit of the individual (Molyneux, Peshu and Marsh, 2005; Tekola et al., 2009). There may also be difficulties in deciding what is a 'clinically relevant' result and whether only results that indicate a condition for which care can be locally obtained be returned (Murphy et al., 2008). There is an additional concern regarding cost, as giving back of individual results adds to project budgets (Bledsoe et al., 2012).

2.10.4. Study withdrawal

Although considerations of justice and cessation of possible benefits to the experimental public in longitudinal HDSS study areas is important, there is very little literature on this topic. Carel and Rennie (2008) discuss this and note that

consent to participate in a longitudinal HDSS does not include any time frame in the information sheets (Carrel and Rennie, 2008). Additionally, these considerations might be more important if the research organisation running the HDSS provides health care to the experimental public. In this case, dissolution of an HDSS will be ethically complex as the health care provided by the research organisation will end when the HDSS closes (Carrel and Rennie, 2008).

Another important issue with specific reference to HDSS and other longitudinal research study areas is the sustainability of services provided to study participants forming the experimental public that were part of a health intervention study, when the studies end (Carrel and Rennie, 2008). There has been more literature on obligations of researchers in relation to post clinical trial settings (Emanuel *et al.*, 2004; Grady, 2005; CIOMS, 2016) than about public health service interventions (Nuffield Council on Bioethics, 2005; Participants, 2002).

This thesis explores these four principles of bioethics (fair benefit, informed consent and confidentiality, human biological samples and study withdrawal) in relation to ethics in practice in longitudinal health research study areas through a case study in Southern Africa.

2.11. Involving publics in research governance

In their work in rural Kenya and South Africa, Molyneux et al (2009) emphasised that the relationships that are formed between researchers and local stakeholders are essential in enhancing the social value of research. Research partnerships can empower participants, amplify the voice of the experimental public in study areas and assist in aligning research priorities and impacts to real life problems (Hoekstra *et al.*, 2018). These relationships, if developed with trust, respect and active engagement between all parties can help to build long term partnerships (Hyder *et al.*, 2012). Given that in most longitudinal HDSS study areas, there may be inequities between the researchers and local stakeholders, Emmanuel et al (2004) suggest that considerable attention needs to be given to finding avenues to create

collaborative partnerships between these parties. These partnerships may go some way towards addressing the unequal balance of power between the public and the researchers (Marsh *et al.*, 2008; Hyder *et al.*, 2012). Partnerships can also allow for discussion and resolution of dilemmas in a manner that allows different points of view to be heard, and compromises to be negotiated (Emanuel *et al.*, 2004). The longitudinal nature of HDSSs require that consideration needs to be taken of political, social and cultural changes as well as changes in health needs when planning or undertaking public engagement (Hyder *et al.*, 2012). Local leadership can also change over time, and researchers planning public engagement strategies in longitudinal health research need to take this into consideration (Marsh *et al.*, 2008).

One common method used to improve public engagement in research governance is through working with Community Advisory Boards (CABs). Some CABs are involved deeply in research design and defining research topics (Hyder *et al.*, 2012), while others are set up to act as consultants, educating the public about the research and advising on research protocols (MacQueen *et al.*, 2012).

There are recognised difficulties in achieving equal collaborative partnerships in many research and other settings given local and global power relations. Effective engagement and involvement in research governance as part of public engagement can strengthen a 'weak public', increasing participatory parity (Fraser, 1995) and in addition is in line with the civic science paradigm (Bäckstrand, 2003; Levine, 2011) as set out earlier as part of the conceptual approach of this thesis.

2.12. Public engagement during knowledge brokerage

An important strand of public engagement is knowledge transfer and dissemination of research findings (Lavery *et al.*, 2010). In the last 20 years, such engagement has been promoted in more traditional, non- participatory research (Dickert and Sugarman, 2005; Tindana *et al.*, 2007). A recent review of 205 Canadian research studies about arthritis found that only 4 studies identified reported public

engagement at all stages of the research process (Lin *et al.*, 2018). Strategies for knowledge dissemination and transfer are being developed as part of public engagement programmes in some HDSS study areas, as in the Kenya Medical Research Institute (Marsh *et al.*, 2008), the Navrongo Health Research Centre in Ghana (Tindana *et al.*, 2011) and MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt) in South Africa (Madhavan *et al.*, 2007; Twine, Kahn and Lewando Hundt, 2017a). However, knowledge dissemination activities to the research participants are not always routinely included in longitudinal HDSS study area activities for example in the Niakhar HDSS in Senegal (Mondain, Delaunay and Ouédraogo, 2016).

Terms such as knowledge dissemination, transfer and translation are often used interchangeably as shown by Lafrenière et al (2013) in their systematic review of 19 studies. Lefrenière et al's definition of a Knowledge Dissemination Intervention (KDI) was used in this study: '*an active intervention that aims at communicating research data to a target audience via determined channels, using planned strategies for the purpose of creating a positive impact on the acquisition of knowledge, attitudes and practice*' (Lafrenière et al., 2013:2). The effectiveness of a KDI can then be measured by knowledge acquisition, changes in attitude and changes in practice. Despite there being over 20 years of discussion about and implementation of public engagement in research, there is little evaluation of KDIs. An evaluation of 175 research organisations in Canada showed that only 10 had evaluated their KDIs for effectiveness (Lavis *et al.*, 2006).

There is a lack of evaluation of the effectiveness of KDIs, very little longitudinal evaluation and most KDI evaluations focus on those that target health professionals. The reported interventions mostly show changes in knowledge and attitudes but rarely in practices (Lafrenière *et al.*, 2013).

As part of ethics in practice and democratisation of science, effective knowledge dissemination strategies need to be integral to research projects. Sharing of data can be seen to be an aspect of the principle of fair benefit, and increasingly,

research funding agencies are also recognising that they have a role to play in ensuring knowledge dissemination occurs (Day *et al.*, 2018; McElfish, Purvis and Long, 2018; Terry *et al.*, 2018). Day et al (2018) reviewed 108 HIV clinical trials, and found that approximately 45% of trials reviewed conducted public engagement prior to and during the trial, whereas only 3% involved the public in analysing the data, and 10% consulted the public regarding dissemination of results (Day *et al.*, 2018)

As this requirement gains ground, there is a need for knowledge brokers to ensure effective knowledge dissemination interventions ('transforming knowledge'), and develop collaborative links between researchers and publics. These can be individuals or organisations. Knowledge brokers are often on the boundary between researchers and publics, and as such have insights into both world views (Meyer, 2011; Schlierf and Meyer, 2013). Such knowledge brokers can work in both research organisations and other organisations such as government departments or NGOs. There is a growing demand for evidence-based policy and practice that is slowly creating a 'pull' for relevant research results, moving from unilateral dissemination to multidirectional creation and use of information (Godfrey, Funke and Mbizvo, 2010).

A recent systematic review by Bornbaum et al. (2015) analysed 29 articles on knowledge brokerage and identified 10 key components (Bornbaum *et al.*, 2015) as shown in Table 1. Sharing research information with research participants is an important part of knowledge brokerage between universities and the wider public (Bornbaum *et al.*, 2015). Often researchers give less attention to the dissemination of research findings to participants and beneficiaries than to academic peers and policymakers. There is now an acknowledged need for knowledge brokerage, aiming to develop collaborative links between researchers and stakeholders, increase knowledge transfer and translation, and build knowledge users' capacities to apply relevant findings to policy and practice (Meyer, 2011). Knowledge brokers may work in research organisations, universities, governments or NGOs. They often work on the boundary between researchers and various publics, since one of

their roles is to exchange information and, as such, have insights into different world views (Schlierf and Meyer, 2013). However, the effectiveness of knowledge broker activities, although acknowledged as important, is difficult to evaluate and seldom assessed (Bornbaum *et al.*, 2015). There may be unrealistic expectations of direct impact, while indirect ones are difficult to identify and evaluate (Elliott and Popay, 2000). For example, even collecting metrics of hits on a website, does not elucidate how the information is being used. Despite this, there is increasing pressure on governments and service providers to develop evidence-based policy and practice (Gilson and McIntyre, 2008; Theobald *et al.*, 2011).

Table 1: 10 dimensions of knowledge brokerage adapted from Bornbaum et al (5:2015)

1. Identify, engage and connect with stakeholders
2. Facilitate collaboration
3. Identify and obtain relevant information
4. Facilitate development of analytic and interpretive skills
5. Create tailored knowledge products
6. Project coordination
7. Support communication and information sharing
8. Network development, maintenance and facilitation
9. Facilitate and evaluate change
10. Support sustainability

Increasingly, guidelines on good fieldwork practice are calling for public engagement and participation in research at all stages of the research process, from design, through fieldwork planning and implementation, to monitoring and analysis and distribution of results (South African Department of Health, 2007; UNAIDS/WHO, 2007; Carrel and Rennie, 2008; Rennie and Sugarman, 2009; UK National Institute for Health Research, 2014). Literature on public participation in science recognises that data collection is dependent on the willingness of people to not only participate in research by answering questions and giving of their time but also sharing their local expertise and knowledge (Fortmann, 2011). Public participation in science, especially in research governance, is related to civic science (Bäckstrand, 2003; Levine, 2011) and the idea that science and health are public goods.

This literature review of current publications on dimensions of public engagement has drawn on research in bioethics and social sciences. This thesis uses concepts from civic science, such as science as a common good and weak and strong publics, in relation to experimental publics (Fraser, 1995; Montgomery and Pool, 2017), models of public engagement (Tritter and McCallum;2005), as well as exploring issues of ethics in practice to contribute to public engagement in longitudinal health and demographic surveillance system study areas in the Global South.

CHAPTER THREE: SETTING AND METHODS

3.1. The Agincourt health and demographic surveillance system study area

The Agincourt HDSS study area is based in the Bushbuckridge Municipal sub-district of Ehlanzeni municipality in the rural Mpumalanga Province of South Africa (Figure 5). The area is 500km northeast of Johannesburg, with the Kruger National Park conservation area on its eastern border. In 2018, the area covered 450km^2 with a population of 125 000 people in 19 500 households in 27 administratively defined villages https://www.agincourt.co.za. The Bushbuckridge sub-district was part of the Gazankulu 'homeland' or 'bantustan' during the pre-1994 apartheid era. The majority of the population are ethnically Tsonga, and speak the local language Shangaan. Some 30% of the sub-district population comprises former Mozambican refugees owing to the area's location alongside the western border of Mozambique. The majority of these former Mozambican refugees now have permanent residence status in South African (Polzer, 2008; Twine *et al.*, 2016).

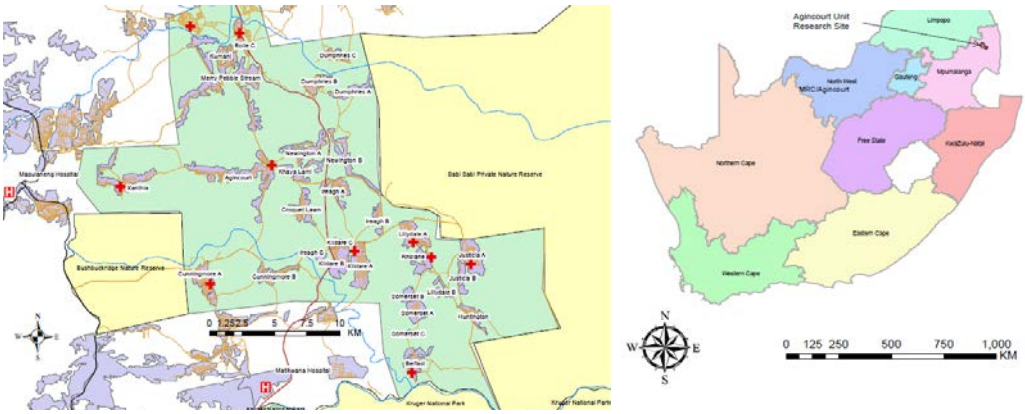


Figure 5: Location of the MRC/Wits-Agincourt Unit HDSS study area in rural north east South Africa and details of the study area

Since the first democratic elections in 1994, there has been infrastructure development, with prepaid electricity available in all villages, some gravel roads now tarred and a slow programme of improving water provision although

household still mainly access water from communal stand pipes. Every village has a primary school and most a high school but the quality of education remains poor. There are two health centres and six clinics within the HDSS study area, with three district hospitals 25–60km away (Kahn *et al.*, 2012).The area is dry in winter (May to October), and although many households practice supplementary farming, the land allocated during apartheid for resettlement is too small for total reliance on subsistence farming. Unemployment is high with most formal employment being male migration to industry e.g. mining, manufacturing and agriculture (Collinson *et al.*, 2014). There is a growing number of women joining the temporary migrant labour force on nearby farms and, local employment is predominantly in the public and informal sector. South Africa's non-contributory social grant system is a main source of household income, together with remittances from labour migrants (Lippman *et al.*, 2018).

The development of the MRC/Wits Rural Public Health and Health Systems Research Unit (Agincourt) began in 1992, when the Agincourt HDSS was established as a platform for health systems research and development. Early findings indicated a dearth of accurate vital registration data in the rural area of South Africa in which the HDSS was established, namely Bushbuckridge (Tollman et al., 1999). Annual health and socio demographic updates are conducted with the 116,500 people living in 21 300 households in the 27 adjacent villages in the Agincourt HDSS since 1992. Updates include information on births, deaths, in and out migration, socio-economic status and education, family structure and various, scheduled updates on, for example, health care utilization and food security.

Data derived from vital registration of births, deaths and causes and death, as well as illness, are essential for effective public health policy and planning. Such data is also useful for monitoring health services and their effectiveness in improving the quality of life of the target population. The MRC/Wits-Agincourt Unit started its HDSS in 1992, a couple of years before democratic change, in order to inform district health planning in the new South Africa. There was a strong possibility that, owing to apartheid policies which restricted movement and ensured separate

development, there could be suspicion around a research endeavour collecting personal details on every member of a large population. Thus, public engagement activities were essential, and discussions with a range of key community members was carried out prior to HDSS fieldwork starting (Tollman, 2008).

The Agincourt HDSS regularly updates all vital events – births, deaths, in- and out-migrations – in a defined geographical area over time. The baseline census was in 1992 when the HDSS was undertaking decentralised health systems research and development to inform the rural efforts of the fledgling post-apartheid South African Ministry of Health (Tollman *et al.*, 1999; Kahn *et al.*, 2012). Since 2017, the mandate of the MRC/Wits-Agincourt Unit is

> *'In partnership with host communities and local institutions, to better understand and respond to the dynamics of health, population and social transitions in rural South and Southern Africa, in order to mount a more effective public health, public sector and social response and thereby inform national, regional and global policy (Tollman, 2017)'.*

Situated in a resource-poor rural environment, the MRC/Wits-Agincourt Unit undertakes community-oriented research to elucidate causal pathways, test interventions across the life-course, inform health and social systems, and strengthen evidence to guide policy and programmes.

Broadly, all Unit research addresses four fundamental questions:

- The unpredictability and pace of evolving health, population and social transitions
- The interacting social and biological determinants and consequences – highlighting vulnerability and resilience – at key stages along the life course
- When, where and how to intervene most effectively
- The implications for health and social sector responses in order to achieve a more equitable and socially and economically productive society.

Despite government's focus on improving access to care post-apartheid, access to health services remain inequitable (Harris *et al.*, 2014). Findings from the Agincourt HDSS and nested research undertaken in the study area indicate rapid health, social and demographic transitions (Tollman *et al.*, 2008). The objectives of the MRC/Wits-Agincourt Unit have expanded to include determinants of these transitions, cross-site collaboration and production of public access datasets (Kahn et al., 2012). More recently, work of the MRC/Wits-Agincourt Unit has extended to include a portfolio of observational, intervention and evaluation research with an increasing number of projects nested in the study area. The unit also conducts intervention studies with cross-site collaboration, and produces public access datasets, with the goal of mounting more effective public health, public sector and social responses (Kahn et al., 2012). These expanded research foci enable to MRC/Wits-Agincourt Unit to contribute to health policy and planning in South Africa (Tollman *et al.*, 2008). Cohort studies and clinical trials are particularly relevant in this thesis.

The work of the MRC/Wits-Agincourt Unit involves national and international collaborations. It is one of just a few HDSS study areas worldwide located in an academic institution based within the host country, started by academics from the host country, who have continued to maintain the study area for over 25 years. Observational and interventional research studies, led by local and international collaborators, have been nested in the Agincourt HDSS and use the HDSS database for sampling (for example Gómez-Olivé et al., 2010; Wagner et al., 2014; Pettifor et al., 2015; Gaziano et al., 2017). Most projects are still internationally sponsored, however there are growing numbers of South African principal investigators, and South African and African project managers working in the HDSS. There were 30 nested studies at various stages in 2018, of which nine were led by international collaborators, 13 South African led and eight jointly led (Paper 3: Twine, Lewando Hundt, and Kahn, 2019: Figure 1, page 4).

In this case study, a village is defined as a cluster of households in a defined geographical area with identifiable village leadership, and a name that residents

commonly use to define their village of residence. There are 27 administratively defined villages in the MRC/Wits-Agincourt Unit study area, and two levels of governance – traditional and civic. Each village has a traditional leader called an 'induna.' The political power of the traditional leaders (indunas) and their traditional councils has decreased considerably since democratic change in 1994, but they remain respected leaders in the community, and are consulted on most matters. Traditional councils meet every week. However, they are no longer the only form of governance at the village level, with civic governance also in place.

Local civic governance operates at three levels – Municipal, Ward and Community Development Forum (CDF). Each village has a CDF made up of two representatives from every Community Based Organisation in the village, and the Induna (Chief) as a representative of the Traditional Council. There are seven municipal wards that have villages in the HDSS study area, each of which has a ward councillor who is accountable to the municipal offices and to the CDF. Approximately five villages elect one ward councillor, paid by the municipality, two years after every national election (Twine, Kahn and Lewando Hundt, 2017a).

From the onset of work in the area, public engagement has been a priority, and in 2004 a dedicated public engagement office was established to further develop the interaction with village leaders and communities concerning forthcoming HDSS update rounds and nested research projects. The PhD researcher, Rhian Twine, has led the Public Engagement Office (PEO) of the MRC/Wits-Agincourt Unit since 2004. The PEO organises KDIs (Bornbaum *et al.*, 2015), key to which are feedback and discussion of research findings at village meetings with regular production of tailored knowledge products such as village 'fact sheets' to support local development initiatives. Annually, more targeted meetings are held with local service providers to discuss research results and their implications for programmes and service provision (Twine, Kahn and Lewando Hundt, 2017a). Key to the work of the PEO is ongoing networking with service providers, decision makers and policy implementers in the study area. This is to ensure that HDSS and other study participants can be referred to relevant points of care when problems arise,

and to ensure that relevant stakeholders are consulted during community entry and feedback processes. In addition to these activities, the PEO has established a Community Advisory Group (CAG) consisting of representatives from each village included in the HDSS. CAG members have ongoing training and meet monthly when research projects are presented and discussed. Project-specific advisory groups of eight randomly selected CAG members are established for large studies. Lead study investigators and project managers have to consult and work with the public engagement team concerning how to access the experimental public and how to disseminate project results. More recently, activities have extended to active involvement in the training and monitoring of the informed consent process for all research projects in the study area, as well as monitoring refusal rates and the reasons for these (Twine, Kahn and Lewando Hundt, 2017b).

3.2. Methods and data analysis

Research for this thesis is based on a single case study (Yin, 2014) of public engagement throughout the research process, with a longitudinal HDSS study area comprising the case study area. The design of this case study uses mixed qualitative/quantitative methods, summarised in Table 2 and then described in more detail. Qualitative work was analysed using an interpretative paradigm. The case study includes data at key stages of the research process – consultation about **protocol development**, dilemmas in ethics in practice **during data collection**, and **dissemination and knowledge transfer of results** – and more generally on the views of local leaders and service providers about living and working in a longitudinal HDSS study area.

A **case study** was chosen as the most appropriate method as it captures the complexity of a real life situation, allowing for exploration of the links between the situation and the effects on a population, utilising multiple sources of information. In this research, a variety of ongoing activities were being considered, over a period of time, in one geographically demarcated case study area. There were many different actors involved in data collection, with varying perspectives, and a case

study methodology allowed for qualitative, interpretative data collection and analysis. A case study often involves mixed methods allowing for triangulation and enhances the reliability and validity of findings. There were a variety of research methods used in this case study: the Delphi technique, participatory visualisation, individual semi-structured interviews, focus group discussions, ethnographic field notes, critical incident scenarios, written reflections and secondary documentary analysis.

Table 2: Methods and data analysis of case study

Research process stage	**Retrospective data**	**Prospective data**	**Data analysis**
Consultation during **protocol development** – Paper 1	-	Delphi technique during 3 workshops with 26 lay and professional experts in youth health needs. Participatory visualisation with above stakeholder group and researchers expert in youth health needs.	K coefficient of consensus Participatory visualisation
Ethics in practice during **data collection** – Paper 2	-	8 focus groups with a total of 56 residents; and 24 individual interviews with residents. Ethnographic field notes from 2015 / 2016 used to develop scenarios for critical incident analysis. Written reflections from 10 researchers and research managers.	Thematic analysis using NVIVO 10 Manual thematic analysis of researcher reflections
		Five focus groups with a total of 45 village Community Development Forum members; 11 (15*) individual interviews with service providers living in the study area;	Thematic analysis using NVIVO 10
Views of residents who are service providers about **living in a longitudinal health research study area** – Paper 3	-		
Dissemination and knowledge transfer of findings – Paper 4	Documentary analysis from annual reports on community feedback from 2004 to 2016		Descriptive statistics

*Paper 4: four additional interviews were included with leaders and service providers who were not resident in the study area

3.2.1. Method 1: Modified Delphi technique and participatory visualisation

Public engagement in protocol development in relation to adolescent health priorities was undertaken using two qualitative methods: a modified Delphi technique and participatory visualisation as a participatory approach to achieving a consensus. Three workshops were held with lay and professional experts, who were living and working in the study area, and who had interest / expertise in health issues relating to youth. Two members of the adolescent health research team joined as participants in the last workshop. Health is affected by a range of social determinants, and the lay and professional experts were purposefully identified by the three staff members of the PEO. Thirty-two people were invited to participate in this exercise from different sectors: health service providers, educators, youth service providers, local and district municipal officials, the African National Council Youth League, the MRC/Wits-Agincourt Unit Community Advisory Group, male and female adolescents and parents.

In the first two workshops, a modified Delphi technique was used to achieve group consensus for lay and professional experts regarding health priorities for adolescents in the area. The results of the group consensus were shared with the participants and researchers in the final workshop to obtain consensus between priorities emerging from the Delphi process and priorities identified by the research team in prior formative research, and input obtained on possible intervention partners and a research advisory group (or stakeholder forum). The information from this engagement process was used in an intervention mapping process (Draper *et al.*, 2014) in order to develop an intervention to pilot for Project Ntshembo ('hope'). The engagement provided a locally derived, empirical base for developing the trial and enabling researchers to assess how aligned their objectives were with community and public sector views. The workshops were held over the course of 3 weeks, during October and November of 2012; detail of the study processes are in Figure 6.

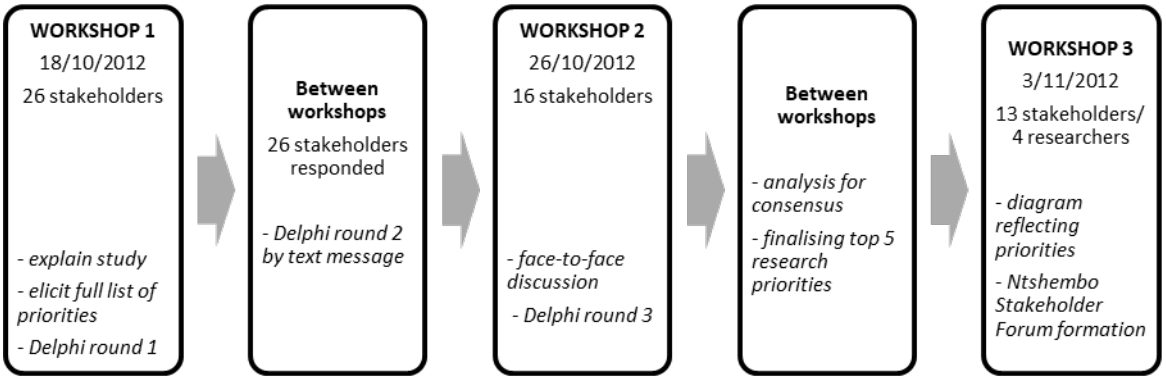


Figure 6: Overview of study design for process of consultation during protocol development (Twine et al., 2016)

The Delphi technique was used in order to identify issues that both lay and professional experts in adolescent health regarded as important for the focus of a proposed intervention study to improve the health of youth (Twine *et al.*, 2016). This technique is a method of generating issues, and then eliciting decision making regarding ranking of these issues, with groups of experts using a series of voting and ranking exercises (Hasson, Keeney and McKenna, 2000). It is a flexible group facilitation technique that was modified for this research. Delphi participants do not usually meet face-to-face so that participants do not know each other and do not influence each other's opinions. Generation of the issues, voting and ranking are often done by post, email or using sms technology. For this research, face-to-face meetings were held since the experts were from diverse backgrounds, and although all understood English, there were varied levels of literacy. It was necessary to have detailed discussion about the research and the methodology so that all experts had the same understanding of the work. Additionally, at the end of the three meetings, a research advisory group had to be formed, and participants needed to know each other in order for the most suitable people to be nominated. All voting and ranking was completed anonymously in the face-to-face meetings. A detailed account of the method is in the published Paper 1 (Twine *et al.*, 2016). Non- parametric analysis was used to determine when consensus had been reached (Schmidt, 1997) as the data did not need to fit a normal distribution and needed to be ranked (Norris *et al.*, 2014).

Participatory visualisation was used in the final face-to-face meeting of the lay and professional experts to which researchers were also invited. This is a method where a visual tool is used to show the relationships between issues (Cornwall and Jewkes, 1995). It is a method that allows the voices of all participants to be heard, and all stakeholders as well as the researchers participated in this process. Participants were invited to write each of the issues on separate pieces of paper and then append them on a wall, adjusting their relative positions until agreement was reached on the visual representation of the relationship of the issues to each other. All participants were able to move the papers until the final picture was agreed upon. The aim was to discuss and agree upon relationships between the issues that had been decided upon as priorities by the lay and professional experts, and how they aligned to those that had been identified through prior research in the study area. The method enabled participants to develop a visual tool to identify issues as a team and all were considered expert decision makers.

3.2.2. Method 2: Semi-structured individual, focus and natural group interviews

Qualitative interviews, conducted to collect data from research participants and service providers in the area, were used in Papers 2, 3, and 4. Twenty-four individual and eight natural group interviews were held with residents from two villages who had participated in research studies in the case study area. Fifteen individual semi-structured and five focus group interviews were held with resident local village leaders and service providers from across all villages. Data were analysed thematically using NVivo 10 (QSR 2012).

To recruit village residents, two villages with diverse characteristics were purposively chosen – one far from and one close to the MRC/Wits-Agincourt Unit offices; one with a larger and one a smaller population; and one with a higher and one a lower average household socio-economic status. A table was used outlining the number of participants needed from each village, ensuring equal gender and spread across three age groups (18-24, 25-49 and 50+ years) (Table 3) so as to

guide the fieldworkers in their recruitment. The fieldworkers recruited door-to-door until there were 24 eligible participants, 12 from each village.

Table 3: Selection of participants from each of the two selected villages (n=12 per village)

	18 – 24 years	**25 – 49**	**50+**
Male	2	2	2
Female	2	2	2

Eight natural group interviews were also conducted with an average of ten participants in each group. Natural groups were made up of: older men who were assistants to the village chief (induna); older men who were cattle herders; younger men in a soccer team; younger men in a traditional dance team; older women attending church; older women who drank tea together; younger women from a church group and; younger women from a traditional dance team. Interviews were conducted by two local, Shangaan speaking research assistants in 2016, at participants' homes or other locations of their choosing. There were 56 participants in total involved in these natural group interviews (Table 4).

Table 4: Total number of residents interviewed in the 2 villages

	Individual interviews	**Natural group interviews**	**Total**
Local village residents	24	56 participants in 8 groups	80

A purposive sample of 56 local leaders and service providers was selected from individuals working within organisations involved in governance or service provision at the village and sub-district level, and who were also resident in the study area. There were 45 participants in the focus group interviews and 11 in individual interviews. Two representatives of village leadership from each of the 23 villages that had been involved in the HDSS for more than ten years participated in four focus group interviews of between eight to eleven participants and the managers of eight home-based care organisations participated in another focus group (Table 5). Representatives from the traditional councils and municipalities, clinic and education managers were all interviewed individually. The participants were aged between 25 and 70 years, and were balanced by gender. Twine

conducted these interviews and focus group interviews along with a research assistant in 2015 / 16. Interviews were undertaken in participants' homes, or in a village venue chosen by the participant.

Semi-structured interviews with key informants were conducted as these are an effective method of obtaining the opinions of participants on specific topics. Qualitative interviews differ from quantitative questionnaires in that they allow participants to express their opinions more freely. Qualitative interviews allow for depth of knowledge, rather than the breadth aimed for in quantitative interviews that often involve many participants (Blaxter, Hughes and Tight, 2010). The interview guides were semi-structured to allow for exploration of new topics that might arise during the interviews. Semi-structured interviews allow for more flexibility in the direction of the conversation than fully pre-prepared question guides (Dahlgren, Emmelin and Winkvist, 2007). The topic guide for these interviews are in Appendix A.

Focus group and natural group interviews allow for interactivity and for gaining insight into a number of individuals' views about a particular topic (Hennick, Hutter and Bailey, 2011). Natural group discussions are group discussions that occur with people forming an existing group based around a shared interest so all the participants know each other (Beckerleg et al, 2007, Green and Thorogood, 2009). Focus groups bring together people with similar characteristics who may or may not be known to each other. Group interviews were chosen for this case study as a way to obtain participants' shared understandings of their experiences as residents in a longitudinal health research area. Group interviews involve semi-structured discussion with a selected group of individuals to gain information about their views and experiences of a subject using a topic guide. The interaction between group members may assist participants to bring various views and experiences to light, that may otherwise not be raised in individual interviews (Morgan and Krueger, 1993). The topic guide for these interviews are in Appendix A.

Table 5: Sample size and criteria for participant selection of local village leaders and service providers (Twine, Lewando Hundt and Kahn, 2017b)

Organisation	Focus group interviews	Individual interviews	Notes on selection process
CDFs	4 focus groups each ranging from 8-11 participants from 4-6 villages. Total from all 4 focus groups was 35 people in all from 20 villages (3 did not send representatives)		1 or 2 participants from each CDF (one a long-term member; one with a shorter term).
Traditional Councils		2 (1)* Traditional Council secretaries 2 Indunas	There are three Traditional Councils and one has only one village in the research study area Hence, secretaries of only 2 Traditional Councils were interviewed. Each recommended an Induna for interview from within their Council, who had represented their village for the full 25 years of research.
Municipalities		2 (1) regional municipal managers 3 ward councillors	The PEO works with only 2 regional municipalities and both regional municipal managers were interviewed. The PEO works with 9 ward councillors and interviews were done with the three who have the most villages in their wards included in the HDSS study area.
Department of Health	Focus group with managers of 8 Home Based Care Organisations (HBCs)	4 (1) clinic managers	4 individual interviews with the clinic managers of the four busiest clinics, and 1 focus group with the managers of all eight HBCs based at 8 clinics.
Department of Education		2 (1) education circuit managers	The PEO works with five education circuits but only interviewed circuit managers from the two that have several schools in the research study area.
Total participants	**45 people in 5 focus group interviews**	**15 (4)**	

*Numbers in brackets reflect individuals who were not resident in the case study area

All semi-structured individual and group interviews were tape recorded with the exception of one individual interview where the participant refused to be recorded, and notes were taken during the interview. The interviews were translated into English and transcribed by the Shangaan speaking fieldworkers who either conducted the interviews themselves, or accompanied Twine when she conducted the interviews.

The data of these qualitative interviews contributed to the findings in three of the published papers from this case study on public engagement since they contained views on aspects of the co-production of knowledge and mechanisms for widening participation in research governance (Paper 3: Twine, Lewando Hundt and Kahn, 2019), on village-based dissemination of research findings (Twine, Kahn and

Lewando Hundt, 2017a), and on being a service provider or village leader living and working in an HDSS area (Twine, Lewando Hundt and Kahn, 2017b). Data analysis was undertaken using NVIVO 10 with independent parallel reading of a selection of the interviews by two of the researchers Twine and Lewando Hundt. The main thematic analysis was undertaken by Twine with the involvement of Lewando Hundt to strengthen validity and reliability. Data from residents' interviews were analysed by Twine in 2018 focusing on ethics in practice.

3.2.3. Method 3: Ethnographic field notes and critical incident scenarios

Ethnographic fieldwork using detailed ethnographic field notes (Dahlgren, Emmelin and Winkvist, 2007) were taken about everyday dilemmas of ethics in practice that occurred in the case study area between 2015 and 2017. These were used to develop scenarios for critical incident analysis (Lister and Crisp, 2007). The method allows for collection of data about what people do, and not only what they say. Field notes are important in order to recall the details of incidents (Hammersley and Atkinson, 2007) with the aim of capturing a 'thick description' without interpretation (Geertz, 1973) for later analysis.

Field notes are part of the daily practice of participant observation used mainly within anthropology. The field notes taken by the researcher on dilemmas of ethics in practice relating to public engagement in the research process covered a wide range of topics including:

- Concerns about study withdrawal
- Confidentiality issues
- The taking of informed consent
- Adverse events
- Breaches of research protocol that resulted in unintended harm
- Disclosure of abuse requiring referral in the field.

There were two main emergent themes from the qualitative semi-structured interviews with the experimental public related to ethics in practice: informed consent and confidentiality, and reporting individual results from biomedical screening. In order to elicit the views of researchers about these concerns of the experimental public, two incidents that had occurred and that reflected these issues were taken from the field notes, shortened and developed into critical incident scenarios headed 'Informed consent' and 'Reporting back results' to elicit researchers' reflections on these ethics in practice issues (Table 6). The rationale of asking researchers about these dilemmas in practice was to explore the congruence or lack of congruence with those of the experimental public and their ideas for addressing these dilemmas in future practice.

Table 6: Critical incident scenarios (Twine, Lewando Hundt and Kahn, 2019)

Scenario on giving back individual results: An information sheet and informed consent form was sent to the Public Engagement Office for review. Participants were being asked to give a blood sample for HIV testing, but there was no mention in the informed consent of how the participants were going to be given the HIV test results. Upon follow up with the Principal Investigators, it was confirmed that there was no plan for reporting back individual HIV results to participants, and no budget for this. It emerged that the US partner in the study had previously requested more money from the budget for study costs in the US, and this request had been accommodated by the investigating team.
Scenario on informed consent: The recruitment of young women for a study involved consenting for HIV testing. In this case, the young woman was 13 years old and lived with her maternal grandmother. Her father lived elsewhere and her mother died nine years previously. As per approved procedures, the father was called by cell-phone to obtain consent for the caregiver (grandmother) to provide consent for the young woman's participation in the study. The field worker did not speak directly to the father, but allowed the grandmother to conduct the conversation – and the grandmother did not inform him of the HIV testing component of study enrolment. This constituted a protocol violation as the field worker should have personally had this discussion with the father. The father and grandmother and the young woman consented. The young woman was found to be HIV positive during testing and she told her grandmother the result of the test. The father contacted the study team, angry that his daughter was tested without his permission. It appears that the young woman was infected perinatally and that her father had not informed her, nor her grandmother of her status.

These scenarios were sent electronically to purposively selected researchers who had been involved in nested studies in the case study area. The criteria for their selection were that they had worked within the study area on a nested study within the last three years, and equal representation was given to researchers from South Africa and external to South Africa. Any investigator employed by the university was excluded from this sample owing to possible conflict of interest. The ten individuals included principal investigators, research managers, project site managers and project coordinators (Table 7). The use of electronic responses may have limited the possibility of discussion with researchers to encourage dialogue and depth of data since these critical incident scenarios were open to interpretation. However, given the geographic spread of the participants, a pragmatic decision was made to use the same method with all participants.

Table 7: Number and location of principal investigators and research managers responding to critical incidents 'researchers' (Twine, Lewando Hundt and Kahn, 2019)

	Full time in South Africa	International	TOTAL
Principal Investigator / Project Manager	1	4	5
Project Site Manager / Project Coordinator	4	1	5
TOTAL	5	5	10

Participants were given two weeks to respond to two questions after reflecting on the two scenarios: 'Describe how you would have taken action (if any) if you were in the research team involved' and; 'What issues does this scenario raise regarding ethics in the field (ethical issues that arise during fieldwork)?' There was also space for additional comments. Manual thematic data analysis was undertaken on the responses to these questions.

3.2.4. Method 4: Secondary analysis of village feedback reports and questionnaires

Secondary analysis of quantitative data from reports from 14 annual village meetings from 2001-2015 as well as 762 feedback questionnaires administered after the meetings from 2005-2015 (Table 8) was undertaken and published in Twine, Kahn and Lewando Hundt, 2017a.

Table 8: Annual village meetings: number of reports and questionnaires 2001-2015

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	Total
Number of reports on annual knowledge dissemination intervention	1	1	0	1	1	1	1	1	1	1	1	1	1	1	1	**14**
Number of feedback questionnaires from attendees	-	-	-	-	82	91	68	33	0	85	25	99	98	122	59	**762**

Secondary documentary analysis was conducted on the annual reports and feedback questionnaires from village-based feedback meetings from 2004 to 2015 (Cheng and Phillips, 2014). These reports had records of how many people attended, what questions were asked, as well as changes in practice over time. Since the reports covered more than a decade of village-based dissemination meetings, a longitudinal analysis was possible to capture changes over time. Data were analysed using summary statistics in Excel as well as descriptive analysis.

3.3. Ethical considerations

3.3.1. Positionality and reflexivity

When research is conducted where a researcher lives and works, s/he is both an insider and outsider. I am a white, middle aged, South African (originally from

Zimbabwe but living in South Africa since the age of 17) married female with a history of living and working in the health field, and in the study area, since 1986. I arrived at rural Tintswalo Hospital, one of the three district hospitals that provide service to the population in the MRC/Wits-Agincourt Unit study area in that year for my first ever job as an occupational therapist. I left that position in 1987 and worked with people from the same culture further north for a total of 4 years. Following a stint in the UK, I returned to Tintswalo Hospital in 1994, this time with my Zimbabwean partner and our 2-year-old daughter, Robyn Tintswalo. I worked for Wits University in a teaching post, and remained there until 2004 when I joined the MRC/Wits-Agincourt Unit to run the public engagement office. I remarried during this time, my husband also works for Wits University, and we have an 11-year old daughter Samantha Tinyiko, who speaks fluent Shangaan.

There are a number of attributes that I have to consider when reflecting on my positionality. These are my longevity in the area, the differences between my own culture and that of the majority of the people with whom I work, my training as a health care professional, my smallest daughter speaking fluent Shangaan and the perception of the people with whom I work that I speak better Shangaan than I do, my Christian beliefs, and the ‘respect’ that the people in the area still hold for white people in South Africa and my position as manager of the public engagement office of the Unit.

My longevity in this area linked to my long-term involvement with the Department of Health as a health professional and member of the Unit means that I have influence at local, district and provincial levels of governance. I am known to people working at these levels, and know many who are now in positions of power based on their own longevity. As a resident of Bushbuckridge I am seen as an insider in contrast to MRC/Wits-Agincourt interns, students and researchers from abroad or from cities and institutions elsewhere in South Africa.

Conversely, even though I have been working in this same rural area for over 25 years, I am still an outsider. The case study area was part of a former homeland,

Gazankulu, and the population is almost exclusively black African. Despite being South African, aspects of my own 'xilungu' (white) culture differs in many respects to the 'xintu' (traditional) African Shangaan culture of the people with whom I work. This, for example, with respect to beliefs about bewitchment, the role of ancestors, and the notion of Ubuntu (solidarity). However, we share other beliefs, including Christianity and allegiance to the values of the new South Africa. I am nominally conversant in the local Shangaan dialect of xiTsonga.

Aside from my personal attributes, my position as the manager of the public engagement team within the MRC/Wits-Agincourt Unit is an aspect of my positionality during this research of which I was very aware. The most challenging part of doing this research was to separate my role as manager of public engagement from my role as a researcher. This was not easy and took some time before I could foreground my role as a researcher when undertaking PhD activities and relinquish my work hat.

This research was not an evaluation of the work of my office, myself and the Public Engagement Officers with whom I work directly, but rather a case study of public engagement in research in this particular case study area, which would place public engagement activities at longitudinal HDSS study areas within the wider field of experimental publics in global health and civic science.

I am seen as an insider / outsider in my work setting but during the research, this took on additional dimensions which had to be managed. In order to clarify my role as a researcher when collecting data, I explained to all the participants of focus groups and individual interviews that I was with them as a PhD student and requested that they be very honest with their views. I was accompanied by an interpreter who also reinforced the purpose of the interviews and encouraged people to be open. As I am well known in the area and was aware that the culture and history tends to make it difficult to be directly critical, I was aware of the possibility of socially desirable responses. When people were very positive, I would explain how we could only improve or change ways of working if they were openly

critical. For example, one clinic sister was exceedingly positive but when nudged, talked about ways in which researchers could be 'better neighbours' to the clinics.

The first paper (Paper 1: Twine et al., 2016) on involvement in research design drew on a Delphi exercise where I was one of three researchers so that my positionality was less central. One strength of my being an insider for this paper was that it enabled recruitment of relevant stakeholders whom I already knew to be interested in adolescent health. My insider status was useful for Papers 2 (Twine, Lewando Hundt and Kahn, 2017b) on the experience of an experimental public, and 3 (Twine, Lewando Hundt and Kahn, 2019) on the ethics of practice in longitudinal health research. My tacit knowledge as an insider assisted with interpretation and analysis of the data within a realistic contextual setting. One supervisor had more of outsider perspective being an overseas social scientist and discussions continually challenged my own insider views and interpretations. This was an essential part of the critical supervision process. The paper on knowledge dissemination (Paper 4: Twine, Kahn and Lewando Hundt, 2017a) was based on secondary analysis of reports and therefore was not impacted by my position but was an analysis of a routine annual activity of the PEO.

3.3.2. Ethical clearance

All work in this study was approved by the University of the Witwatersrand Human Research Ethics Committee (M140361), and permissions gained from the Mpumalanga Departments of Health and Education. The certificate and letters are attached as Appendix B.

CHAPTER FOUR: RESULTS

Results will be discussed in three sections in relation to the three research questions:

1. To what extent can public engagement in a longitudinal health research area foster the co-production of knowledge?
2. What is distinctive about research ethics in practice in longitudinal health research study areas?
3. What is the impact of knowledge dissemination, transfer and translation of research findings through public engagement in a longitudinal health research study area?

Relevant links to each of the four published papers will be made as shown in Table 9.

Table 9: Public engagement throughout the research process in a health and socio-demographic surveillance system in rural South Africa

		PAPERS			
		1. Involvement of stakeholders in determining health priorities of adolescents in rural South Africa.	2. The 'experimental public' in longitudinal health research: views of local leaders and service providers in rural South Africa	3. Dilemmas in Ethics in practice in a Longitudinal Health Surveillance System: identifying opportunities for widening participation of residents	4. Assessing the effectiveness of a longitudinal knowledge dissemination intervention: Sharing research findings in rural South Africa

RESEARCH QUESTIONS	1. To what extent can public engagement in a longitudinal research study area foster the co-production of knowledge?	Co-production of knowledge
		• Methods
		  o Delphi
		  o Visual participation
		• Aligning agendas
		• User focused research objectives
			Civic science
			• Strong and weak publics
			• Research governance
				Strong and weak publics
				• Research governance
				• Eliciting voice of experimental publics	

	2. What is distinctive about research Ethics in practice in longitudinal health research study areas?	Strong and weak publics
		• Formation of research advisory group
			Civic science
			• Ethics in practice
			  o Giving blood and reporting back individual screening results
			  o Informed consent and confidentiality
				Ethics in practice
				• Informed consent
				• Study withdrawal
				• Giving blood and reporting back individual screening results
					Ethics in practice
					• Fair benefits
					  o Research results

	3. What is the impact and reach of knowledge dissemination, transfer and translation of research findings through public engagement?		KDIs
			• Impact
			  o Knowledge acquisition
			  o Attitude
			  o Practice
			• Reach
					Co-production of knowledge
					• Enhanced public focus - interpretation of data
					• More appropriate KDIs

4.1. To what extent can public engagement in a longitudinal research area foster the co-production of knowledge?

Paper 1 (Twine et al., 2016) is an analysis of the co-production of knowledge in the early stages of the research process - in relation to setting research priorities, developing a protocol, and establishing a research advisory group (RAG) for a project on adolescent health. Public engagement at all stages of the research process can result in strengthening the co-production of knowledge. In relation to co-production of knowledge *during protocol development*, the public engagement process described in Paper 1 (Twine et al., 2016) of this case study, aimed to align stakeholder and researcher-identified priority health needs of adolescents. The methods used were a modified Delphi process in two workshops, and participatory visualisation in a final workshop. Lay and professional experts (for stakeholder characteristics see page 40, second paragraph) worked with researchers to produce a research agenda about adolescents and their health. This was used to develop a research protocol for a pilot study to assess the feasibility and acceptability of using adolescent-focused community health workers to deliver a complex, multilevel intervention to reduce obesity in adolescents, before submission to a funder for a larger randomised controlled trial (RCT).

The modified Delphi technique was used during the first two face-to-face workshops – it was deemed modified since the technique is usually conducted without participants ever meeting each other. These face-to-face workshops allowed for learning to take place between lay and professional experts, and indeed there was active deliberation and engagement between all participants. The anonymous voting process always used in this technique allowed people's opinions to be taken into account equally and without influencing each other. The Delphi technique was flexible enough to accommodate these specific requirements and ensured that everyone's opinion was taken into account regardless of status. After two workshops, a list of adolescent health needs was agreed upon by the lay and professional experts.

In the third workshop, the list of priority health needs formulated by the lay and professional experts was successfully aligned to a similar list developed by adolescent health researchers, using participatory visualisation. This method proved a useful, inclusive way of breaking down hierarchies, and enabled participants to communicate non-verbally as well as verbally. Both stakeholders and researchers stood and rearranged the different pieces of paper, each of which had one of the items from the two lists written on it. There was active deliberation and discussion involving all participants regarding how the final product should reflect the views of both groups on adolescent health needs, and there was agreement on the final visual representation of the issues in relation to each other. Together, a picture depicting the relationship between the topics was developed and is produced in Paper 1, page 4, Figure 1 (Twine et al., 2016).

Both lay experts and researchers agreed that the process had led to a common understanding of the issues adolescents face in the study area, and together they discussed possible joint solutions to these problems. The process provided a locally derived, empirical base allowing the researchers to assess how aligned their views were to the local views of the health needs of adolescence. The opinions of the lay and professional experts were used to adapt the research protocol. As a result of this exercise, behaviour change theories were included in the approach as the poor standard of health literacy and the high levels of peer pressure highlighted by the lay and professional experts had not been adequately taken into consideration by the researchers.

However, a limitation of the process was that attrition was high over the three workshops, at 50%. Only 35% of the lay and expert stakeholders attended all three workshops. For government officials, the main reason for not attending all workshops was being summoned unexpectedly to meetings, and the main reasons for other stakeholders was illness (Table 10).

Table 10: Number of participants at each stage of the Delphi process (Twine et al., 2016:7)

Activity	Total	Male	Female	Aged	Aged 30
Workshop 1	26	9	16	11	14
Text	26	9	16	11	14
Workshop 2	16	4	11	7	8
Workshop 3	13	7	6	6	7

At the third workshop, a research advisory group for this study was established. The aim was to involve lay experts in research governance at all stages of the research process. Participants now knew each other, and made joint decisions about the formation and membership of the research advisory group, which included nominations of young people, service providers, political representatives and community-based organisations, some who were not themselves present. The next meeting will be to discuss the progress of a pilot project, and further develop the funding bid later in 2019.

In the interviews analysed for Paper 3 (Twine, Kahn and Lewando Hundt, 2019), members of the experimental public expressed that they would like to be more involved in the co-production of knowledge. For example, one clinic manager was concerned that the research was not always locally relevant. This could indicate a wish for closer alignment of the research priorities of the experimental public and the local service providers with those of the researchers. These comments showed that the experimental public was clear that greater consultation in the research process would be mutually beneficial.

> *'We need to consult with the community. Then the community will come up with ideas of how exactly we can improve.' (*Participant 7, FGD4 CDF)

> *'I once discussed with a researcher about how we can make research more relevant to our facilities. He said that often the research is designed elsewhere and our hands are tied. But even though sometimes the research does not seem local, we know that sometimes it is important for national and*

*provincial level. We sometimes gossip about this.' (*Clinic operations manager 1)

The co-production of knowledge was also an element of Paper 4 (Twine, Kahn and Lewando Hundt, 2017a). This was a longitudinal analysis of a KDI of research findings from 2005-2016 that was part of the key public engagement activities of the case study area. As set out in the Methods, this included analysis of the annual reports of the KDI and qualitative semi-structured individual and group interviews with local leaders and service providers.

The analysis showed that members of organisations – such as individual service providers, clinic nurses, home-based carers and local leaders – asked for explanations and requested further results during targeted face-to-face dissemination meetings held with them. For example, the police requested information about violent crime and suicide in order to support a bid for a local police station. Requests for information indicate an understanding of the usefulness of research findings in developing policy and in practice. Some requests could inform future research direction.

'I see that there are not so many 11 to 14 year olds having babies, but there are some. Could you let us know how relevant household economic circumstances are, or if there are any other things we can learn about the households of these girls? Maybe then we can do something.' (Ward councillor, man, after a presentation on fertility rates).

Members of the public were also asked how they thought that the KDI practices in the study area could be improved, thus eliciting their voices to influence practice of research processes. Their suggestions, which included use of radio and social media, indicated an understanding of the purposes for the KDI.

There is also evidence that having run KDIs in the study area over a long period of time had led to enhanced opportunities for collaborative discussion regarding the

relevance of research and research results. Three new villages were added to the study area in 2007. The data collected for Paper 4 was from the 20 original villages that had been in the study area since 1992, as well as the three new villages. Residents from the new villages asked more service-related questions than research-related questions compared to the original villages (Figure 7). This could show that KDI activities over time contribute to understanding that the role of research is not to deliver services, but to contribute towards knowledge.

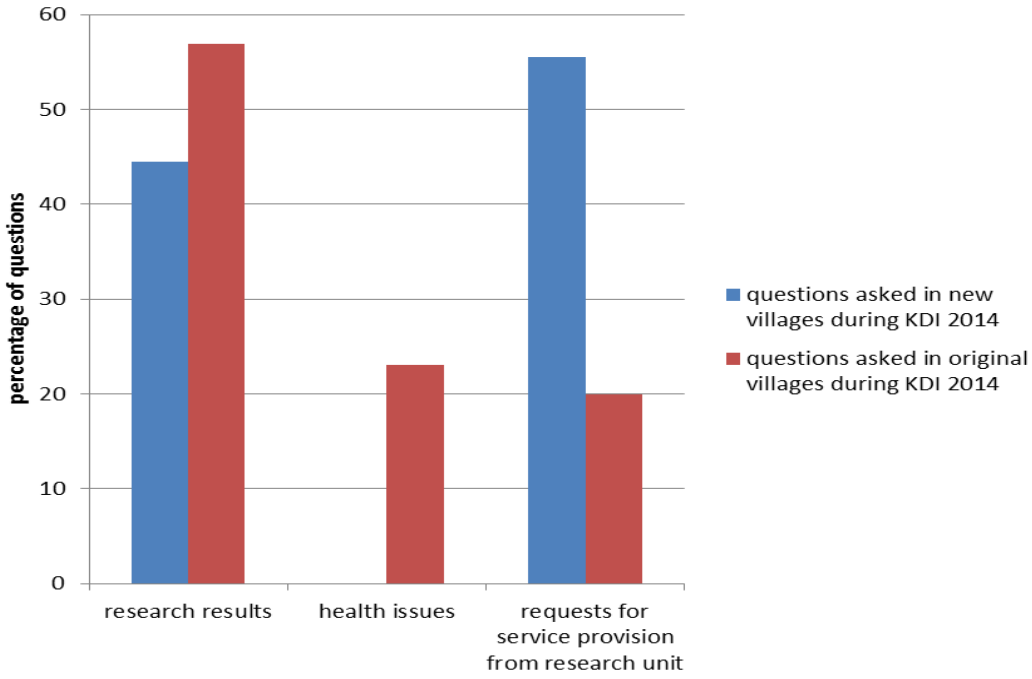


Figure 7: Difference between questions asked in original vs new village, 2014

4.2. What is distinctive about research ethics in practice in longitudinal health research study areas?

Day to day ethical dilemmas that occur during the fieldwork stage of the research process have been described as ethics in practice (Guillemin and Gillam, 2004). The analysis of dilemmas in ethics in practice drew on three methods that generated different qualitative data. The first was semi-structured individual, focus and natural group interviews with members of the experimental public (local leaders, service providers and residents). The second method used the

researcher's ethnographic field notes about dilemmas in ethics in practice that were collected between 2015 and 2017. The third method was based on written reflections on critical incident scenarios, developed by the researcher from her field notes, that were chosen to illustrate concerns directly raised by the experimental public in their interviews. These were sent to a purposive sample of researchers and research managers who had led studies in the case study area. These three methods and the selection of the samples are set out in detail in the Methods section and in Papers 2 and 3. Ethical dilemmas raised by the experimental public are reported in Paper 2, (Twine, Lewando Hundt and Kahn, 2017b). Paper 3 includes both the voices of the experimental public along with those of the researchers regarding three ethical dilemmas (Twine, Lewando Hundt and Kahn, 2019. Figure 2 in Paper 2 (Twine, Lewando Hundt and Kahn, 2017b: 5) summarises the themes that emerged during deductive and inductive analysis of the interview data. The emergent themes relevant to ethics in practice included being a participant in research projects, taking of blood and reporting individual screening results, consent, confidentiality and anonymity, and what happens when research ends (Twine, Lewando Hundt and Kahn, 2017b).

Critical incident scenarios, developed from ethnographic field notes collected during 2015-2017, illustrated the two main concerns expressed by the interviewees in relation to being involved in research as a participant, namely giving back results of individual screening tests, and informed consent and confidentiality. The critical incident scenarios are in the Methods section and Paper 4 (Twine, Lewando Hundt and Kahn, 2019).

4.2.1. Informed consent and confidentiality

All members of the experimental public that were interviewed had been research participants in the past in the case study area, and showed some understanding of the concept of informed consent and confidentiality. Mention was made of the voluntary nature of consent, and more nuanced understandings of what should

happen during informed consent such as providing adequate information about the research.

> *'If you don't understand, the field workers give you a chance to say that. They say that participating is voluntarily. You are allowed to say no. Even during the interview, they allow you to stop if you are not comfortable with their research.'* (Middle aged man 3, village 1)

> *'The problem is that they don't say what is going to happen at the research laboratory. My grandmother was supposed to know what will happen to her. She needed to have more information.'* (Young woman 2, village 1)

Interviewees reported that there are instances of silent refusals – where potential participants run away, or hide when they see research-branded vehicles coming towards their houses. This was linked to concerns about confidentiality, or in the words of the interviewees 'keeping secrets.' Some interviewees mentioned that there is trust in researchers maintaining confidentiality, reporting that "X keeps confidentiality" (P6, Man, CDF FGD 3). However, interviewees also reported that they have concerns about 'keeping secrets' during the publication process. One participant also worried that over time, researchers and 'Wits' - the local name for the research organisation - have come to know everything about participants, and wanted reassurance that confidentiality would be maintained.

> *'Yes, people run away when they see university cars because people don't want to be published. Let's keep the secrets.'* (P6, man).

> *'What I have experienced is that Wits comes to know everything about this particular person, and so that's why people don't want to be published. But you can ask me anything - I can give you answers so long as you keep my secret.'* (CDF FGD 1, P3, Woman).

Some of these concerns around confidentiality were linked to fieldworkers being resident in one of the case study villages. Unit policy is for fieldworkers to be recruited from the villages in the HDSS study area, but sometimes doubts were raised about their ability to keep confidentiality given their local status.

> *'I think some challenges my colleagues have already mentioned is the issue of privacy. Some Wits fieldworkers are just young people like us, and we meet them anywhere and a few of them could talk about my information in the wrong place at the wrong time.'* (CDF FGD 2, Man)

However, most interviewees reported a high level of trust in the fieldworkers, saying that they were well trained and respectful.

> *'When they approach your gate they are smiling, they greet you and they will introduce themselves, telling you where they come from. They will ask for your permission to work and afterwards they will say thank you.' (*Older man 1, FGD village 2)

Refusals were linked to participants not wanting to take part in studies that collected blood. Male village leaders presented themselves as advocates for research, and offered to use their influence in the villages to ensure that consent rates were high. This misplaced good intention could be seen as coercive influence owing to their status in a small village.

> *'We can motivate our communities to give fieldworkers time when they arrive in their households, and they must also listen to them when they explain about their work and we can also encourage them to participate in their research. You know there are people who sometimes refuse to go to the university when they want to take their blood because they are saying that the university benefits from their blood. I know if they are being encouraged by us as community leaders, they will understand and they will participate easily.'* (Induna 2, Man)

Whilst local leaders understood and valued the need for confidentiality, they also discussed whether it would be possible to breach confidentiality in cases where the information could help them assist an individual.

> *'Is it possible for the university to have an open debate about results that they get from households, or is it a secret thing if someone has got disease of some kind? We get basic information like 'So many people have got this disease in your village' but we don't know who those people are. How can we then help those households in order to prevent such things, because the university gets information and puts it in a secret, secret place?'* (CDF FGD 4, P7, Man)

Interviewees were clear that very often the fieldworkers did not know the reasons for, nor the details of study procedures involved in the research studies they were conducting, and could not answer questions posed to them during the taking of informed consent. This was true for both the annual population data updates, and nested studies. This made it difficult for potential participants to make informed decisions regarding their participation in the studies.

> *'One of your field workers told me that it's their job. They were taught to ask those questions but they don't know what happens afterwards.' (*Older woman 1, village 1)

Particular mention was made by interviewees and by researchers of instances where there were age disparities between younger fieldworkers and older potential participants that concerned interviewees. A suggestion was made that a younger family member should be brought in to assist their older family member to understand the research and make his or her own informed choice. Concerns about age disparity were also mentioned in terms of sensitive questions, with the possibility of older people being less truthful when answering questions about sex, for example, if fieldworkers were much younger than they were. Mention was also

made by both interviewees and researchers that more time might be needed on informed consent.

> *'Yes we understand most of the information on the informed consent. Some read it and sign with understanding. But with old people I think they don't understand everything. It would be better if you read it when there is a relative there who can understand what you are saying. Old people will agree to anything as a sign of respect even if they didn't understand. I think your field workers need to take their time in the field.'* (Middle aged woman 1, village 2)

> *'This means that the research team is taking advantage of older people that they find at a household because they can't read and write, so they don't read and explain the consent form very well. They summarise what is on the consent form and leave the important issues behind. They have violated the protocol and if this can be known by the ethics committee, they can stop the research because we did not follow the protocol.' (*Project site manager / Project coordinator 3)

> *'In our culture we were taught that you talk about sex in your bedroom with your partner. But with research, they send a young girl to an old person to ask those questions. We don't know whether they are going to keep the secrets as we don't know them. We used to lie.' (*Young woman 1, village 1)

Researchers also mentioned that fieldworkers might not spend enough time on informed consent. Their concern was that fieldworkers might have unrealistic targets and take shortcuts in order to reach them. They said that even though fieldworkers might be well trained, they might make their own decisions when implementing the fieldwork rather than ask for guidance when facing dilemmas of ethics in practice.

> *'This brings up two issues. The first is the field worker violating protocol. Unfortunately, this happens despite careful training and a detailed protocol.*

Situations arise that are not straightforward (this situation is unlikely to be something the fieldwork team had discussed or planned for) and field workers do not always make the right choice and often do not ask their supervisors for advice. Field workers need to be trained to ALWAYS ask for advice and direction when in doubt of proper procedure.' (Principal investigator / Project manager 3)

'The training for the field workers needs to be revised and reinforced and maybe the research manager should consider whether there are adequate on-going quality checks.' (Principal investigator / Project manager 5)

Both interviewees and researchers mentioned that high levels of trust in the researchers and the fieldworkers may influence the decision to consent to participate in studies. Even if the potential participant did not understand the research activities they were being asked to participate in, there were reports that they often consented owing to trust. Researchers in particular, mentioned that if participants consented without understanding the implications, there would be a greater likelihood for ethics in practice issues to emerge, affecting the participant, their families, the public and the research, as well as the trust in the researchers working in the case study area. Researchers mentioned that improved fieldworker training and quality checks during fieldwork would help to mitigate this.

4.2.2. Giving blood and reporting back individual screening results

Blood, urine, faeces, blood pressure, BMI and hair have all been collected from members of the experimental public in this case study area. Blood was mentioned most often by interviewees indicating it to be the type of human biological sample that created the most concern. Collection of blood in the case study area started at the same time as HIV studies were introduced, with a concurrent increase in visible resources – both human and infrastructure. For example, the number of cars increased from seven to 24 in the same year as the HIV studies began. There is variation in how different nested studies deal with human biological samples and

return screening results to individual participants. A short time before these interviews, a researcher doing an HIV study distributed a card to participants with a study identifier code on it, and asked them to go to the nearest clinic after a few weeks, to collect their HIV results. Another study had collected eight tubes of blood from participants and given very few point-of-care results (results given at the time of sample collection), and had no plans to report individual results back to participants should clinically relevant results (results indicating a health condition for which there is local treatment) be found during laboratory testing.

Members of the experimental public reported that they found it helpful to receive point-of-care results and mentioned examples of when this had benefited the health of individual participants.

> *'I think it's helpful for me as an individual and the community at large because when they take my blood and examine it, they give me the results. They give advice or refer me to the clinic and when I follow the medication properly, I get help.' (*Home based carer 11, FGD)

Service providers were generally extremely positive about point-of-care results, mentioning that giving participants their blood pressure results at point-of-care during the research process helped them in their work. The clinic managers reported that they were grateful for referrals from researchers in these cases. However, the process of sending participants to collect HIV test results at the clinic created issues for the clinic staff. Sometimes clinic staff were not able to find, or had not yet been sent the results, when participants asked for them. Lay health counsellors who had not been involved in pre-test screening found it difficult to handle the post-test screening.

> *'There was a project where patients had an HIV test in the community and they were given the bar code to come with it to the clinic. Our lay counsellors were having a problem because they had to counsel the person*

who had not done the pre-test counselling, but they had to give results – not an easy thing.' (Clinic Manager 2, Female)

The interviewees were clear that they expected the research team to give them the results of laboratory tests done on biological samples collected during research procedures. Giving results immediately on the day of taking the sample was most appreciated and beneficial to the health of the individual. However, interviewees expressed the view that results of tests that had be done later, when samples were sent to external laboratories, should be delivered personally to participants, whether the result was clinically relevant or not.

Reflections from the researchers on the reporting back of individual screening results showed clear understanding of the need to feedback individual screening results to participants. They were committed to giving as many point-of-care results as possible as part of fair benefit, but were of the opinion that results that came back from laboratories could only be reported back to participants if they were clinically relevant.

*'If you are going to require them to give you their time and physical bodies for your research then you must show respect by letting them know the results of the test you are conducting, particularly if it is a test that is of high burden in their community and could save their life and the lives of other people.' (*Principal investigator / Project manager 3)

All researchers raised issues that needed careful consideration during decisions and actions pertaining to feedback of individual screening results to participants, some common to all studies, and some specific to one study." They noted that since this aspect of the research process needed resourcing, it should be included in study budgets from the outset. A researcher noted that there was tension between the ethical imperative of reporting back individual results and the availability of funds. Researchers reported that this issue needed careful planning, and consultation and could be a sensitive matter.

'Ethically, this scenario points out to the need to give back results of the study to research participants. These results can be at two levels; giving results at broader community level on general issues coming out of the study and giving results to individuals in case of specific tests. The latter is more sensitive and requires careful planning.' (Project site manager / Project coordinator 2)

Members of the experimental public were of the opinion that if there were enough resources for fieldworkers to come and collect the blood, there should be resources to delivery results later.

Let's say sometimes people are coming to your household to do some tests - they don't come and tell you that what we have found - they say you have to go to the office to find out. But they visited you to find out what is happening exactly with your life, so I think it should be advisable for them to come back to you as an individual and tell you the blood test results. (CDF FGD 4, P1, Woman)

Researchers also noted that reporting back individual screening results to participants is important for the longevity of the research in the case study area, by maintaining the trusting relationships with the experimental public. No adverse events were reported by either the experimental public or researchers regarding reporting back individual screening results to participants.

'We have to do this to prevent refusals and the researchers must not take advantage of people participating in their study….if they [participants] think that they have been used but didn't get their results, they will refuse when other studies similar to that one come.' (Project site manager / Project coordinator 3)

There were reports from the interviewees that sometimes participants did not understand the reason for collection of blood, with some saying that participants think that the blood is being sold or being used to make money by the University.

> '*Those who are taken to the university offices to have blood taken are saying that we are no longer going there because the university is making money with our blood'* (Induna 2, man)
> *'Lots of older people are running because people who went to Wits to give blood came back and started telling people that the university takes blood and sells it.'* (CDF, FGD, P5, man)

4.2.3. Study withdrawal

For the past 10 years, intervention studies have been conducted in the case study area – these include individual and cluster RCTs, both community and clinic based. An example is a cluster RCT which placed lay health workers in the primary care clinics, whose duties included phoning people with hypertension to remind them to come for their 3-monthly check-ups and to follow-up defaulters, and assisting clinic nurses in prepacking chronic medications (Thorogood *et al.*, 2014). Another example is an individual RCT to test impact of a cash transfer, conditional on school attendance, on HIV incidence in young women. This involved collecting young women from their homes annually for three follow-up visits to complete study procedures, including an HIV test. Half of these young women and their households received a cash incentive if they attended school (Pettifor *et al.*, 2016). Findings in Paper 2 (Twine, Lewando Hundt and Kahn, 2017b) indicate that when the hypertension study ended, some participants defaulted from their treatment as they were waiting for their phone call, having become dependent on the reminder. This despite the lay health workers alerting them to the end of the study. When the study on HIV incidence in young women ended, interviewees expressed concern that the young women were no longer involved in the study, and so were no longer receiving cash, nor being incentivised to go to school.

The findings of this thesis on public engagement in a longitudinal research and health and demographic surveillance study area concerning dilemmas of ethics in practice pertain to issues of informed consent, confidentiality, fair benefit and respect for participants as illustrated by the giving of blood, reporting back of individual screening results, and study withdrawal. Dissemination of research findings is also a key part of the research process and is central to public engagement and the concept that science is a public good.

4.3. What is the impact of knowledge dissemination, transfer and translation of research findings through public engagement in a longitudinal health research study area?

One strand of public engagement within research is the dissemination of research findings (Lavery *et al.*, 2010). Paper 4 of this thesis (Twine, Lewando Hundt and Kahn, 2017a) examined a KDI in the case study area, which focussed on routine, annual reporting back of research findings to the public and service providers between 2001 and 2015. The KDI aimed to share research findings with the experimental public in order to increase knowledge acquisition about the research and related activities in the case study area, and change the attitudes and practices of participants and services providers ((Lafrenière *et al.*, 2013). The KDI consisted of annual village-based meetings and face-to-face meetings with various relevant service providers, using tailored knowledge products such as village fact sheets and flip charts. Data were analysed from the reports on the KDI from 2001 to 2015, 762 feedback questionnaires completed by attendees, and qualitative interviews with local leaders and service providers conducted during 2015/2016. These included emergent themes on the KDI and on knowledge and understandings of the annual data update and other research studies conducted in the case study area (Twine, Lewando Hundt and Kahn, 2017b).

4.3.1. Knowledge acquisition

The KDI that was evaluated in this study showed some evidence of a modest change in knowledge acquisition, mostly concerning results from the annual HDSS update, although results from nested studies were also found to be useful. During focus group discussions with village leaders, annual HDSS update findings were always mentioned.

> *'… they are giving us the figures of the people living in the specific villages, and it helps us to know how many people have died each year. It also helps us to know the figures of the children who were born. We are also able to know the people who migrate outside and those [who] immigrated into our village.'* (CDF member, woman)

Feedback from the questionnaires completed after village-based meetings reported that the most useful information was about HIV and tuberculosis (34%), followed by causes of death (19%) and then village demographics (16%). Other unexpected reports of useful information were about the work of the unit (4%), most likely linked directly to how to apply for a job within the unit (1%) (Figure 8).

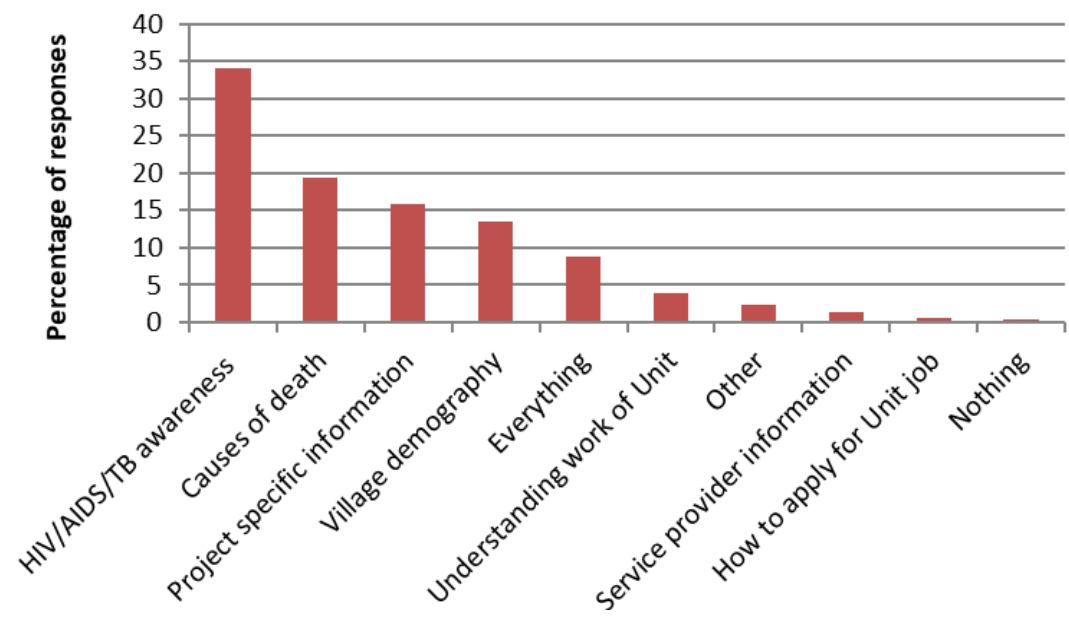


Figure 8: Information attendees at village-based feedback meetings found most useful, 2001-2015

4.3.2. Change in attitudes

There was evidence of changes in attitudes towards the work of the research unit over time. This was illustrated by the changes in questions asked at both village-based (Figure 9) and targeted face-to-face meetings with service providers. While the number of questions relating to research results increased from 2002 to 2014, the number of requests for governmental services decreased over the same period. During 2014, the Unit increased the number of villages in the case study area. A concurrent increase in the number of requests for services from the unit and a small increase in requests for government services is possibly due to residents in the new villages still learning about the role of research. This suggests that the residents in the original villages, who had been part of the experimental public for longer, had a clearer understanding of the role of the research reflecting a change in knowledge and attitude over time.

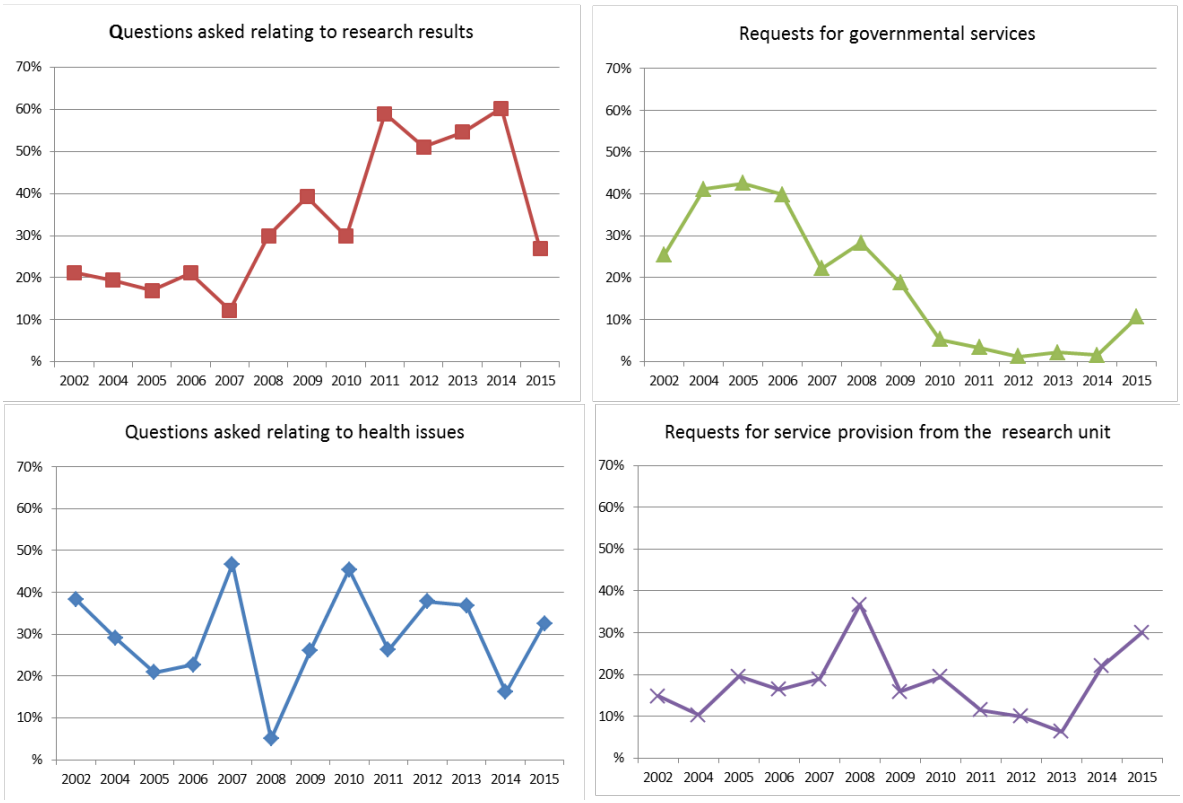


Figure 9: Trends in categories of questions asked at village-based meetings, 2002-2015 (Twine, Kahn and Lewando Hundt, 2017a:152)

The types of questions asked at village-based meetings changed depending on which results were presented and which service provider was present at the meeting. Questions fell into four broad categories: examples of questions asked in each category are included below, and illustrate that attendees of village-based-meetings understood the results and were interested in them (Twine, Kahn and Lewando Hundt, 2017a, p153).

1. 'Research results: *How do you include people in the census who out migrated from the village?* (2014); *How do you recruit participants for studies?* (2015)
2. Requests for services from the research unit: *Can you assist people with epilepsy to get a wheelchair?* (2011); *Can Wits do something about bilharzia, because if we go to the clinic they don't help us and our children keep urinating blood?* (2011)
3. Health: *If I'm HIV-positive and sleep with someone who is also HIV-positive, what's going to happen?* (2014); *How do I know I have heart disease?* (2015)
4. Requests for government services: *We are drinking water from wells and dams and the water is not healthy. Where can we get water for the vegetables we have planted?* (2008); *How can you help an older person who does not have a pension, but who also doesn't have an identity document, carer [or] relatives?* (2008)'.

Interviews revealed that there were nuanced understandings of the work of the activities of the unit. There was an understanding of the relevance of research results locally, nationally and internationally.

> *I once discussed with a project site manager from a Wits project about how we can make research more relevant to our facilities. He said that often the research is designed elsewhere and our hands are tied. But even though sometimes the research does not seem local, we know that sometimes it is important for national and provincial level. (Clinic Manager 1, Woman)*

However, not all interviewees understood the research, particularly the relevance of questions that were not purely demographic but more social or economic. Concerns about local relevance and benefit of these social and economic questions were frequently raised. Some interviewees understood that results might be beneficial at a national or provincial level, but were unclear about their local relevance.

Over the past eight years, there has been an increase in the frequency of requests for data directly from the researchers for the public, who use the information for service delivery planning or for their own studies. For example, data on the number of children in a village have been used in proposals or bids for additional schools, village maps provided by the PEO used to plan where water pipes can be placed, information on violence related deaths and suicides used to successfully motivate for a police station and local NGOs have used the information for planning their social responsibility programmes.

4.3.3. Changes in practice

Reports about change in practice centred mainly on results reported back at both the individual and village level from the additional nested studies conducted in the case study area. Since 2000, there has been an increase in the number of biomedical research studies focussing on HIV, cardiometabolic risk and disease, and adolescent health for example. Interviewees indicated that reporting back of individual findings from these studies has resulted in changes in individual health seeking behaviours. This is not only linked to giving back individual results. Village or case study area-level data is also reported back at village feedback meetings and at face–to-face meetings with service providers. Increasing awareness of issues relating to public health has influenced some villages to take action, for example, forming a women's soccer team and an exercise groups for older adults. Figure 10 also shows that some individuals take action, for example 54% of respondents reporting

that they started to work in community development projects after the previous year's feedback activity in their village.

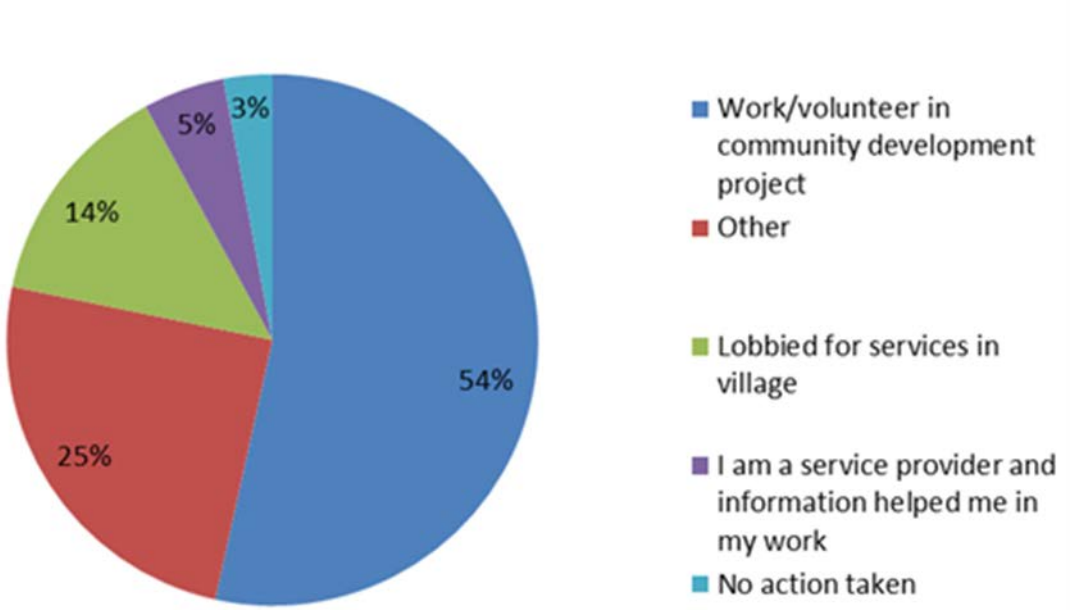


Figure 10: Reported activities undertaken subsequent to the previous year's KDI (Twine, Kahn and Lewando Hundt, 2017a: Figure 6 p153).

There has been some evidence that through eliciting the views of the public, governance practices within research activities have also been changed. This not only applies to direct suggestions for improving the KDIs by including more targeted meetings, but also, for example, to improved fieldworker training, more careful consideration of characteristics of fieldworkers for projects targeting specific participants,

4.3.4. Reach

Only 2-4% of the adult population in each village attended the village-based meetings (Figure 11). Even if 25% of those attending shared the information that they gained at these meetings, knowledge transfer dissemination would be limited.



Figure 11: Proportion of population over 18 years attending village-based meetings, 2001-2015 (Twine, Kahn and Lewando Hundt, 2017a:155)

However, even though the number of people attending meetings is not growing, different people attend annually, so the overall number of people learning about unit activities and results is increasing over time. Anecdotal evidence and experience by the PEO team suggests that the proportion of people attending these village-based meetings is greater than those attending other meetings called in the village. Village leaders make use of the public engagement office's (PEO) village-based meetings to make other important announcements to the population. Sometimes, the two hours of input and discussion that the PEO prepares for these meetings is compromised by this action by village leaders. Although tailored knowledge products in the form of one-page fact sheets outlining findings from different research projects were distributed at both village and face-to-face meetings, these were reported as too complicated and not well translated into the local language. There is little evidence that these fact sheets were referred to or further distributed by participants at the meetings.

The findings of this thesis concerning public engagement throughout the research process of a health and demographic surveillance study area have included issues relating to the co-production of knowledge in the development of a research

protocol, dilemmas of ethics in practice in data collection, and a longitudinal village-based knowledge dissemination intervention. The discussion will position these research findings within the literature and clarify their original empirical and theoretical contribution to knowledge.

CHAPTER FIVE: DISCUSSION AND CONCLUSIONS

This thesis and its related publications makes an original contribution to knowledge both empirically and theoretically concerning public engagement during all stages of the research process in longitudinal health and demographic surveillance system (HDSS) research study areas.

The original empirical contribution is that the thesis is the first body of work as a case study of this topic focusing on rural Southern Africa, adding to similar research conducted by Molyneux, Kamuya and others at the Kilifi HDSS, Kenya in East Africa, and work led by Tindana at the Navrongo HDSS in Ghana, West Africa. The research extends empirical understandings of public engagement in a longitudinal health and demographic research study area over time in South Africa where the particular history of inequity and apartheid still shapes research interactions and is reflected in issues such as high response rates and silent refusals. The work is original in that in Papers 1, 2 and 3 it foregrounded the voices of the experimental public at different stages of the research process and in Paper 4 contrasted the views of the experimental public with those of researchers on dilemmas arising from ethics in practice that were raised by residents. The work highlights features of public engagement that need to be considered given the work in an HDSS study area is longitudinal and takes place in one geographically defined population over time. The work has also applied the term ‘experimental public’ to the public in a longitudinal HDSS study area, where it has been used previously in relation to clinical trials (Montgomery and Pool, 2017; Twine, Lewando Hundt and Kahn, 2017b). This makes it explicit that the villages in the study setting are geographically defined for the purposes of research in a way that is not necessarily congruent with political and administrative boundaries and therefore do not form a single community other than for the purposes of research.

Theoretically, the research positions public engagement within civic science framing science as a public good (Bäckstrand, 2003). This research argues that if public engagement occurs throughout the research process, a weak experimental public can become stronger with increased participatory parity within the activities of a longitudinal health and demographic surveillance study area. Figure 12 shows how increasing public engagement throughout the research process involves greater scientific engagement with democracy and civic society. Ways of increasing participatory parity at the MRC/Wits-Agincourt Unit include widening participation through for example, greater involvement of the experimental public in decision making in the earlier stages of research, working with study specific research advisory groups, adjusting recruitment and other policies, for example training of fieldworkers, to align with concerns raised by the experimental public and development of researcher guidelines focusing on risk management with regards to ethics in practice. More work needs to be done to increase participatory parity for example working towards greater reach in knowledge dissemination activities, and developing strategies to reduce attrition in, and routinize meetings with, research advisory groups.

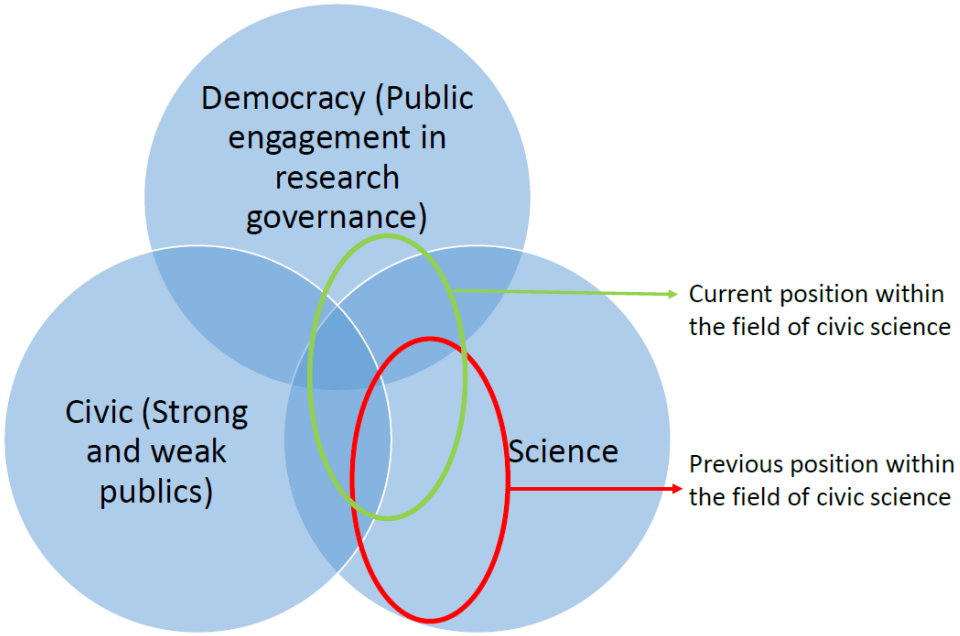


Figure 12: Current and previous positions of the longitudinal health research study area in the field of civic science. Adapted version of Figure 1, p.6 from Garlick and Levine (2017).

Another aspect of the original contribution to knowledge is that the research extends understandings of public engagement in longitudinal settings by synthesising the conceptual models of public engagement (Tritter and McCallum 2006) with those of knowledge brokerage (Bornbaum et al 2015) emphasising how in longitudinal settings, public engagement is complex, dynamic, multidimensional and uses multiple strategies. This thesis applies principles developed for public involvement in health care to public engagement in all stages of the research process, using Tritter and McCallum's model of public engagement (Tritter and McCallum, 2006). They identified that Arnstein's ladder of citizen participation did not capture the complexity of public engagement which they argued was multipronged, multi directional and used multiple strategies (Arnstein, 1969). Similarly, in terms of complexity, Bornbaum identified 10 tasks and activities that were part of knowledge brokerage conceiving it as dynamic and multidimensional (Bornbaum et al, 2015). Figure 13 synthesises these notions into a hub and spokes model of public engagement in longitudinal health and demographic surveillance system study areas.

This model allows for assessment or monitoring of the degree to which projects are working within each dimension of public engagement over time, the volume of each wedge being a reflection of engagement in that dimension. Different dimensions could have different levels of engagement – and changes over time can be noted. The wedges could alter showing the changing public engagement practices within a setting over time. Spokes denoting activities within each dimension can be added or subtracted as engagement evolves. There is no ideal set of spokes in this model, rather the tool is for developing and monitoring public engagement activities in different and unique longitudinal health research study areas.

Discussion of the dimensions of public engagement from the research will follow, positioning them within the published literature.

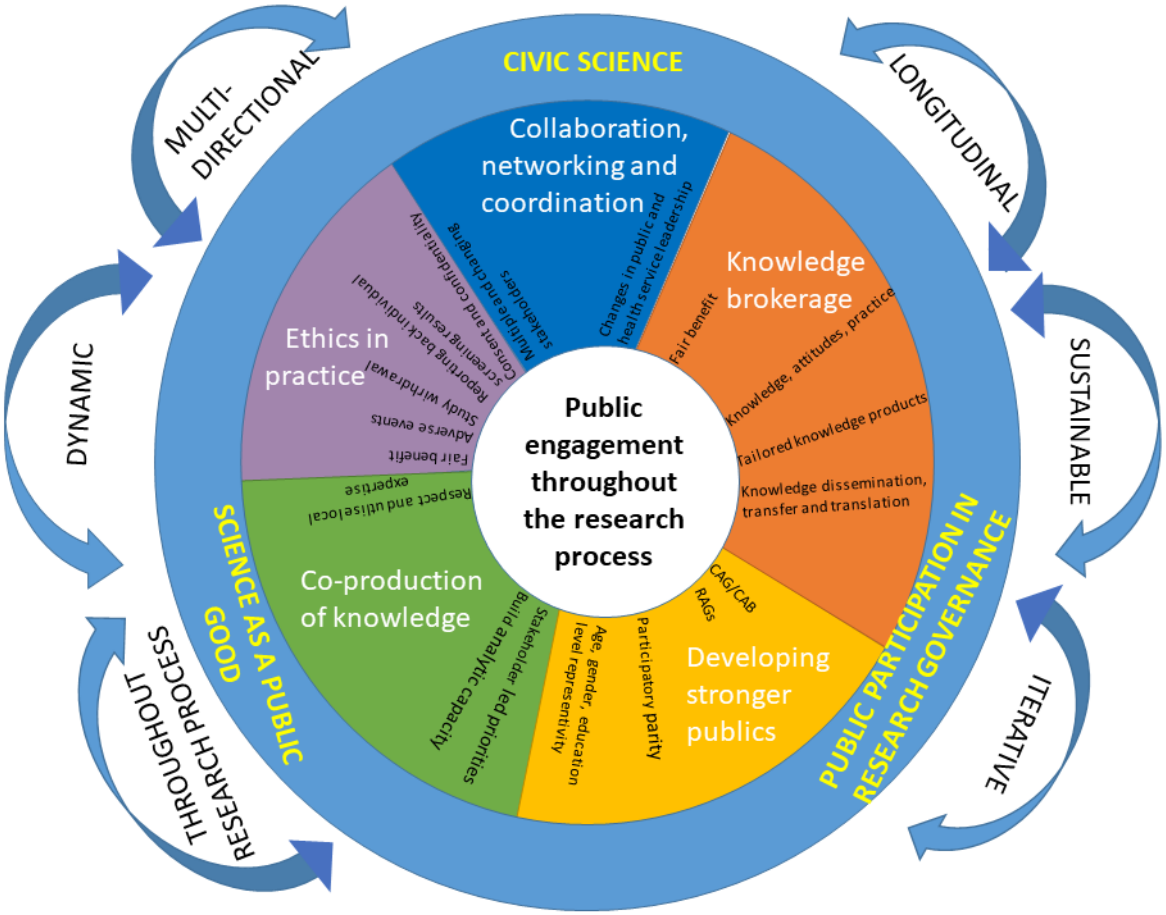


Figure 13: The hub and spokes model of public engagement in longitudinal health and demographic surveillance study areas.

5.1. Civic science

Civic science provides a conceptual framework through which to view public engagement throughout the research process in a longitudinal health research study area. Public involvement and engagement in the research process by residents in this HDSS area is part of what Backstrand (2003) would consider to be participation and representation in civic science. It could also be seen as part of the residents living within the longitudinal study area becoming a stronger public with more participatory parity (Fraser, 1995; Gurdasani *et al.*, 2015). The published papers in this study extend understandings of the mechanisms, processes and meaning of public engagement in a longitudinal HDSS study area in relation to involving stakeholders and residents in developing research priorities. This is done

in particular areas, such as research on young peoples' health (Twine *et al.*, 2016), by seeking the views of residents on research governance (Twine, Lewando Hundt and Kahn, 2017b), consulting researchers and residents on dilemmas of ethics in practice (Twine, Lewando Hundt and Kahn, 2019), and developing knowledge interventions for sharing research findings that are more focused and interactive to inform social action (Twine, Khan and Lewando Hundt, 2017a).

Clearly there is not participatory parity between the researchers and the residents. The structure of international and national funding of research is such that the residents remain the experimental public (Montgomery and Pool, 2017). Nevertheless, internationally, there is interest from governments and research funding organisations in public involvement, benefit to end users, and impacts of research that they fund (Tindana *et al.*, 2007), so that this area of practice will come under increasing scrutiny in research bids and reviews of research governance. Ethics in practice or in the field have been identified by others (Guillemin and Gillam, 2004; Kamuya, Marsh, *et al.*, 2013) but in this study, they have been identified by research participants and residents and then discussed with investigators rather than through only the gaze of the researcher or participant.

5.2. Public engagement and the co-production of knowledge

The findings in this thesis indicate that sustained and diverse engagement with the experimental public in longitudinal health research study areas can encourage the co-production of knowledge. These results reinforce Tritter and McCallum's model of public engagement which is multipronged, multidirectional and uses multiple strategies (Tritter and McCallum, 2006). This is all the more relevant as a model applied within a longitudinal HDSS study area. Indeed, one of the original conceptual contributions to knowledge of this thesis is using this model of public engagement in a longitudinal setting rather than within a health service or cross-sectional research study.

The co-production of knowledge can influence and have positive impacts on all stages of the research process, including developing user-focused objectives, questions, information, user friendly questionnaires and interview guidelines, assisting with more appropriate recruitment strategies, enhancing consumer-focused interpretation of data and more appropriate knowledge dissemination interventions (Brett *et al.*, 2014). An engagement strategy was developed as part of this thesis that resulted in successful co-production of knowledge during protocol development, whereby user-focused objectives and questions were created (Twine *et al.*, 2016). Public engagement during the research process resulted in the formation of a research advisory group for a nested study that would be involved in research governance and co-production of knowledge throughout the research process (Twine *et al.*, 2016). Public engagement processes eliciting the voices of the experimental public regarding their own experiences of longitudinal health research can widen participation of the public in research governance and co-production of knowledge (Twine, Lewando Hundt and Kahn, 2019; Twine, Lewando Hundt and Kahn, 2017b). The findings from this thesis indicate that sustained public engagement through KDIs can assist in building stronger publics in longitudinal health research study areas (Twine, Kahn and Lewando Hundt, 2017a).

Garlick and Levine (2017) have developed the notion that civic science can be effective if scientific knowledge is paired with democratic responsibilities, and civic action (see Figure 1, page 6) (Garlick and Levine, 2017). Co-production of knowledge can be seen through this paradigm, with public involvement in research governance guiding democratic responsibilities, and civic action being led by strong, as opposed to weak, publics (Fraser, 1995). In this case study, there is evidence that sustained public engagement has created a stronger public and increased public engagement in research governance. The longer an experimental public has been part of the study area, the greater their understanding of research, and the more they are able to be involved in the co-production of knowledge. Figure 12 (page 81) indicates how the position of the longitudinal health research study area within the field of civic science has changed over time.

The process of co-production of knowledge is not without its challenges. Some researchers are concerned that lay perspectives cannot be represented by a few people, such as those in a research advisory group. They also worry that lay input might be biased (Entwistle *et al.*, 1998). A challenge identified during this case study is that of attrition of lay and professional experts, especially representatives who have full time employment. This can be due to unexpected demands on their time, poor planning by their managers and high work-loads (Twine *et al.*, 2016; Twine, Kahn and Lewando Hundt, 2017a). There is also the challenge of ensuring the diversity and inclusivity of these groups in relation to age, gender and education. The moving goalposts of research project timing owing to funding, planning and ethical requirements sometimes affects the timing of meetings of research advisory groups, as was seen in this case study. This may lead to loss of interest or availability to participate in the co-production of knowledge.

An additional strategy for widening participation in research governance and co-production of knowledge is a Community Advisory Board or Group (CAB/CAG) (Simwinga, Porter and Bond, 2018). CAB/CAG members also need adequate training, and a constitution that is upheld, for example regarding length of terms of office. With the growth of nested research studies in study areas such as this, monthly CAB/CAG meetings cannot engage with the detail and governance of each project so study-specific advisory groups can be set up to advise on information sheets, review topic guides and advise during data collection and dissemination. Widening participation through mechanisms for consultation with residents and researchers regarding activities in a longitudinal health study area could assist in guiding decisions around governance in all these research activities, in order to enhance both accountability of researchers and fair benefit (Bäckstrand, 2003; Emanuel *et al.*, 2004; Kamuya, Marsh, *et al.*, 2013; Molyneux and Bull, 2013; Simwinga, Porter and Bond, 2018).

5.3. Ethics in practice in longitudinal health research study areas

Guillemin and Gillam (2004) use the term 'ethics in practice' mainly in relation to fieldwork during qualitative research in the social sciences. The original contribution from this thesis is that this case study has used the notion of ethics in practice to reflect on ethically important situations in longitudinal health and demographic surveillance study areas. Ethics in practice areas identified by the experimental public in this case study were: informed consent, human biological samples and study withdrawal.

5.3.1. Informed consent and confidentiality

The ethical principles of respect and autonomy are usually reflected in procedural ethics through informed consent (Kass *et al.*, 2014). The findings of this thesis published in Paper 2 and 3 (Twine, Lewando Hundt and Kahn 2017b, Twine, Lewando Hundt and Kahn, 2019) support findings in previous published literature from research centres in Kenya and Ethiopia; that while the process of informed consent in the field is often complex and requires careful attention (Molyneux, Peshu and Marsh, 2004, 2005; Tekola *et al.*, 2009; Kamuya *et al.*, 2015), it is critical to ethics in practice.

Levels of informed consent are high in this setting. In 2016 there was a 0.1% refusal rate for the annual HDSS update and in studies collecting human biological samples the refusal rate was on average 10%. Allotey et al (2014) noted that a recruitment rate of 85% in the annual update in an HDSS in the South East Asia Community Observatory (SEACO) in Malaysia could suggest a successful public engagement process. The difference between the low refusal rates in the MRC/Wits-Agincourt HDSS annual updates and the studies collecting samples is to be expected given the less invasive nature of the annual updates. Such low refusal rates, when compared to the refusal rate in SEACO suggest an effective engagement and consenting process in the MRC/Wits-Agincourt HDSS. However, the low refusal rates in the case study area of this

thesis may also be related to the specific historical and political context. The population was disempowered during apartheid, and deprived of access to formal education. Specifically, in 2010, one study in the longitudinal HDSS study area, found that of 5056 people aged 50 years and over, 55% had no formal education and 24% had six or less years of education (Ameh *et al.*, 2014).

In this case study, there were indications from interviewees that an intersectionality of age, gender and education may affect consent. The older female, less educated resident, may feel obliged to consent when asked to by a younger, more educated fieldworker, whether male or female (Twine, Lewando Hundt, and Kahn, 2019).

Owing to cultural changes, younger fieldworkers may respect their elders less than in the past (Stadler, 2003). Cultural considerations regarding older people's lack of trust in younger fieldworkers, or of younger fieldworkers contravening cultural practices through having to ask sensitive questions to their elders, have also been discussed in relation to informed consent in other longitudinal HDSS study areas (Tekola *et al.*, 2009; Kamuya *et al.*, 2015).

A current dilemma in this research setting is that younger fieldworkers, owing to greater access to post-secondary education post-apartheid, are more likely to be appointed as fieldworkers than applicants who are older. This is considered a benefit by the population in the area, as youth unemployment is extremely high. These fieldworkers are more likely to understand research and be able to use technology, which is vital, as data collection has moved from being paper-based to electronic. Although there is benefit to the youth that only fieldworkers from the study villages are recruited, this can create issues of trust in fieldworkers' ability to maintain confidentiality, as in other studies in Africa (Molyneux *et al.*, 2013).

Despite these high levels of consent, interviewees in this study reported that sometimes participants hid when they saw fieldworkers approaching their households. Molyneux et al (2005) and Hyder et al (2012) have highlighted that the decision to sign an informed consent may be made because of a high level of trust

in the fieldworker and the research institution, or because of real or perceived benefits from the study. The findings in this case study are similar. Kamuya et al (2015) and Tekola et al (2015) discuss the complexities of gaining informed consent in research studies, noting the importance of how and what information is presented, and that cultural issues affect the decision to sign consent. This has been found elsewhere in rural sub-Saharan Africa, despite informed consent including the right to refuse (Kamuya *et al.*, 2015). A silent refusal (Kamuya et al 2015) is an expression of agency although it is indirect through avoidance and is typical of people who have less power.

In these study areas, there are different spheres of consent (Nuffield Council on Bioethics, 2002; Emanuel *et al.*, 2004), but issues related to village and household consent were not raised directly as a concern by the interviewees in this study. The results from this study indicate that community leaders are supportive of the work of the researchers, but also that they are not averse to using their influence to encourage residents to participate. Service providers and leaders wanted individual information so that they could identify people with special needs, such as those in extreme poverty – to target for assistance (Twine, Lewando Hundt, Kahn 2017b). This may be a unique feature of longitudinal research study areas, since leaders who have received population-based data that has assisted them in planning service delivery, may have a different perspective on participation. As mentioned by Nakaringe (2009), judgement as to the balance between incentives/benefits and not compromising informed consent can be assisted by increased public engagement prior to research starting.

Often, there is a conflict between researcher's targets, and handling of consent. Fieldworkers' performance is often assessed by how many people they recruit into studies, and this may affect the way they explain the study, perhaps omitting some of the more negative procedures. Unique to longitudinal health and demographic surveillance study areas, negative experiences by participants of the consent process will influence consent rates for future studies in the study area.

Unique to longitudinal health and demographic surveillance study areas is that enormous amounts of information are collected on the same individuals over time (Aquino *et al.*, 2013) . The results from this case study indicate that the experimental public is aware that there is a great deal of data available about their lives, and that there is an onus on the data section and the researchers to maintain confidentiality of this information. Linked to this are issues about maintaining confidentiality during publishing – reported in this case study as 'keeping secrets.' Longitudinal health and demographic surveillance study areas are geographically defined, and so their population is readily identifiable (Marshall and Rotimi, 2001).

Field worker training and support can mitigate ethical issues that occur in the field (Tekola *et al.*, 2009; Kamuya *et al.*, 2015) and it is clear that training at the onset of a study needs to be followed up with frequent monitoring and supervision of the field workers in a study on the taking of informed consent. Calls for standardised training for field workers were made at a workshop involving nine African longitudinal health research institutions in 2015 (Jao *et al.*, 2015).

In summary, the results in this case study support previous findings that the informed consent process is complex and that there are particular considerations regarding consent and confidentiality that are unique to longitudinal health and demographic surveillance study areas. For informed consent, these include considering village, household and individual consent, and attempting to ensure that consent at all levels is given without duress. Particular attention needs to be given to ensuring individual consent is not given owing to high levels of trust that have been developed over time, or owing to reluctance to defy collective village or household-level consent, rather than as an informed choice. With regard to confidentiality, of specific concern in longitudinal health and demographic surveillance study areas is that data are collected about the same people, and the geographic area is easily recognised and always mentioned when results are published. Care needs to be taken to maintain the anonymity of both individuals and the villages they are resident in within the numerous longitudinal datasets. Authors need to think seriously about how to reduce the levels of possible

stigmatisation when reporting results in published papers, example by not producing maps where individuals, or specific communities' results are identifiable.

5.3.2. Giving blood and reporting back individual screening results

Ethics in practice issues that arise from the collection of blood and other human biological samples are fairly common in Africa (Geissler, 2005; Stadler and Saethre, 2011; Montgomery and Pool, 2017). In these anthropological analyses of local explanations of blood taking, all authors are clear that whereas researchers view these explanations as rumours and misunderstandings that show the population needs to be further educated, these 'rumours' illustrate historical, cultural and social realities that were and are part of the sub-Saharan African context. In this setting, the collection of blood coincided with increased funding and a visible increase in the number of vehicles driving around the study area. The experimental public attribute this to their blood was being sold and the money being used to buy more vehicles. This dilemma reflected the way in which the experimental public rationalised how international research is funded and resourced (Twine, Lewando Hundt and Kahn, 2017b). The lay explanation reflected the current structure of international research. Current global health research with international partners (many nested research projects have international collaborators in the case study area) and funding, have the collection of human biological samples as an essential part of researching the global burden of disease, for example, in relation to HIV/AIDs, aging and genomic studies (Tindana *et al.*, 2015).

Researchers recognised an ethical imperative to report individual screening results to participants, as noted in the literature (Shalowitz and Miller, 2005; Bledsoe *et al.*, 2012). With respect to individual results that required laboratory testing and therefore could not be given on the day of the test, participants would like all such results to be returned to them once available. However, researchers were of the opinion that only clinically relevant results needed to be given back to participants.

This needs further consultation, as there are also complications such as who decides which result is clinically relevant (Murphy *et al.*, 2008).

Supporting the findings from Bledsoe et al (2012), no adverse events were reported by participants regarding the giving back of individual screening test results, and giving individual results seemed to create a positive attitude towards research, and might be seen as a fair benefit from the research (Shalowitz and Miller, 2005; CIOMS, 2016). Provision of individual screening results is only mentioned in one review guideline (ICH-GCP (1996)) in Lairumbi et al's (2011) review of research ethics guidelines, although it is clear from this paper that participants view this as a real benefit. In countries such as South Africa, where there is free primary health care available for many conditions, there may be less risk of therapeutic misperceptions (Appelbaum et al., 1987; Molyneux, Peshu and Marsh, 2005) when giving individual test results. Researchers and residents both noted that earlier involvement and ongoing participation of local residents in proposal development might prevent ethical dilemmas owing to collection of human biological samples arising in the ethics in practice.

In summary, the concerns expressed by the experimental public relating to giving blood were similar in this research to those expressed in other studies, and the contextual analysis of this case study concurs with the previous anthropological analyses. What is distinctive and an original contribution to knowledge is that some of these concerns relating to the reporting back of individual clinical results of the experimental public were shared with the researchers who reflected on them as a dilemma of ethics in practice. There are budgetary and procedural implications for future research studies in this longitudinal health and demographic research study area that are already being implemented. These are generalisable and provide possibilities for future regional or international guidelines on the reporting back of individual clinical results. For the international collaborators, this is less of an urgent dilemma of ethics in practice, as their involvement and commitment is time limited. However, for researchers in a longitudinal study area, this is a distinctive

feature of ethics in practice as part of fair benefit to the experimental public and research governance.

5.3.3. Study withdrawal

What actions should be taken when a study ends is an ethical dilemma that is increasingly being discussed in guidelines for conducting research in developing countries (Nuffield Council on Bioethics, 2002; Participants, 2002; CIOMS, 2016). While intervention research is important in order to develop and test new and better ways of delivering health services, the countries in which they are tested do not always have the resources to implement and sustain them post trial should they prove worthwhile (Tollman, 2001; Zong, 2008). Involving policy makers and service providers in the development and implementation of intervention studies may assist with the difficulties that occur when studies end and there are no resources to maintain interventions that prove effective (Emanuel *et al.*, 2004).

Findings in Paper 2 (Twine, Lewando Hundt and Kahn, 2017b) place issues related to withdrawal of studies within the complex dimension of fair benefit. Fair benefit is an essential ethical consideration that is gaining traction in more recent guidelines concerning health research in developing countries (Nuffield Council on Bioethics, 2002; Carslon, Boyd and Webb, 2004; Lairumbi *et al.*, 2011; Molyneux *et al.*, 2012; Mondain, 2013; CIOMS, 2016). Ethical dilemmas related to reporting back individual screening results, described above, and population-wide aggregated data, described below, can also be regarded within the dimension of fair benefit.

Ethics in practice can be framed within civic science as part of the accountability of researchers, at individual and institutional levels, to the experimental public that they work with. In longitudinal research in low resource settings such as the Global South, the unequal relations of power and education are stark and robust ethics in practice is a key part of public engagement within collaborative international and national research studies. In this thesis, ethics in practice has focused on confidentiality, consent, and fair benefit during data collection, as these were

concerns raised by the experimental public and shared with researchers. It can be argued that public engagement activities in the research process have increased the participatory parity of this weak public and strengthened researcher accountability in relation to individual and institutional interactions by eliciting their views and taking action on them within the research setting (see 'The way forward'). Whilst ethics in practice has primarily focused on data collection in the research process, knowledge dissemination, transfer and dissemination of findings is clearly also part of public engagement.

5.4. Knowledge dissemination, transfer and translation of research findings

It is widely recognised that knowledge dissemination, transfer and translation of research findings into practice and policy is a key part of the research process and is part of public engagement activities. It is considered an essential component of the principle of social value and fair benefit in research (Emanuel *et al.*, 2004; Guillemin and Gillam, 2004; CIOMS, 2016). One of the ways of doing this is through a knowledge dissemination intervention (KDI) such as that undertaken and analysed in this case study (Twine, Kahn and Lewando Hundt, 2017a). The effectiveness of KDIs can be assessed by three outcomes: knowledge acquisition, changes in attitudes, and practice (Lafrenière *et al.*, 2013). Findings in Paper 4 show that the KDI examined in this thesis showed limited success in terms of these three outcomes (Twine, Kahn and Lewando Hundt, 2017a). Reach was limited with only two to four percent of the adult population attending village-based meetings. Although overall reach was likely higher, since attendance was not static and different people attended each year, even if a quarter of attendees shared the information following the meetings, knowledge sharing would be modest. Face-to-face meetings with service providers were much appreciated, but given that few service providers could identify where the fact sheets distributed were stored, reach was limited, as the information discussed and provided in the fact sheets was clearly not shared. Additionally, reach and therefore knowledge sharing was

limited, as often service provider face-to-face meetings did not occur and service providers did not attend the village-based meetings owing to their workload.

It can be said that changes in knowledge and attitude became apparent as residents of villages more recently added to the longitudinal HDSS study area asked more service related questions at village-based meetings, unlike residents of villages that had been in the longitudinal HDSS study area for many years who asked more research-related questions. This suggests a change in knowledge and attitude since, over time, a growing acceptance and understanding of research was demonstrated (Twine, Kahn and Lewando Hundt, 2017a). This shows that a routinised KDI can lead to changes in knowledge and attitudes. A caveat is that it is possible, but not probable, that residents have stopped asking for services as they have 'given up' on expecting to receive service provision from the researchers.

Evidence of changes in practice were also apparent. (Twine, Kahn and Lewando Hundt, 2017a). Some attendees at village-based meetings reported that they had adapted their health behaviour following a meeting, and some reported that they had started to volunteer in community-based organisations. There were more changes in practice evident as service providers and village leaders reported using annual update and other research data for their service delivery planning (Twine, Kahn and Lewando Hundt, 2017a, Twine, Lewando Hundt and Kahn 2017b).

Bornbaum et al (2015) in their literature review of knowledge brokerage identified 10 key activities and tasks of knowledge brokerage. The KDI in this thesis clearly included three of these: obtaining relevant information (research findings), creating tailored knowledge products (factsheets), and supporting communication and knowledge sharing (village and face-to-face meetings) (Bornbaum *et al.*, 2015). Although the reach of the KDI was limited, it also covered a few more activities and tasks of knowledge brokerage, owing to its longitudinal nature. Between 2001-2015, it developed from being linear to becoming multi-pronged through adding face-to-face meetings with service providers, engaging with new stakeholders, and building local capacity in the interpretation of research data (Bornbaum *et al.*,

2015). The evidence for these activities was that village leaders had begun to use the village-based meetings as a platform to discuss locally relevant topics, indicating that these meetings had become embedded and routinised, and were considered a useful public forum. The KDI format and processes changed over time as described in Paper 4 (Twine, Kahn and Lewando Hundt, 2017a) and developed from being a linear one-way exchange of information to being more interactive and multi-pronged. Knowledge brokerage literature (Conklin *et al.*, 2013; Dagenais, Laurendeau and Briand-Lamarche, 2015) acknowledges that this process is complex and more effective if multidimensional. Knowledge brokerage in a longitudinal health and demographic research study area involves the experimental public and other stakeholders such as political representatives and service providers with whom partnerships develop over time.

The findings from Papers 2 and 4 about KDIs indicate that KDIs are an essential component of knowledge brokerage within public engagement in longitudinal health and demographic surveillance study areas. Unique to longitudinal study areas is that various KDIs can be implemented and lessons learnt to continuously improve on knowledge brokerage practice. KDIs are one element within knowledge brokerage that is complex, dynamic and multidimensional.

5.5. Limitations

The data collected for this case study highlighted many sub-areas of interest, and a selection had to be made for exploring breadth of topic over depth of topic. This made it more difficult to give absolute answers to the research questions, although it allowed for a wider range of topic.

In terms of the methods, it is possible that data collected from researchers might have been richer had the interviews been conducted face to face rather than the more pragmatic choice of being self administered questions via email. The views of fieldworkers, all of whom are resident in the case study area, were not elicited in this case study. This is a limitation, as there is literature on the complex relationships between fieldworkers and the experimental public (Molyneux *et al.*,

2013; Kamuya *et al.*, 2014) indicating the importance of this topic. There is not much literature on this topic in relation to longitudinal health research study areas – most of the literature focusses on how this relationship might affect informed consent.

Not all aspects of civic science or ethics in practice were covered in this case study. Intersectionality between gender, age, educational and socio-economic levels, and how these relate to ethics in practice and public engagement, have not been fully explored even though the effect that age disparities between participants and fieldworkers had during data collection was reported. Also, although some mention was made regarding how decision making power is delegated between the Global South and Global North collaborators, this was not fully explored as part of the analysis. The role of the Community Advisory Group and research project advisory group that are a common method of public engagement globally, was not a focus of this case study.

In this digital age, social media is becoming more of a focus during KDIs, and was not part of the KDI examined in this case study. Additionally, with regards to KDIs, interventions that focus on working with policy makers were not part of this case study of public engagement, which focussed on the experimental public resident and working in the case study area.

5.6. The way forward

Further research in this area is needed regarding how research that explores the intersectionality of gender, ethnicity, age, and socio-economic status impact on public engagement throughout the research process. Longitudinal HDSS study areas are usually located in resource-poor, under-developed areas where educational levels are low and there is often social, economic and gender inequities. The exploration of how these historical, political and social factors affect public engagement and the ethics in practice in the research process would be illuminating.

As experimental publics grow stronger and are able to influence research agendas more effectively, opportunities for more participatory research will arise. Participatory research in itself also builds stronger publics. One such current project is a partnership between the Mpumalanga Provincial Department of Health, University of Aberdeen and the MRC/Wits-Agincourt Unit is the 'Verbal Autopsy with Participatory Action Research' project, VAPAR. The public in three villages, along with policy makers and service providers, have been involved in defining the research topic, analysing the data and are now following up on action plans developed during the participatory action research (PAR) process. (Brooks et al., 2017; Wariri et al., 2017). Comparative research on public engagement in longitudinal research and demographic surveillance study areas is a possible future research area utilising existing networks such as INDEPTH and the South African Populations Research Infrastructure Network (SAPRIN).

Further debate on the use of the term 'experimental public', originally suggested by Montgomery and Pool (2017) as an alternate term to 'trial communities' could elicit a term more specific to publics defined by their residence within an HDSS study area. Opportunities for such debate could arise within the INDEPTH Network. This may be necessary as it could be argued that the term 'the experimental public' risks the entire population being seen as one undifferentiated group, despite some potential differences.

The Public Engagement Offices of longitudinal HDSS study areas, working together with the experimental publics, could work with 'small groups of thoughtful, committed citizens' (Margaret Mead, 1984) concerned with ensuring that research is indeed a public good and contributing towards solving pressing societal issues. Research reward systems are seldom based on public engagement with the science, or ethical and moral responsibilities of researchers (Garlick and Levine, 2017). Continuing to locate public engagement in longitudinal HDSS study areas within the field of civic science, could contribute towards researchers' understandings of how research can be a resource for building civic engagement, democratic citizenry and changes in policy and practice. Increasing public

participation in research governance may help to ensure that the voices of the experimental public are heard, and the science moves forward in an inclusive manner, with science being viewed as a public good.

5.7. Conclusion

Public engagement activities can strengthen civic science and democratic involvement within a longitudinal HDSS study area. This case study of public engagement in research in a longitudinal HDSS study area in rural South Africa is an original contribution to knowledge in this area in relation to international global public health.

To explore and extend understandings of public engagement in a longitudinal HDSS study area where **all** residents are participants, a variety of ongoing activities were considered, over a period of time, as a case study. Data were collected from records kept about community feedback campaigns, interviews and focus group discussions with participants, service providers, village leaders and researchers. Data were viewed through the lens of civic science.

In analysing the data, and in writing the papers for this thesis, the focus was on public engagement throughout the research process. Thus attention was given to co-production of knowledge, for example, in defining or refining the research question during protocol development, and public involvement in research governance; to engagement during the research process when issues related to the ethics in practice arise; and engagement once fieldwork is complete and knowledge dissemination starts. Additionally, since the case study was on a longitudinal HDSS study area, views on the experience of the experimental public involved in the research along with views of researchers were also explored.

A number of important factors emerged from this thesis that can be used to guide public engagement in this, and other longitudinal health research areas. A synthesis of models of public engagement and knowledge brokerage was

developed into a hub and spokes model of public engagement that could guide longitudinal research organisations to be leaders in promoting research as a public good and enhancing scientific engagement with civic society.

REFERENCES

Allotey, P, Reidpath, DD, Devarajan, N et al. (2014). Cohorts and community: A case study of community engagement in the establishment of a health and demographic surveillance site in Malaysia. *Global Health Action*. 7(1):1–9. doi.org/10.3402/gha.v7.23176.

Ameh, S, Gómez-Olivé, FX, Kahn, et al. (2014). Predictors of health care use by adults 50 years and over in a rural South African setting. *Global Health Action*. 7(1):1–11. doi.org/10.3402/gha.v7.24771.

Appelbaum, PS, Roth, LH, Lidz, CW et al. (1987). False hopes and best data: Consent to research and the therapeutic misconception. *The Hastings Center Report*. 17(2):20. doi.org/10.2307/3562038.

Aquino, E, Vasconcellos-Silca, P, Coeli, CM et al. (2013). Ethical issues in longitudinal studies: the case of ELSA-Brasil. *Rev Saúde Pública.* 47(Supl 2). doi.org/10.1590/S0034-8910.2013047003804.

Arnstein, SR. A ladder of citizen participation. (1969). *Journal of the American Planning Association*. 35(4):216–224. doi.org/10.1080/01944366908977225.

Bäckstrand, K. (2003). Civic science for sustainability: Reframing the role of experts, policy-makers and citizens in environmental governance. *Global Environmental Politics*. 3(4):24–41. doi.org/10.1162/152638003322757916.

Beresford, A. (2015). Power, patronage, and gatekeeper politics in South Africa. *African Affairs*. 114(455):226–248. doi.org/10.1093/afraf/adu083.

Bertram, MY, Steyn, K, Wentzel-Viljoen, E et al. (2012). Reducing the sodium content of high-salt foods: Effect on cardiovascular disease in South Africa. *South African Medical Journal*. 102(9):743–745. doi.org/10.7196/SAMJ.5832.

Blaxter, L, Hughes, C & Tight, M. (2010). How to research. McGraw Hill, Maidenhead. doi.org/10.1017/CBO9781107415324.004.

Bledsoe, MJ, Grizzle, WE, Clark, BJ et al. (2012). Practical implementation issues and challenges for biobanks in the return of individual research results. *Genetics in Medicine*. 14(4):478–483. doi.org/10.1038/gim.2011.67.

Bornbaum, CC, Kornas, K, Peirson, L et al. (2015). Exploring the function and effectiveness of knowledge brokers as facilitators of knowledge translation in health-related settings: A systematic review and thematic analysis. *Implementation Science*. 10(1):1–12. doi.org/10.1186/s13012-015-0351-9.

Boyte, HC. (2011). Constructive politics as public work: Organizing the literature. *Political Theory*. 39(5): 630-660. Doi.org/10.1177/0090591711413747

Brett, J, Staniszewska, S, Mockford, C et al. (2014). Mapping the impact of patient and public involvement on health and social care research: A systematic review. *Health Expectations*. 17(5):637–650. doi.org/10.1111/j.1369-7625.2012.00795.x.

Brooks, C, D'Ambruoso, L, Kazimierczak, K, et al. (2017). Introducing visual participatory methods to develop local knowledge on HIV in rural South Africa. *BMJ Global Health*. 2(3):e000231. doi.org/10.1136/bmjgh-2016-000231.

Carrel, M & Rennie, S. (2008). Demographic and health surveillance: Longitudinal ethical considerations. *Bulletin of the World Health Organization*. 86(8):612–616. doi.org/10.2471/BLT.08.051037.

Carslon, R, Boyd, K & Webb, D. (2004). The revision of the Declaration of Helsinki - past, present and future. *British Journal of Clinical Pharmacology.* 57:695–713.

Cheng, HG & Phillips, MR. (2014). Secondary analysis of existing data: opportunities and implementation. *Shanghai Archives of Psychiatry*. 26(6) 371-375. doi.org/10.11919/j.issn.1002-0829.214171.

CIOMS in collaboration with the WHO. (2016). International Ethical Guidelines for Health-related Research Involving Humans, Biomedical Research. Geneva. Available from: http://www.sciencedirect.com/science/article/B6VC6-45F5X02-9C/2/e44bc37a6e392634b1cf436105978f01.

Collinson, MA, White, MJ, Bocquier P et al. (2014) 'Migration and the epidemiological transition: Insights from the Agincourt sub-district of northeast South Africa.' Global Health Action. 7(SUPP.1), pp. 1–15. doi: 10.3402/gha.v7.23514.

Conklin, J, Lusk, E, Harris, M et al. (2013). Knowledge brokers in a knowledge network: the case of Seniors Health Research Transfer Network knowledge brokers. *Implementation Science*. 8(1):1–10. doi.org/10.1186/1748-5908-8-7.

Constitution of the Republic of South Africa, 1996. Available from: http://www.justice.gov.za/legislation/constitution/SAConstitution-web-eng.pdf

Cornwall, A & Jewkes, R. (1995). What is participatory research. *Social Science & Medicine*. 41(12):1667–1676. doi.org/10.1016/0277-9536(95)00127-s.

Dagenais, C, Laurendeau, MC & Briand-Lamarche, M. (2015). Knowledge brokering in public health: A critical analysis of the results of a qualitative evaluation. *Evaluation and Program Planning*. 53:10–17. doi.org/10.1016/j.evalprogplan.2015.07.003.

Dahlgren, L, Emmelin, M & Winkvist, A. (2007). Qualitative Methodology for International Public Health. 2nd Edition ed. Umea, Sweden: Umea University.

Day, S, Blumberg, M, Vu, T et al. (2018). Stakeholder engagement to inform HIV clinical trials: a systematic review of the evidence. *Journal of the International AIDS Society*. 21:5–18. doi.org/10.1002/jia2.25174.

Dickert, N & Sugarman, J. (2005). Ethical goals of community consultation in research. *American Journal of Public Health.* 95(7):1123–1127. doi.org/10.2105/AJPH.2004.058933.

Doumbo, OK. (2005). Global voices of science. It takes a village: medical research and ethics in Mali. *Science*. 307(5710):679–681. doi.org/10.1126/science.1109773.

Draper, CE, Micklesfield, LK, Kahn, K et al. (2014). Application of Intervention Mapping to develop a community-based health promotion pre-pregnancy intervention for adolescent girls in rural South Africa: PROJECT Ntshembo (Hope). *BMC Public Health.* 14(SUPPL. 2):1–14. doi.org/10.1186/1471-2458-14-S2-S5.

Dutta, MJ. (2004). The unheard voices of Santalis: Communicating about health from the margins of India. *Communication Theory.* 14(3):237–263. doi.org/10.1111/j.1468-2885.2004.tb00313.x.

Elliott, H & Popay, J. (2000). How are policy makers using evidence? Models of research utilisation and local NHS policy making. *Journal of Epidemiology and Community Health*. 54(6):461–468. doi.org/10.1136/jech.54.6.461.

Ellis, C. (2007). Telling secrets, revealing lives: Relational ethics in research with intimate others. *Qualitative Inquiry*. (2007). 13(1). 3-29.

Emanuel, EJ, Wendler, D, Killen, J et al. (2004). What makes clinical research in developing countries ethical? The benchmarks of ethical research. *The Journal of Infectious Diseases*. 189(5):930–937. doi.org/10.1086/381709.

Entwistle, VA, Renfrew, MJ, Yearley, S et al. (1998). Lay perspectives: advantages for health research. *British Medical Journal*. 316(7129):463–466. doi.org/10.1136/bmj.316.7129.463.

Filipe, A, Renedo, A & Marston, C. (2017). The co-production of what? Knowledge, values, and social relations in health care. *PLoS Biology.* 15(5):1–6. doi.org/10.1371/journal.pbio.2001403.

Fortmann, L. (2011). Giving back, moving forward. *Journal of Research Practice*. 10(2):1–5.

Fraser, N. (1995). From redistribution to recognition? Dilemmas of justice in a 'post-Socialist' age. *New Left Review*. (212):68–93. doi.org/10.1002/9780470756119.ch54.

Friedman, S. (2006). Participatory governance and citizen action in post-apartheid South Africa. Discussion Paper no. 164, Decent Work Programme, International Institute for Labour Studies, Geneva..Available from: http://www.ilo.org/wcmsp5/groups/public/---dgreports/---inst/documents/publication/wcms_193613.pdf

Garlick, JA & Levine, P. (2017). Where civics meets science: building science for the public good through Civic Science. *Oral Diseases*. 23(6):692–696. doi.org/10.1111/odi.12534.

Gaziano, TA, Abrahams-Gessel, S, Gomez-Olive, FX et al. (2017). Cardiometabolic risk in a population of older adults with multiple co-morbidities in rural South Africa: the HAALSI (Health and Aging in Africa: longitudinal studies of INDEPTH communities) study. *BMC Public Health*. 17(1):1–10. doi.org/10.1186/s12889-017-4117-y.

Geertz, C. (1973). Thick Description: Toward an Interpretive Theory of Culture. In: The Interpretation of Culture: Selected Essays. New York: Basic Books. 3–20.

Geissler, PW. (2005). 'Kachinja are Coming!': Encounters Around Medical Research Work in a Kenyan Village. *Africa*. 75(02):173–202. doi.org/10.3366/afr.2005.75.2.173.

Geissler, P. W., & Molyneux, C. (2011). Evidence, Ethos and Ethnography: The Anthropology and History of Medical Research in Africa. Berghahn Books.

Geissler, PW & Pool, R. (2006). Editorial: Popular concerns about medical research projects in sub-Saharan Africa - A critical voice in debates about medical research ethics. *Tropical Medicine and International Health*. 11(7):975–982. doi.org/10.1111/j.1365-3156.2006.01682.x.

Gibson, A, Hundt, GL & Blaxter, L. (2014). Weak and strong publics: Drawing on Nancy Fraser to explore parental participation in neonatal networks. *Health Expectations*. Feb;17(1):104–15.

Gilson, L & McIntyre, D. (2008). The interface between research and policy: Experience from South Africa. *Social Science and Medicine.* 67(5):748–759. doi.org/10.1016/j.socscimed.2008.02.005.

Godfrey, L, Funke, N & Mbizvo, C. (2010). Bridging the science-policy interface: A new era for South African research and the role of knowledge brokering. *South African Journal of Science*. 106(5):1–8. doi.org/10.4102/sajs.v106i5/6.247.

Gómez-Olivé, FX, Thorogood, M, Clark, BD et al. (2010). Assessing health and well-being among older people in rural South Africa. *Global Health Action*. 3(1):2126. doi.org/10.3402/gha.v3i0.2126.

Grady, C. (2005). The challenge of assuring continued post-trial access to beneficial treatment. *Yale Journal of Health Policy, Law and Ethics*. 1(1):425–436.

Guillemin, M & Gillam, L. (2004). Ethics, reflexivity, and "Ethically important moments" in research. *Qualitative Inquiry*. 10(2):261–280. doi.org/10.1177/1077800403262360.

Gurdasani, D, Carstensen, T, Tekola-Ayele, F et al. (2015). The African Genome Variation Project shapes medical genetics in Africa. *Nature*. 517(7534):327–332. doi.org/10.1038/nature13997.

Hammersley, M & Atkinson, P. (2007). Ethnography principles in practice. 3rd ed. London and New York: Routledge.

Harris, B, Eyles, J, Penn-Kekana, L et al. (2014). Adverse or acceptable: Negotiating access to a post-apartheid health care contract. *Globalization and Health*. 10(1):1–14. doi.org/10.1186/1744-8603-10-35.

Hasson, F, Keeney, S & McKenna, H. (2000). Research guidelines for the Delphi survey technique. *Journal of Advanced Nursing*. 32(4):1008–1015. doi.org/10.1046/j.1365-2648.2000.t01-1-01567.x.

Hennick, M, Hutter, I & Bailey, A. (2011). Qualitative Research Methods. SAGE Publications Ltd.

Hess, C & Ostrom, E (ed). (2007). Understanding knowledge as a commons: From theory to practice. The MIT Press, Cambridge, Massachusetts London, England

Hoekstra, F, Kelly, MJ, Sibley et al. (2018). A review protocol on research partnerships: a Coordinated Multicenter Team approach. *Systematic Reviews.* 7(217).

Hosegood, V & Madhavan, S. (2010). Data availability on men's involvement in families in sub-Saharan Africa to inform family-centred programmes for children affected by HIV and AIDS. *Journal of the International AIDS Society.* 13(SUPPL. 2):1–7. doi.org/10.1186/1758-2652-13-S2-S5.

Hyder, AA, Krubiner, CB, Bloom, G et al. (2012). Exploring the Ethics of Long-Term Research Engagement with Communities in Low- and Middle-Income Countries. *Public Health Ethics*. 5(3):252–262.

Jao, I, Kombe, F, Mwalukore, S et al. (2015). Research stakeholders' views on benefits and challenges for public health research data sharing in Kenya: The importance of trust and social relations. *PLoS ONE*. 10(9):1–18. doi.org/10.1371/journal.pone.0135545.

Jentsch, B & Pilley, C. (2003). Research relationships between the South and the North: Cinderella and the ugly sisters? *Social Science and Medicine.* 57(10):1957–1967. doi.org/10.1016/S0277-9536(03)00060-1.

Kahn, K, Collinson, MA, Gómez-Olivé, FX et al. (2012). Profile: Agincourt health and socio-demographic surveillance system. *International Journal of Epidemiology*. 41(4):988–1001. doi.org/10.1093/ije/dys115.

Kamuya, DM, Marsh, V, Kombe, FK et al. (2013). Engaging communities to strengthen research ethics in low-income settings: Selection and perceptions of members of a network of representatives in coastal Kenya. *Developing World Bioethics.* 13(1):10–20. doi.org/10.1111/dewb.12014.

Kamuya, DM, Theobald, SJ, Munywoki, PK et al. (2013). Evolving friendships and shifting ethical dilemmas: Fieldworkers' experiences in a short term community based study in Kenya. *Developing World Bioethics*. 13(1):1–9. doi.org/10.1111/dewb.12009.

Kamuya, DM, Marsh, V, Njuguna, P et al. (2014). "When they see us, it's like they have seen the benefits!": Experiences of study benefits negotiations in community-based studies on the Kenyan Coast. *BMC Medical Ethics*. 15(1):1–16. doi.org/10.1186/1472-6939-15-90.

Kamuya, DM, Theobald, SJ, Marsh, V et al. (2015). The one who chases you away does not tell you go: Silent refusals and complex power relations in research consent processes in coastal Kenya. *PLoS ONE*. 10(5). doi.org/10.1371/journal.pone.0126671.

Kass, NE, DeLuca, AN, Coetzee, L et al. (2014). Applying ethical principles to international community-based research. *IRB Ethics and Human Research.* 36(3):1–8.

Kelly, AH, MacGregor, H & Montgomery, CM. (2017). The publics of public health in Africa. *Critical Public Health*. 27(1):1–5. doi.org/10.1080/09581596.2016.1254178.

Kirkby, P. (1999). A guide to actively involving young people in research: For researchers, research commissioners, and managers. INVOLVE support

project. Available from: https://www.invo.org.uk/wp-content/uploads/2012/01/InvolvingYoungPeople2004.pdf
Koen, J, Wassenaar, D & Mamotte, N. (2017). The 'over-researched community': An ethics analysis of stakeholder views at two South African HIV prevention research sites. *Social Science and Medicine*. 194(October):1–9. doi.org/10.1016/j.socscimed.2017.10.005.
Lafrenière, D, Menuz, V, Hurlimann, T et al. (2013). Knowledge dissemination interventions: A literature review. *SAGE Open*. 3(3):1–14. doi.org/10.1177/2158244013498242.
Lairumbi, GM, Michale, P, Fitzpatrick, R et al. (2011). Ethics in practice: The state of the debate on promoting the social value of global health research in resource poor settings particularly Africa. *BMC Medical Ethics*. 12. Available from: https://bmcmedethics.biomedcentral.com/articles/10.1186/1472-6939-12-22.
Lavery, J V., Tinadana, PO, Scott, TW et al. (2010). Towards a framework for community engagement in global health research. *Trends in Parasitology*. 26(6):279–283. doi.org/10.1016/j.pt.2010.02.009.
Lavis, JN, Lomas, J, Hamid, M et al. (2006). Assessing country-level efforts to link research to action. *Bulletin of the World Health Organization*. 84(8):620–628. doi.org/10.2471/BLT.06.030312.
Levine, P. (2007). Collective action, civic engagement, and the knowledge commons. In: Understanding knowledge as a commons from theory to practice. 247–275.
Levine, P. (2011). Seeing like a citizen: The contributions of Elinor Ostrom to "Civic Studies". *The Good Society*. 20(1):3–14. doi.org/10.1353/gso.2011.0010.
Lin, CY, Loyola-Sanchez, A, Hurd, K et al. (2018). Characterization of indigenous community engagement in arthritis studies conducted in Canada, United States of America, Australia and New Zealand. *Seminars in Arthritis and Rheumatism.* doi.org/10.1016/j.semarthrit.2018.11.009.
Lippman, SA, Leddy, AM, Neilands, TB et al. (2018). 'Context matters: Community social cohesion and health behaviors in two South African areas.' *Health & Place*. 50(December 2017):98–104. doi: https://doi.org/10.1016/j.healthplace.2017.12.009.
Lister, PG & Crisp, BR. (2007). Critical incident analyses: A practice learning tool for students and practitioners. *Practice.* 19(1):47–60. doi.org/10.1080/09503150701220507.
MacQueen, KM, Harlan, S V., Slevin, KW et al. (2012). Stakeholder engagement toolkit for HIV prevention trials. FHI360. Available from: www.fhi360/hivstakeholder.
MacQueen, KM, Bhan, A, Frohlich, J et al. (2015). Evaluating community engagement in global health research: the need for metrics. *BMC Medical Ethics*. 16(1):44. doi.org/10.1186/s12910-015-0033-9.
Madhavan, S, Collinson, M, Townsend, NW et al. (2007). The implications of long term community involvement for the production and circulation of population

knowledge. *Demographic Research*. 17(13). doi.org/10.4054/DemRes.2007.17.13.
Margaret Mead. (1984). Available from: https://en.wikiquote.org/wiki/Margaret_Mead (accessed 24 October 2018).
Marsh, V, Kamuya, D, Rowa, Y et al. (2008). Beginning community engagement at a busy biomedical research programme: Experiences from the KEMRI CGMRC-Wellcome Trust Research Programme, Kilifi, Kenya. *Social Science & Medicine*. 67(1982):721–733.
Marsh, VM, Kamuya, DK, Parker, MJ et al. (2011). Working with concepts: The role of community in international collaborative biomedical research. Public Health Ethics. 4(1):26–39. doi.org/10.1093/phe/phr007.
Marshall, PA & Rotimi, C. (2001). Ethical challenges in Uganda. *The American Journal of the Medical Sciences*. 322(5):241–245.
McElfish, PA, Purvis, RS & Long, CR. (2018). Researchers' experiences with and perceptions of returning results to participants: Study protocol. *Contemporary Clinical Trials Communications*. 11(June):95–98. doi.org/10.1016/j.conctc.2018.06.005.
Meyer, M. (2010). The rise of the knowledge broker. *Science Communication*. 32 (1), pp.118-127. <10.1177/1075547009359797>. <hal-00493794>
Molyneux, S & Bull, S. (2013). Consent and community engagement in diverse research contexts: Reviewing and developing research and practice. *Journal of Empirical Research on Human Research Ethics*. 8(4):1–18. doi.org/10.1525/jer.2013.8.4.1.
Molyneux, C, Goudge, J, Russell, S et al. (2009). Conducting health - related social science research in low income settings: ethical dilemmas faced in Kenya and South Africa. *Journal of International Development*. 21(2):309–326.
Molyneux, CS, Peshu, N & Marsh, K. (2004). Understanding of informed consent in a low-income setting: Three case studies from the Kenyan coast. *Social Science and Medicine*. 59(12):2547–2559. doi.org/10.1016/j.socscimed.2004.03.037.
Molyneux, CS, Peshu, N & Marsh, K. (2005). Trust and informed consent: Insights from community members on the Kenyan coast. *Social Science and Medicine*. 61(7):1463–1473. doi.org/10.1016/j.socscimed.2004.11.073.
Molyneux, S, Mulupi, S, Mbaabu, L et al. (2012). Benefits and payments for research participants: Experiences and views from a research centre on the Kenyan coast. *BMC Medical Ethics*. 13(1):1. doi.org/10.1186/1472-6939-13-13.
Molyneux, S, Kamuya, D, Madiega, PA et al. (2013). Field Workers at the Interface. *Developing World Bioethics*. 13(1). doi.org/10.1111/dewb.12027.
Mondain, N. (2013). Exploring respondents' understanding and perceptions of demographic surveillance systems in Western Africa: methodological and ethical issues. *African Population Studies*. 24(3):149–165. Available from: http://aps.journals.ac.za/pub/article/view/297/261.
Mondain, N, Delaunay, V & Ouédraogo, V. (2016). Reporting results back in health and demographic surveillance systems (HDSS): an ethical requirement and

a strategy for improving health behaviours. *African Population Studies.* Vol. 30, No. 2, (Supp.).
Montgomery, CM & Pool, R. (2017). From 'trial community' to 'experimental publics': how clinical research shapes public participation. *Critical Public Health*. 27(1):50–62. doi.org/10.1080/09581596.2016.1212161.
Moodley, K, Sibanda, N, February et al. (2014). "It's my blood": ethical complexities in the use, storage and export of biological samples: perspectives from South African research participants. *BMC Medical Ethics*. 15:4. http://www.biomedcentral.com/1472-6939/15/4
Morgan, D & Krueger, R. (1993). When to use focus groups and why. In: Successful focus groups: Advancing the state of the art. Morgan D.L, Ed. Thousand Oaks, CA: SAGE Publications. 3–19. Available from: doi: 10.4135/9781483349008.
Murphy, J, Scott, J, Kaufman, D et al. (2008). Public expectations for return of results from large-cohort genetic research. *American Journal of Bioethics*. 8(11):36–43. doi.org/10.1080/15265160802513093.
Nakibinge, S, Maher, D, Katende, J et al. (2009). Community engagement in health research: Two decades of experience from a research project on HIV in rural Uganda. *Tropical Medicine and International Health*. 14(2):190–195. doi.org/10.1111/j.1365-3156.2008.02207.x.
The National Institute for Health Research UK. (2015). Going the extra mile. Available from: https://www.nihr.ac.uk/patients-and-public/documents/Going-the-Extra-Mile.pdf.
Norris, SA, Anuar, H, Matzen, P et al. (2014). The life and health challenges of young Malaysian couples: results from a stakeholder consensus and engagement study to support non-communicable disease prevention. *BMC public health*. 14(Suppl 2):S6. Available from: http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed12&NEWS=N&AN=25080995.
Nuffield Council on Bioethics. (2005). Research related to healthcare in developing countries. ISBN 1-904384-06-4. doi.org/10.1017/CBO9781107415324.004.
Ostrom, E. (2005). Understanding Institutional Diversity. Princeton University Press.
Paradis, E & Varpio, L. (2018). Difficult but important questions about the ethics of qualitative research. *Perspectives on Medical Education*. 7:65–66. doi.org/10.1007/s40037-018-0414-0.
Participants in the 2001 Conference on Ethical Aspects of Research in Developing Countries. (2002). Fair Benefits for Research in Developing Countries. *Science*. 298(December):64–65. doi.org/10.1126/science.1076899.
Pettifor, A, Lippman, SA, Selin, AM et al. (2015). A cluster randomized-controlled trial of a community mobilization intervention to change gender norms and reduce HIV risk in rural South Africa: study design and intervention. *BMC Public Health.* 15(1):1–7. doi.org/10.1186/s12889-015-2048-z.
Pettifor, A, MacPhail, C, Hughes, JP et al. (2016). The effect of a conditional cash transfer on HIV incidence in young women in rural South Africa (HPTN 068):

a phase 3, randomised controlled trial. *The Lancet Global Health*. 4(12):e978–e988. doi.org/10.1016/S2214-109X(16)30253-4.

Polzer, T. (2008). Invisible integration: How bureaucratic, academic and social categories obscure integrated refugees. *Journal of Refugee Studies.* 21(4):476–497. doi.org/10.1093/jrs/fen038.

Pratt, B & de Vries, J. (2018). Community engagement in global health research that advances health equity. *Bioethics*. 32(7):454–463. doi.org/10.1111/bioe.12465.

Rennie, S & Sugarman, J. (2009). HIV Prevention Trials Network Ethics Guidance for Research. 1–50. Available from: http://www.hptn.org/web documents/EWG/HPTNEthicsGuidance020310.pdf.

Reynolds, L & Sariola, S. (2018). The ethics and politics of community engagement in global health research. *Critical Public Health.* 28(3):257–268. doi.org/10.1080/09581596.2018.1449598.

Ritchken, E. (1995). Leadership and conflict in Bushbuckridge: Struggles to define moral economies within the context of rapidly transforming political economies. PhD thesis. University of the Witwatersrand.

Sankoh, O & Byass, P. (2012). The INDEPTH network: Filling vital gaps in global epidemiology. *International Journal of Epidemiology*. 41(3):579–588. doi.org/10.1093/ije/dys081.

Schlierf, K & Meyer, M. (2013). Situating knowledge intermediation: Insights from science shops and knowledge brokers. *Science and Public Policy.* 40(4):430–441. doi.org/10.1093/scipol/sct034.

Schmidt, RC. (1997). Managing Delphi surveys using nonparametric statistical techniques. *Decision Sciences*. 28(3):763–774.

Shalowitz, DI & Miller, FG. (2005). Implications of respect for participants. *Journal of The American Medical Association*. 294(6):737–740. doi.org/10.1001/jama.294.6.737.

Simwinga, M, Bond, V, Makola, N et al. (2016). Implementing community engagement for combination prevention: Lessons learnt from the first year of the HPTN 071 (PopART) Community-Randomized study. *Current HIV/AIDS Reports*. 13(4):194–201. doi.org/10.1007/s11904-016-0322-z.

Simwinga, M, Porter, J & Bond, V. (2018). Who is answerable to whom? Exploring the complex relationship between researchers, community and Community Advisory Board (CAB) members in two research studies in Zambia. *Critical Public Health*. 28(3):318–328. doi.org/10.1080/09581596.2018.1440072.

South African Department of Health. (2007). Guidelines for Good Practice in the Conduct of Clinical Trial. 1–72. Available from: http://www.doh.gov.za/docs/policy/trials/trials-full.html.

Stadler, J. (2003). Rumor, gossip and blame: Implications for HIV/AIDS prevention in the South African lowveld. *AIDS Education and Prevention*. 15(4):357–368. doi.org/10.1521/aeap.15.5.357.23823.

Stadler, J & Saethre, E. (2011). Rumours about blood and reimbursements in a microbicide gel trial. *African Journal of AIDS Research*. 9(4):345–353. doi.org/10.2989/16085906.2010.545636.

Tekola, F, Bull, SJ, Farsides, B et al. (2009). Tailoring consent to context: Designing an appropriate consent process for a biomedical study in a low income setting. *PLoS Neglected Tropical Diseases*. 3(7). doi.org/10.1371/journal.pntd.0000482.

Terry, RF, Littler, K, Olliaro, PL et al. (2018). Sharing health research data – the role of funders in improving the impact [version 1; referees : 3 approved with reservations]. *F1000Research*, 7:1641

The National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research. (1979). The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research. Washington D.C.

Theobald, S, Tulloch, O, Crichton, J et al. (2011). Strengthening the research to policy and practice interface: Exploring strategies used by research organisations working on sexual and reproductive health and HIV/AIDS*. Health Research Policy and Systems*. 9(SUPPL.1):S2. doi.org/10.1186/1478-4505-9-S1-S2.

Thorogood, M, Goudge, J, Bertram, M et al. (2014). The Nkateko health service trial to improve hypertension management in rural South Africa: Study protocol for a randomised controlled trial. *Trials*. 15(1):1–9. doi.org/10.1186/1745-6215-15-435.

Tindana, P, De Vries, J, Campbell, M et al. (2015). Community engagement strategies for genomic studies in Africa: A review of the literature*. BMC Medical Ethics*. 16(1):1–12. doi.org/10.1186/s12910-015-0014-z.

Tindana, PO, Singh, JA, Tracy, CS et al. (2007). Grand Challenges in Global Health: Community Engagement in Research in Developing Countries. *PLoS Medicine*. 4(9):e273. doi.org/10.1371/journal.pmed.0040273.

Tindana, PO, Rozmovits, L, Boulanger, RF et al. (2011). Aligning community engagement with traditional authority structures in global health research: A case study from Northern Ghana. *American Journal of Public Health*. 101(10):1857–1867. doi.org/10.2105/AJPH.2011.300203.

Tollman, S. (2001). Fair partnerships support ethical research. *British Medical Journal*. (Compat Ed.). 323(7326):1417–1419.

Tollman, SM. (2008). Closing the Gap. PhD Thesis. Umea University. doi.org/10.1007/978-1-4471-4516-5.

Tollman, SM & Zwi, AB. (2000). Health system reform and the role of field sites based upon demographic and health surveillance. *Bulletin of the World Health Organization*. 78(1):125–134. doi.org/10.1590/S0042-96862000000100019.

Tollman, SM, Herbst, K, Garenne, M et al. (1999). The Agincourt demographic and health study - Site description, baseline findings and implications. *South African Medical Journal*. 89(8):858–864.

Tollman, SM, Kahn, K, Sartorius, B et al. (2008). Implications of mortality transition for primary health care in rural South Africa: a population-based surveillance study. *The Lancet*. 372(9642):893–901. doi.org/10.1016/S0140-6736(08)61399-9.

Tollman, S. (2017). Medical Research Council / University of the Witwatersrand Rural public health and health transitions research unit- the Agincourt unit. Director's report.

Tritter, JQ & McCallum, A. (2006). The snakes and ladders of user involvement: Moving beyond Arnstein. *Health Policy.* 76(2):156–168. doi.org/10.1016/j.healthpol.2005.05.008.

Twine, W & Hunter, LM. (2011). Adult mortality and household food security in rural South Africa: Does AIDS represent a unique mortality shock? *Development Southern Africa*. 28(4):431–444. doi.org/10.1080/0376835X.2011.605559.

Twine, R, Kahn, K, Scholtz, A & Norris, SA. (2016). Involvement of stakeholders in determining health priorities of adolescents in rural South Africa. *Global Health Action*. 9(1):1–9. doi.org/10.3402/gha.v9.29162.

Twine, R, Kahn, K & Lewando Hundt, G. (2017a). Assessing the effectiveness of a longitudinal knowledge dissemination intervention: Sharing research findings in rural South Africa. *Gateways: International Journal of Community Research and Engagement*. 10:143. doi.org/10.5130/ijcre.v10i1.5111.

Twine, R, Hundt, GL & Kahn., K (2019). Dilemmas in Ethics in practice in a Longitudinal Health Surveillance Site: identifying opportunities for widening participation of residents. *Frontiers in Sociology.* 4:33. doi:10.3389/fsoc.2019.00033.

Twine, R, Lewando Hundt, G & Kahn, K. (2017b). The 'experimental public' in longitudinal health research: views of local leaders and service providers in rural South Africa. *Global Health Research and Policy*. 2(1):26. doi.org/10.1186/s41256-017-0046-7.

UK National Institute for Health Research. (2014). Patient and public involvement in health and social care research: A handbook for researchers. Available from: https://www.rds-eastmidlands.nihr.ac.uk/resources/RDS_PPI Handbook_2014_v6 FINAL.pdf.

UNAIDS/WHO. (2007). Ethical considerations in biomedical HIV prevention trials. Geneva: WHO/UNAIDS.

Upshur, REG, Lavery, J V. & Tindana, PO. (2007). Taking tissue seriously means taking communities seriously. *BMC Medical Ethics.* 8:1–6. doi.org/10.1186/1472-6939-8-11.

Wagner, RG, Ngugi, AK, Twine, R et al. (2014). Prevalence and risk factors for active convulsive epilepsy in rural northeast South Africa. *Epilepsy Research*. 108(4):782–791. doi.org/10.1016/j.eplepsyres.2014.01.004.

Wariri, O, D'Ambruoso, L, Twine, R et al. (2017). Initiating a participatory action research process in the Agincourt health and socio–demographic surveillance site. *Journal of Global Health*. 7(1). doi.org/10.7189/jogh.07.010413.

Woolley, JP, McGowan, ML, Teare, HJA et al. (2016). Citizen science or scientific citizenship? Disentangling the uses of public engagement rhetoric in national research initiatives*. BMC Medical Ethics*. 17(1):1–17. doi.org/10.1186/s12910-016-0117-1.

Ye, Y, Wamukoya, M, Ezeh, A et al. (2012). Health and demographic surveillance systems: A step towards full civil registration and vital statistics system in sub-Sahara Africa? *BMC Public Health*. 12(1):1. doi.org/10.1186/1471-2458-12-741.

Yin, RK. (2014). Case Study Research Design and Methods. 5th ed. Thousand Oaks, CA.

Zong, Z. (2008). Should post-trial provision of beneficial experimental interventions be mandatory in developing countries? *Journal of Medical Ethics*. 34(3):188–192. doi.org/10.1136/jme.2006.018754.

APPENDIX A: Topic guides for semi-structured individual, natural and focus group interview

STUDY TITLE: EXTENT AND TYPE OF KNOWLEDGE TRANSFER AND EXPERIENCE OF RESEARCH OF COMMUNITIES LIVING IN A LONGITUDINAL HEALTH RESEARCH STUDY AREA

Interviewer script: I want to thank you for taking the time to meet with me today. My name is Rhian Twine and I am from the MRC/Wits Agincourt Unit.

I'd like to talk with you about your experiences as someone who has participated in the community feedback and other research activities of the MRC/Wits Agincourt Unit. The first aim of this study is to find out wether the way that we share of research results with community stakeholders in the Agincourt health and socio-demographic surveillance system (HDSS) is working. The second aim is to study the experience, knowledge and understanding of community leadership, public sector stakeholders and political leadership who live and work in an area where health and population research has been going on for over 20 years concerning participation in research activities in the study area. We will talk about the way that the MRC/Wits Agincourt Unit interacts now and in the past with the community and the service providers who live in the Agincourt study area. We hope that in the end we can identify more strategies and methods of public engagement. Please remember that there are no 'right' or 'wrong' answers to any of the questions.

General information – fill in for each participant

#	Question	Format
1.	Gender	1 Male 2 Female
2.	Organisation or government/community office respondent representing	

Main questions	*Elaborative questions*
Theme one: The work of the MRC/Wits Agincourt Unit	
1. Please describe the work that the MRC/Wits Agincourt unit is doing in the villages in which it works?	– *What research does the unit mainly focus on?*

2. What do you like or dislike about the work that Wits is doing in these villages?	– *Can you describe at least one research project that is currently underway in the MRC/Wits Agincourt Unit?* – *Do you know of any other current research projects?* – *What is the longest running research project that the unit runs?*
Theme two: Involvement with MRC/Wits Agincourt Unit	
3. Please describe how the MRC/Wits Agincourt unit involves you in its work?	– *Do you ever get invited to events organised by the unit – describe* – *Do you feel that you can influence the research done by the Agincourt unit/ How?* – *Would you like to be more involved and if so, how* – *Do you think that if you were more involved then there would be more benefit for the community? If yes or no, then how*
4. Think back a few years – has the way that the MRC/Wits Unit worked with you changed in any way?	— *What events do you remember attending that was organised by the MRC/Wits Agincourt unit* — *Have you ever been able to influence the way that the unit did its work in the past?*
Theme three: Benefits from working with the Wits Agincourt Unit	
4. Has your community benefitted from the work of the MRC/Wits Agincourt Unit in any way and if so, how? 5. Describe any challenges you or your community experienced because of the work that Wits does? 6. Have you ever asked the unit for any assistance and if yes – for what and did the unit help? 7. How has the work that Wits does changed your community?	—

8. Villages outside the study area often ask us to be included in the study area – why do you think they want to be in the study area? (Perceived vs real benefits)	– *Do you think villages outside see benefits that are not true - describe*
Theme four: Experience of the community research results feedback programme of the MRC/Wits Agincourt Unit	
10How do the research participants and the CDF/Traditional Council/Ward Councillor/Municipality/Clinic staff/Home Based Care Organisation get feedback about the results of the research that is done in these villages?	– *Where did you last hear about any results from the unit?* – *Can you describe how the research feedback event was organised?* – *Have you ever received any written research feedback from the unit?* – *Can you describe the written research feedback?*
11Has the information you have received from the MRC/Wits Agincourt Unit been useful to you as CDF/Traditional Council/Ward Councillor/Municipality/Clinic staff/Home Based Care Organisation	— *Do the research participants and CDF/Traditional Council/Ward Councillor/Municipality/Clinic staff/Home Based Care Organisation ever use this information (more than just giving it to for e.g. the WC) – please describe all instances.* Probe for both the research participant/s and the particular respondent/s you are interviewing points of view. – *Who else do you think we should present this information to?* — *Where is the file/handouts we gave you last year?*
12How can we improve the way we give research result feedback?	– *Who are the best people to attend these meetings – probe for both village and the particular change agent you are interviewing?* – *How often should we give this information?* – *Is there information you think we should be giving you that we do not?* — *Is there a different way that we need to present or give this information to the CDF/Traditional Council/Ward Councillor/Municipality/Clinic*

	staff/Home Based Care Organisation organizations?
Theme five: Additional information	
13Do you have any other comments about the MRC/Wits Agincourt Unit and the work that it does?	

APPENDIX B: Ethics certificates

R14/49 Ms Rhian Twine et al

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M140361

NAME: (Principal Investigator)	Ms Rhian Twine et al
DEPARTMENT:	School of Public Health MRC/Wits Rural Public Health Transitions Research Units Agincourt
Health	Bushbuckridge, Mpumalanga Province
PROJECT TITLE:	Public engagement throughout the research process in a health and socio-demographic surveillance site in rural South Africa
DATE CONSIDERED:	28/03/2014
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	
APPROVED BY:	Professor PE Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	09/04/2014

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**.

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

MPUMALANGA PROVINCIAL GOVERNMENT

Building No.3
No. 7 Government Boulevard
Riverside Park Extension 2
Nelspruit
1200
Republic of South Africa

Private Bag X 11285
Nelspruit, 1200
Tel: 013 766 3429
int: +27 13 766 3429
Fax: 013 766 3458
int: +27 13 766 3458

Department of Health

Litiko Letemphilo | Umnyango WezaMaphilo | Departement van Gesondheid

Enquiries: Themba Mulungo (013) 766 3511

03 March 2014

Ms. Rhian Twine
P.O. Box 2
ACORNHOEK
1360
South Africa

PUBLIC ENGAGEMENT THROUGHOUT THE RESEARCH PROCESS IN A HEALTH AND SOCIO-DEMOGRAPHIC SURVEILLANCE SITE IN RURAL SOUTH AFRICA

1. The request for provincial support **[not financially]** in relation to the above-mentioned research is hereby approved in principle, provided that you supply the Department of Health with your ethical clearance from the WITS University

2. The onus lies with the researcher to seek approval from the above-mentioned institution

Please do not hesitate to call should you require additional assistance

Kind regards

MPUMALANGA PROVINCE
DEPARTMENT OF HEALTH
PLANNING & INFORMATION
2014 -03- 03
PRIVATE BAG X 11285
NELSPRUIT 1200

MR. MOLEFE MACHABA
RESEARCH AND EPIDEMIOLOGY

03/03/2014
DATE

Siyanakekela

MPUMALANGA
A Pioneering Spirit

APPLICATION TO CONDUCT RESEARCH STUDY FOR RHIAN TWINE

education
DEPARTMENT: EDUCATION
MPUMALANGA PROVINCE

Private Bag X 11341
Nelspruit 1200
Government Boulevard
Riverside Park
Building 5
Mpumalanga Province
Republic of South Africa

Litiko leTemfundvo Umnyango weFundo Departement van Onderwys Umnyango wezeMfundo
Enquiries: H.A. Baloyi (013) 766 5476

MS RHIAN TWINE
AGINCOURT HEALTH & POPULATION UNIT
P.O. BOX 2
ACCORNHOEK
1360

RE: APPLICATION TO CONDUCT RESEARCH: MS RHIAN TWINE

Your application to conduct research was received on the 28 February 2014. The title of your study reads: "Public engagement in a health and socio-demographic surveillance site in rural South Africa." Although the aims and objectives of your study do not speak to the education sector challenges, the outcome of the study will indirectly affect and impact our education environment. Your request is approved subject to you observing the provisions of the departmental research manual which is attached. You are also requested to adhere to your University's research ethics as spelt out in your research ethics document.

In terms of the attached manual (2.2. bullet number 4 & 6) data or any research activity can only be conducted after school hours as per appointment. You are also requested to share your findings with the relevant sections of the department so that we may consider implementing your findings if that will be in the best interest of department.

For more information kindly liaise with the department's research unit @ 013 766 5476 or a.baloyi@education.mpu.gov.za.

The department wishes you well in this important project and pledges to give you the necessary support you may need.

Sisonke Sifundzisa Sive

MPUMALANGA
A Pioneering Spirit

APPLICATION TO CONDUCT RESEARCH STUDY FOR RHIAN TWINE

APPROVED/NOTAPPROVED:

MRS MOC MHLABANE
HEAD OF DEPARTMENT
2 3, 14
DATE

APPENDIX C: Published papers

Paper 1

Global Health Action

ORIGINAL ARTICLE

Involvement of stakeholders in determining health priorities of adolescents in rural South Africa

Rhian Twine[1]*, Kathleen Kahn[1,2,3], Alexandra Scholtz[1,4] and Shane A. Norris[5]

[1]MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt), School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; [2]Umeå Centre for Global Health Research, Epidemiology and Global Health Unit, Department of Public Health and Clinical Medicine, Umeå University, Umeå, Sweden; [3]INDEPTH Network, Accra, Ghana; [4]F. Hoffmann-La Roche AG, Basel, Switzerland; [5]MRC/Wits Developmental Pathways for Health Research Unit, Department of Paediatrics, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa

Background: When developing intervention research, it is important to explore issues from the community perspective. Interventions that promote adolescent health in South Africa are urgently needed, and Project Ntshembo ('hope') aims to improve the health of young women and their offspring in the Agincourt sub-district of rural northeast South Africa, actively using stakeholder involvement throughout the research process.
Objective: This study aimed to determine adolescent health priorities according to key stakeholders, to align stakeholder and researcher priorities, and to form a stakeholder forum, which would be active throughout the intervention.
Design: Thirty-two stakeholders were purposefully identified as community members interested in the health of adolescents. An adapted Delphi incorporating face-to-face discussions, as well as participatory visualisation, was used in a series of three workshops. Consensus was determined through non-parametric analysis.
Results: Stakeholders and researchers agreed that peer pressure and lack of information, or having information but not acting on it, were the root causes of adolescent health problems. Pregnancy, HIV, school dropout, alcohol and drug abuse, not accessing health services, and unhealthy lifestyle (leading to obesity) were identified as priority adolescent health issues. A diagram was developed showing how these eight priorities relate to one another, which was useful in the development of the intervention. A stakeholder forum was founded, comprising 12 of the stakeholders involved in the stakeholder involvement process.
Conclusions: The process brought researchers and stakeholders to consensus on the most important health issues facing adolescents, and a stakeholder forum was developed within which to address the issues. Stakeholder involvement as part of a research engagement strategy can be of mutual benefit to the researchers and the community in which the research is taking place.

Keywords: *stakeholder involvement*; *stakeholder*; *adolescents*; *health priorities*; *Delphi*

Responsible Editor: Diana Gil-Gonzalez, University of Alicante, Spain.

*Correspondence to: Rhian Twine, MRC/Wits Agincourt Unit, PO Box 2, Acornhoek 1360, South Africa, Email: Rhian.Twine@wits.ac.za

Received: 15 July 2015; Revised: 15 December 2015; Accepted: 21 December 2015; Published: 15 March 2016

Paper context

To inform an intervention addressing health problems facing adolescents in rural South Africa, we involved lay and professional stakeholders. Three workshops brought researchers and stakeholders to consensus, using the Delphi method and participatory visualisation, on the most important issues facing adolescents, and a stakeholder forum was formed. It was agreed that intervention needs to focus on behavioural change and improving health literacy. As the intervention goes ahead, there will be continuous involvement of the stakeholder forum.

Background

Although there is a growing literature on stakeholder involvement in health research (1, 2), there is still a need for literature describing the *how* and effects of such involvement (3). This paper describes one step in a process of stakeholder involvement, using a variety of adapted

Global Health Action 2016. © 2016 Rhian Twine et al. This is an Open Access article distributed under the terms of the Creative Commons Attribution 4.0 International License (http://creativecommons.org/licenses/by/4.0/), allowing third parties to copy and redistribute the material in any medium or format and to remix, transform, and build upon the material for any purpose, even commercially, provided the original work is properly cited and states its license.

Citation: Glob Health Action 2016, **9**: 29162 - http://dx.doi.org/10.3402/gha.v9.29162

methods that aimed to achieve consensus between researchers and professional and lay stakeholders regarding the health priorities of adolescents in a rural area of South Africa.

Almost one in five persons in the world is an adolescent, totalling 1.2 billion people ages 10–19 years globally. The state of their health is important for their lives now and in the future, and young women's health will impact on the next generation (4). There is increasing evidence that risk profiles developed during adolescence – including poor eating habits and lack of physical exercise, resulting in obesity – can lead to chronic non-communicable diseases later in life (5). Sub-Saharan African populations have the fastest growing proportion of adolescents, coupled with the worst regional adolescent health profile (6).

Among South African adolescents, the percentage of overweight female adolescents increased from 24.3% in 2002 to 29.0% in 2008, while female obesity rose from 5.0 to 7.5% over the same period (7). In rural South Africa, levels of female adolescent overweight and obesity reached a prevalence of 25% at 18 years of age (8), while high levels of stunting persisted in childhood (9). In South Africa, 27.3% of women under the age of 20 years nationally reported already having a child, and there was an HIV prevalence of 5.5% in females aged 15–19 years (10). These results indicate that South Africa, both urban and rural, is well into the epidemiologic transition, confronting increasing risk of non-communicable disease while simultaneously dealing with infectious diseases, especially the HIV epidemic (11).

Given the importance of adolescent health for future adult health, adolescence may offer a unique window of opportunity to intervene and positively impact on individuals' health trajectories into adulthood (5). Consequently, we are developing a community-based intervention to optimise the health of young women in South Africa. Project Ntshembo, meaning 'hope' in the local Tsonga language, plans to create a continuum of care-seeking and self-care behaviour from pre-pregnancy through pregnancy, childbirth, and infancy.

There is a growing awareness of the importance of taking into account perspectives and experiences of people other than researchers in determining the relevance of research and uptake of its results (12). Participating populations and their local service providers understand the relevance of research to their communities (13) and can be involved as stakeholders in research projects, assisting in ensuring the respect, empowerment, and protection of populations making up research participants (14).

An essential and early stage in the development of the Project Ntshembo intervention is to understand health priorities from the perspective of the community where the intervention will be delivered and evaluated. We therefore defined a series of stakeholder involvement activities for the duration of the planned project, as follows.

Project start-up: Involving stakeholders at this stage should help shape the research agenda. The aim is to discuss issues sufficiently so that all stakeholders perceive the issue as important and to gain consensus about health priorities for adolescents. This ensures that stakeholders are on board in appreciating the pertinence of the research.

Preliminary findings: Sharing preliminary findings with stakeholders not only increases awareness but can tease out issues, helping to shape, refine, and ensure that later stages of intervention development are targeted appropriately.

Project progression: Through ongoing involvement during research progress, stakeholders can assist with problem-solving, for example by contributing ideas to improve cohort retention or adherence to intervention strategies.

Project end: If stakeholder involvement has been effective, such stakeholders could become, or engage with, policy 'champions' to act on research findings – potentially enabling the outputs to be used more widely and have greater impact.

Beyond the project: If the intervention proves effective or lessons learnt are important, the dynamic should shift to policy champions and stakeholders using the researchers as stakeholders while they endeavour to implement policy changes (15).

The aim of this paper is to describe stakeholder involvement in the start-up phase of Project Ntshembo, specifically to gain consensus on the priority health needs of adolescents in rural areas of South Africa, using an adapted Delphi technique; to align stakeholder- and researcher-identified priority health needs of adolescents using participatory visualisation; and to establish a stakeholder forum.

Methods

Study setting

This study took place in the Agincourt health and socio-demographic surveillance system (HDSS) site, which has been run by the Medical Research Council/Wits University Rural Public Health and Health Transitions Research Unit since 1992. The site covers 420 km^2 in the Agincourt sub-district of rural north-east South Africa, Mpumalanga Province, 500 km from Johannesburg, with the Kruger National Park on its eastern border. The area is representative of rural areas of South Africa in that it fits into one of two definitions of *rural* appearing in the *Comprehensive Rural Development Framework Version 1 July 2009* – settlements in the former apartheid homelands, with no major economic base apart from migrant labour and remittances, typified by poverty and underdevelopment and where traditional authorities operate a land tenure system (16). In 2013, the population was 111,500 people in 18,500 households in 31 villages. Although some 30% of the sub-district population comprises former Mozambican refugees, over 80% of these people are now

Citation: Glob Health Action 2016, **9**: 29162 - http://dx.doi.org/10.3402/gha.v9.29162

South African permanent residents or citizens. From 2004, people holding permanent residence have been able to access all government services, and this ability has improved the livelihoods of the former Mozambican refugees and enabled their successful integration (17). Since 1994, the area has seen an increase in infrastructure development: prepaid electricity is now available in all villages, gravel roads are being tarred, and a programme of improving water provision is underway, albeit slowly. The quality of education is poor, although every village has at least one primary school and most have a high school. There are two health centres and six clinics within the Agincourt HDSS site, with three district hospitals 25–60 km away. A process of community engagement in research has evolved in this site over the years, with a dedicated LINC office (learning, information dissemination, and networking with the community) established in 1994. This office is responsible for community engagement and liaises closely with civic and traditional village leadership, as well as local service providers (18), resulting in relationships of mutual trust and respect.

Study design

In the first two of a series of three workshops (Fig. 1), we used an adapted Delphi technique and face-to-face discussions during workshops to determine stakeholder priorities on health needs of adolescents. The Delphi technique is a group facilitation technique that was developed as a research method to deal with opinions, not facts (19). The method seeks to obtain consensus on the opinions of 'experts' (referred to as *stakeholders* in this paper) through a number of sequential voting rounds, using anonymously completed questionnaires with the responses from each questionnaire fed back in summarised form to the experts. Additional rounds of voting are conducted until consensus is reached. Usually, the Delphi is conducted with groups of experts with similar levels of expertise, who do not know who the other participants are and who never actually meet. The most common method of conducting the Delphi is via post, email, or mobile phone (20). We adapted the Delphi in that some stakeholders knew each other, there were both lay and professional experts in the stakeholder group, and we held workshops where stakeholders came together for face-to-face discussion on results and for anonymous voting. Given the rural context, the LINC office considered the face-to-face format most suitable, since relying on post or email was not feasible. Although all stakeholders were literate, levels of literacy varied and discussion during the consensus process ensured that all stakeholders had the same understanding of the aims of the study. We used text messaging for voting between workshops. All activities were conducted in English.

Participants

There is no absolute consensus on what defines a community in any process of stakeholder involvement in research (13, 21). However, for work conducted by and with the LINC office, the community is defined as those individuals living in the Agincourt HDSS site who could be participants in the research or be affected by the research activities, as well as groups, organisations, and service providers who could be involved with, interested in, or affected by the research activities in the site.

Given that health is inextricably linked to a broad range of social determinants, inputs from various perspectives are needed to cover the range of health priorities of rural adolescents. The LINC office purposefully identified key individuals from the community interested in the health of adolescents who were already part of the LINC office network as stakeholders (research participants and their local service providers) for this study. A group of 32 diverse community members were invited to participate, including lay and professional stakeholders representing the following sectors: South African Department of Health (District), public health clinics, Department of Education (District), high school educators, local and district government, youth service providers, community leadership, African National Council (ANC) Youth League (this population predominantly supports the ANC, which was at the time

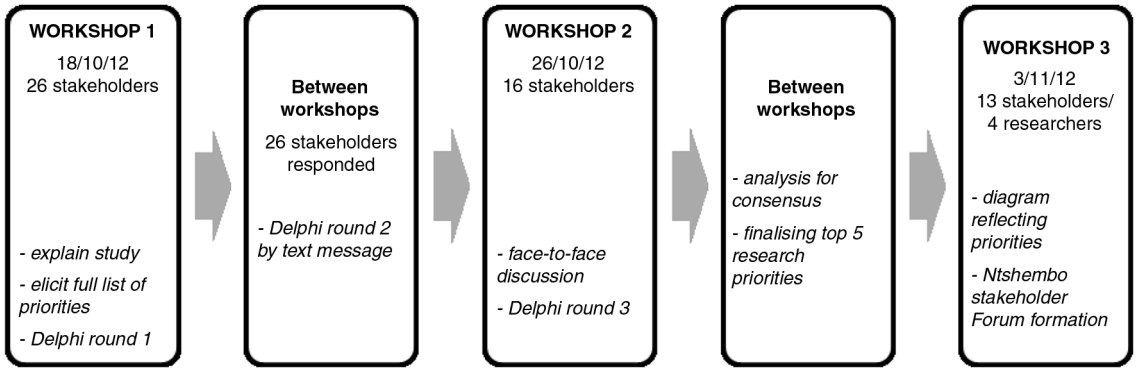


Fig. 1. Overview of study design.

the only political party with an active youth league in the area), MRC/Wits-Agincourt Unit Community Advisory Group, male and female adolescents, and parents.

Data collection

Determining stakeholder adolescent health priorities

The first workshop aimed to explain the study, describe the adapted Delphi technique, elicit a list of adolescent health priorities from the stakeholders, and conduct the first round of voting. Facilitators collected questionnaires listing adolescent health priorities that the stakeholders had previously completed and generated a full list of all issues mentioned in these questionnaires. Stakeholders were then asked to vote on what they individually thought were the top 10 health priorities from the full list in a secret ballot, ranking them from most to least important. Results were then collated and the top five adolescent health priorities were identified.

The top five priorities generated during Round 1 were sent by text message to each participant before the second workshop with detailed instructions to 1) validate the consolidated list of issues and 2) rank the priorities from the list. A ranked list was thus generated as Round 2.

As the final step in the Delphi process, we had to test consensus. Stakeholders attended a second workshop, where they were given the results from Round 2, divided into groups for discussion, and then asked to present their discussion points in a plenary. Finally, they were asked to individually re-rank the priorities in a secret ballot.

Data analysis determined that consensus was reached on the top five ranked adolescent health priorities based on the final vote conducted during the second workshop.

Aligning stakeholder and researcher priorities

Once stakeholder consensus on the top five adolescent health priorities was reached, a final workshop was conducted to engage stakeholders around the results of formative research relevant to Project Ntshembo that had recently been carried out in the site. Formative research was a critical first step to inform all aspects of intervention design (22). It focused on adolescent health and access to services (23); overweight and obesity (8); community beliefs and practices around adolescent health, pregnancy, delivery, and infant feeding (24); access to food and dietary choice (25); and attitudes and perceptions of young women regarding physical activity (26). This final workshop aimed to align stakeholder views with scientific evidence. Participatory visualisation (27) was used to generate a diagram (Fig. 2) showing the relationships between the two sets of priorities. In this technique, topics (in this case the two lists of priorities) are written onto separate pieces of paper, which can be stuck to a wall and moved around by any group member until their position shows their relationship to each other, to the agreement of all group members. Participatory visualisation

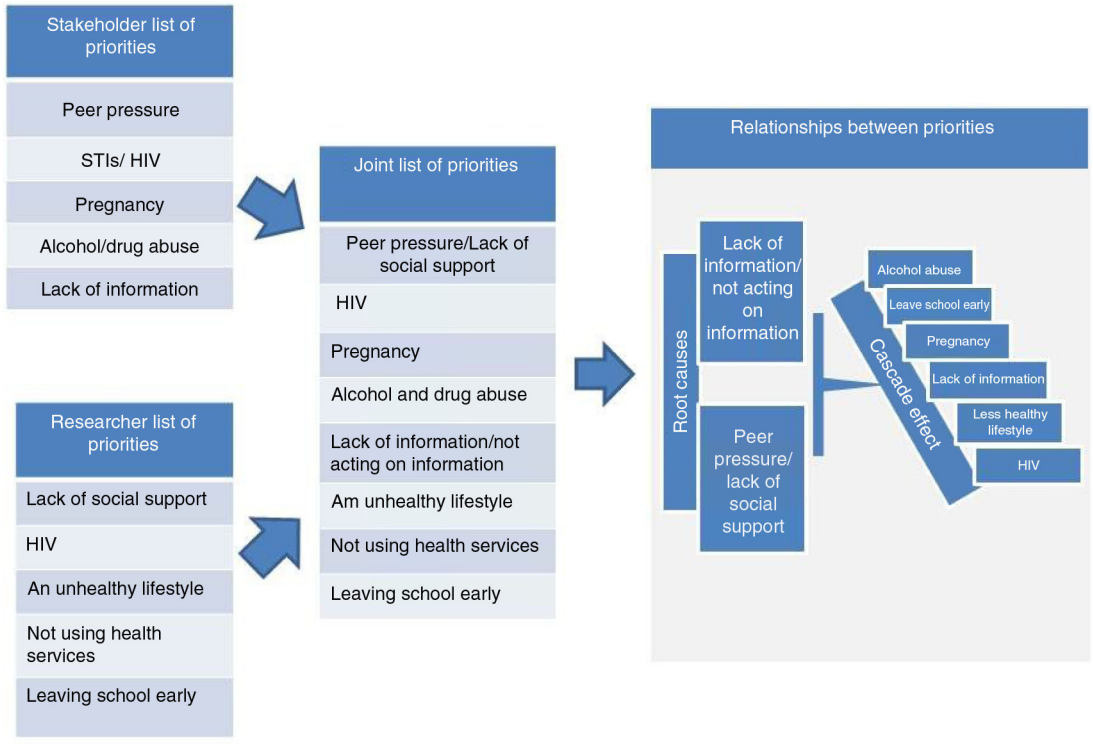


Fig. 2. Diagram showing the relationships between stakeholder and researcher adolescent health priorities.

Citation: Glob Health Action 2016, **9**: 29162 - http://dx.doi.org/10.3402/gha.v9.29162

ensures equal participation, produces a large number of ideas, and provides a sense of closure that is often not found in less structured group methods. Stakeholders and researchers were randomly allocated into four smaller groups to brainstorm on both sets of priorities. Each group reported back to the plenary. Further discussion was facilitated, and all group members were encouraged to move the priorities appearing on the papers around on the wall until agreement was reached. Finally, a diagram was developed showing the links between the main issues affecting adolescents in a rural area of South Africa. Field notes recording the discussions were taken, because the content of the discussions added depth to the description of the relationships between priorities.

Forming a stakeholder forum

Additionally, during the final workshop suitable candidates were identified to become members of the Ntshembo Stakeholder Forum. Stakeholders first discussed criteria for inclusion in the stakeholder forum and then nominated and voted for forum members. They also identified organisations in the area that already provided, or had the potential to provide, services to adolescents, with which the researchers could work during the intervention.

Ethics approval

Prior to study commencement, ethical approval was obtained from University of the Witwatersrand Human Research Ethics Committee (Medical) (certificate number M2120661), and written permission was obtained from the Mpumalanga Provincial Government Department of Education and Department of Health and Social Development, for their officials to be involved. Signed informed consent was obtained from all study participants.

Data analysis

When using Delphi, it is important to know when consensus has been reached so as to make the right decision about when to stop the voting process. We determined consensus through the use of non-parametric statistics, as proposed by Schmidt (19). Non-parametric analysis is statistical analysis used where the data do not need to fit a normal distribution and need to be ranked. The mean rank for each priority was calculated, taking into account the number of times it was voted for and its ranking, and consensus was assessed using the Kendall coefficient, W, in non-parametric analysis. A coefficient of 0.1 and under shows weak agreement, whereas 0.7 and above indicates strong agreement and that consensus has been reached (28). Values of 0.9 to 1.0 indicate unusually strong agreement.

Results

Adolescent health priorities identified by stakeholders

Fifty issues faced by adolescents were originally listed by stakeholders – ranging through health issues (e.g. HIV, pregnancy, obesity), social issues (e.g. peer pressure, uninvolved parents), moral issues (e.g. lack of spiritual education, cultural norms), community issues (e.g. lack of water, violence, poverty), and difficulties inherent in being an adolescent (e.g. hormones, attitudes). In the first round of voting, a list of 10 issues was prioritised, with five issues receiving 50% or more of the votes as shown in Table 1.

In the 7 days between the first and second workshops, these five issues were sent by text message to the stakeholders in random order and they were asked to confirm that these were the most important issues and rank them from most important to least important. All stakeholders

Table 1. Results of Rounds 1, 2, and 3 of the Delphi voting

Round 1		Round 2		Round 3	
Priority	% of stakeholders who voted for this issue	Priority	% of stakeholders who voted for this issue	Priority	Final ranked list
Peer pressure	65	Peer pressure	52	Peer pressure	1.03
Pregnancy	64	Pregnancy	40	STIs/HIV	2.66
Alcohol/drug abuse	51	STDs/HIV	44	Pregnancy	3.09
Lack of information	39	Lack of information	44	Alcohol/drug abuse	4
STIs/HIV	37	Alcohol/drug abuse	24	Lack of information	5
Crime	36				
Obesity	31				
Lack of respect/discipline	28				
Poverty	27				
Hormones	25				

STIs, sexually transmitted infections.

responded confirming that these five were the most important issues. The final ranking, shown in Table 1, followed voting at the end of the second workshop. At this stage, we tested consensus and because Kendall's coefficient (*W*) was 0.718 (strong consensus), we were able to accept this ranked list as the final result.

Peer pressure remained as the top priority throughout all voting rounds. Sexually transmitted infections (STIs) and HIV moved up in each consecutive round and finally ranked second. Pregnancy moved from second to third most important during the process, and alcohol/drug abuse and lack of information were finally ranked fourth and fifth.

Aligning stakeholder- and researcher-identified priority health needs of adolescents

At the final workshop, the researchers presented the top five adolescent health needs they had identified from previous formative research in the site, both published and unpublished. They were as follows, in no particular order: leaving school early, not using health services, leading an unhealthy lifestyle, lack of social support, and HIV.

Participatory visualisation brought the similar, but not identical, priorities of the researchers and stakeholders into a useful diagram (Fig. 2).

During deliberations, it was agreed by all participants (stakeholders and researchers) that two priorities could be joined between the stakeholders' and the researchers' lists, making a final list of eight priorities. More obviously, *HIV* from the stakeholders' list and *HIV/STIs* from the researchers' list were grouped as one priority. Less obviously, *lack of social support* from the researchers' list and *peer pressure* from the stakeholders' list were grouped as one. Stakeholders and researchers felt that behaviours encouraged through peer pressure could be discouraged if appropriate social support was available. As one stakeholder noted:

> Because of being poor, it is not only peers who force you, but the situation can lead to the family forcing you to do things.

During the plenary, stakeholders and researchers unanimously agreed that *peer pressure* and *lack of information or having information but not acting on it* were the root causes of all the other priorities, hence their position at the top of the diagram. In the words of one stakeholder:

> Lack of information (or not acting on information) starts it all. We need to take responsibility; otherwise you fall prey to peer pressure, and alcohol abuse, pregnancy, HIV follow.

Further discussion focused on how all of the priorities were linked, creating a 'crossover, cascade' effect. For example, lack of information and peer pressure were identified as clear links to possible pregnancy, which could cause adolescents to leave school early. Conversely, leaving school early could lead to lack of information as well as pregnancy.

Interestingly, there was not much discussion about HIV as a health priority among adolescents, although it was listed in the final eight priorities. Some discussion centred on a perception that young people seem to be more afraid of becoming pregnant than of contracting HIV and other STIs. Most of the discussion about HIV focused on adolescents not acting on information and not accessing health services.

> People know about HIV and how to prevent it – but they either ignore the information, or decide not to access the available health services.

This is another example of how the group felt that the priorities crossed over and caused cascades of problems.

Although obesity did not feature as one of the top eight topics, the group discussions identified that having an unhealthy lifestyle can be linked directly to obesity. Discussions around obesity centred on youth being lazy and watching too much television. This applied especially to young women, who no longer need to walk so far to fetch water and do not play football or other sports. Again, discussion linked this to lack of information, with one stakeholder noting that

> Not acting on information is linked to not having a healthy lifestyle. You know, but you don't act e.g. with nutrition and sport.

The conclusion of the discussion can be summed up by another quote from a stakeholder:

> The eight areas are very interlinked … lack of information is the core which starts the sequence of events.

Participants agreed that we had reached a stage of common understanding of the issues adolescents face in the area, and we were involved in jointly creating possible solutions to some of these issues.

Establishing a stakeholder forum

We were able to convene 26 stakeholders representing 12 constituencies. Attrition was 50% overall, with 13 stakeholders in the third and final workshop. Table 2 shows the breakdown of stakeholders at each workshop by age and sex.

Female participation was higher at all workshops except the final one. The ratio between younger and older participants was relatively even for all activities. Throughout the process of attending three workshops

Citation: Glob Health Action 2016, **9**: 29162 - http://dx.doi.org/10.3402/gha.v9.29162

Table 2. Participants at each stage

Activiy	Total	Male	Female	Aged under 30 years	Aged 30 years and over
Workshop 1	26	9	16	11	14
Text message voting	26	9	16	11	14
Workshop 2	16	4	11	7	8
Workshop 3	13	7	6	6	7

and voting via text message between workshops, stakeholders deliberated and actively engaged with each other and the researchers.

Attrition was high at 50% over the three workshops, with 35% ($n=9$) of participants coming to all three. Of the 31% ($n=8$) who came to two workshops, 15% ($n=4$) had genuine reasons for not attending the third, and 7% ($n=2$) sent a proxy to the third. For government officials, the main reason for not attending the second and third workshops was being called unexpectedly to meetings. For other community members, illness was a main reason for not attending the later workshops.

In the third workshop, stakeholders listed 14 organisations already working in the area that could be called upon by the stakeholder group and researchers to work with Project Ntshembo, ranging from eco-garden clubs in schools to LoveLife (www.lovelife.org.za), a non-governmental organisation that aims to reduce HIV in adolescents though promoting healthy lifestyles and self-esteem in youth.

The stakeholders agreed on a list of five criteria for inclusion in the Ntshembo Stakeholder Forum: having time to attend four meetings annually, being interested in working with adolescents, having the confidence to speak out in group settings, a diverse group of people, and commitment to the aims of Project Ntshembo. Participants chose 12 members for the stakeholder forum, all of whom had been involved in this process, with 8 of the 12 attending the third workshop.

Discussion

This stakeholder involvement process provided a locally derived, empirical base for developing the intervention and allowed researchers to assess how aligned their objectives were with the views of the community in which the work was to take place. The adolescent health priorities generated were very important in the development of the intervention, as they pointed to a poor standard of health literacy, as well as the need for behavioural change techniques and theories to form an important part of the intervention development. Behaviour change is complex, and the intervention cannot focus solely on transfer of knowledge and skills, but needs to take into account adolescent perceptions of others, cultural and societal norms, adolescent and adult attitudes and beliefs about adolescent behaviours, and the degree to which the adolescent feels that he or she has the capacity and agency to change his or her behaviour (29).

Much discussion centred on peer pressure and the contribution that lack of social support makes to exacerbating the effects of peer pressure. Mention of the cross-over and cascade effect reminded the researchers that there are interactions between many factors that affect health-promoting and health-seeking behaviours. We need to consider personal factors, such as self-efficacy and self-esteem, that might influence or be influenced by interpersonal factors such as peer pressure, how these fit within cultural and structural factors such as poverty, and whether the area is rural or urban (30).

There was not much discussion around HIV and its importance in adolescent health. This could be due to a number of reasons: perhaps the issue of HIV is too obvious to discuss, or there may still be denial of HIV as an important health issue in this age group. Alternatively, it could be that HIV is still stigmatised and it is difficult to talk about it in a group setting.

The stakeholder involvement process described in this paper demonstrates one method by which public engagement in health research can be achieved, at a collaborative level (31). Stakeholder involvement resulted in a diagram, developed through consensus, that showed how problems affecting adolescents' health relate to each other. This diagram was used in the development of a viable intervention (29). The formation of a stakeholder forum, with stakeholders themselves setting the criteria for membership and voting for forum members, ensured that this first step in public engagement will lead to continued engagement throughout the planned intervention. The forum will work with the researchers throughout Project Ntshembo to further develop public engagement strategies, share preliminary findings, refine and target the interventions, discuss research progress, problem-solve, and identify policy champions to act on research findings. Ongoing engagement is one of the key principles of any engagement process (21).

Engagement is an inherently interactive activity, and for this reason the Delphi technique was adapted to include face-to-face discussion during workshops. This was an innovative way of obtaining agreement and facilitating involvement of all stakeholders. These discussions ensured stakeholders understood and actively engaged in the process.

We attribute the success of recruiting 26 stakeholders to the first workshop to the long-standing relationship with the community. Eight of the twelve elected Ntshembo Stakeholder Forum members were at all three workshops, and the other four had attended at least one workshop.

Limitations

The exclusive use of the English language during all study activities may have been a barrier to free and full discussions, as English is not the vernacular in that area. It is also possible that the heterogeneity of the group might have affected participation of the lay stakeholders should they have felt that their views were not as relevant as the professional stakeholders. This could also have been true with younger stakeholders not feeling as secure about their opinions as the older stakeholders. It is possible that the face-to-face discussions may have influenced stakeholders' voting choices.

Conclusion

In order to address the problems facing adolescents in the Agincourt sub-district, we wanted to begin public engagement activities through stakeholder involvement with individuals from the community and public sector who had experience in and potential influence over the health and well-being of adolescents. The three workshops brought researchers and community members to a point where they agreed on the most important issues facing adolescents and developed a stakeholder forum within which to tackle these. Consensus was reached that the intervention needs to focus primarily on behavioural change to reduce peer pressure and to improve health literacy and health-seeking behaviours. When Project Ntshembo goes ahead, it will be important to have continuous support from the Ntshembo Stakeholder Forum, as community representatives. They need to be involved from the start-up phase of the project, where priority issues were discussed and agreed upon, through to the end of the project and beyond, when the impact of the intervention is evaluated and, if effective, potentially scaled up.

The rhetoric is that public engagement is important in health research, but in practice researchers may be uncertain as to how to conduct public engagement activities. If there is a clear aim, if the researchers and stakeholders understand why the engagement activities are necessary and if there is an expectation and understanding that the process will be dynamic, then stakeholder involvement has the potential for mutual benefit for both research and the community in which research is taking place.

Authors' contributions

RT developed the study methodology and participated in the execution of all research activities. SN and KK conceptualised the parent study, Project Ntshembo, and both participated in the final workshop. KK also assisted in obtaining ethical approval and advised on earlier drafts of the paper. AS assisted in all aspects of the development and execution of the research activities. All authors read and approved the final manuscript.

Acknowledgements

This work was supported by the Wellcome Trust (Grants 058893/Z/99/A; 069683/Z/02/Z; 085477/Z/08/Z) and the MRC/DfiD African Research Leader Scheme (UK). Wayne Twine and Gillian Lewando-Hundt are acknowledged for comments on an earlier draft of this paper.

Conflict of interest and funding

The authors have not received any funding or benefits from industry or elsewhere to conduct this study.

References

1. Tindana PO, Singh JA, Shawn TC, Upshur REG, Daar AS, Singer PA, et al. Grand challenges in global health; community engagement in research in developing countries. PLoS Med 2007; 4: 1–5.
2. Marsh V, Kamuya D, Rowa Y, Gikonyo C, Molyneux S. Beginning community engagement at a busy biomedical research programme: experiences from the KEMRI CGMRC-Wellcome Trust Research Programme, Kilifi, Kenya. Soc Sci Med 2008; 67: 721–33.
3. Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, et al. Mapping the impact of patient and public involvement on health and social care research: a systematic review. Health Expect 2014; 17: 637–50.
4. Sawyer S, Afifi RA, Bearinger L, Blakemore S, Dick B, Ezeh A, et al. Adolescence: a foundation for future health. Lancet 2012; 379: 1630–40.
5. Viner RM, Ross D, Hardy R, Kuh D, Power C, Johnson A, et al. Life course epidemiology: recognising the importance of adolescence. J Epidemiol Community Health 2015; 69: 719–20.
6. Patton G, Coffey C, Cappa C, Currie D, Riley L, Gore F, et al. Health of the world's adolescents: a synthesis of internationally comparable data. Lancet 2012; 379: 1665–75.
7. Reddy SP, Resnicow K, James S, Funani IN, Kambaran NS, Omardien RG, et al. Rapid increases in overweight and obesity among South African adolescents: comparison of data from the South African National Youth Risk Behaviour Survey in 2002 and 2008. Am J Public Health 2012; 102: 262–8.
8. Kimani-Murage EW, Kahn K, Pettifor JM, Tollman SM, Dunger DB, Gomez-Olive XF, et al. The prevalence of stunting, overweight and obesity, and metabolic disease risk in rural South African children. BMC Public Health 2010; 10: 158.
9. Kimani-Murage EW. Exploring the paradox: double burden of malnutrition in rural South Africa. Glob Health Action 2013; 6: 19249, doi: http://dx.doi.org/10.3402/gha.v6i0.19249
10. Gómez-Olivé FX, Angotti N, Houle B, Klipstein-Grobusch K, Kabudula C, Menken J, et al. Prevalence of HIV among those 15 and older in rural South Africa. AIDS Care 2013; 25: 1122–8.
11. Mayosi BM, Flisher AJ, Lalloo UG, Sitas F, Tollman SM, Bradshaw D. The burden of non-communicable diseases in South Africa. Lancet 2009; 374: 934–47.
12. Popay J, Williams G. Public health research and lay knowledge. Soc Sci Med 1996; 42: 759–68.

13. Marsh VM, Kamuya DK, Parker MJ, Molyneux CS. Working with concepts: the role of Community in International Collaborative Biomedical Research. Public Health Ethics 2011; 4: 26–39.
14. Nuffield Council on Bioethics (2002). Ethics of research related to healthcare in developing countries. London, UK. Available from: http://nuffieldbioethics.org/wp-content/uploads/2014/07/Ethics-of-research-related-to-healthcare-in-developing-countries-I.pdf [cited 14 September 2015].
15. ESRC (2011). Guide to planning public engagement. Economic and Social Research Council. Shaping Society. Available from: http://www.esrc.ac.uk/public-engagement/public-engagement-guidance/guide-to-public-engagement/ [cited 23 March 2012].
16. South African Ministry of Rural Development and Land Reform (2009). The comprehensive rural development framework Version 1 July 2009. pp. 8–9. Available from: http://www.ruraldevelopment.gov.za/phocadownload/Documents/crdp_version1-28july09.pdf [cited 19 October 2015].
17. Polzer T. Invisible integration: how bureaucratic, academic and social categories obscure integrated refugees. J Refugee Stud 2008; 21: 476–97.
18. Kahn K, Collinson MA, Gomez-Olive FX, Mokoena O, Twine R, Mee P, et al. Profile: Agincourt health and socio-demographic surveillance system. Int J Epidemiol 2012; 41: 988–1001.
19. Schmidt RC. Managing Delphi surveys using nonparametric statistical techniques. Decision Sci 1997; 28: 763–74.
20. Okoli C, Pawlowski SD. The Delphi method as a research tool: an example, design considerations and applications. Inf Manage 1994; 42: 15–29.
21. Lavery JV, Tindana PO, Scott TW, Harrington LC, Ramsey JM, Ytuarte-Nunez C, et al. Towards a framework for community engagement in global health research. Trends Parasitol 2010; 26: 279–83.
22. Gittelsohn J, Steckler A, Johnson C, Pratt C, Grieser M, Pickrel J, et al. Formative research in school and community-based health programs and studies: 'state of the art' and the TAAG approach. Health Educ Behav 2006; 33: 25–39.
23. Geary R, Gómez-Olivé FX, Kahn K, Tollman SM, Norris S. Barriers to and facilitators of the provision of a youth-friendly health services programme in rural South Africa. BMC Health Serv Res 2014; 14: 259.
24. Madhavan S, Harrison A, Sennott C. Management of non-marital fertility in two South African communities. Cult Health Sex 2013; 15: 614–28.
25. Feeley A, Kahn K, Twine R, Norris S. Exploratory survey of informal vendor-sold fast food in rural South Africa. South Afr J Clin Nutr 2011; 24: 199–201.
26. Micklesfield L, Pedro T, Kahn K, Kinsman J, Pettifor J, Tollman S, et al. Physical activity and sedentary behavior among adolescents in rural South Africa: levels, patterns and correlates. BMC Public Health 2014; 14: 40.
27. Cornwall A, Jewkes R. What is participatory research? Soc Sci Med 1995; 41: 1667–76.
28. Norris SA, Anuar H, Matzen P, Cheah JCH, Jensen BB, Hanson M. The life and health challenges of young Malaysian couples: results from a stakeholder consensus and engagement study to support non-communicable disease prevention. BMC Public Health 2014; 14(Suppl 2): S6.
29. Draper CE, Micklesfield LK, Kahn K, Tollman SM, Pettifor JM, Dunger DB, et al. Application of Intervention Mapping to develop a community-based health promotion prepregnancy intervention for adolescent girls in rural South Africa: Project Ntshembo (Hope). BMC Public Health 2014; 14(Suppl 2): S5.
30. Eaton L, Flisher A, Aar L. Unsafe sexual behaviour in South African youth. Soc Sci Med 2003; 56: 149–65.
31. Kirkby P. A guide to actively involving young people in research: for researcher commissioners, and managers: INVOLVE Support Unit. 2004. Available from: http://www.invo.org.uk/wp-content/uploads/documents/InvolvingYoungPeople2004.pdf [cited 19 May 2015].

Paper 2

Twine et al. Global Health Research and Policy (2017) 2:26
DOI 10.1186/s41256-017-0046-7

Global Health
Research and Policy

RESEARCH Open Access

The 'experimental public' in longitudinal health research: views of local leaders and service providers in rural South Africa

Rhian Twine[1*], Gillian Lewando Hundt[1,2] and Kathleen Kahn[1,3,4]

Abstract

Background: The concept of 'experimental public' has been recently applied to publics involved in clinical trials. This term could also be applied to publics involved in longitudinal research such as health and demographic surveillance systems. The ethics of practice and public engagement with these experimental publics are of key importance and include issues of informed consent, confidentiality, collection of body tissue samples and fair local benefit.

Methods: Individual (n = 11) and focus group (n = 5) qualitative semi-structured interviews were conducted with 56 local leaders and service providers regarding their views about research activities in a longitudinal health research study site run by the MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt) in rural South Africa. Deductive and inductive thematic analysis was undertaken using NVivo software to identify the emergent themes.

Results: There was an understanding of the usefulness of collecting demographic data, but reasons for gathering other contextual data such as on food security, as well as the reasons for collection of blood was less clear. While appreciation was expressed for feedback of individual results such as blood pressure levels during home-based data collection, there were requests for more results from biomarkers, and for these to be given at home, rather than at the clinic. There were reports of indirect refusals, and offers by leaders to assist in reducing refusal rates. There were concerns about confidentiality, especially in the publication of results. Some leaders would have liked to receive more individual level data for planning of services, although they understood this would breach confidentiality. Service providers were concerned about the withdrawal of some services post intervention trials.

Conclusions: This experimental public has, over time, developed a nuanced understanding of the reasons for research and the procedures undertaken. Discussions concerning fair benefit ranged from requests for more individual clinically-relevant results for participants, to understanding how research results could assist in planning of public health services at local and national levels. The concerns illustrate the complexity of the ethics of practice which has implications for policy, practice and governance for those working in longitudinal health research sites globally.

Keywords: Experimental public, Longitudinal health research, HDSS, Rural, Ethics of practice

* Correspondence: rhian.twine@wits.ac.za
[1]MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt), School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa
Full list of author information is available at the end of the article

BioMed Central

© The Author(s). 2017 **Open Access** This article is distributed under the terms of the Creative Commons Attribution 4.0 International License (http://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license, and indicate if changes were made. The Creative Commons Public Domain Dedication waiver (http://creativecommons.org/publicdomain/zero/1.0/) applies to the data made available in this article, unless otherwise stated.

Background

There has been some recent discussion of publics in public health in Africa [1] which critically explores the complexities, dimensions and dynamics of working with and being part of publics in global health research in Africa. This paper is a contribution to the emergent literature in this field through an analysis of the views of local leaders and service providers about the activities of a longitudinal health research site which operates in rural South Africa.

The concept of 'experimental publics' has been proposed by Montgomery and Pool (2017), rather than 'trial communities' in relation to study participants of clinical trials. Their rationale is that 'communities' is a term that is employed uncritically when in reality the individuals or clusters involved in trials or public health research are socially constructed with geographic, demographic or health-related inclusion and exclusion criteria. This paper extends the concept of experimental publics by applying it beyond a time-bound clinical trial, to a population being studied within a longitudinal health and socio-demographic surveillance system (HDSS). Through prospective census rounds, an HDSS monitors health, social and demographic variables of an entire geographically defined population. Special modules and status observations can be added to provide more detail, such as education, food security, health care utilisation and labour migration [2]. The MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt) has run an HDSS since 1992. It is within this research setting that the data for this paper were collected. Scientific papers covering close to 25 years of research, have generally referred to the population living in this research site as 'the community' [3–9]. All households in the original study villages have been included in an annual census since 1992 and in newer villages as they were added to the site. Data has been collected on all individuals, and as such all residents, both permanent and those who temporarily migrate out for work, study and other purposes, form an experimental public. Within this overarching experimental public are nested research studies covering diverse study designs, which sample participants according to specific inclusion criteria; these participants form smaller, time-bound experimental publics.

Another emergent area is the ethics of practice in public health research and the increasing attention and debate about the processes, relevance and benefit of health research to the population living in low and middle income countries [10, 11] and specifically in HDSS sites [12, 13]. Public perceptions and expectations in longitudinal research studies need to be taken into account [14], and there is an increased onus on public health researchers to develop public engagement strategies that aim to bring local value to the research itself [15–18].

A distinction has been made between *procedural ethics* (theory and regulatory board requirements) *and ethics in practice* (dealing with ad hoc situations occurring during field research) [19], which can also extend to include a socio-political approach to the ethics of practice drawing on relevant sociological and anthropological approaches [20]. Areas of ethics of practice that will be dealt with in this paper are informed consent [18, 21], confidentiality and anonymity [22–24], taking blood samples for screening [25], providing participants with blood results, and fair benefit when studies end [26, 27].

There is a body of literature exploring the complexities of the consenting process in rural African contexts [28, 29]. The consenting process is often influenced by cultural, gender and social norms, and this can affect the 'voluntariness' of participants' decisions [18, 21]. In longitudinal surveillance sites, where the entire population is the experimental public, consent is often negotiated collectively (as in village or household) as well as individually [30]. This approach may affect the potential participants' freedom to directly refuse to participate in studies, and result in actions such as not honouring appointments after consenting to participate. Kamuya et al. [31], in a longitudinal health research site in rural Kenya, describe this 'hesitating to participate without explicitly refusing' as a 'silent refusal' (3:2015). Their work illustrates that although ethical principles such as autonomy are universally applied [26], such principles need to be negotiated in different cultural contexts [28, 31].

Ensuring confidentiality and anonymity are part of both procedural ethics and ethics in practice. In HDSS sites the location of the experimental publics is described, often with maps, in many publications. While the participation in research studies may have individual or collective health care benefits, there is a possibility that research results (such as HIV prevalence or cause-specific mortality rates) may be construed by others to typify only the experimental public rather than the general population [22, 32]. An additional concern is that local fieldworkers are often employed to conduct interviews, since they speak the local language, and share the local culture. However, study participants might not trust them to keep confidentiality [24].

Concerns about body tissue collection have been raised by experimental publics for many years as ways to express deeper issues about the configuration of international health research in Africa. In HDSS sites, there may be trials or observational studies that include the collection of blood and other tissue samples. Rumours around blood taking are built through historical experiences and social belief structures, influenced by cultural practices [33–36]. In one instance there were rumours that blood was being sold for cash by the researchers in the context of a microbicide gel trial in South Africa, in

which reimbursements were given for participation in the trial [25]. Clinical researchers and service providers involved with the trial saw these stories as exemplifying misunderstandings, but the authors interpreted these lay explanations as a critique of relations between researchers and local participants, expressions of popular resistance and related to local ideas of gender and morality.

Another important issue with specific reference to HDSS and other longitudinal research sites is the sustainability of services provided to study participants forming the experimental public when health service intervention studies end [30]. There has been more literature on obligations of researchers in relation to post clinical trial settings [37–39] than about public health service interventions [10, 26]. These ethics of practice issues are explored in this paper through an analysis of the views of local leaders and service providers on the past and present research activities in one site. The aim of this paper is to contribute to the emerging debate on the ethics of practice, and focusses on the understandings of local leaders and service providers, as part of the experimental public in a longitudinal health surveillance study site, concerning the research activities.

Methods

Setting

This work was undertaken within the MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt) research site that hosts a longitudinal HDSS established in 1992. The research site is based in the rural Bushbuckridge Municipal sub-district in Mpumalanga Province, northeast South Africa, 500 kms from Johannesburg (Fig. 1). The Bushbuckridge sub-district was part of the Gazankulu 'homeland' during the pre-1994 apartheid era. Some 30% of the sub-district population comprises former Mozambican refugees, owing to the area's location alongside the western border of Mozambique.

The research site was expanded in 2007 and again in 2014 to accommodate trials and now includes 27 adjacent villages [6].

A 'village' is defined as a cluster of households in a geographically defined area, which has a name and recognised leadership structure, and is geographically separate from other villages. These villages fall under three Traditional Councils, and three Municipal Offices. The power and influence of the traditional leaders (indunas) and their traditional councils has decreased considerably since democratic change in 1994, but they are still respected leaders in the community and are consulted on most matters. Local political governance operates at three levels – Municipal, Ward and Community Development Forum (CDF). There are six municipal wards, each of which has a ward councilor who is accountable to the municipal offices and to the CDF. Each village CDF is made up of two representatives from every Community Based Organisation in the village, as well as the Induna (Chief) as a representative of the Traditional Council.

Since 1994, there has been some development of the region's infrastructure evident in tarred roads, prepaid electricity, and improving yet inadequate water provision. Quality of education remains poor although every village has at least one primary school and most a high school. In the pre-2008 study site, where participants for this study were drawn, there are two health centres and six clinics, with three district hospitals 25–60kms away [3]. Unemployment is high with most formal employment being

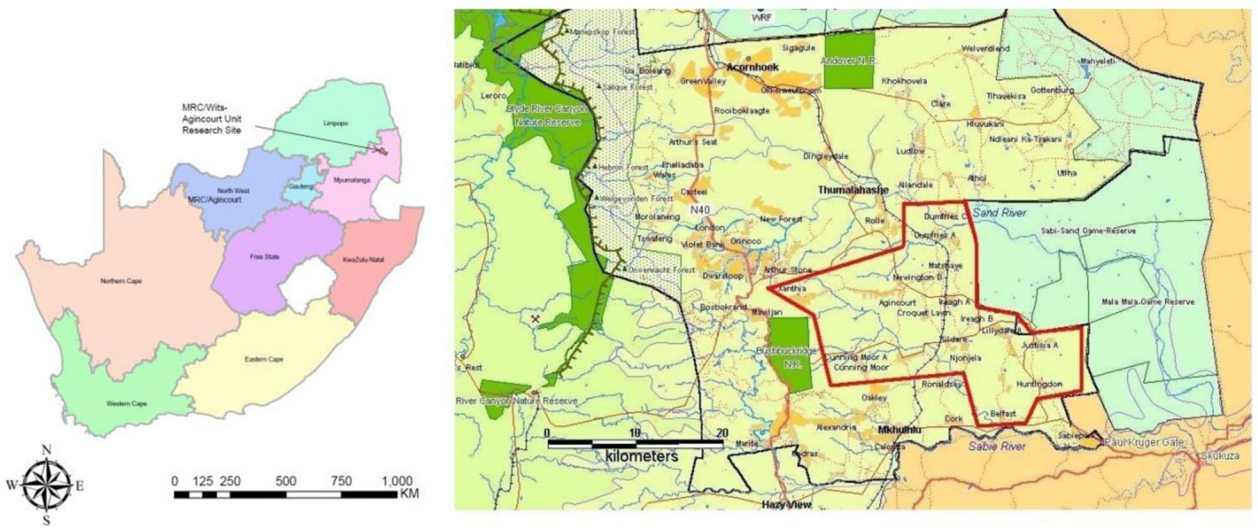


Fig. 1 Agincourt HDSS study area in South Africa and details of the HDSS site in 2007. Source: adapted from Freeman, P.H 2002 [54]

male men migrating to work in industry, largely mining, manufacturing and agriculture, but with an increasing number of women joining the temporary migrant labour force. Remittances from these migrant labourers, as well as South Africa's non-contributory social grant system are the main sources of household income [40].

The Agincourt HDSS, which updates vital events annually, including births, deaths, and migration in and out , was established in 1992. Since 2000, in addition to the annual census update, there has been a growing number of observational, intervention and evaluation studies with international and local collaborators. Public engagement has been ongoing and in 2004, a dedicated Public Engagement Office (PEO) was established to further develop knowledge brokerage activities through public engagement with the experimental public within the site, i.e. villagers, local representatives and service providers. This office engages locally regarding forthcoming research activities and organizes village-based dissemination of HDSS results and research findings. Annual meetings are held with local service providers to discuss the relevance of research results for their work. A Community Advisory Group consisting of nominated representatives from each village meets monthly and all research projects are discussed. All research project leaders have to work with the PEO concerning how to conduct community entry for each project, and the PEO delivers training on and monitors informed consent processes and facilitates dissemination of research results.

Research design

This is a qualitative study using semi-structured individual and focus groups interviews carried out in 2015–16. RT conducted the interviews with the help of a fieldworker acting as note taker, except for the interviews with the indunas where their roles were reversed. A purposive sample was selected of individuals working within organisations involved in governance or service provision at the village and sub-district level. Since this paper focuses on longitudinal engagement in research, we have included only the 19 villages which have been within the study site from its inception in 1992 and four that were added in 2007.

Details of the participants and the inclusion criteria are summarised in Table 1.

In total there were 60 participants, 45 of whom took part in the focus group discussions and 15 in individual interviewees. Unlike the local leaders, four of the service providers interviewed lived outside the site, so these were excluded from the analysis. They were a municipal manager, a traditional council secretary, a clinic manager and an education circuit manager. The final sample for analysis included individual interviews with 11 service providers rather than 15 and a total sample of 56 people. The participants were aged between 25 and 70 years, and were balanced by gender.

The questions in the topic guide for both the focus groups and the individual interviews focused on three topics: knowledge and understanding of the work of the research unit; experiences or involvement in the work of

Table 1 Sample size and criteria for focus groups and interviews

Organisation	Focus groups	Individual interviews	Notes on selection process
CDFs	4 focus groups ranging from 8 to 11 participants from 4 to 6 villages. 35 people in all from 20 villages (3 did not send representatives)		1 or 2 participants from each CDF (one a long-term member; one with a shorter term).
Traditional Councils		2 (1) Traditional Council secretaries 2 Indunas	There are three Traditional Councils and one has only one village in the research site. Hence secretaries of only 2 Traditional Councils were interviewed. Each recommended an Induna for interview from within their Council, who had represented their village for the full 25 years of research.
Municipalities		2 (1) regional municipal managers 3 ward councilors	The PEO works with only 2 regional municipalities, and both regional municipal managers were interviewed. The PEO works with 9 ward councilors and interviews were done with the three who have the most villages in their wards included in the HDSS study area.
Department of Health	Focus group with managers of 8 Home Based Care Organisations (HBCs)	4 clinic managers	4 individual interviews with the clinic managers of the four busiest clinics and 1 focus group with the managers of all eight HBCs based at 8 clinics.
Department of Education		2 (1) education circuit managers	The PEO works with five education circuits, but only interviewed circuit managers from the two that have several schools in the research site.
Total participants	45 people in 5 FGDs	15 (11)	

NB Numbers in brackets represent final sample included in the paper

the unit; and perceived and real benefits and concerns regarding working with, and the work of, the unit. Probing questions were designed to explore participant's knowledge on the focus of the research, and of current and completed research projects. Questions were also asked about whether research results were useful, if participants had ever been invited to events held by the unit, if they were involved in any other way in unit activities, or had been able to influence unit activities. The benefits of being involved in research as well as any concerns about involvement were also probed.

A limitation of the study is that interviews were conducted by the first author who is conversant in the local language and who manages the PEO office. She was aware of her positionality and steps were taken to mitigate any bias through having a local interpreter and note taker present at each interview. The researchers were aware of the possibility of participants giving socially desirable responses, and interviewees were encouraged to give honest responses even if that meant being critical.

Analysis

All interviews and focus groups were recorded; with the exception of one where the participant consented to be interviewed but refused to be recorded so extensive field notes were written. The interviews were transcribed and translated from Shangaan into English where necessary. The interviews with the two indunas were conducted exclusively in Shangaan while in most other interviews a mixture of English and Shangaan was spoken. The transcripts were imported into the QSR NVivo software (version 10) [41] and analysed thematically both deductively and inductively [42]. The deductive approach was by coding the data according to the topics of the topic guide, and the inductive approach was the identification of emergent themes in the language of the respondents within the interviews such as 'Keeping secrets' or 'Taking blood'. In order to deal with inter-rater reliability, two of the authors read a selection of the interviews independently to identify key themes which formed the initial coding template to which additional inductive codes were added.

Results

Themes that emerged during inductive analysis of the four topics, shown in Fig. 2, were: counting people, nested research projects, taking blood, giving back of screening test results, consent, confidentiality and anonymity, and when research ends. Counting of people was mentioned in all groups and interviews except for two, and nested research projects, both as an activity of the unit, as well as having some benefits to the unit were mentioned in all but one. Taking of blood was discussed in some detail in five groups/interviews, mainly by village leaders, but including the Home Based Care

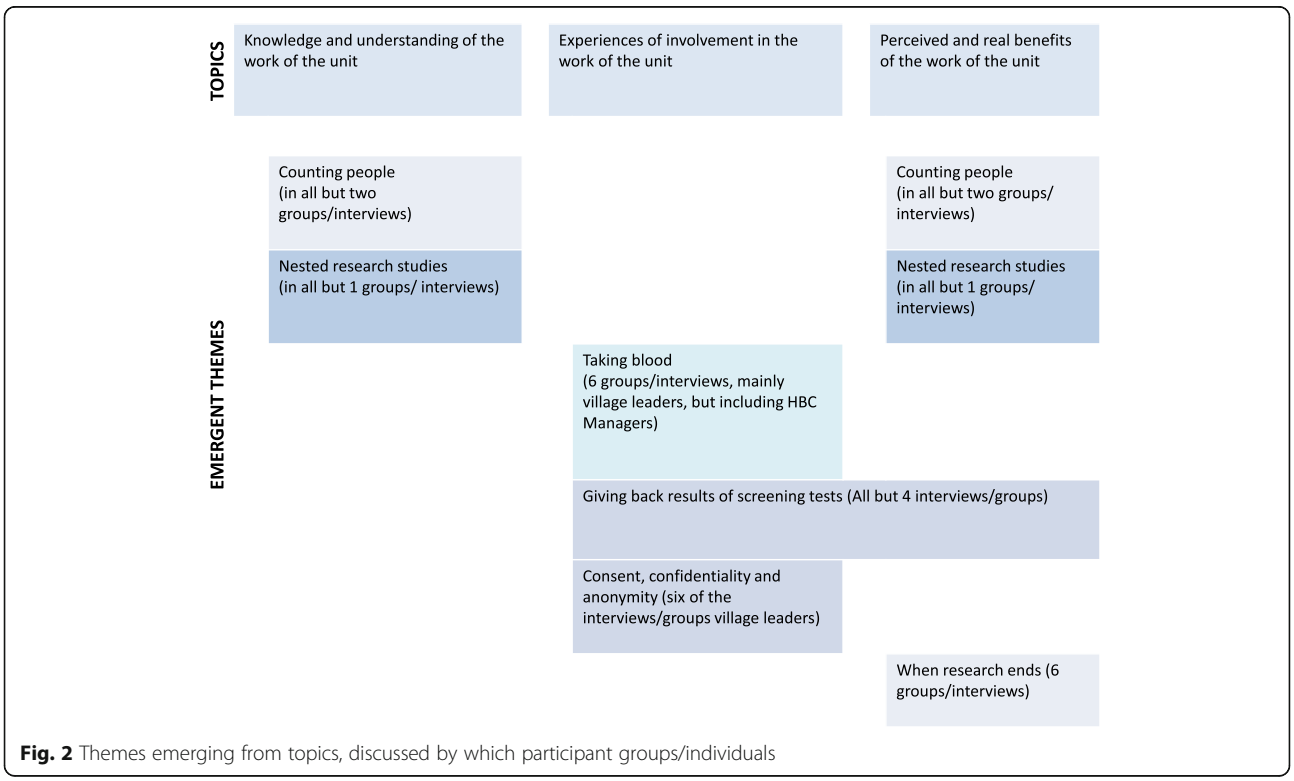


Fig. 2 Themes emerging from topics, discussed by which participant groups/individuals

managers, mostly as a concern. Giving back results of screening tests created positive and negative comment, and was discussed in all but four interviews/groups. Consent, confidentiality and anonymity were again mostly a concern of village leaders i.e. discussed in six of the interviews/groups with the CDFs, ward councilors, traditional council secretaries and indunas. What happens when research ends was discussed in six groups/interviews, but was mostly of concern to the clinic operations managers.

Counting people

The interviewees referred to the MRC/Wits-Agincourt Unit as 'Wits' which is the common shortened version of the University of the Witwatersrand used globally, and this term will be used throughout. When asked about the research activities in the area, the first activity that most participants mentioned was that Wits counts people, referring to the annual census of households.

What I have noticed is that they are counting people. (Induna 2, Man)

Wits counts people. They also want to know how many people are employed in a household and how many people are living in that household. (HBC Manager FGD P2, Woman)

Apart from general population variables (births, deaths, migrations), selected modules are added to the census at regular, albeit less frequent, intervals. For example food security is run every three years, and socio-economic status biannually until 2015 when it became annual. Not all participants understood the relevance of questions that were not purely demographic.

There are complaints that the community have (I don't know maybe it's true)… they say that sometimes it is frustrating when you come to their places and ask how do you eat? Meanwhile they have nothing on the plate. (Ward Councillor 2, Man)

We see Wits people going door to door asking questions like what you eat, about our toilets, cows, access to water, if we have a stove. I know this information might help you or assist the government to know about how people are living in their villages. But we as a community, how do we benefit? (CDF FGD 1, P4, Woman)

The questions about how often we eat meat are good because they want to know how vulnerable we are. (HBC Managers, FGD P4, Woman)

The census is seen as providing useful information for planning of services for the Municipal Integrated Development Plan (IDP) and other service delivery planning such as the clinics knowing their catchment area statistics. Some participants were aware that results might not show immediate benefit at the local level, but would be useful at a national level. However, some participants were not fully aware of how results were, or could be used.

In our village we looked at the results and found that our village is too small, so we went to the chief to extend our village by 500 new stands. (CDF FGD 2, P7, Man)

Every year we are getting the numbers of houses, numbers of young people, adults and numbers of those who have died, from Wits and it helps us because now we know our catchment area. (Clinic Manager 4, Woman)

Even though sometimes the research does not seem local, we know that sometimes it is important for the national and provincial levels' (Clinic Manager 1, Woman)

Is there anywhere you send these research results - maybe the government is aware because you are taking something that you find and hand it over to the government to help with some problems that they are facing. (CDF FGD 1, P1, Man)

Wits uses a different way of defining a household to that of the municipality, and this was mentioned as a problem when using HDSS statistics for planning. Households in publications are defined as those where members eat together, even if they sleep in buildings on a separate stand, whereas village leaders need to know how many actual occupied stands there are in order to provide services for each house.

I can say I have used the results for profiling but Wits would say that there is one family if they all cook and eat in one place, but I suggest you expand that profiling to use stand numbers. Population is defined the same, but household is different. But I still use the data for development such as planning for water pipes and looking at indigent households. (Ward Councilor 2, Man)

Maybe my child she builds her own place to stay on a new stand, but when she wants to eat she comes to my place, but during the night she goes home to sleep.

Wits counts her as living in my place. (CDF FGD 4, P1, Woman)

Nested research studies

Since 2000, the unit has had an increasing number of nested health research studies focusing on non-communicable diseases such as stroke and hypertension [43], HIV and other sexually transmitted diseases [8, 44], obesity and metabolic disease risk in children and adolescents [45, 46] and adult health and ageing [47, 48]. This has meant that members of the experimental public living within the HDSS area have been participants in different studies and as such have been part of smaller, shorter duration experimental publics, some of which have involved health screening. Each study is based on a sample drawn from the HDSS households and various screening tests have been administered to study participants at home and in the Wits research laboratory. Screening tests in different studies have included measurement of blood pressure, blood glucose, cholesterol, body mass index and HIV status and screening for stroke and epilepsy.

In the past Wits was only counting people but now they are helping us as a community about different illnesses. (Induna 1, Man)

Wits helps us finding how many people are infected by illness and also helps us finding the number of people suffering from high blood pressure, sugar diabetes and the other illnesses like epilepsy. (CDF FGD 4, P2, Woman)

Participants mentioned that there is an increasing awareness of symptoms, and the diseases with which they are linked, such as stroke, or heart disease. Some, like the clinic operational managers, believed that the results would assist them to improve service delivery as well as the health of their patients.

Wits is helping us because people were hiding themselves without knowing the different illnesses that they were suffering from and were too afraid to go to the clinic. Now most people are aware of any illness they may have. (CDF FGD 3, P8, Woman)

The older people do not find it simple to attend clinics to check for high blood, sugar diabetes and everything, but Wits goes to the household directly and tests you for sugar diabetes and high blood and that's helping very much. (FGD CDF 4, P4, Man)
I understand you are doing research, and the purpose of it I believe is to improve the health of patients because after your research, I understand you are going to bring some information here to help us..... If you carry on referring people with high blood to us, I think this can assist the patients. (Clinic Manager 2, Woman)

People also mentioned how greater awareness of the health issues affecting people had encouraged some changes in behaviour at a village level.

We now have a ladies soccer team, and when they gather they talk about HIV/AIDS and they are no longer scared about it. We also have the old age groups some of them are having high blood pressure and others TB so every morning we are going to the soccer field and we also have a machine to measure their blood pressure. (CDF FGD 2, P1 Female)

Taking blood and giving back results of screening tests

Not all biomarker results are given to research participants at the time of sample collection. In a population-based HIV prevalence study, participants were given a card with a study identifier barcode, and were asked to go to the clinic to collect their HIV result in two weeks [44] as the study team did not include trained HIV counsellors. This created problems for the clinic staff including not being able to find test results so having to turn participants away, and difficulties for lay counsellors who were not involved in the pre-test counselling but then had to handle the post-test counselling. This was not a method that study participants or clinic staff felt was the best way to deliver results.

There was a project where patients had an HIV test in the community and they were given the bar code to come with to the clinic. Our lay counsellors were having a problem because when they had to counsel the person they had not done the pre-test counselling, but they had to give results - not an easy thing. (Clinic Manager 2, Female)

Let say sometimes people are coming to your household to do some tests - they don't come and tell you that what we have found - they say you have to go to the office to find out. But they visited you to find out what is happening exactly with your life, so I think it should be advisable for them to come back to you as an individual and tell you the blood test results. (CDF FGD 4, P1, Woman)

This raises an important ethics of practice issue concerning the way in which results from screening tests conducted in research studies are handled. While being screened at home was seen as beneficial, taking blood samples has raised some concerns. Some participants

reported that villagers did not understand why blood was being taken or thought that blood was being sold by Wits.

Those who are taken to Wits offices to have blood taken are saying that we are no longer going there because Wits is making money with our blood. (Induna 2, Man)

Lots of older people are running because people who went to Wits to give blood, they came back and started telling people that Wits takes blood and sells it. (CDF FGD 2, P5, Man)

I have never come across any challenges about the work of Wits besides those who are complaining about blood - that they don't know what Wits wants do with their blood at the end. (Induna 1, Man)

Concerns about blood taking are common in health research in Africa and are often framed in ways that illuminate relations between researchers and participants and social inequalities [25, 33, 35]. This recurring narrative of blood being sold, reveals an understanding that the collection of blood is integral to the scientific and economic enterprise of funded health research, although remains somewhat of a mystery.

Consent, confidentiality and anonymity

Some of the local leaders reported that research participants sometimes run away or hide when they see Wits vehicles approaching, and some of the interviewees felt this was due to fear of being screened. Clearly, not being at home when fieldworkers visit is an indirect way of refusing consent to participate in a study. In this site, there are very low refusal rates for the annual census update (18 household refusals out of 21,500 households (0,1%) in 2016), and an average refusal rate of 5–10% for nested research studies. Studies drawing blood, particularly those with several tubes being collected, attract the highest refusal rates. The right to withhold consent is explained before every interview, but historically in this context, there is a difficulty in directly refusing participation as has been shown elsewhere in rural Sub-Saharan Africa [31]. Male village and municipal leaders who were interviewed presented themselves as possible advocates to use their influence to assist Wits in encouraging people to be research participants. These could be seen as misplaced good intentions in that informed consent needs to be given freely without duress or coercion.

We as community leaders can contribute in enhancing awareness, particularly in those areas that Wits is facing challenges. (Municipal Manager 2, Man)

We can motivate our communities that they must give Wits people time when they arrive in their households, and they must also listen to them when they explain about their work and we can also encourage them to participate in their research. You know there are people who sometimes refuse to go to Wits when they want to take their blood because they are saying that Wits benefits from their blood. I know if they are being encouraged by us as community leaders, they will understand and they will participate easily. (Induna 2, Man)

Another theme raised in the interviews was that of the importance of 'keeping secrets'. Although there were some comments that Wits had a good reputation for keeping confidentiality, such as one FGD participant saying "Wits keeps confidentiality" (P6, Man, CDF FGD 3), there were worries expressed about secrets about their lives being published.

"Yes, people run away when they see Wits cars because people don't want to be published. Let's keep the secrets." (P6, Man)

"What I have experienced is that Wits comes to know everything about this particular person, and so that's why people don't want to be published. But you can ask me anything - I can give you answers so long as you keep my secret." (CDF FGD 1, P3, Woman)

There is an understanding amongst local leaders that Wits research involves not only collecting data but also publishing it, and a concern regarding confidentiality and anonymity in relation to the publication of research findings concerning aspects of their lives.

However, there were also requests from some representatives for research data that would identify for them individuals with problems, such as specific illnesses or extreme economic vulnerability, in order to help them. While leaders understand and value the need for anonymity and confidentiality, some would like confidentiality to be breached where the information can help individuals. In some cases, just being given epidemiological patterns and profiles was not regarded as sufficient.

Is it possible for Wits to have an open debate about results that they get from households, or is it a secret thing if someone has got disease of some kind? We get basic information like 'So many people have got this disease in your village' but we don't know who are those people. How can we then help those households in order to prevent such things, because Wits gets information and puts it in a secret, secret place? (CDF FGD 4, P7, Man)

We have a problem with people who don't have identity documents and would like Wits to come find out who does and doesn't have their documents, because we need to know how to help people whose parents were not born in South Africa and are now dead. (HBC Managers FGD, P3, Woman)

Some of these concerns about confidentiality were directly related to doubts about trusting the local fieldworkers to keep secrets [24].

I think some challenges my colleagues have already mentioned is the issue of privacy. Some Wits fieldworkers are just young people like us, and we meet them anywhere and a few of them could talk about my information in the wrong place at the wrong time. (CDF FGD 2, Man)

Remind the fieldworkers that they must keep confidentiality, when I give them the information they must keep it secret. (CDF FGD 1, Woman, P4)

When research ends

A trial on hypertension management [43] placed lay health workers in the clinics for two years, to assist with making appointments, calling patients to remind them of their appointments, completing the triage when patients arrived at the clinics (blood pressure, temperature and weight) and pre-packing medications. The clinic managers felt that the lay health workers assisted in increasing adherence to medication for people with hypertension, and were disappointed that the study ended, pointing out that the study had created some dependence on the lay health workers.

People were benefiting a lot because those lay health workers kept reminding their clients about the date when they were supposed to collect their treatments. They also followed up those who were defaulting. (Traditional Council Secretary 2, Man)

It's more painful to the clients because every day the patients are just complaining, and some of them are defaulting from the treatment because they are expecting the call. (Clinic Manager 4, Woman)

The benefits of studies and effects of withdrawal from the field was also discussed in relation to a trial of a cash incentive to keep young women in secondary school in order to examine the impact on HIV incidence [8]. Data collection for this study took place at the weekends with transport provided to take groups of young women to the laboratory.

They were taking the young girls during the weekend to teach them but since they are no longer taking them, the community is getting worried about why they are no longer taking them because they have noticed that it was keeping them busy. (CDF FGD 2, P1, Woman)

Discussion

This paper explores the views of local leaders and service providers who form part of the experimental public of a long running HDSS site on aspects of the ethics of practice [19]. Montgomery and Pool (2017) have set out a cogent argument for the replacement of the term 'trial communities' with that of 'experimental publics'. Here, it is being applied to the setting of a longitudinal HDSS site which carries out an annual census of all households with additional studies including health service interventions, trials and observational studies. The qualitative data for this paper were from interviews with a sample of 56 leaders and service providers living in the 23 villages that had been part of the site since 2007, 19 of which have been involved since its inception in 1992.

The results suggest that this experimental public, which has been involved in an annual population census since 1992 and smaller time-limited studies since 2000, has developed a nuanced understanding of research activities, data collected for publication, and the relevance of results for policy especially locally, but also nationally and internationally.

The views and concerns of this experimental public highlight issues relevant to the ethics of practice of research, or ethics in the field, in HDSS and other longitudinal health research sites [19]. Fair benefit, both during and at the end of studies is an essential component of research planning and implementation [11, 13, 14, 26]. This is also one of more recent ethical considerations mentioned in the fifth revision of the Helsinki Declaration [27]. Our participants expressed a range of views on benefits, including need for individual benefits while acknowledging the value of government use of results for service planning, and appreciating that questions about food security shed light on vulnerability and inequality within rural populations. Village leaders and service providers also recognized that research results were useful for service planning in their areas.

Consent, confidentiality and anonymity, while considered an integral part of the process of procedural ethics (autonomy and the informed consent process [49]), are also important considerations for the ethics of practice. Societal norms impact on these processes [18, 28–30], an example being 'silent refusals' [31]. In this setting, there are high levels of consent but leaders and service providers reported that people sometimes hide when they see fieldworkers coming to their house. Indirect

refusals are an indication of resistance in a setting where direct refusal may involve defying collective patriarchal consent negotiated at the village or household level. Another dimension of this was the view expressed by village leaders that they could use their influence to encourage recalcitrant individuals to take part in studies. In line with international guidelines [26], consent for the census and each study is first negotiated at the village level through meetings or letters and then at the individual level. These statements by the village leaders showed that they felt involved with giving consent at the village level but are not fully cognizant of individuals' rights to refuse to participate in research.

'Keeping secrets' emerged as an issue expressed in a number of different ways by the interviewees. There were concerns that material published needed to keep the secrets of the research participants which relates directly to issues of confidentiality and anonymity. Small area, geographically defined HDSS sites can be identified in publications even though villages and individuals are anonymized [22]. In addition, local fieldworkers collect data, which they could link to individuals were they to talk about findings in public places – this was an expressed concern of the participants. On the other hand, some of the leaders and service providers expressed a wish for more personalized information as well as the aggregated data in order to respond to need at the village level which would breach confidentiality and anonymity [26]. This shows the complexity and sensitivity of anonymity and confidentiality issues within a longitudinal experimental public.

The collection of blood and other biological samples in research studies is a contested issue that causes concerns amongst experimental publics, in Africa as well as elsewhere [33, 36]. In Kenya researchers were characterised as 'kachinga', blood thieves [33], and in South Africa there were rumours that the researchers were selling blood for cash in a trial of Microbicide gels [25]. In this setting, there were reported concerns that blood taken during studies was being collected for sale. While not factually true, it captures the financing structure of international research in which biomarkers of the physical bodies of the experimental public sustain the scientific research activities and global reputation of a research site [50]. Dismissal of these concerns by researchers, who interpret them simply as rumours or distorted understandings, has often occurred, but anthropologists are clear that they need to be understood and contextualised historically, socially and culturally [34].

There were mixed views about the collection of blood and other screening tests. The participants felt these increased awareness of illness conditions resulting in people being more willing to seek health care. Also expressed, was a request for HIV screening results to be given to individuals at home rather than having to collect them at the clinic.

Another concern in guidelines on research in developing countries [10, 26] is what actions should be taken when the research ends. In this setting, the interviewees expressed concern about the withdrawal of a health service intervention introduced in a trial to improve screening and treatment of hypertension [43]. The lay health workers stopped their activities at the end of the two year study and both the service providers and village leaders commented on their withdrawal. Resources and manpower are scarce and therefore sustainability of health service interventions is rarely possible even if they are effective [51, 52]. Efforts at ensuring collaboration between researchers, health service providers and policy makers are becoming more mainstream in low income countries, but uptake of research results into future policy and practice may be limited owing to limited resources [38].

Conclusion

There is a long history of international medical and public health research in Africa much of which is funded by international bodies based in the global north and carried out with participation of researchers from these countries. Recently there has been increasing focus by mainly social scientists and ethicists on key aspects of these activities including consent, anonymity and fair benefit. This paper makes a contribution to the emerging debate on the publics of public health research in Africa [1] and to the landmark research on aspects of ethics of practice and public engagement in longitudinal health research sites in sub-Saharan Africa [16, 20, 53]. In particular, this paper develops the concept of experimental publics proposed by Montgomery and Pool [36] to those within longitudinal HDSS sites, through exploring the views of local leaders and service providers within one established study setting. The concerns explored here on ethics of practice illustrate the complex dimensions of consent, anonymity, confidentiality and fair benefit which have implications for policy, practice and governance for those engaged in global health research in longitudinal health research sites internationally.

Abbreviations

CDF: Community Development Forum; FGD: Focus group discussion; GLH: Gillian LewandoHundt; HBC: Home based carers; HDSS: Health and Socio-Demographic Surveillance System; HIV: Human Immunodeficiency Virus; HREC: Human Research Ethics Committee; IDP: Integrated Development Plan; IPHTRE: Improving Population Health Through Research Exchange; KK: Kathleen Kahn; MRC: Medical Research Council; PEO: Public Engagement Office/rs; RT: Rhian Twine

Acknowledgements

None of the work would be possible without the long standing participation of the experimental public in the MRC/Wits-Agincourt Unit HDSS study area.

We thank Violet Ndlovu and Meriam Maritze who assisted with data collection and transcription.

Funding
This project was supported by the University of the Witwatersrand, the South African Medical Research Council, the South African National Research Foundation through their Community Engagement Funding Instrument (grant 93,314), the EU Marie Curie Improving Population Health Through Research Exchanges' (IPHTRE) grant and the Wellcome Trust (grants 058893/Z/99/A; 069683/Z/02/Z; 085477/Z/08/Z; 085477/B/08/Z).

Availability of data and materials
The datasets generated during this study are available from the corresponding author on reasonable request.

Author contributions
RT, GLH and KK planned the study. RT implemented the study and RT conducted the analysis and linked the findings to the literature supported by GLH. KK provided critical revision of the manuscript. All authors read and approved the final manuscript.

Ethics approval and consent to participate
Ethical clearance was obtained from the University of the Witwatersrand's Human Research Ethics Committee (HREC) (Medical) (Certificate number M140361) and permission for interviewing service providers obtained from the Mpumalanga Provincial Departments of Health and Education Research Offices. Written informed consent was gained from all participants prior to data collection.

Consent for publication
Not applicable.

Competing interests
The authors declare that they have no competing interests.

Author details
[1]MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt), School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa. [2]Division of Health Sciences, Warwick Medical School, University of Warwick, Coventry, UK. [3]INDEPTH Network, Accra, Ghana. [4]Epidemiology and Global Health Unit, Department of Public Health and Clinical Medicine, Umeå University, Umeå, Sweden.

Received: 23 February 2017 Accepted: 28 June 2017
Published online: 06 September 2017

References

1. Kelly AH, MacGregor H, Montgomery CM. The publics of public health in Africa. Crit Public Health. 2016;27(1):1–5.
2. Kahn K, Tollman SM, Collinson MA, Clark SJ, Twine R, Clark BD, Shabangu M, Gómez-Olivé FX, Mokoena O, Garenne ML. Research into health, population and social transitions in rural South Africa: Data and methods of the Agincourt Health and Demographic Surveillance System. Scand J Public Health. 2007;35:8–20.
3. Kahn K, Collinson MA, Gomez-Olive FX, Mokoena O, Twine R, Mee P, Afolabi SA, Clark BD, Kabudula CW, Khosa A, et al. Profile: Agincourt health and socio-demographic surveillance system. Int J Epidemiol. 2012;41(4):988–1001.
4. Tollman S, Herbst K, Garenne M, Gear J, Kahn K. The Agincourt demographic and health study - site description, baseline findings and implications. S Afr Med J. 1999;89(8):858–64.
5. Lippman SA, Maman S, MacPhail C, Twine R, Peacock D, Kahn K, Pettifor A. Conceptualizing Community Mobilization for HIV Prevention: Implications for HIV Prevention Programming in the African Context. PLoS One. 2013; 8(10):e78208.
6. Twine R, Kahn K, Scholtz A, Norris SA: Involvement of stakeholders in determining health priorities of adolescents in rural South Africa. Glob Health Action. 2016;9(0):29162.
7. Wagner RG, Ngugi AK, Twine R, Bottomley C, Kamuyu G, Gómez-Olivé FX, Connor MD, Collinson MA, Kahn K, Tollman S, et al. Prevalence and risk factors for active convulsive epilepsy in rural northeast South Africa. Epilepsy Res. 2014;108(4):782–91.
8. Pettifor A, MacPhail C, Hughes JP, Selin A, Wang J, Gómez-Olivé FX, Eshleman SH, Wagner RG, Mabuza W, Khoza N, et al. The effect of a conditional cash transfer on HIV incidence in young women in rural South Africa (HPTN 068): a phase 3, randomised controlled trial. Lancet Glob Health. 2016;4(12):e978–88.
9. SASPI Project Team. The prevalence of stroke survivors in rural South Africa. Stroke. 2004;35:627–32.
10. Participants in the 2001 Conference on Ethical Aspects of Research in Developing Countries. Fair Benefits for Research in Developing Countries. Science. 2002;298(5601):2133-4.
11. Lairumbi GM, Michael P, Fitzpatrick R, English MC. Ethics in practice: the state of the debate on promoting the social value of global health research in resource poor setting particularly Africa. BMC Public Health. 2011;**12:**22.
12. Marsh VM, Kamuya DK, Parker MJ, Molyneux CS. Working with Concepts: The Role of Community in International Collaborative Biomedical Research. Public Health Ethics. 2011;4(1):26–39.
13. Mondain N, Bologo AE, Arduin P. Exploring respondents' understanding and perceptions of demographic surveillance systems in Western Africa: methodological and ethical issues. Afr Popul Stud. 2010;24(3):149–65.
14. Molyneux S, Mulupi S, Mbaabu L, Marsh V. Benefits and payments for research participants: Experiences and views from a research centre on the Kenyan coast. BMC Med Ethics. 2012:**13**(1).
15. Madhavan S, Collinson MA, Townsend NW, Kahn K, Tollman SM. The implications of long term community involvement for the production and circulation of population knowledge. Demogr Res. 2007;17:369–88.
16. Tindana PO, Singh JA, Tracy CS, Upshur RE, Daar AS, Singer PA, Frolich J, Lavery JV. Grand Challenges in Global Health; Community Engagement in Research in Developing Countries. PLoS Med. 2007;4(9):1–5.
17. Allotey P, Reidpath DD, Devarajan N, Rajagobal K, Yasin S, Arunachalam D, Debora Imelda J, Soyiri I, Davey T, Jahan N, et al. Cohorts and community: a case study of community engagement in the establishment of a health and demographic surveillance site in Malaysia. Glob Health Action. 2014:**7**(0).
18. Molyneux S, Bull S. Consent and Community Engagement in Diverse Research Contexts: Reviewing and Developing Research and Practice. Participants in the Community Engagement and Consent Workshop, Kilifi, Kenya. J Empir Res Hum Res Ethics. 2011;8(4):1–18.
19. Guillemin M, Gillam L. Ethics, Reflexivity, and "Ethically Important Moments" in Research. Qual Inq. 2004;10(2):261–80.
20. Wenzel Geissler P and Molyneux C, editors. Evidence, Ethos and Experiment. The Anthropology and History of Medical Research in Africa. New York: Berghahn Books; 2011.
21. Duombo OK. It takes a village: Medical research and ethics in Mali. Science. 2005;307:679–81.
22. Marshall PA, Rotimi C. Ethical Challenges in Community-Based Research. Am J Med Sci. 2001;322(5):241–5.
23. Tindana P, Rozmovits L, Boulanger RF, Bandewar SVS, Aborigo RA, Hodgson AVO, Kolopack P, Lavery JV. Aligning Community Engagement With Traditional Authority Structures in Global Health Research: A Case Study From Northern Ghana. Am J Public Health. 2011;101(10):1857–67.
24. Molyneux S, Kamuya D, Madiega PA, Chatler T, Angwenyi V, Geissler PW. Fieldworkers at the interface. BMC Med Ethics. 2014;13(1):ii-iv.
25. Stadler J, Saethre E. Rumours about blood and reimbursements in a microbicide gel trial. Afr J AIDS Res. 2010;9(4):345–53.
26. Nuffield Council on Bioethics: Ethics of research related to healthcare in developing countries. 2002.
27. Carlson RV, Boyd KM, Webb DJ. The revision of the Declaration of Helsinki: past, present and future. Br J Clin Pharmacol. 2004;57:695–713.
28. Tekola F, Bull SJ, Farsides B, Newport MJ, Adeyemo A, Rotimi CN, Davey G. Tailoring Consent to Context: Designing an Appropriate Consent Process for a Biomedical Study in a Low Income Setting. PLoS Negl Trop Dis. 2009;3(7):e482.
29. Molyneux C, Mutemi N, Peshu K, Marsh VM. Trust and Informed Consent: Insights from Community Members on the Kenyan Coast. Soc Sci Med. 2005;61:1463–73.
30. Carrel M, Rennie S: DeBull World Health Orgmographic and health surveillance: longitudinal ethical issues 2008.pdf>. 2008;86(86):612–616.
31. Kamuya DM, Theobald SJ, Marsh V, Parker M, Geissler WP, Molyneux SC. "The One Who Chases You Away Does Not Tell You Go": Silent Refusals and Complex Power Relations in Research Consent Processes in Coastal Kenya. PLoS One. 2015;10(5):e0126671.
32. Tindana P, De Vries J, Campbell M, Littler K, Seeley J, Marshall P, Troyer J, Ogundipe M, Alibu VP, Takubu A, et al. Community engagement strageies

for genomic studies in Africa: a review of the literature. BMC Med Ethics. 2011;16:24.
33. Geissler PW. Kachinja are Coming!: Encounters Around Medical Research Work in a Kenyan Village. Africa. 2005;75(2);173-202.
34. 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):975–82.
35. Upshur REG, Lavery JV, Tindana PO. Taking tissue seriously means taking communities seriously. BMC Med Ethics. 2007;8:1.
36. Montgomery CM, Pool R. From 'trial community; to 'experimental publics': how clinical research shapes public participation. Critical Public Health. 2017;27(1):50–62.
37. Council for International Organizations of Medical Sciences. International ethical guidelines for biomedical research involving human subjects. Bulletin of Medical Ethics. 2002;182:17.
38. Emanuel EJ, Wendler D, Killen J, Grady C. What Makes Clinical Research in Developing Countries Ethical? The Benchmarks of Ethical Research. J Infect Dis. 2004;189(5):930–7.
39. Grady C. The Challenge of Assuring Continued Post-Trial Access to Beneficial Treatment. Yale J Health Policy Law Ethics. 2013;5(1):425–36.
40. Collinson MA, White MJ, Bocquier P, McGarvey ST, Afolabi SA, Clark SJ, Kahn K, Tollman SM: Migration and the epidemiological transition: insights from the Agincourt sub-district of northeast South Africa. Global Health Action. 2014;1:7(1):23514.
41. QSR international PL: NVivo qualitative data analysis software; Version 10; 2012.
42. Hennink M, Hutter I, Bailey A. Qualitative Research Methods. London: SAGE Publication Ltd; 2011.
43. Thorogood M, Goudge J, Bertram M, Chirwa T, Eldridge S, Gómez-Olivé FX, Limbani F, Musenge E, Myakayaka N, Tollman S, et al. The Nkateko health service trial to improve hypertension management in rural South Africa: study protocol for a randomised controlled trial. Trials. 2014;2014(15):435.
44. Gómez-Olivé F, Angotti N, Houle B, Klipstein-Grobusch K, Kabudula C, Menken J, Williams J, S Tollman, S Clark: Prevalence of HIV among those 15 and older in rural South Africa. AIDS Care. 2013.
45. Kimani-Murage EW, Kahn K, Pettifor JM, Tollman SM, Dunger DB, Gomez-Olive XF, Norris SA. The prevalence of stunting, overweight and obesity, and metabolic disease risk in rural South African children. BMC Public Health. 2010;10:158-171.
46. Kimani-Murage EW, Kahn K, Pettifor JM, Tollman SM, Klipstein-Grobusch K, Norris SA. Predictors of adolescent weight status and central obesity in rural South Africa. Public Health Nutr. 2011;14(06):1114–22.
47. Tollman SM, Norris SA, Berkman LF. Commentary: The value of life course epidemiology in low- and middle-income countries: an ageing perspective. Int J Epidemiol. 2016;45:997–9.
48. Gómez-Olivé FX, Thorogood M, Clark B, Kahn K, Tollman S: Self-reported health and health care use in an ageing population in the Agincourt sub-district of rural South Africa. Glob Health Action. 2013;6(0);19305.
49. World Medical Association Declaration of Helsinki. Ethical Principles for Medical Research Involving Human Subjects. JAMA;2000;284(23);3043-5.
50. Edström J, MacGregorH. The Pipers Call the Tunes in Global Aid for AIDS: The global financial architecture for HIV funding as seen by local stakeholders in Kenya, Malawi and Zambia. Global Health Governance. 2010; 4(1). http://blogs.shu.edu/ghg/2010/12/20/the-pipers-call-the-tunes-in-globalaid-for-aids/.
51. Tollman, SM. Fair partnerships support ethical research. (Education and debate). British Medical Journal. 2001;323.7326(2001);1417-20.
52. Zong Z. Should post-trial provision of beneficial experimental interventions be mandatory in developing countries? J Med Ethics. 2008;34:188–92.
53. Molyneux S, Geissler PW. Ethics and the ethnography of medical research in Africa. Soc Sci Med. 2008;67(5):685–95.
54. Freeman PH: CBNRM and AIDS in Bushbuckridge, Northern Province, South Africa: An Exploratory Geographic Analysis: Development Ecology Information Service, USAID; 2002.

Submit your next manuscript to BioMed Central and we will help you at every step:

- We accept pre-submission inquiries
- Our selector tool helps you to find the most relevant journal
- We provide round the clock customer support
- Convenient online submission
- Thorough peer review
- Inclusion in PubMed and all major indexing services
- Maximum visibility for your research

Submit your manuscript at
www.biomedcentral.com/submit

BioMed Central

Paper 3

frontiers in Sociology

ORIGINAL RESEARCH
published: 25 April 2019
doi: 10.3389/fsoc.2019.00033

Dilemmas of Ethics in Practice in Longitudinal Health Research: Identifying Opportunities for Widening Participation of Residents

Rhian Twine[1]*, *Gillian Lewando Hundt*[1,2] and *Kathleen Kahn*[1,3,4]

[1] MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt), School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa, [2] Division of Health Sciences, Warwick Medical School, University of Warwick, Coventry, United Kingdom, [3] INDEPTH Network, Accra, Ghana, [4] Epidemiology and Global Health Unit, Department of Public Health and Clinical Medicine, Umeå University, Umeå, Sweden

Background: Mechanisms for widening participation of local participants in research studies can improve governance of public health research. Research conducted in longitudinal health study areas depends on there being mutual trust and respect over time between the local residents and researchers. Ethics in practice needs consideration alongside procedural ethics. By widening participation of the experimental public—local residents and resident service providers—ethics in practice and accountability are strengthened.

Methods: The study was undertaken in a longitudinal health study area in rural South Africa using multiple qualitative methods. The sample included 35 individual and five group interviews with resident local leaders and service providers, 24 individual and eight group interviews with residents of the study area, and ten researchers' reflections on two critical incidents from ethnographic field notes on dilemmas of ethics in practice. The interviews were all audio-recorded (besides one where consent to record was not given) and then transcribed verbatim and translated from Shangaan into English. Thematic analysis was conducted.

Results: Residents requested the reporting back of personal screening test results from research studies, and raised informed consent issues. Researchers recognized the importance of mechanisms to increase their accountability to residents throughout the research process, and the complexity of informed consent and fieldwork procedures within research studies.

Conclusion: This study elicited the views of residents and researchers in a longitudinal health study area to seek guidance on how to strengthen participation in research governance. Three strategies were identified by participants to widen participation of the experimental public. Firstly, increasing study budgets so that individual screening test results could be personally delivered back to participants. Secondly, more rigorous field staff training in informed consent and study procedures with ongoing monitoring and supervision from researchers. Thirdly, increased earlier involvement of residents in research protocol development through study advisory groups. Additional

OPEN ACCESS

Edited by:
Annette Louise Boaz, Kingston University, United Kingdom

Reviewed by:
Simone Louise Sherriff, Sax Institute, Australia
Dorcas Kamuya, KEMRI Wellcome Trust Research Programme, Kenya

***Correspondence:**
Rhian Twine
rhian.twine@wits.ac.za

Specialty section:
This article was submitted to Medical Sociology, a section of the journal Frontiers in Sociology

Received: *09 October 2018*
Accepted: *03 April 2019*
Published: *25 April 2019*

Citation:
Twine R, Lewando Hundt G and Kahn K (2019) Dilemmas of Ethics in Practice in Longitudinal Health Research: Identifying Opportunities for Widening Participation of Residents. Front. Sociol. 4:33. doi: 10.3389/fsoc.2019.00033

strategies include deeper involvement of Community Advisory Groups and more focused dissemination of research results to specific audiences. In general, there is a need to identify strategies for increased accountability of researchers and participatory governance through involvement of the experimental public in all aspects of longitudinal public health research as part of the ethics in practice and democratization of science.

Keywords: ethics in practice, longitudinal health research, widening participation, informed consent, returning individual results

LAY SUMMARY

This paper is an analysis of the views residents, service providers, and local and foreign researchers had about being involved in health research in one study area over a long period of time. It is important to understand how long term health research over long periods of time in the same population affects those involved. In this study we recorded the views of residents, service providers, and local and foreign researchers involved in health research in 31 villages in an under-developed rural area of South Africa strongly affected by the legacy of apartheid. There are some signs of development with better access to schooling, water, electricity, and shops. However, employment remains low.

Research in this study area started in 1992 to generate health and population data to inform decentralized district health systems development, policy, and planning. Health and socio-demographic information about the entire population of 120,000 people is updated annually. More recently, other studies such as testing of health service interventions have been carried out in the same study area. More effort has been put into involving research participants in research, and trying to see that they get fair benefit.

To this end we held group discussions and had individual interviews with residents, local leaders and service providers. We also asked for written reflections from researchers. The table below shows who we gathered information from:

	Individual interviews	Group discussions	Written reflections
Residents	24	56 participants in 8 groups	
Service providers and village leaders	11	45 participants in 5 groups	
Researchers			11

The topics that we were interested in, determined as important through analysis of ethnographic fieldnotes, were:

- Informed consent, for example, why participants agree to participate in research even when they don't really understand what the research will involve
- Feeding back personal results from medical screening tests to each individual research participant.

Our results showed that health research participants needed to agree to sign multiple consent forms in order to be included in the research. We found that residents often did not understand the research. We learnt that we need to put more effort and time into training of our fieldworkers so that they fully understand the research project. Standardized training and clear guidelines for researchers about how to train and monitor fieldworkers are needed.

Participants were clear that individual results from screening tests should be delivered personally or at the time of doing the test. Researchers agreed that this was important, and that they needed to plan how to do, and pay for, this activity and include these costs as an integral part of the study budget. We also learnt that we need to think more about our employment strategies—for example, employing female fieldworkers to interview females if sensitive issues are discussed.

All participants said that activities to encourage earlier involvement and widening participation of local residents throughout the research process might prevent some of the problems that arise during research, such as rumors regarding the reasons for collection of blood samples, and consequent high refusal rates. These may help to ensure that researchers are accountable, and that residents receive full benefit from research.

INTRODUCTION

Research conducted in health and demographic surveillance systems (HDSSs), aims to provide information that allows health policy makers and planners to deliver better health services for their populations (INDEPTH, 2012). These longitudinal centers are mostly in resource poor areas, and it is important to ensure that fair benefit of the research is considered at the local level. Public engagement activities in these centers build partnerships with local residents and service providers and support the ethical conduct of research in the field (Participants in the 2001 Conference on ethical aspects of research in developing countries, 2002; Tindana et al., 2007; Lairumbi et al., 2011; Allotey et al., 2014; Simwinga et al., 2018).

Guillemin and Gillam (2004) have suggested that ethics in practice (dealing with situations occurring during field research), needs consideration alongside procedural ethics (theory and regulatory board requirements). These situations can be called "ethically important moments" (Guillemin and Gillam, 2004: p.266), and involve "critical reflection both on the kind of knowledge produced from research and how that knowledge is generated" (Guillemin and Gillam, 2004: p. 274). Researchers working in African HDSS sites have pointed out that consideration of different cultural and social world views between participants and themselves is crucial (Duombo, 2005; Molyneux

and Bull, 2013). Actions taken to alleviate these situations can lead to more nuanced and enlightened ethical theory (Guillemin and Gillam, 2004). Geissler and Molyneux (2011) utilize the term "ethos" of medical research to distinguish this type of socio-political approach to ethics in practice, which draws on sociology and anthropology in relation to a contextual approach and reflexivity in the field.

Part of ethics in practice is the important issue of fair benefit to research participants. The challenge of what is fair benefit from research has received increasing attention. The International Ethical Guidelines for Biomedical Research Involving Human Subjects, with specific reference to research in resource poor countries, state that "Before instituting a plan to undertake research in a population or community in low-resource settings, the sponsor, researchers, and relevant public health authority must ensure that the research is responsive to the health needs or priorities of the communities or populations where the research will be conducted . . . and . . . also make every effort, in cooperation with government and other relevant stakeholders, to make available as soon as possible any intervention or product developed, and knowledge generated, for the population or community in which the research is carried out" (CIOMS, 2016: p. 3). In their systematic review of nine African and seven international ethics guidelines, Lairumbi et al. (2011) found that half of the guidelines specifically discussed benefits to participants, communities and to society in general, both during and after research studies. There was considerable variation between the guidelines regarding how much responsibility researchers should have for giving benefit, as well as what these benefits might be. While there have been gains in developing ethical guidelines for health research in resource poor areas, this lack of consensus could result in different interpretations and practices regarding ensuring fair benefit from research (Nuffield Council on Bioethics, 2002; Participants in the 2001 Conference on ethical aspects of research in developing countries, 2002; Lairumbi et al., 2011; Molyneux et al., 2012).

Feeding back biomedical results that might have an impact on the health needs of individual research participants is a controversial topic that can be included in ethics in practice. Giving back results is part of the ethical imperatives of respect for person, reciprocity, beneficence, and justice (Shalowitz and Miller, 2005; Bledsoe et al., 2012), and can foster a positive attitude toward health research. Those against giving individual results argue that specimens should be given for the good of science and mankind and results might cause harm if they have not been validated, or tracking has not been adequate and the wrong result is returned (Bledsoe et al., 2012). However, in their review of articles published prior to 2005, Shalowitz and Miller (2005) found that there were very few reports of such harm, and most individuals found their test results beneficial. There is also a concern that giving back individual biomedical results might lead to "therapeutic misconception" (Appelbaum et al., 1987). This term alludes to participant's possible confusion between research and medical care and has been documented (Molyneux et al., 2005; Tekola et al., 2009). There may also be difficulties in deciding what is a "clinically relevant" result and whether only results that indicate a condition for which care can be locally obtained be returned (Murphy et al., 2008). There is an additional concern regarding cost, as giving back of individual results adds to project budgets (Bledsoe et al., 2012).

International public health research has been viewed as being carried out on "experimental publics" (Kelly et al., 2016; Montgomery and Pool, 2017; Twine et al., 2017). This term has been applied in recent public health literature to the research population in clinical trials or in this case in a health surveillance study area. The term is used as the research participants are defined by the research design and do not form a community with administrative and geographical boundaries for other purposes. In longitudinal health surveillance sites, there are regular, often more than annual updates of individual and household demographic data, Geographical Information System maps of villages, and specific smaller, nested research studies (Ye et al., 2012). Ethics in practice when working with experimental publics in these settings is particularly critical, so that vital processes of research governance which consider and include the participation and views of local residents are routinized (Nuffield Council on Bioethics, 2002; Kamuya et al., 2013; MacQueen et al., 2015).

In their work in rural Kenya and South Africa, Molyneux et al. (2009) emphasized that the relationships with fieldworkers who are locally recruited are ongoing before, during and after the research are a factor in ethics in practice. Given that in most HDSSs, there may be inequities between the researchers and locals, Emmanuel et al. suggest that considerable attention needs to be given to finding avenues to create collaborative partnerships between these parties. These partnerships allow for discussion and resolution of dilemmas, in a manner that allows different points of view to be heard, and compromises to be negotiated (Emmanuel et al., 2004).

Key to partnerships between the researcher and participants is the relationship between the field worker and the participant (Molyneux et al., 2013; Kamuya et al., 2015), which starts with informed consent. While individual informed consent is seen as a prerequisite in procedural ethical reviews, it has complexities in execution. These include how field workers understand the research processes, how they explain the methodology, how household dynamics play themselves out, local cultural beliefs, how the participants understand the information, what information is included and how the final decision is made, communicated and influenced (Tekola et al., 2009; Kamuya et al., 2015). Matters influencing the final decision can include attributes of the field worker such as whether he/she is known to the participant, age or gender disparities between the fieldworker and the participant, the real or perceived benefits from participating in the study and the level of trust placed in the researchers/research institution. In poorly resourced settings, with few opportunities for health care, decisions to participate in research may be taken in the hope that despite being informed otherwise, care might be given (Molyneux et al., 2005).

Increasingly, public engagement and participation in research is being called for at all stages of the research process, from design, through fieldwork planning, and implementation, to monitoring and analysis and distribution of results in guidelines

on good fieldwork practice (South African Department of Health, 2007; UNAIDS/WHO, 2007; HPTN, 2009; UK National Institute for Health Research, 2014). Literature on public participation in science recognizes that data collection is dependent on the willingness of people to not only participate in research by answering questions and giving of their time but also sharing their local expertise and knowledge (Fortmann, 2014). Public participation in science, especially in research governance is related to civic science (Bäckstrand, 2003; Levine, 2011) and the idea that science, and health, are public goods. The notion of access to health care as a human right and as such a public good, is upheld both by the UN Universal Declaration of Human Rights—Article 25 (United Nations, 1948)—and in three sections of the South African Constitution (South African Government, 1996). The focus of this paper is on participation of the experimental public in research governance processes and will make a contribution to the growing literature on ethics in practice (Guillemin and Gillam, 2004) in longitudinal health study areas.

RESEARCH DESIGN

Setting

This study was conducted in the Agincourt Health and Socio-Demographic Surveillance System (Agincourt HDSS) study area, hosted by the MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt) (MRC/Wits-Agincourt Unit) in the rural Bushbuckridge Municipal sub-district of Mpumalanga Province, South Africa. Established in 1992, the original aim was to contribute to developing decentralized district health systems. The area is situated in the former Mhala District of the Gazankulu "homeland" formed during the apartheid years. These areas, under self-rule but not independent, suffered limited development and poor investment in health, infrastructure and education (Niehaus et al., 2001). In 1994, South Africa held its first democratic elections, and a new democracy was born. Under this new system, over a period of time, the area was renamed Bushbuckridge. The area is situated 500 km north east of Johannesburg, and is still characterized by high unemployment, with high rates of labor migration and a legacy of the apartheid system of forced labor migration. Poor education standards persist and, although infrastructure has seen some considerable development since 1994, there are still poor roads and limited water supply (Kahn et al., 2012; Collinson et al., 2014). Annual health and socio demographic census updates have been conducted with the 116,500 people residing in 21 300 households in the 27 adjacent villages in the Agincourt HDSS since 1992. Updates include information on births, deaths, in and out migration, education and socio-economic status, family structure and various, scheduled updates on, for example, food security, and health care utilization.

Despite an increased focus on access to health care post-*apartheid*, access remains inequitable in South Africa (Harris et al., 2014). Findings from the Agincourt HDSS and its nested studies, particularly those that indicate rapid health, social, and demographic transitions, contribute to health policy and planning (Tollman, 2008). The objectives of the MRC/Wits-Agincourt Unit have expanded to include reasons for, and dynamics of, these transitions, deepening observational work through cohort studies. The unit also conducts intervention studies with cross-site collaboration, and produces public access datasets, with the goal of mounting more effective public health, public sector and social responses (Kahn et al., 2012).

The work of the MRC/Wits-Agincourt Unit is collaborative, international and the boundaries of the work are global. It is one of the few HDSS sites worldwide that is led by an academic institution based in the host country. Other research studies, including trials, observational, and intervention studies, run by local and international collaborators have been nested in the Agincourt HDSS using the HDSS dataset for sampling (Gómez-Olivé et al., 2013; Thorogood et al., 2014; Pettifor et al., 2016; Gaziano et al., 2017). Although most projects are still internationally sponsored, there are growing numbers of South African principal investigators, and South African and African project managers working in the site. In 2018, there were 30 nested studies at various stages of which nine were led by international collaborators, 13 South African led and eight jointly led (**Figure 1**).

All projects based in the MRC/Wits-Agincourt HDSS can be classified as community-based, and public engagement is intrinsic to such research. A Public Engagement Office (PEO) was formally started in 2004, to formalize and expand previous public engagement activities. RT leads this office. The PEO works with Principal Investigators and project managers of studies, keeping investigators alert to ethics in practice issues. There is a Community Advisory Group (CAG) consisting of one person elected by the Community Development Forum (CDF) of each village that meets monthly. Smaller study advisory groups, comprising eight randomly selected CAG members are formed for most nested studies. There are village-based meetings and targeted briefings with traditional and civic village leaders, local, district, and provincial governmental and relevant non-governmental service providers, before a study commences to discuss the upcoming project, and at its conclusion to disseminate results (Twine et al., 2017).

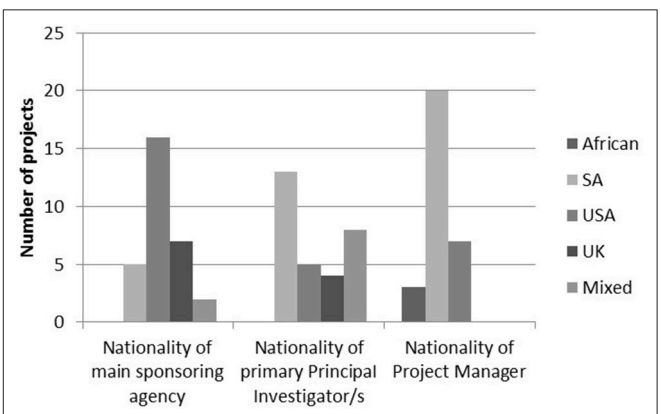


FIGURE 1 | Nationalities of main sponsoring agency, primary principal investigator/s, and project managers in 2018.

Study Procedures

This is a case study using multiple qualitative methods that included semi-structured individual, focus group and natural group interviews, ethnographic field notes, and critical incident scenarios (Crisp et al., 2005). The semi-structured individual, natural group, and focus group interviews were conducted with village residents, local leaders, and service providers all from within the study area. These interviews explored their experiences of being involved in the activities of the longitudinal research site. Interview guides were field-tested with the Community Advisory Group. Natural group interviews are group discussions that occur with people forming an existing group so all the participants know each other. Generally, they are based round a shared interest (Beckerleg et al., 1997; Green and Thorogood, 2009). Group interviews with resident groups were natural group interviews but the group interviews with village leaders and home-based carers were focus group interviews.

To recruit village residents, two villages with diverse characteristics were chosen—one far from and one close to the MRC/Wits-Agincourt Unit offices, one with a large and one a small population, and one with a higher and one a lower average household socio-economic status. A table outlining how many participants were needed from each village, ensuring gender and spread across three age groups (18–24, 25–49, and 50+ years). The fieldworkers recruited door-to-door until there were 24 eligible participants. None of the participants were known to the fieldworkers previously. Eight natural group interviews were also conducted with an average of ten participants in each group. Natural groups were made up of: older men who were assistants to the village chief and a group of cattle herders; younger men in a soccer team and in a traditional dance team; older women attending church or who drank tea together; younger women from a church group or a traditional dance team (**Table 1**). Interviews were conducted by two local, Shangaan speaking fieldworkers in 2016, at participant's homes or other locations of their choosing, and no one apart from the participants and the fieldworkers were present. To avoid socially desirable responses, the interviewers were trained to encourage critical views by explaining that only through these can practice be improved. The reasons for the research were also outlined in the consent form.

A purposive sample of 56 local leaders and service providers was selected from individuals working within organizations involved in governance or service provision at the village and sub-district level, and who were also resident in the study area. Some of these participants knew RT prior to the interviews. Recruitment and logistical arrangements were telephonic. There were 45 participants in the focus group interviews and 11 in individual interviews. Two representatives from village leadership from each of the 23 villages that had been involved in the HDSS for over 10 years, participated in four focus group interviews of between eight to eleven participants and the managers of eight home-based care organizations participated in another focus group interview (**Table 1**). Representatives from the traditional councils and municipalities, clinic, and education managers were all interviewed individually. The participants were aged between 25 and 70 years, and were balanced by gender. RT conducted these interviews and the natural group interviews along with a fieldworker in 2015/16. Interviews were undertaken in a venue in the village chosen by the participants, and no-one was present aside from the researchers and the participants.

Data from residents' interviews were analyzed by RT in 2018 focusing on ethics in practice. The emergent themes were informed consent, collection of body tissue samples, confidentiality, adverse events, referral vs. health care provision, end of study withdrawal and benefits such as the HDSS providing employment.

RT took field notes on ethics in practice incidents in the study area during 2015–2017. The purpose of these field notes was to capture and reflect through "thick description" (Geertz, 1973) on "ethically important moments" (Guillemin and Gillam, 2004: p. 266). In 2018, three critical incident scenarios (Crisp et al., 2005) were selected from the field notes depicting situations illustrating the ethics in practice issues that local residents had raised. They were on informed consent, giving back of individual screening results and adverse events. In this paper two are being used. All three scenarios were sent electronically to 10 purposively selected researchers who had been involved in nested studies in the Agincourt HDSS. The criteria for their selection were that they had worked within the study area on a nested study within the last 3 years and equal representation was given to researchers from South Africa and external to South Africa. The ten individuals included: principal investigators, research managers, project site managers, and project coordinators (**Table 2**). Any researcher who was employed by the HDSS was excluded; this involved 4 men and 1 woman. The researchers who met the criteria included 8 female and 2 male researchers. Gender was not a consideration in the selection of the sample, rather the focus was on having carried out research in the study area within the time period and not being an employee. All the researchers responded with reflections and comments. The case studies were anonymised so that the

TABLE 1 | Research participants living within the study area—"residents."

	Individual interviews	Group interviews
Local village residents	24	56 participants in 8 groups
Service providers and village leaders resident in the area	11	45 participants in 5 groups

TABLE 2 | Senior researchers and senior field staff responding to critical incidents—"researchers."

	Permanent resident or citizen in South Africa	International	Total
Senior researchers—principal investigators and project managers	1	4	5
Senior field staff—project site managers and project coordinators	4	1	5
Total	5	5	10

study was not identified, and as the researchers were sent the scenarios electronically and replied individually, there was no known sharing of reflections.

Participants were given 2 weeks to reflect on the scenarios and respond to two questions: "Describe how you would have taken action (if any) if you were in the research team involved" and "What issues does this scenario raise regarding ethics in practice (ethical issues that arise during fieldwork)?"

Analysis

All interviews were digitally recorded with the exception of one interview where the participant refused and field notes were taken. The recordings were translated and transcribed from Shangaan into English by the local fieldworkers. Transcripts were not returned to participants for comment as they had been transcribed directly from Shangaan recordings into English. Selected transcripts and questionnaires were read in full by RT and GH independently in order to identify emergent themes for the initial coding, which was both deductive following the topic guide and inductive in terms of emergent themes within the topics and in addition to the topics. QSR NVivo software (version 10) was used for the coding of interviews with residents. RT undertook manual thematic analysis for the data from researchers.

Ethics Approval and Consent

Ethical clearance was obtained from the University of the Witwatersrand's Human Research Ethics Committee (Medical) (Certificate numbers M140361 and M140737) and permission for interviewing service providers obtained from both the Mpumalanga Provincial Departments of Health and Education Research Offices. Written informed consent was gained from all participants prior to data collection.

RESULTS

Informed Consent

All interviewed residents had been participants in the annual HDSS census update and in various nested research projects, and reflected on their experiences of informed consent. Some residents mentioned that the process had been clear and that they had known what they were agreeing to, but there were instances where a resident, or a family member who had been approached to be a study participant, had not understood fully what agreeing to participate in the study involved.

> "If you don't understand, the field workers give you a chance to say that. They say that participating is voluntarily. You are allowed to say no. Even during the interview, they allow you to stop if you are not comfortable with their research." *Middle aged man 3, village 1*
>
> "The problem is that they don't say what is going to happen at the research laboratory. My grandmother was supposed to know what will happen to her. She needed to have more information." *Young woman 2, village 1*

Although some residents said that they had understood the reasons for the research, others said they had not. Residents also spoke about instances when they had asked the field workers questions about the reasons for the research, and the field workers themselves did not know.

> "I don't have a problem with these questions as the one who came explained everything. They were checking whether we are eating modern food only and not cultural food. That's why they are asking all these questions." *Older man 8, NGI village 2*
>
> "I don't want to be asked questions about food as they won't give me money to buy food afterwards. The problem is that they don't tell us why they are asking these questions. All they say is that they are working." *Older man 4, NGI village 2*

The majority of the residents described a high level of trust in the field workers employed in the MRC/Wits-Agincourt Unit, referred to as "Wits" locally. They said that the field workers were well trained and respectful.

> "They introduce themselves and they ask for your time. Though the research questions are not good, the field workers are respectful." *Older man 4*
>
> "When they approach your gate they are smiling, they greet you and they will introduce themselves, telling you where they come from. They will ask for your permission to work and afterwards they will say thank you." *Older man 1, NGI village 2*
>
> "If I have problems and I don't have someone to share my problems with, I can share with Wits people, particularly when that study is related to my problems." *Middle aged woman I, village 2*

The signing of consent forms without understanding the implications was raised as an issue for older participants. Owing to a high level of trust and respect for the field workers, residents thought that older people sometimes agreed to answer the questions even if they did not fully understand the reasons for the study.

> "Yes we understand most of the information on the informed consent. Some read it and sign with understanding. But with old people I think they don't understand everything it would be better if you read it when there is a relative there who can understand what you are saying. Old people will agree to anything as a sign of respect although they didn't understand. I think your field workers need to take their time in the field." *Middle aged woman 1, village 2*

Residents did talk about particular instances where they felt uncomfortable divulging confidential information to young field workers on sensitive issues such as the nested research studies on aging which have sexual behavior questionnaires that include topics such as frequency of having sex, multiple sexual partners, and contraception. Disclosing details about intimate sexual behavior with a young person was considered inappropriate and there were some doubts about confidentiality.

> "In our culture we were taught that you talk about sex in your bedroom with your partner. But with Wits, they send a young girl to an old person to ask those questions. We don't know whether they are going to keep the secrets as we don't know them. We used to lie." *Young woman 1, village 1*

As informed consent was a key concern to interviewees, the critical incident scenario in **Box 1**, summarized from RT's field notes was sent to 10 researchers.

Researchers' responses to this situation were that it is a complicated situation that has implications for the participant and the family, the study itself and for future nested studies in the longitudinal study area.

> "Firstly, there is need to protect the study from possible withdrawal by the participant and other participants which would affect other studies of the Unit. Secondly there is need to protect the life of the young girl by ensuring that she gets all the necessary clinical and family care. Thirdly there is need to protect the family from possible conflicts and disintegration." *Senior Field Staff 2*

Researchers talked about field workers, despite being trained, being under pressure and taking shortcuts in order to meet targets.

> "This brings up two issues. The first is the field worker violating protocol. Unfortunately, this happens despite careful training and a detailed protocol. Situations arise that are not straightforward (this situation is unlikely something the fieldwork team had discussed or planned for) and field workers do not always make the right choice and often do not ask their supervisors for advice. Field workers need to be trained to ALWAYS ask for advice and direction when in doubt of proper procedure. This kind of scenario requires further discussion and training." *Senior Research Staff 3*

Researchers, like the residents, also mentioned that older participants might have more difficulty understanding research processes.

> "The field worker was supposed to talk to the father directly and not via the grandmother. The field worker had more information about the study and HIV testing compared to the grandmother. The grandmother did not know the major issues surrounding HIV/AIDS." *Senior Field Staff 2*

Researchers spoke about the importance of field worker training and quality assurance procedures being in place to ensure that proper informed consent practices are followed.

> "The training for the field workers needs to revised and reinforced and maybe the research manager should consider whether there are adequate on-going quality checks" *Senior Researcher 5*

Giving Individual Results From Clinical Screening Conducted as Part of a Study

Increasing numbers of studies in the site include some form of clinical screening in addition to interviews. For example, this can be measuring blood pressure, taking venous blood for glucose levels, dry blood spots for HIV testing or collecting urine samples. Residents liked having their individual results from these tests immediately.

> "Researchers came to my house and checked us, blood was taken by pricking our fingers and results were given at the same time. They also checked our blood pressure.… this helped me …as I was given the results at the same time. I was happy as they came to our home and checked the whole family including the elders. We were all given the results. I remember my mother's blood pressure was high as she was angry that morning. She was told and given a referral letter to the clinic and she came back home with treatment." *Young man 1, NGI village 1*

However, there were many instances where residents talked about either themselves or people they knew who had had blood taken and did not receive their results.

> "But there is a participant who told me……..they had taken a lot of blood and this worried him a lot because he didn't get any results after they took his blood." *Headman 2*

In the past, for tests without immediate results participants were sometimes referred to the clinics to get their results. Residents felt that if the researchers could arrange to collect tissue samples at participants' homes, or transport participants to the research laboratory to collect samples, results should be delivered to them personally at home. The clinic managers also expressed challenges with giving research screening results as there were delays in getting the research results to the clinics, and participants became irritated.

> "You cannot take blood from one person but not give results. Then you come again and you want to collect more blood for another study. Where is the first blood? Where did you send it? People need their own results and not as a group. My child's [nasal] mucus was taken, but there are no results. I think that is wrong.…. Bring back your findings. If you can do so, people will be interested to participate. That's my request." *Young woman 2, village 1*

Box 1 | Scenario on informed consent.

The recruitment of young women for a study involved consenting for HIV testing. In this case, the young woman was 13 years old and lived with her maternal grandmother. Her father lived elsewhere and her mother died 9 years previously. As per approved procedures, the father was called by cell-phone to obtain consent for the caregiver (grandmother) to provide consent for the young woman's participation in the study. The field worker did not speak directly to the father, but allowed the grandmother to conduct the conversation—and the grandmother did not inform him of the HIV testing component of study enrolment. This constituted a protocol violation as the field worker should have personally had this discussion with the father. The father and grandmother and the young woman consented. The young woman was found to be HIV positive during testing and she told her grandmother the result of the test. The father contacted the study team, angry that his daughter was tested without his permission. It appears that the young woman was infected perinatally and that her father had not informed her, nor her grandmother of her status.

"A challenge I had was that there are those who are being tested for HIV at their homes and being given stickers to come to the clinic for the results. Someone in the clinic had to check for their results in the computer. The results were not available even though it was after quite a long period. That can lead people to not accept field workers the next time because they have had a bad experience." *Clinic operations manager 3*

Residents, particularly service providers and local leaders, were clear that more consultation earlier in the research process would be helpful to everyone.

"We need to consult with the community. Then the community will come up with ideas of how exactly we can improve." *Participant 7, FGI4 CDF*

Given that getting individual screening results was an important concern in almost all the interviews, the following scenario in **Box 2**, based on field notes about an actual critical incident, was sent to 10 researchers for their views.

All the 10 researchers wrote that it was ethically important to give participants back results from screening tests. Some acknowledged that although research may only have policy impact later on, more immediate benefit to participants is important and a right.

"If you are going to require them to give you their time and physical bodies for your research then you must show respect by letting them know the results of the test you are conducting, particularly if it is a test that is of high burden in their community and could save their life and the lives of other people." *Senior Research Staff 3*

Researchers also wrote that giving back of results would assist future studies in the longitudinal health research area, by helping to maintain trust.

"We have to do this to prevent refusals and the researchers must not take advantage of people participating in their study.…if they [participants] think that they have been used but didn't get their results, they will refuse when other studies similar to that one come." *Senior Field Staff 3*

"It also raises an issue of partnership ethics. The US partner is weighing their needs higher than the local implementing partner which is also a violation of respect for persons. Given the local budget is running the project I would emphasize the US partner needs to be more accommodating, as without the local buy in, there is no study." *Senior Research Staff 3*

Box 2 | Scenario on giving back results.

An information sheet and informed consent form was sent to the Public Engagement Office for review. Participants were being asked to give a blood sample for HIV testing, but there was no mention in the informed consent of how the participants were going to be given the HIV test results. Upon follow up with the Principal Investigators, it was confirmed that there was no plan for reporting back individual HIV results to participants, and no budget for this. It emerged that the US partner in the study had previously requested more money from the budget for study costs in the US, and this request had been accommodated by the investigating team.

Researchers problematized the giving back individual results as part of research activities, but were clear it was sensitive and required planning, consultation and funding. A researcher noted that there is a tension between availability of funds and costs of giving back individual screening results, and that international researchers needed to be mindful of fair benefit and researcher accountability to the experimental public.

"….giving back the results …. must be done carefully. The research participants must consent and suggest where he/she would be comfortable to get the results. Some would not be happy to have their results at the clinic and that needs to be considered." *Senior Field Staff 2*

"Research should be adequately funded, allowing for treating the participants with consideration and dignity. Maybe, in future, this should be considered earlier in the development process." *Senior Research Staff 5*

Researchers also mentioned the importance of thinking about giving back of results during the project planning phase, and including local researchers and residents in project planning.

"Why was reporting of individual results not a priority during proposal and budget development? What did the study team plan to do when they got the HIV results?" *Senior Field Staff 4*

DISCUSSION AND CONCLUSION

The findings from this study using multiple qualitative methods have implications for widening participation of the experimental public as part of study processes in longitudinal health research sites. Issues that arose relating to informed consent and giving of individual results from screening tests are discussed.

Public health research studies often involve complicated field work processes, with multiple informed consent sheets. It is clear from the results that the resident interviewees felt that sometimes neither participants or field workers fully understood study activities, nor the reasons for the research itself. This was reported as being more of an issue with older people. Age differences between participants and field workers was important when older participants were reported as being reluctant to answer questions on their sexual behavior to young field workers, or those of a different gender to themselves.

Residents also reported that, especially but not only for older people, a high level of trust in and respect for field workers influenced participants to sign consent forms despite not understanding the implications. Researchers said that if information in the consent was misunderstood, or not understood, and unrealistic expectations raised, there would be implications for the participant, his/her family, the study itself as well as for future studies in the study area.

The results in this paper reinforce previous findings that informed consent is often complex and requires careful attention. Molyneux et al. (2005) also highlight that the decision to sign an

informed consent may be made because of a high level of trust in the field worker and the research institution, or because of real or perceived benefits from the study. Kamuya et al. (2015) and Tekola et al. (2009) discuss the complexities of gaining informed consent in research studies, noting the importance of how and what information is presented, and that cultural issues affect the decision to sign consent. Field worker training and support can mitigate ethical issues that occur in the field (Tekola et al., 2009; Kamuya et al., 2015) and it is clear that training at the onset of a study needs to be followed up with frequent monitoring and supervision of the field workers on the taking of informed consent. Calls for standardized training for field workers have been made at a workshop in 2015 involving nine African longitudinal health research institutions in Kombe (2015).

Cultural considerations regarding older people's lack of trust in younger fieldworkers, or of younger fieldworkers contravening cultural practices through having to ask sensitive questions to their elders have also been discussed in relation to informed consent in other HDSS study areas (Tekola et al., 2009; Kamuya et al., 2015). The older population in this study area understands research to a lesser extent than the fieldworkers owing to disparities in access to education during the apartheid area. In 2010, one study in the HDSS found that of 5,056 people aged 50 years and over, over 55% had no formal education and 24% had six or less years of education (Ameh et al., 2014). Owing to cultural changes, younger fieldworkers may respect their elders less than in the past (Stadler, 2003). This may lead to elders being submissive, or untruthful in their responses. A current related dilemma in this research setting, is that younger fieldworkers, owing to greater access to post-secondary education post-apartheid, are more likely to be appointed as fieldworkers than applicants who are older. This is considered a benefit by the population in the area, as youth unemployment is extremely high. These fieldworkers are also more likely to understand research and be able to use technology which is vital as data collection has moved from being paper-based to electronic.

Participants appreciated receiving individual results at the time of doing the screening tests, but were clear that results from samples sent off for testing should be delivered personally, or given at the time of doing the test, whether positive or negative. Researchers agreed that there was an ethical imperative to give participants their results, both immediately from screening tests and for those that were sent away for analysis, were positive and clinically relevant and for which treatment was available locally. This would benefit individuals, and future research studies would also benefit as participants would feel that their dignity and interests was being respected and would be more willing to participate in further studies. Researchers wrote that giving individual results required careful planning and resourcing, needed to be included from the proposal development stage, and that this consideration of fair benefit may require budgetary adjustments.

Supporting the findings from Bledsoe et al. (2012), no adverse events were reported by participants regarding receiving individual screening test results, and giving individual results seemed to create a positive attitude toward research, and was seen as a fair benefit from the research (Shalowitz and Miller, 2005; CIOMS, 2016). Provision of individual screening results as part of public health research in general rather than specifically in longitudinal settings is only mentioned in one guideline ICH-GCP (1996) in Lairumbi et al.'s (2011) review of research ethics guidelines. It is clear from this paper that participants view this as a real benefit. In countries such as South Africa, where there is primary health care free for many conditions, there may be less risk of therapeutic misconceptions (Appelbaum et al., 1987; Molyneux et al., 2005) when giving individual test results.

Currently in this HDSS, consultation with the PEO and the CAG often only occurs after proposals have been written, funded and ethical approvals obtained. Widening participation through mechanisms for consultation with residents and researchers regarding activities in a longitudinal health study area could assist in guiding decisions around governance in all these research activities, in order to enhance both accountability of researchers and fair benefit (Bäckstrand, 2003; Emmanuel et al., 2004; Levine, 2011; Kamuya et al., 2013; Molyneux and Bull, 2013,; Simwinga et al., 2018).

Implications for Practice in Longitudinal Health Study Areas

These issues are not unique to this rural, South African setting and there are implications for other longitudinal health study areas globally. There is a need to identify strategies and mechanisms to ensure increased accountability of researchers and stronger participatory governance through involvement of the experimental public in all aspects of longitudinal public health research as part of ethics in practice. From these findings, two strategies have been identified by researchers and residents: improved field worker training and ongoing supervision during data collection, and increased involvement of residents in protocol development, data collection and dissemination.

Development of accredited training modules on informed consent and other ethics in practice for field workers is one strategy to address some of the informed consent issues. More time needs to be budgeted for training, so that research teams can be certain that fieldworkers understand the reasons for the research and the fieldwork processes. Understanding findings from prior research in the study area will allow fieldworkers to better understand the reasons for the research and possibly allow for more targeted dissemination of findings to participants. In areas where research is conducted in collaboration with external principal investigators and research managers, adequate orientation on public engagement, field operations, and ongoing supervision requirements for fieldwork is needed. In this HDSS, there are frequent meetings between on-site research managers and field teams. One possible way forward could be to have a monthly ethics in practice forum for fieldworkers and research staff to reflect on ethical dilemmas encountered in the field. These are essential to supporting fieldworkers, and allow for team discussion around dilemmas that may arise. Additionally, monthly meetings between research managers of different nested projects to discuss fieldwork issues enhances their ability to manage fieldwork. Clear guidelines for principal investigators

and research managers outlining requirements for protocols, management of ethical issues, public participation, training, and monitoring of fieldworkers also need to be in place and accessible.

One strategy for widening participation is a CAG (Lairumbi et al., 2011; Simwinga et al., 2018). CAG members need adequate training and a constitution that is upheld, for example regarding length of terms of office. With the growth of nested research studies in this HDSS, monthly CAG monthly meetings cannot engage with the detail and governance of each project so Study Advisory Groups were established to advise on information sheets, review topic guides and advise during data collection and dissemination.

Other strategies to widen participation in longitudinal health research areas could include more considered approaches to recruitment and deployment of fieldworkers, ensuring for example that female fieldworkers interview female participants if there are sensitive issues to be discussed, more focused dissemination of research results to specific audiences, monitoring of reasons for refusal to participate and suggestion boxes in the study area. A number of these strategies have been implemented in the study area already, and more strategies to widen participation are planned, including regular focus groups with individuals and service providers around their experience of living and working in this study area. A key lesson learnt during implementation of strategies to widen participation is that it is not possible to include all residents in the study area, and champions are important, but representation needs careful consideration. Public participation in research is not static, and continued assessment of existing strategies is required, consultation and development of new relationships should be ongoing (Lavery et al., 2010).

This paper builds on and extends previous work on ethics in practice in longitudinal health research areas. It highlights the importance of widening the participation of residents who form the experimental public in research governance mechanisms in these settings in order to ensure the longevity of these institutions. Widening participation is intrinsic to the democratization of science as a public good (Bäckstrand, 2003; Levine, 2011) and can enhance both the lives of research participants and the quality of the research.

ETHICS STATEMENT

Ethical clearance was obtained from the University of the Witwatersrand's Human Research Ethics Committee (HREC) (Medical) (Certificate numbers M140361 and M140737) and permission for interviewing service providers obtained from both the Mpumalanga Provincial Departments of Health and Education Research Offices. Written informed consent was gained from all participants prior to data collection.

AUTHOR CONTRIBUTIONS

RT, GL, and KK planned the study. RT implemented the study and RT conducted the analysis and linked the findings to the literature, supported by GL. KK provided critical revision of the manuscript.

FUNDING

This project was supported by the University of the Witwatersrand, the South African Medical Research Council, the South African National Research Foundation through their Community Engagement Funding Instrument (Grant 93314), the EU Marie Curie Improving Population Health Through Research Exchanges' (IPHTRE) grant and the Wellcome Trust (Grants 058893/Z/99/A; 069683/Z/02/Z; 085477/Z/08/Z; 085477/B/08/Z) that supported the health and socio-demographic surveillance system.

ACKNOWLEDGMENTS

Without the participation of the people living and working in the Agincourt HDSS study area, none of this work would be possible. We thank Jocelyn Watkins, Violet Ndlovu, and Meriam Maritse who assisted with data collection and transcription.

REFERENCES

Allotey, P., Reidpath, D. D., Devarajan, N., Rajagobal, K., Yasin, S., Arunachalam, D., et al. (2014). Cohorts and community: a case study of community engagement in the establishment of a health and demographic surveillance site in Malaysia. *Glob. Health Action* 7:23176. doi: 10.3402/gha.v7.23176

Ameh, S., Gómez-Olivé, F. X., Kahn, K., Tollman, S. M., and Klipstein-Grobusch, K. (2014). Predictors of health care use by adults 50 years and over in a rural South African setting. *Glob. Health Action*. 7:24771. doi: 10.3402/gha.v7.24771

Appelbaum, P. S., Roth, L. H., Lidz, C. W., Benson, P., and Winslad, W. (1987). False hopes and best data: consent to research and the therapeutic misconception. *Hastings Cent. Rep.* 17, 20–24. doi: 10.2307/3562038

Bäckstrand, K. (2003). Civic science for sustainability: reframing the role of experts, policy-makers and citizens in environmental governance. *Glob. Environ. Politics* 3, 24–41. doi: 10.1162/152638003322757916

Beckerleg, S., Lewando Hundt, G., Belmaker, I., Abu Saad, K., and Borkan, J. (1997). Eliciting local voices - the use of natural group interviews. *Anthropol. Med*. 4, 273–288.

Bledsoe, M. J., Grizzle William, E., Clark Brian J, and Zeps N. (2012). Practical implementation issues and challenges for biobanks in the return of individual research results. *Genet. Med.* 14, 478–483. doi: 10.1038/gim.2011.67

CIOMS (2016). *International Ethical Guidelines for Health-related Research Involving Humans*. Geneva: WHO.

Collinson, M. A., White, M. J., Bocquier, P., McGarvey, S. T., Afolabi, S. A., Clark, S. J., et al. (2014). Migration and the epidemiological transition: insights from the Agincourt sub-district of northeast South Africa. *Glob. Health Action* 7:23514. doi: 10.3402/gha.v7.23514

Crisp, B., Green Lister, P., and Dutton, K. (2005). *Integrated Assessment: New Assessment Methods Evaluation of an Innovative Method of Assessment-Critical Incident Analysis*. Working paper. Glasgow: Scottish Institute for Excellence in Social Work Education. Available online at: https://strathprints.strath.ac.uk/id/eprint/38310

Duombo, O. K. (2005). It takes a village: medical research and ethics in Mali. *Science* 307, 679–681. doi: 10.1126/science.1109773

Emmanuel, E. J., Wendler, D., Killen, J., and Grady, C. (2004). What makes clinical research ethical in developing countries. *J. Int. Dev.* 189, 930–937. doi: 10.1086/381709

Fortmann, L. (2014). Giving back, moving forward. *J. Res. Pract.* 10:M10. Available online at: http://jrp.icaap.org/index.php/jrp/article/view/399/353

Gaziano, T. A., Abrahams-Gessel, S., Gomez-Olive, F. X., Wade, A., Crowther, N. J., Alam, S., et al. (2017). Cardiometabolic risk in a population of older adults with multiple co-morbidities in rural South Africa: the HAALSI (Health and Aging in Africa: longitudinal studies of INDEPTH communities) study. *BMC Public Health* 17:206. doi: 10.1186/s12889-017-4117-y

Geertz, C. (1973). "Thick description: toward an interpretive theory of culture," in *The Interpretation of Culture: Selected Essays by Clifford Geertz* (New York, NY: Basic Books), 3–20. Available online at: https://chairoflogicphiloscult.files.wordpress.com/2013/02/clifford-geertz-the-interpretation-of-cultures.pdf

Geissler, P. W., and Molyneux, C. (2011). *Evidence, Ethos and Ethnography: The Anthropology and History of Medical Research in Africa*. Oxford: Berghahn Books.

Gómez-Olivé, F., Angotti, N., Houle, B., Klipstein-Grobusch, K., Kabudula, C., Menken, J., et al. (2013). Prevalence of HIV among those 15 and older in rural South Africa. *AIDS Care* 25, 1122–1128. doi: 10.1080/09540121.2012.750710

Green, J., and Thorogood, N. (2009). *Qualitative Methods for Health Research, 2nd Edn*. Thousand Oaks, CA: Sage.

Guillemin, M., and Gillam, L. (2004). Ethics, reflexivity, and "ethically important moments in research. *Qual. Inq.* 10, 261–280. doi: 10.1177/10778004032 62360

Harris, B., Eyles, J., Penn-Kekana, L., Thomas, L., and Goudge, J. (2014). Adverse or acceptable: negotiating access to a post-apartheid health care contract. *Glob. Health* 10:35. doi: 10.1186/1744-8603-10-35

HPTN (2009). By Rennie, S. and Sugarman, J. and the HPTN Ethics Working Group. Bethesda, MD, NIAID: National Institutes of Health

ICH-GCP (1996). *International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use. Guideline for Good Clinical Practice E6(R1)*. Available online at: https://www.ich.org/fileadmin/Public_Web_Site/ICH_Products/Guidelines/Efficacy/E6/E6_R1_Guideline.pdf

INDEPTH (2012). *INDEPTH Network*. Retrieved 10 December 2012. Availabile online at: http://www.indepth-network.org/

Kahn, K., Collinson, M. A., Gómez-Olivé, F. X., Mokoena, O., Twine, R., Mee, P., et al. (2012). Profile: Agincourt health and socio-demographic surveillance system. *Int. J. Epidemiol.* 41, 988–1001. doi: 10.1093/ije/dys115

Kamuya, D. M., Marsh, V., Kombe, F. K., Geissler, W. P., and Molyneux, S. C. (2013). Engaging communities to strengthen research ethics in low-income settings: selection and perceptions of members of a network of representatives in coastal Kenya. *Dev. World Bioeth.* 13, 10–20. doi: 10.1111/dewb.12014

Kamuya, D. M., Theobald, S. J., Marsh, V., Parker, M., Geissler, W. P., and Molyneux, S. C. (2015). "The one who chases you away does not tell you go": silent refusals and complex power relations in research consent processes in Coastal Kenya. *PLoS ONE* 10:e0126671. doi: 10.1371/journal.pone.01 26671

Kelly, A. H., MacGregor, H., and Montgomery, C. M. (2016). The publics of public health in Africa. *Crit. Public Health* 27, 1–5. doi: 10.1080/09581596.2016.1254178

Kombe, F. (2015). Enhancing quality and integrity in biomedical research in Africa: an international call for greater focus, investment and standardisation in capacity strengthening for frontline staff. *BMC Med. Ethics* 16:77. doi: 10.1186/s12910-015-0071-3

Lairumbi, G. M., Michael, P., Fitzpatrick, R., and English, M. C. (2011). Ethics in practice: the state of the debate on promoting the social value of global health research in resource poor setting particularly Africa. *BMC Public Health* 12:22. doi: 10.1186/1472-6939-12-22

Lavery, J. V., Tindana, P. O., Scott, T. W., Harrington, L. C., Ramsey, J. M., Ytuarte-Nuñez, C., et al. (2010). Towards a framework for community engagement in global health research. *Trends Parasitol.* 26, 279–283. doi: 10.1016/j.pt.2010.02.009

Levine, P. (2011). Seeing like a citizen: the contributions of elinor ostrom to civic studies. *Good Soc.* 20, 3–14. doi: 10.1353/gso.2011.0010

MacQueen, K. M., Bhan, A., Frohlich, J., Holzer, J., and Sugarman, J. (2015). Evaluating community engagement in global health research: the need for metrics. *BMC Med. Ethics* 16: 44. doi: 10.1186/s12910-015-0033-9

Molyneux, C., Goudge, J., Russell, S., Chuma, J., and Gumede, T. (2009). Conducting health-related social science research in low income settings: ethical dilemmas faced in Kenya and South Africa. *J. Int. Dev.* 21, 309–326. doi: 10.1002/jid.1548

Molyneux, C. S., Peshu, N., and Marsh, K. (2005). Trust and informed consent: insights from community members on the Kenyan coast. *Soc. Sci. Med.* 61, 1463–1473. doi: 10.1016/j.socscimed.2004.11.073

Molyneux, S., and Bull, S. (2013). Consent and community engagement in diverse research contexts: reviewing and developing research and practice. participants in the community engagement and consent workshop, Kilifi, Kenya, March 2011. *J Empir Res Human Res Ethics* 8, 1–18. doi: 10.1525/jer.2013.8.4.1

Molyneux, S., Kamuya, D., Madiega, P. A., Chatler, T., Angwenyi, V., and Geissler, P. W. (2013). Fieldworkers at the interface. *BMC Med. Ethics* 13, ii–iv. doi: 10.1111/dewb.12027

Molyneux, S., Mulupi, S., Mbaabu, L., and Marsh, V. (2012). Benefits and payments for research participants: experiences and views from a research centre on the Kenyan coast. *BMC Med. Ethics* 13:13. doi: 10.1186/1472-69 39-13-13

Montgomery, C. M., and Pool, R. (2017). From trial community; to "experimental publics": how clinical research shapes public participation. *Crit. Public Health* 27, 50–62. doi: 10.1080/09581596.2016.1212161

Murphy, J., Scott, J., Kaufman, D., Geller, G., LeRoy, L., and Hudson, K. (2008). Public expectations for return of results from large-cohort genetic research. *Am. J. Bioeth.* 8, 36–43. doi: 10.1080/15265160802513093

Niehaus, I., Mohlala, E., and Shokane, K. (eds.). (2001). *Witchcraft, Power, and Politics: Exploring the Occult in the South African Lowveld*. London: Pluto Press.

Nuffield Council on Bioethics (2002). *The Ethics of Research Related to Healthcare in Developing Countries, 2002*. Available online at: http://nuffieldbioethics.org/wp-content/uploads/2014/07/Ethics-of-research-related-to-healthcare-in-developing-countries-I.pdf

Participants in the 2001 Conference on ethical aspects of research in developing countries (2002). Fair benefits for research in developing countries (2001). *Science* 298:2133. doi: 10.1126/science.1076899

Pettifor, A., MacPhail, C., Hughes, J. P., Selin, A., Wang, J., Gómez-Olivé, F. X., et al. (2016). The effect of a conditional cash transfers on HIV incidence in young women in rural South Africa (HPTN 068): a phase 3, randomised controlled trial. *Lancet Glob. Health* 4, e978–e988. doi: 10.1016/S2214-109X(16)30253-4

Shalowitz, D. I., and Miller, F. G. (2005). Disclosing individual results of clinical research implications of respect for participants. *JAMA*. 294, 737–740. doi: 10.1001/jama.294.6.737

Simwinga, M., Porter, J., and Bond, V. (2018). Who is answerable to whom? Exploring the complex relationship between researchers, community and Community Advisory Board (CAB) members in two research studies in Zambia. *Crit. Public Health*. 28, 1–11. doi: 10.1080/09581596.2018.14 40072

South African Department of Health (2007). *Guidelines for Good Practice in the Conduct of Clinical Trials in Human Participants in South Africa*. Pretoria: Government Printers.

South African Government (1996). *Constitution of the Republic of South Africa, Act 108 of 1996*. Pretoria: Government Printers.

Stadler, J. (2003). Rumor, gossip and blame: implications for HIV/AIDS prevention in the South African Lowveld. *AIDS Educ. Prevent.* 15, 357–368. doi: 10.1521/aeap.15.5.357.23823

Tekola, F., Bull, S. J., Farsides, B., Newport, M. J., Adeyemo, A., Rotimi, C. N., et al. (2009). Tailoring consent to context: designing an appropriate consent process for a biomedical study in a low income setting. *PLoS Negl. Trop. Dis.* 3:e482. doi: 10.1371/journal.pntd.0000482

Thorogood, M., Goudge, J., Bertram, M., Chirwa, T., Eldridge, S., Gómez-Olivé, F. X., et al. (2014). The Nkateko health service trial to improve hypertension management in rural South Africa: study protocol for a randomised controlled trial. *Trials* 2014:435. doi: 10.1186/1745-6215-15-435

Tindana, P. O., Singh, J. A., Shawn, T. C., Upshur, R. E., Daar, A. S., Singer, P. A., et al. (2007). Grand challenges in global health; community

engagement in research in developing countries. *PLoS Med.* 4, 1–5. doi: 10.1371/journal.pmed.0040273

Tollman, S. (2008). *Closing the Gap: Applying Health and Socio-Demographic Surveillance to Complex Heatlh Transitions in South and Sub-Saharan Africa*. Ph.D., Umeå University.

Twine, R., Hundt, G. L., and Kahn, K. (2017). The "experimental public" in longitudinal health research: views of local leaders and service providers in rural South Africa. *Glob. Health Res. Policy* 2:26. doi: 10.1186/s41256-017-0046-7

UK National Institute for Health Research (2014). *Patient and Public Involvement in Health and Social Care Research: A Handbook for Researchers*.

UNAIDS/WHO (2007). *Ethical Considerations in Biomedical HIV Prevention Trials*.

United Nations (1948). *Universal Declaration of Human Rights*. Geneva: UNAIDS/World Health Organization.

Ye, Y., Wamukoya, M., Ezeh, A., Emina, J. B., and Sankoh, O. (2012). Health and demographic surveillance systems: a step towards full civil registration and vital statistics system in sub-Sahara Africa? *BMC Public Health* 12:741. doi: 10.1186/1471-2458-12-741

Conflict of Interest Statement: RT and KK both work for the MRC/Wits-Agincourt Unit in which this study was undertaken.

The remaining author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Copyright © 2019 Twine, Lewando Hundt and Kahn. This is an open-access article distributed under the terms of the Creative Commons Attribution License (CC BY). The use, distribution or reproduction in other forums is permitted, provided the original author(s) and the copyright owner(s) are credited and that the original publication in this journal is cited, in accordance with accepted academic practice. No use, distribution or reproduction is permitted which does not comply with these terms.

Paper 4

Gateways: International Journal of Community Research and Engagement

Vol 10 (2017)

Assessing the Effectiveness of a Longitudinal Knowledge Dissemination Intervention

Sharing Research Findings in Rural South Africa

Rhian Twine
Kathleen Kahn
University of the Witwatersrand
Gillian Lewando Hundt
University of Warwick

© 2017 by R Twine, K Kahn & G Lewando Hunt. This is an Open Access article distributed under the terms of the Creative Commons Attribution 4.0 Unported (CC BY 4.0) License (https://creativecommons.org/licenses/by/4.0/), allowing third parties to copy and redistribute the material in any medium or format and to remix, transform, and build upon the material for any purpose, even commercial, provided the original work is properly cited and states its license.

Citation: Twine, R, Kahn, K & Lewando Hunt, G 2017, 'Assessing the effectiveness of a longitudinal knowledge dissemination intervention: Sharing research findings as part of knowledge brokerage in rural South Africa', *Gateways: International Journal of Community Research and Engagement*, vol. 10, pp. 143–163. doi: 10.5130/ijcre.v10i1.5111

Corresponding author:
Rhian Twine
Rhian.Twine@wits.ac.za

DOI: http://dx.doi.org/10.5130/ijcre.v10i1.5111

ISSN 1836-3393
Published by UTS ePRESS
http://epress.lib.uts.edu.au/journals/index.php/ijcre/index

Health and demographic surveillance systems (HDSSs) carry out longitudinal research and operate in geographically defined areas (Sankoh & Byass 2012). Most HDSSs are located in sub-Saharan Africa and Asia, and are generally situated in rural, resource-poor settings. HDSSs collect population data including births,deaths, in-migrations and out-migrations, as well as health and socio-economic data. Following the baseline census of a defined geographic area, data is collected through regular census rounds during which household and individual characteristics are updated, and thus characteristics of the population living within the HDSS study area are monitored (Ye et al. 2012).

The setting for this article is the South African Medical Research Council/University of the Witwatersrand Rural Public Health and Health Transitions Research Unit (Agincourt) (MRC/Wits-Agincourt Unit) that has run a HDSS in rural northeast South Africa since 1992 (Kahn et al. 2012). The HDSS was established towards the end of the apartheid era in order to gather annual health and population data to inform the future development of a post-apartheid district health system (Tollman 1999). Despite progressive health/other policies in the post-apartheid era, inequalities persist (Naidoo 2012). Two decades after democratic change was introduced in 1994, findings from the annual census updates and nested health and social studies in the study area continue to contribute to health policy and planning in South Africa (Tollman 2008). These findings indicate rapid health, social and demographic transitions. The objectives of the MRC/Wits-Agincourt Unit have expanded to include reasons for these transitions, cross-site collaboration and facilitation of public access to datasets (Kahn et al. 2012).

The longitudinal nature of HDSSs necessitates the fostering of continuing relations between university researchers, participants, policy-makers and service providers. This is particularly important when there are inequities in power and information between the researchers, research participants and those who use the research information (Nuffield Council on Bioethics 2002) – as is the case in most HDSS settings. The concept

of civic science (Bäckstrand 2003) promotes public engagement by research institutions with participants, policy-makers and the wider public as a strategy that addresses these inequities.

One strand of public engagement with research is the dissemination of research findings (Lavery et al. 2010). Knowledge dissemination is part of public engagement programs at some HDSS sites, as in the KEMRI-Wellcome Trust Research Programme (Marsh et al. 2008), the Navrongo Health Research Centre in Ghana (Tindana et al. 2011) and the MRC/Wits-Agincourt Unit in South Africa (Madhavan et al. 2007), but are not always routinely included, as in the Niakhar HDSS in Senegal (Mondain et al. 2016). Through the International Network for the Demographic Evaluation of Populations and their Health (INDEPTH) some HDSS sites work together in various research areas including migration and mortality; however, a common platform for work in knowledge dissemination across INDEPTH HDSSs is yet to emerge. There is increasing interest among funding agencies such as the Wellcome Trust and the Economic and Social Research Council UK for evidence around best practice in public engagement activities and public engagement practitioners are also beginning to form networks such as the online MESH Network supported by the Global Health Network.

This article examines a knowledge dissemination intervention (KDI) of the MRC/Wits-Agincourt Unit focusing on the annual sharing of research results to the population and service providers within it's study area from 2001 to 2015. It presents a single, longitudinal case study (Yin 1994) of this KDI as part of broader knowledge brokerage activities, using the evaluation framework proposed by Lafrenière et al. (2013) to assess effectiveness. The main objective of this KDI is to share research findings with villagers, village leaders and service providers in the study area in order to: increase knowledge acquisition about research activities and study results; change the attitudes of participants and service providers so that multi-directional, collaborative discussion can occur regarding the relevance of research; and positively influence participants' and service providers' practices in individual and public health. We analyse data from annual KDI reports from 2001 to 2015, 762 feedback questionnaires of attendees, and qualitative interviews involving 60 local leaders/service providers undertaken in 2015–2016, and discuss the activities of the public engagement office (PEO), established in 2004 by the MRC/Wits-Agincourt Unit, while undertaking this KDI. In response to the research question, 'What is the effectiveness of this KDI as measured by knowledge acquisition and changes in attitudes and practices of the residents and service providers in the case study area?', the data suggests modest impact, and a number of ongoing challenges. In conclusion, the authors suggest ways to improve effectiveness, which would be of interest to other practitioners working in KDIs in similar contexts.

LITERATURE REVIEW

Terms such as 'knowledge dissemination', 'transfer' and 'translation' are often used interchangeably, as shown by Lafrenière et al. (2013) in their systematic review of the effectiveness of KDIs. A KDI can be defined as 'an active intervention that aims at communicating research data to a target audience via determined channels, using planned strategies for the purpose of creating a positive impact on the acquisition of knowledge, attitudes and practice' (Lafrenière et al. 2013, p. 2). KDIs can be implemented through for example meetings, debates and other interactive activities, websites, distribution of fact sheets and policy briefs, to a range of audiences ranging from lay persons to policy-makers (Mondain et al. 2016). KDIs have a number of components: a clear message, a specific audience, a particular format, a plan for delivery and an evaluation of effectiveness, which necessitates the articulation of a clear aim. The characteristics of the target audience will determine the wording of the message and the method that is used for its delivery and evaluation (Kothari & Armstrong 2011).

Despite nearly 20 years of calls for greater public engagement in health research (Dickert & Sugarman 2005; Tindana et al. 2007), there is relatively little evaluation of the effectiveness of KDIs. In 2003 it was reported that only one in 10 of 175 applied research organisations in Canada evaluated KDIs for their effectiveness (Lavis et al. 2006). In a systematic review by Lafrenière et al. (2013), 11 of 19 KDIs that had been evaluated for effectiveness focused on the dissemination of results to health professionals, not to research participants, (Bhattacharyya et al. 2011; Mitton et al. 2007; Ward et al. 2009) and generally showed changes in knowledge and attitudes but rarely in practices. Lafrenière et al. (2013) identified a framework for evaluating the effectiveness of KDIs, focussing on knowledge acquisition, changes in attitudes and changes in practices. They suggest that evaluating knowledge acquisition can be achieved by assessing if the KDI has increased participants' knowledge base, while changes in attitudes can be assessed by determining whether or not participants agree with the information presented and could accept it. Changes in practices can be assessed through examining actions taken after the KDI. Apart from the general paucity of evaluation on the effectiveness of KDIs, there is a specific lack of evaluation on longitudinal KDIs (Madhavan et al. 2007).

Often researchers give less attention to the dissemination – and, by implication, reception – of research findings to participants and beneficiaries than they do to academic peers and policy-makers. The voices of participants and local service providers, especially in poorly resourced areas, are seldom considered, even when they are themselves expected to transfer research findings into practice (Molyneux & Geissler 2008). Knowledge dissemination of research findings, with interactive, multi-directional discussion between researchers, participants and

service providers, can help in enhancing benefits (Tindana et al. 2007) and is part of the ethics of practice in research (Guillemin & Gillam 2004). Collaborative discussions about research can help to shift research agendas to be more relevant to the needs of participants and service providers, and this is particularly important in developing countries (CIOMS 2016).

There is currently an increased focus on the role of knowledge brokerage in developing collaborative links between researchers and stakeholders, as a means to increase knowledge transfer and translation, and build users' capacities to apply relevant findings to policy and practice (Meyer 2010). There is increasing pressure on governments and service providers to develop evidence-based policy and practice (Gilson & McIntyre 2008, Strydom et al. 2010). This is slowly creating a 'pull' for the provision of relevant research results through knowledge brokers, moving from unilateral dissemination to multi-directional creation and use of information (Godfrey et al. 2010).

Theoretical approaches to knowledge brokerage include the dissemination model and the systemic model, and both identify interpersonal contact as essential to effective knowledge brokerage (Dagenais et al. 2015). A recent systematic review by Bornbaum et al. (2015) analysed 29 articles on the role of knowledge brokers and identified 10 key domains of knowledge brokerage activity (p. 5):

1 Identify, engage and connect with stakeholders
2 Facilitate collaboration
3 Identify and obtain relevant information
4 Facilitate development of analytic and interpretive skills
5 Create tailored knowledge products
6 Project coordination
7 Support communication and information sharing
8 Network development, maintenance and facilitation
9 Facilitate and evaluate change
10 Support sustainability.

We examine the two domains 'create tailored knowledge products' and 'support communication and information sharing', as they are the most relevant to this case study.

CASE STUDY: THE MRC/WITS-AGINCOURT UNIT HDSS

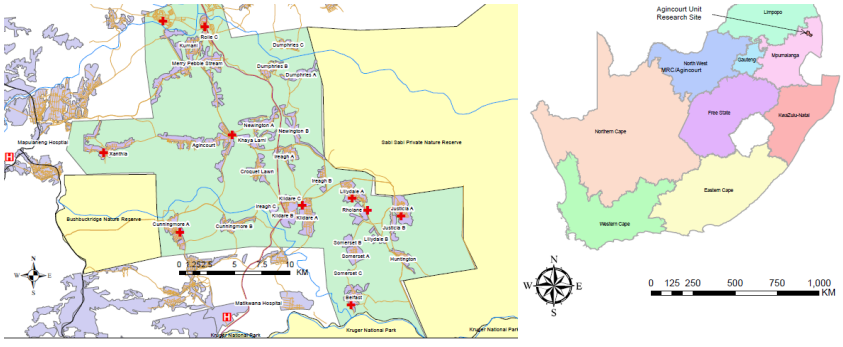


Figure 1: Location of the MRC/Wits-Agincourt Unit HDSS study area in South Africa and details of the study area

Setting and Objectives

The MRC/Wits-Agincourt Unit HDSS study area is located in the Bushbuckridge Municipal sub-district of Ehlanzeni District in rural Mpumalanga Province, South Africa. The area is 500 kilometres northeast of Johannesburg, separated from Mozambique by the Kruger National Park on its eastern boundary (Figure 1). The 1992 baseline census enumerated approximately 57 600 people living in 8900 households in 20 villages (Tollman et al. 1999), which, by 2015, had expanded to 115 000 people in 18 500 households in 27 villages (www.indepth-network.org/member-centres/agincourt-hdss). Some 30 per cent of the sub-district population comprises former Mozambican refugees, the majority of whom are now South African citizens or permanent residents (Twine et al. 2016). The majority of people living in the area are from the Tsonga ethnic group, and speak XiTsonga.

Many households practice supplementary farming, but land allocated during apartheid for resettlement is inadequate for total reliance on subsistence agriculture. Unemployment is high with most formal employment being male migrant labour in mining, manufacturing, agriculture and tourism. South Africa's non-contributory social grant system are a major source of household income, together with remittances from labour migrants. Since 1994, with the dawn of the democratic era in South Africa, there has been infrastructure development with improved provision of electricity, roads, water and schools. Currently, there is one health centre and eight primary health-care clinics within the study area, and three district hospitals 25 to 60 kilometres away (Collinson et al. 2014; Kahn et al. 2012).

The 27 villages in the study area fall under three traditional councils, and three local municipal offices. For the purpose of this article, we define a 'village' as a cluster of households in a geographically defined area, which has a name and leadership structure, and is geographically separate from other villages. Each village has a head man (*induna*), who falls under one of the traditional councils presided over by a chief (*hosi*); traditional councils meet every week. Civic leadership operates at three levels: village-level community development forums (CDFs), wards with an elected ward councillor, and local municipalities. Each village CDF is made up of two representatives from every community-based organisation in the village, and includes the *induna* as a representative of the traditional council (www.agincourt.co.za/index.php/activities/linc/).

From 1992, public engagement activities were undertaken in relation to village-level consent and annual village-based dissemination of research results for every study. In 2004, a dedicated PEO was established by the MRC/Wits-Agincourt Unit, with contributions to its activities included in all research project budgets, in order to further develop knowledge brokerage activities in the study area. There are three full-time staff members at the PEO. Rhian Twine, lead author on this article, manages the office. She is a healthcare professional who has worked in the

area for nearly 30 years; 15 years for the public health services in the district, and 13 years for the MRC/Wits-Agincourt Unit. The two public engagement officers she manages have extensive and long-term experience as fieldworkers/ supervisors of the census and nested research projects as well as in their public engagement roles (25 and 13 years respectively). Both are residents in the study area. A key activity is the KDI, the objective of which is to disseminate research findings to residents and service providers living within the study area. Below, we outline the KDI activities, grouped according to two of the domains of knowledge brokerage defined by Bornbaum (2015).

Creating Tailored Knowledge Products

From 1993 to 2002, only village-specific demographic data were presented. From 2004, three changes were made: GPS village maps with no research household identifiers were distributed to village leaders and service providers; oral and written summaries of HDSS modules on various topics were given, including food security, socio-economic status and uptake of social grants; and dissemination meetings included results from nested research studies.

Over time, village-specific fact sheets increased from two to 14 pages. From 2011, key take-home messages were highlighted at the end of every section and all the information provided was translated into the local language (XiTsonga). Since 2012, village and research project fact sheets have been available on the MRC/ Wits-Agincourt Unit website (www.agincourt.co.za/index.php/activities/linc/#Village fact sheets). From 2015, content was simplified to ensure that people with no more than eight years of education could understand the information, using the 'readability index' in Microsoft Office Word.

Supporting Communication and Information Sharing

Village-based meetings: Since 1993, unit staff has presented aggregated village-specific demographic data through open village-based meetings in each village annually. The practice has continued and since the establishment of the PEO team in 2004, the KDI has been extended in its format, duration and breadth (see Figure 2).

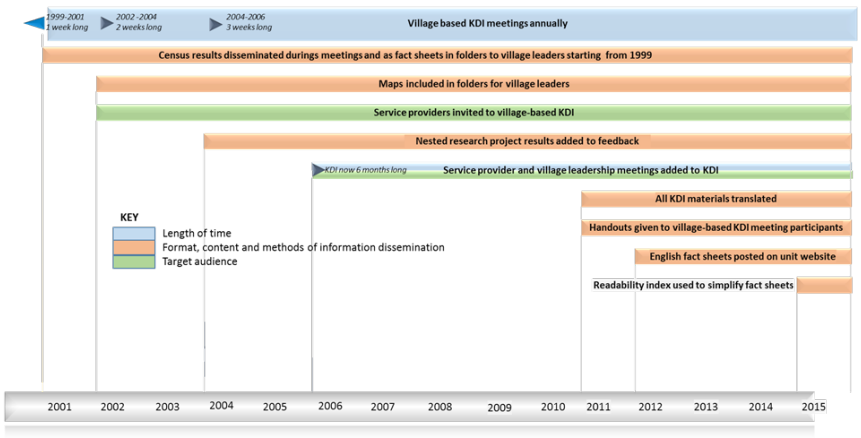


Figure 2: Changes in KDI over time, 2001–2015

Since 2006, village-based meetings to disseminate research findings have taken place over one month (one or two village meetings daily) at the start of an annual six-month period. Three fieldworkers supplement the PEO for this month. On the prior evening, a public engagement officer drives around the village announcing the meeting using a roof-mounted megaphone. Before each meeting starts, the village leadership decides if there are enough people in attendance to proceed; most meetings are held under a tree or in a school. After each presentation, in which various topics are presented by different fieldworkers, audience questions are answered by the fieldworkers. At the conclusion, 50 copies of printed fact sheets on each topic presented are made available to the attendees, and the village leaders are presented with a folder containing the fact sheets as well as a map of their village. Generally, these meetings last for two hours. At the suggestion of local leaders, relevant service providers have been invited to attend since 2002.

The number of villages included in the meetings has increased, with the number of possible village-based meetings going up from 18 in 2001 to 30 in 2015; five new villages were built within the original study area as part of a government housing development program, and eight villages were added to expand the area population, largely to meet the needs of intervention trials. Actual meetings held were always fewer than those planned: out of 289 possible meetings over 2001–2015, 215 took place (74 per cent). Reasons for meeting failure include cancellations or postponements by village leaders if too few people attended, or other village activities that arose and took precedence.



Figure 3: A village-based meeting in 2009

Meetings with village leaders and service providers: During the following five months, PEO staff conduct face-to-face briefings with village leaders, community organisations and service providers, again giving each group a folder containing research data aggregated across the study area to assure confidentiality, and village-specific demographic data, in fact sheets.

Measuring the Effectiveness of a KDI

This longitudinal, mixed-methods case study of a KDI used multiple sources of data (Yin 1994), as shown in Table 1. Quantitative data were from 14 annual village meeting reports (2001–2015) that contained information on attendees, questions

asked and requests for more information, as well as 762 feedback questionnaires that were collected from attendees over 10 years (2005–2015). Attendees were asked at the beginning of the meeting to volunteer to fill in feedback questionnaires with the assistance of a fieldworker after the meeting. The feedback questionnaires, completed after obtaining verbal consent, were largely (50–80 per cent in any one year) completed by younger adults, aged 18–34 years. The number of forms filled in varied depending on whether there was a general village-based meeting immediately following the KDI, the weather, individual willingness, and the meeting's length. Owing to computer crashes, the 2003 annual report and the 2009 feedback questionnaires are missing.

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	Total
Reports on annual KDI	1	1	0	1	1	1	1	1	1	1	1	1	1	1	1	-	14
Feedback questionnaires from attendees	-	-	-	-	82	91	68	33	0	85	25	99	98	122	59	-	762
Qualitative interviews															20 interviews 60 participants		

Table 1: KDI dataset 2001–2015

The qualitative data are from 15 individual semi-structured and five focus group interviews with local leaders and service providers (60 participants in total) carried out in 2015–2016. The interviews were conducted in a mixture of English and XiTsonga and explored the participants' views and experiences of the annual dissemination of research findings. The lead author (Rhian Twine) conducted the interviews with a local fieldworker, taped recordings of which were translated and transcribed by the fieldworker.

The 15 individual interviewees were service providers and traditional leaders within the study area: two traditional council secretaries from two councils (the third covered only one village), who suggested also interviewing one *induna* from each of their traditional councils; three ward councillors, who represented the greatest number of villages; both regional municipal managers; clinic managers from the three busiest clinics; and the two education circuit managers responsible for the majority of schools in the site. Four focus group interviews were held with the CDF chair and/or the health desk representative of each of the 20 villages that had been in the study area since its inception, and 3 added in 2007, and one focus group interview was held with the managers of the eight home-based care organisations in the area. Participants were aged between 25 and 70 years. Only four service providers were not resident in the study area, and there was equal gender representation. Quantitative data were analysed using summary statistics in Excel, as well as descriptive analysis. Qualitative data was analysed thematically using NVivo 10 (QSR 2012).

Ethical clearance was obtained from the University of the Witwatersrand's Human Research Ethics Committee (HREC) (Medical) (certificate no. M140737). All research reported on within the KDI obtained separate ethical clearance from Wits HREC (Medical), the relevant Mpumalanga Province Research and Ethics Committee and, if undertaken with international collaborators, their institutional ethics committees.

Findings

The findings are organised according to the three outcomes for the measurement of effectiveness of KDIs: knowledge acquisition, changes in attitudes and changes in practices (Lafrenière et al. 2013).

Knowledge acquisition

Service providers and village leaders were asked what information was presented and discussed through the KDI. The responses show an understanding of the relevance of the findings to their villages. Census findings were always mentioned first, showing that these were the data with which they were most familiar. Village leaders and service providers found demographics and maps more useful for planning than other results.

> *I'm glad we have Wits in our community because they are giving us the figures of the people living in the specific villages, and it helps us to know how many people have died each year. It also helps us to know the figures of the children who were born. We are also able to know the people who migrate outside and those [who] immigrated into our village.* (CDF member, woman)

The findings from nested studies, added from 2004 onward, were also found to be useful.

> *When Wits came and gave feedback, there were youth and elders in that meeting. When Wits gave them the results about what is happening to the youth about HIV and TB [tuberculosis], they learnt something, they were asking questions. Even the elders were interested in knowing something.* (CDF member, woman)

Respondents, who filled in feedback questionnaires after the village-based meetings, reported that the most useful information was about HIV and tuberculosis (34 per cent), causes of death (19 per cent) and village demographics (16 per cent). A few appreciated learning more about the work of the MRC/Wits-Agincourt Unit (4 per cent) and how to apply for a job within the unit (1 per cent). Information about research results would appear to be more important than other aspects of the unit's work.

Changes in attitudes

The types of questions asked at village meetings and targeted briefings illustrate changing attitudes in relation to both the research activities and research results over time.

Figure 4 illustrates a steady increase in the proportion of questions related to research results, and a concurrent decrease in

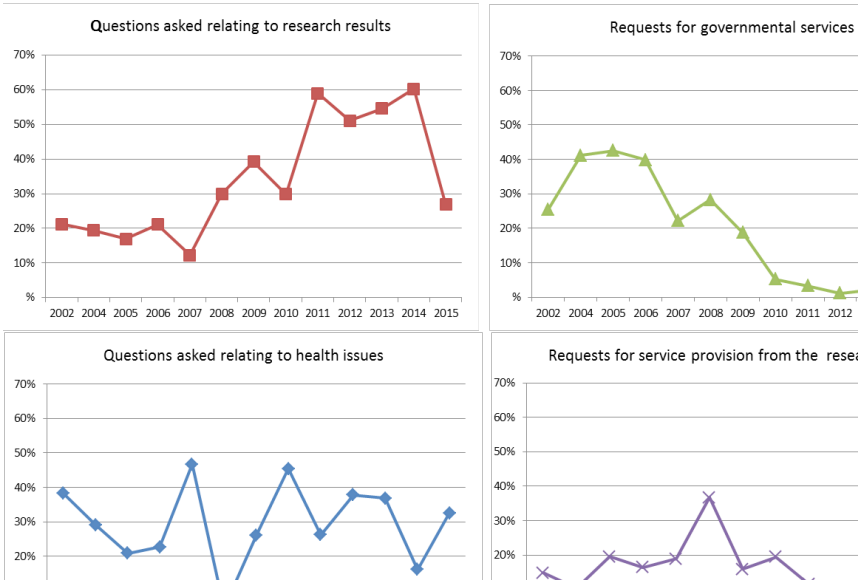


Figure 4: Proportions of questions asked at village-based meetings 2002–2015

requests for government services, and for services from the unit, until 2014. The latter coincided with a lower presence of service providers at the meetings (discussed later). From 2014, enrolment started in the first major randomised control trial in the study area (Pettifor et al. 2016). Due to the scale of the trial, four new villages were added to the study area; data showed these villages had a higher proportion of requests for services than did villages that had been part of the study area since 2001 (Figure 5). This suggests that villagers with a longer exposure to research activities and the KDI had a clearer understanding of the university's role, and were engaged in discussions about research rather than service

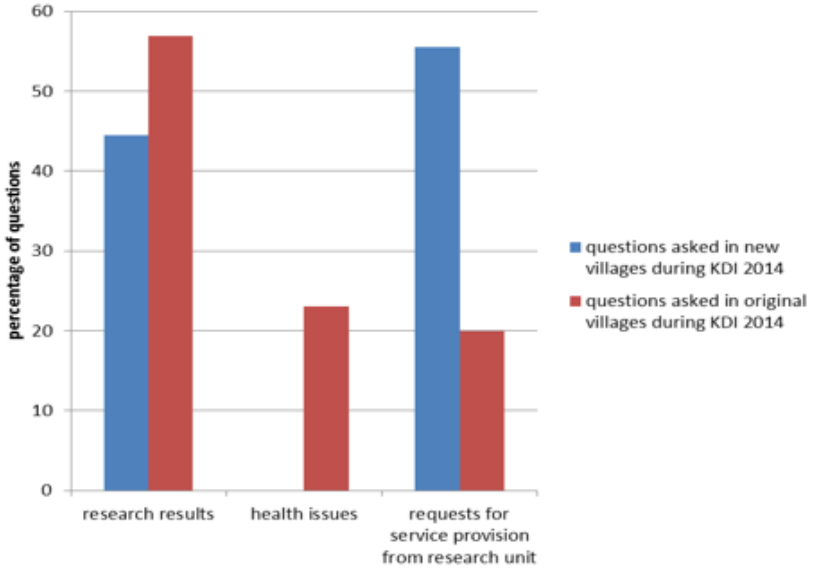


Figure 5: Questions asked in 2014 – comparison of 23 older villages and four new villages included since 2013

provision. This provides evidence of changes in attitudes (and knowledge) about the work of the unit.

Examples of questions asked at village-based meetings are included below. The research topics presented, as well as which service provider attended the meetings, directly influenced questions asked. For example, in 2006, when data on access to child support grants were presented, with child support grant

extension officers present, 45 of the 129 questions related to this issue. From our analysis, questions can be grouped into four main categories:

1 Research results: *How do you include people in the census who out migrated from the village?* (2014); *How do you recruit participants for studies?* (2015)

2 Requests for services from the research unit: *Can you assist people with epilepsy to get a wheelchair?* (2011); *Can Wits do something about bilharzia, because if we go to the clinic they don't help us and our children keep urinating blood?* (2011)

3 Health: *If I'm HIV-positive and sleep with someone who is also HIV-positive, what's going to happen?* (2014); *How do I know I have heart disease?* (2015)

4 Requests for government services: *We are drinking water from wells and dams and the water is not healthy. Where can we get water for the vegetables we have planted?* (2008); *How can you help an older person who does not have a pension, but who also doesn't have an identity document, carer [or] relatives?* (2008)

This suggests that the results were accepted as relevant and applicable to both individuals and service providers in their villages and the surrounding area.

Changes in practices

At meetings, villagers directly questioned service providers, when available, using research results as proof to request further services. There is evidence that service provision was sometimes modified in line with such concerns; for example, after hearing requests for the mobile health clinic service to resume, a clinic manager reinstated it. In another village, pit latrines were supplied soon after presentation of data on households with no latrines.

Over 2001–2015, a total of 762 people completed feedback questionnaires (see Table 2). Of those, 397 had attended village-based meetings the year before; 54 per cent of this group reported that the information motivated them to work or volunteer, while 14 per cent lobbied for services and 3 per cent took no action at all (Figure 6). The 'other' category (25 per cent) included activities such as using the information to teach the youth, starting a vegetable garden at home, and encouraging other villagers to participate in research studies.

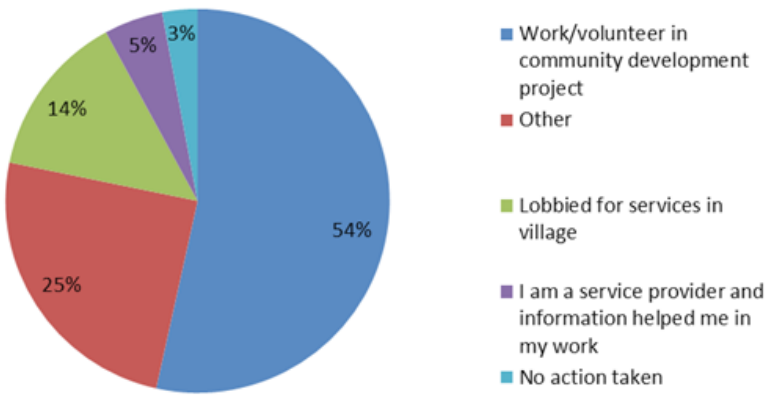


Figure 6: Reported activities undertaken subsequent to the previous year's KDI

Further, out of the total 762 respondents who completed feedback questionnaires, 117 (15.4 per cent) had attended a previous meeting where handouts (tailored knowledge products) were distributed: over 50 per cent of this group reported not using the information, 25 per cent said they had shared the information, and only 8 per cent said the information had led to an improvement in their health behaviour, such as having their blood pressure measured.

The interviews with village leaders and service providers revealed that, for this group, the information was seen as useful for planning services, student assignments and reports.

> *We checked how many people were in our villages, and then worked with home affairs. We have 14 000 people in total but only 8000 people have IDs, so we started a campaign with home affairs.* (Ward councillor, man)

> *In our village, we looked at the results and found that our village is too small. We went to the chief to request to extend our village by 500 new stands [plots to build houses on].* (CDF member, man)

> *It helps us when we do reports because we can quote that, according to Wits, in village X we have got 700 households and 5000 people.* (Traditional council secretary, man)

> *Sometimes they use information in the folders in our schools to set exams, like HIV/AIDS or census information.* (CDF member, man)

The questions below were asked at village leader and service provider briefings, and show a commitment to translating research into policy and practice:

> *I see that there are not so many 11 to 14 year olds having babies, but there are some. Could you let us know how relevant household economic circumstances are, or if there are any other things we can learn about the households of these girls? Maybe then we can do something.* (Ward councillor, man, after a presentation on fertility rates.)

> *According to the statistics presented, cardiac disease is a serious problem in people aged 50 and above. Why is it like that? What can we do in order to solve this problem?* (Clinic manager, woman, in response to a presentation on causes of death.)

In the last five years there have been requests after KDI meetings for further information from villagers, students, leaders, service providers and political organisations for data for use in changes of practices. Women who were starting crèches in the villages requested information on numbers of children under five years in/out of preschool, and village maps indicating sites of

preschools, to support their funding requests. Social work students have needed information for assignments, and high school teachers have requested statistics on HIV for teaching purposes.

Ward councillors have also requested information, such as the socioeconomic and refugee status of households with teenage mothers. The South African Police Service asked for data on suicides and deaths due to violence in the area as evidence to support an application to set up a satellite police station, which was subsequently established. Managers of nearby private game lodges have requested village fact sheets annually for their social responsibility offices. Municipal representatives of the African National Congress, the governing party, ask annually for all village fact sheets for service provision planning.

Challenges and Limitations

To get a better understanding of the extent of the effectiveness of the KDI, coverage is a consideration. The village-based KDI meetings have attracted 2 to 4 per cent of the adult population over 15 years. There is some variation, ranging from 1.5 to 4.3 per cent, as shown in Figure 7, with a significant ($p<0.05$, $R2=0.272$) but weak decline of 0.17 per cent in attendance. This may be due to many of the meetings being held during the week, thus excluding those employed, inadvertent scheduling during cold weather, funerals, and political disputes between village leaders.



Figure 7: Percentage of total population over 18 years attending village-based KDI meetings, 2001–2015

Village leaders gave various explanations for the stable but low attendance rates and for sometimes having to cancel meetings. These were mainly villagers not understanding the relevance of the research feedback, as well as internal village politics. Since 2011, a local government election year, leaders have used the KDI meetings to raise other issues such as elections, water crises and employment with villagers, indicating that these meetings have become a platform for airing critical issues. One village leader suggested that the dissemination should be added onto existing meetings, such as those held by Department of Agriculture as, in his opinion, more people attended these.

The data from the feedback questionnaires sheds a different light on why people don't attend meetings. Of those who completed

questionnaires, 47 per cent were new attendees. As shown in Figure 8, reasons given for not previously attending fell into two major categories: inability to attend (not living in village, visiting/studying elsewhere, not available) and organisational (did not know about it, meeting too early, venue too far, meeting did not happen). Only 1 per cent expressed 'lack of interest' as a reason for non-attendance, indicating an acceptance of the data and its possible usefulness.

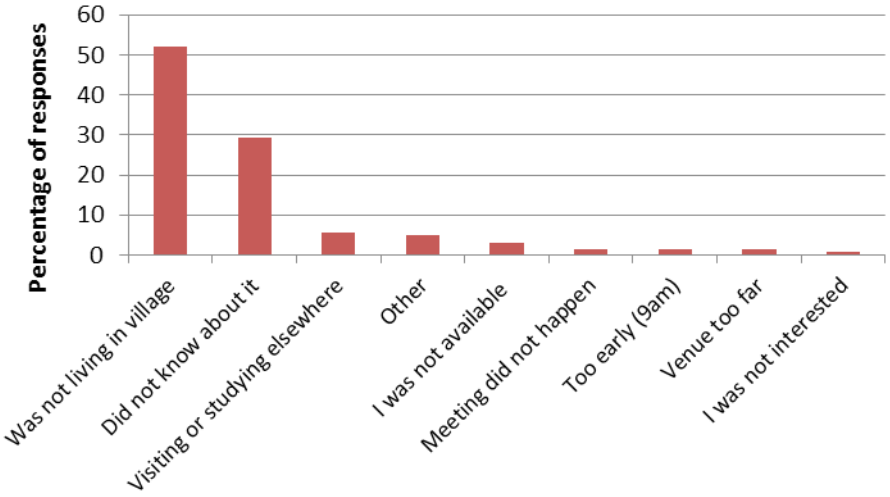


Figure 8: Why people did not attend previous year's meeting

Additionally, despite being invited annually and transport provided, some service providers such as social workers, local youth development NGOs, child support grant social securityofficers, home-based carers and municipal workers have not attended regularly. Health-care providers, ward councillors and community development workers have attended more often. In 2004, all but one of the 17 meetings were attended by service providers, compared to 2014, when service providers attended only seven meetings. The reasons for non-attendance were mainly related to heavy workload. This means that service providers seldom gain knowledge regarding research results, and participants do not benefit from information from service providers during village-based meetings.

> *Wits invites us, but most of the time I fail to take part in those events because I have to attend to some other community issues.* (*Induna*, man)

Service providers reported that handouts were often left in a folder, and some admitted not reading the information. While appreciation was expressed for the translations into XiTsonga, some felt these were not always correct, and some found the font too small. People preferred attending meetings to reading information.

> *We get the results in writing but I personally enjoy when we sit down together so that if I have questions then I can ask and you clarify those points that I could not understand as I was reading the report.* (Education circuit manager, man)

DISCUSSION

The systematic review of KDIs (Lafrenière et al. 2013) identified specific outcomes for the assessment of effectiveness of a KDI: knowledge acquisition and changes in attitudes and practices. This single, mixed-methods longitudinal case study of the dissemination of research results from an HDSS in a rural setting has focused on the effectiveness of the annual KDI using this framework.

This case study does show some evidence of change in knowledge acquisition, but only to a limited extent. Village-based meetings attracted only 2 to 4 per cent of the population, and even if 25 per cent of attendees shared the information gained, knowledge acquisition through village meetings was modest across the study area. Although the audience is not growing, it does not remain static, with different people attending every year. More innovative methods of alerting community members of the upcoming KDI, such as via local radio and strategically placed posters, may increase audience numbers. Even though the number of attendees has been consistently small as a proportion of the village population, village leaders and political representatives have utilised the meetings since 2011 as a platform for discussion of topical village issues. This shows that the meetings have become embedded and routinised, and are considered a useful forum for debate. There have been instances when the amount of time given to research feedback has been compromised owing to the need for village leaders to address the audience on village matters, but, generally, feedback has been allowed to continue as planned with the audience remaining once the PEO staff has left. Since the feedback sessions are already two hours long, the PEO does not make use of village meetings called by other organisations for this KDI, in line with the principle of respect for villagers and service providers underpinning all PEO activities.

Although village-based meetings are limited in terms of coverage, face-to-face briefings with service providers and village leaders show some effectiveness in knowledge acquisition as evidenced by the types of information requested by service providers and village leaders after the KDI activities. This is important, as service providers seldom attended the village meetings, and often missed targeted service provider briefings owing to workload. Given that participants seldom miss meetings owing to lack of interest, and that face-to-face briefings are preferred while hand-outs are seldom read, it would be important for different strategies to be used so as to enable participation. Results clearly show that the KDI had limited effectiveness when solely based on a linear approach and was more effective when multi-pronged. The importance of face-to-face interaction over time has been noted by recent studies and also that varied strategies can be used with different stakeholders (Conklin et al. 2013; Dagenais et al. 2015). This could mean that more frequent meetings are needed, with smaller audiences, which would require concurrent increased human resources in knowledge broker offices.

In regard to changes in attitudes, in villages that had recently been added to the study area, more service-related questions were asked compared to villages that had been in the study area longer, where more questions on research results were asked. These trends suggest a change in attitudes concerning the role and work of the unit, with growing understanding and acceptance that the role of a research unit is not to deliver services, but to undertake research. This is evidence of increased interactive dialogue (Lavis et al. 2003). KDIs, such as this one, do contribute towards changing the attitudes of participants and enhance the possibility of collaborative discussion regarding the relevance of research and research results.

Lastly, there was some evidence of changes in practices, with a few attendees reporting that their health behaviour had altered subsequent to attending a meeting, and a few reporting that they had been motivated to volunteer/work in community projects. Service providers and village leaders had used demographic data for planning at the village level. There was also some evidence of public health service delivery improving after data highlighting these issues were presented.

Implications for Knowledge Dissemination Interventions

We would argue that the process of organising and delivering this KDI is central to knowledge brokerage and supports other domains such as networking, developing collaboration with stakeholders, supporting the sustainability of the HDSS, and building local capacities through the interpretation of research data (Bornbaum et al. 2015).

The MRC/Wits-Agincourt Unit has committed resources for the establishment of a dedicated PEO, which had a clear brief to manage the KDI as knowledge brokers (Bornbaum et al. 2015), and reflects a growing partnership with stakeholders contributing to an increased understanding of the role of research unit and its data by the villagers, leadership and service providers. This has occurred in the social context of the evolving democracy of post-apartheid South Africa, which has involved everyone in a growing awareness of both rights and responsibilities as well as the planning of increased service provision in health, housing and education.

Considerable time and effort was spent writing and translating fact sheets, which proved of limited use. Other methods of dissemination such as theatre, which has been used to effect in this setting (Stuttaford et al. 2006), postal drops of small, focused A5 pictograms, community radio, TV and social media may be useful in communicating results. Radio-based soap operas or talk shows (edutainment) have been effective in engaging the public with health research in Malawi (Nyirenda et al. 2016) and South Africa (Jana et al. 2015). Longitudinal HDSS sites have an opportunity to develop strategies for regular information sharing through community advisory groups (Reddy et al. 2010) and wider village-based dissemination. While difficult to do, it

would be important to clearly articulate the expected outcomes of these different strategies in order to evaluate their effectiveness if undertaken in HDSS sites.

The effectiveness of the KDI in this case study has been assessed in relation to three outcomes: knowledge acquisition, changes in attitudes and changes in practices (Lafrenière et al. 2013). There is evidence of changes in all three outcomes over time; it is doubtful if changes would have been evident without a longitudinal approach. In future KDI activities, clearer, measurable objectives will be needed in order to measure effectiveness more rigorously and information disseminated and methods used need to be adapted further to be more specific, useful and contextual (Legaspi & Orr 2007).

CONCLUSION

Sharing research results with study participants and stakeholders is part of the ethics of practice (Guillemin & Gillam 2004). This links to civic science, which frames research as a public good (Ward et al. 2009). Results from this case study of a KDI to communicate research results across the population of the MRC/Wits-Agincourt Unit study area can be used to inform knowledge brokerage and KDIs in other areas with longitudinal studies (Bornbaum et al. 2015). The results show how this KDI developed from linear presentations with little engagement to multi-pronged, diverse activities (Ward et al. 2009), with some impact on knowledge acquisition, attitudes and practices (Lafrenière et al. 2013). The process of evaluating this KDI has been valuable to the PEO and the results have led to change in knowledge and practice within the office itself. For example, upon realisation of the limited reach of the village-based dissemination meetings, a simple infographic is now distributed annually to each household, alongside the continuing village-based and service provider meetings. Fact sheets are clearer, with shorter messages, and more serious thought is given to both the content of the message and how it is conveyed. A limitation of this study was that the evaluation tools were designed for routine use and not for rigorous analysis. Nevertheless, the findings have led to changes in practice, and more effective evaluation tools are being developed. This KDI of disseminating research findings to research participants, village residents and other stakeholders is a knowledge brokerage activity that, in addition to supporting communication, and sharing information with tailored products, involves other components of knowledge brokerage such as networking, building capacity and sustainability. A holistic approach to knowledge brokerage rather than a focus on one domain captures the interrelatedness and complexities of these activities and allows for the development of nuanced understandings of the processes involved.

Acknowledgments

This project was supported by the University of the Witwatersrand, the South African Medical Research Council and the Wellcome

Trust (Grants 058893/Z/99/A; 069683/Z/02/Z; 085477/Z/08/Z; 085477/B/08/Z). We thank Audrey Khoza and Simon Khosa of the PEO; Jeffrey Tibane, as PEO consultant; Sulaiman Afolabi for HDSS data extraction; and interns Daniel Hughes and Sydney Walker, who assisted with collating data. None of the work would be possible without the participation of the population, service providers and local leaders in the study area.

REFERENCES

Council for International Organizations of Medical Sciences (CIOMS) 2016. International Ethical Guidelines for Health-related Research Involving Humans. Fourth Edition ed. Geneva: WHO

Bäckstrand, K 2003, 'Civic science for sustainability: Reframing the role of experts, policy-makers and citizens in environmental governance,' *Global Environmental Politics*, vol. 3, no. 4, pp. 24–41, doi: https://doi.org/10.1162/152638003322757916

Bhattacharyya, OK, Estey, EA & Zwarenstein, M 2011, 'Methodologies to evaluate the effectiveness of knowledge translation interventions: A primer for researchers and health care managers,' *Journal of Clinical Epidemiology*, vol. 64, pp. 32–40, doi: https://doi.org/10.1016/j.jclinepi.2010.02.022

Bornbaum, CC, Kornas, K, Peirson, L & Rosella, LC 2015, 'Exploring the function and effectiveness of knowledge brokers as facilitators of knowledge translation in health-related settings: A systematic review and thematic analysis,' *Implementation Science,* vol. 10, doi: https://doi.org/10.1186/s13012-015-0351-9 and https://doi.org/10.1186/s13012-015-0358-2

Collinson, MA, White, MJ, Bocquier, P, McGarvey, ST, Afolabi, SA, Clark, SJ, Kahn, K & Tollman, SM 2014, 'Migration and the epidemiological transition: Insights from the Agincourt sub-district of northeast South Africa,' *Global Health Action*, vol. 7, https://doi.org/10.3402/gha.v7.23514

Conklin, J, Lusk, E, Harris, M & Stolee, P 2013, 'Knowledge brokers in a knowledge network: The case of Seniors Health Research Transfer Network knowledge brokers knowledge network seniors,' *Implementation Science*, 8:7 doi: https://doi.org.10.1186/1748-5908-8-7

Dagenais, C, Laurendeau, M-C & Briand-Lamarche, M 2015, 'Knowledge brokering in public health: A critical analysis of the results of a qualitative evaluation,' *Evaluation and Program Planning,* vol. 53, pp. 10–17, doi: https://doi.org/10.1016/j.evalprogplan.2015.07.003

Dickert, N & Sugarman, J 2005, 'Ethical goals of community consultation in research,' *American Journal of Public Health*, vol. 95, pp. 1123–27, doi: https://doi.org/10.2105/AJPH.2004.058933

Gilson, L & McIntyre, D 2008, 'The interface between research and policy: Experience from South Africa,' *Social Science and Medicine*, vol. 67, pp. 748–59, doi: https://doi.org/10.1016/j.socscimed.2008.02.005

Godfrey, L, Funke, N & Mbizvo, GF 2010, 'Bridging the science–policy interface: A new era for South African research and the role of knowledge brokering,' *South African Journal of Science*, vol. 106, doi: https://doi.org/10.4102/sajs.v106i5/6.247

Guillemin, M & Gillam, L 2004, 'Ethics, reflexivity, and "ethically important moments" in research,' *Qualitative Inquiry*, vol. 10, pp. 261–80, doi: https://doi.org/10.1177/1077800403262360

Jana, M, Letsela, L, Scheepers, E & Weiner, R 2015, 'Understanding the role of the OneLove campaign in facilitating drivers of social and behavioral change in southern Africa: A qualitative evaluation,' *Journal of Health Communication*, vol. 20, doi: https://doi.org/10.1080/10810730.2014.925014

Kahn, K, Collinson, MA, Gómez-Olivé, FX, Mokoena, O, Twine, R, Mee, P, Afolabi, SA, Clark, BD, Kabudula, CW, Khosa, A, Khoza, S, Shabangu, MG, Silaule, B, Tibane, JB, Wagner, RG, Garenne, ML, Clark, SJ & Tollman, SM 2012, 'Profile: Agincourt health and socio-demographic surveillance system,' *International Journal Epidemiology*, vol. 41, pp. 988–1001, doi: https://doi.org/10.1093/ije/dys115

Kothari, A & Armstrong, R 2011, 'Community-based knowledge translation: Unexplored opportunities,' *Implementation Science*, vol. 6, pp. 59–64, doi: https://doi.org/10.1186/1748-5908-6-59

Lafrenière, D, Menuz, V, Hurlimann, T & Godard, B 2013, 'Knowledge dissemination interventions: A literature review,' *SAGE Open*, vol. 3, doi: https://doi.org/10.1177/2158244013498242

Lavery, JV, Tinadana, PO, Scott, TW, Harrington, LC, Ramsey, JM, Ytuarte-Nuñez, C & James, AA 2010, 'Towards a framework for community engagement in global health research,' *Trends Parasitol*, vol. 26, pp. 279–83, doi: https://doi.org/10.1016/j.pt.2010.02.009

Lavis, JN, Lomas, J, Hamid, M & Sewankambo, NK 2006, 'Assessing country-level efforts to link research to action,' *Bulletin of the World Health Organization*, vol. 84, pp. 620–28, doi: https://doi.org/10.2471/BLT.06.030312

Lavis, JN, Robertson, D, Woodside, JM, Mcleod, CB, Abelson, J & the Knowledge Transfer Study Group 2003, 'How can research organizations more effectively transfer research knowledge to decision makers?', *The Milbank Quarterly*, vol. 81

Legaspi, A & Orr, E 2007, 'Disseminating research on community health and well-being: A collaboration between Alaska native villages and the academe,' *American Indian and Alaska Native Mental Health Research: The Journal of the National Center*, vol. 14, pp. 24–43

Madhavan, S, Collinson, M, Townsend, NW, Kahn, K & Tollman, SM 2007, 'The implications of long term community involvement for the production and circulation of population knowledge,' *Demographic Research*, vol. 17, pp. 369–88, doi: https://doi.org/10.4054/DemRes.2007.17.13

Marsh, V, Kamuya, D, Rowa, Y, Gikonyo, C & Molyneux, S 2008, 'Beginning community engagement at a busy biomedical research programme: Experiences from the KEMRI CGMRC-Wellcome Trust Research Programme, Kilifi, Kenya,' *Social Science & Medicine*, vol. 67, pp. 721–33, doi: https://doi.org/10.1016/j.socscimed.2008.02.007

Meyer, M 2010, 'The rise of the knowledge broker,' *Science Communication*, vol. 32, pp. 118–127, doi: https://doi.org/10.1177/1075547009359797

Mitton, C, Adair, CE, McKenzie, E, Patten, SB & Perry, BW 2007, 'Knowledge transfer and exchange: Review and synthesis of the literature,' *The Milbank Quarterly*, vol. 85, pp. 729–68, doi: https://doi.org/10.1111/j.1468-0009.2007.00506.x

Molyneux, S & Geissler, PW 2008, 'Ethics and the ethnography of medical research in Africa,' *Social Science and Medicine*, vol. 67, pp. 685–95, doi: https://doi.org/10.1016/j.socscimed.2008.02.023

Mondain, N, Delauney, V & Ouédraogo, V 2016, 'Reporting results back in health and demographic surveillance systems (HDSS): An ethical

requirement and a strategy for improving health behaviours,' *African Population Studies*, vol. 30, pp. 2355–68, doi: https://doi.org/10.11564/30-2-840

Naidoo, S 2012, 'The South African national health insurance: A revolution in health-care delivery!' *Journal of Public Health*, vol. 34, pp. 149–50, doi: https://doi.org/10.1093/pubmed/fds008

Nuffield Council on Bioethics 2002, 'The ethics of research related to healthcare in developing countries,' viewed 18 May 2017, http://nuffieldbioethics.org/wp-content/uploads/2014/07/Ethics-of-research-related-to-healthcare-in-developing-countries-I.pdf

Nyirenda, D, Makawa, TC, Chapati, G, Mdalla, C, Nkolokosa, M, O'byrne, T, Heyderman, R & Desmond, N 2016, 'Public engagement in Malawi through a health-talk radio programme *"Umoyo nkukambirana"*: A mixed-methods evaluation,' *Public Understanding of Science*, viewed 18 May 2017, http://journals.sagepub.com/doi/abs/10.1177/0963662516656110

Pettifor, A, MacPhail, C, Hughes, JP, Selin, A, Wang, J, Gómez-Olivé, FX, Eshleman, SH, Wagner, RG, Mabuza, W, Khoza, N, Suchindran, C, Mokoena, I, Twine, R, Andrew, P, Townley, E, Laeyendecker, O, Agyei, Y, Tollman, S & Kahn, K 2016, 'The effect of a conditional cash transfer on HIV incidence in young women in rural South Africa (HPTN 068): A phase 3, randomised controlled trial,' *The Lancet Global Health*, vol. 4, DOI: doi: http://dx.doi.org/10.1016/S2214-109X(16)30253-4

QSR International 2012, NVivo qualitative data analysis software; Version 10

Reddy, P, Buchanan, D, Sifunda, S, James, S & Naidoo, N 2010, 'The role of community advisory boards in health research: Divergent views in the South African experience,' *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, vol. 7, pp. 2–8

Sankoh, O & Byass, P 2012, 'The INDEPTH Network: Filling vital gaps in global epidemiology,' *International Journal of Epidemiology*, vol. 41, pp. 579–88, doi: https://doi.org/10.1093/ije/dys081

Strydom, WF, Funke, N, Nienaber, S, Nortje, K & Steyn, M 2010, 'Evidence-based policymaking: A review,' *South African Journal of Science*, vol. 106, doi: https://doi.org/10.4102/sajs.v106i5/6.249

Stuttaford, M, Bryanston, C, Hundt, GL, Connor, M, Thorogood, M & Tollman, S 2006, 'Use of applied theatre in health research dissemination and data validation: A pilot study from South Africa,' *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, vol. 10, pp. 31–45, doi: https://doi.org/10.1177/1363459306058985

Tindana, PO, Rozmovits, L, Boulanger, RF, Bandewar, SV, Aborigo, RA, Hodgson, AV, Kolopack, P & Lavery, JV 2011, 'Aligning community engagement with traditional authority structures in global health research: A case study from northern Ghana,' *American Journal of Public Health*, vol. 101, pp. 1857–67, doi: https://doi.org/10.2105/AJPH.2011.300203

Tindana, PO, Singh, JA, Shawn, TC, Upshur, REG, Daar, AS, Singer, PA, Frolich, J & Lavery, JV 2007, 'Grand challenges in global health: Community engagement in research in developing countries,' *PLOS Medicine*, vol. 4, pp. 1–5, doi: https://doi.org/10.1371/journal.pmed.0040273

Tollman, S 2008, *Closing the gap: Applying health and socio-demographic surveillance to complex heatlh transitions in South and sub-Saharan Africa*, PhD, Umeå University

Tollman, S, Herbst, K, Garenne, M, Gear, JS & Kahn, K 1999, 'The Agincourt demographic and health study – site description, baseline findings and implications,' *South African Medical Journal*, vol. 89, pp. 858–64

Tollman, SM 1999, 'The Agincourt field site – evolution and current status,' *South African Medical Journal*, vol. 89, pp. 853–58

Twine, R, Kahn, K, Scholtz, A & Norris, SA 2016, 'Involvement of stakeholders in determining health priorities of adolescents in rural South Africa,' *Global Health Action*, vol. 9, doi: https://doi.org/10.3402/gha.v9.29162

Ward, V, House, A & Hamer, S 2009, 'Developing a framework for transferring knowledge into action: A thematic analysis of the literature,' *Journal of Health Services Research & Policy*, vol. 14, pp. 156–64, doi: https://doi.org/10.1258/jhsrp.2009.008120

Ye, Y, Wamukoya, M, Ezeh, A, Emina, JBO & Sankoh, O 2012, 'Health and demographic surveillance systems: A step towards full civil registration and vital statistics system in sub-Sahara Africa?' *BMC Public Health*, vol. 12, doi: https://doi.org/10.1186/1471-2458-12-741

Yin, RK 1994, *Case study research: Design and methods*, Thousand Oaks, California, Sage Publications Inc.