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Power, culture and researcher identity: an ethos of international academic 'north-south' public health research

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Power, culture and researcher identity: an *ethos* of international academic ‘north-south’ public health research

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A thesis submitted to the School of Postgraduate Studies, Faculty of Medicine and Health Sciences, Royal College of Surgeons in Ireland, in fulfillment of the degree of the Doctor of Philosophy PhD

December 2015

Supervisors:  Professor Ruairí Brugha

Dr Elaine Byrne
Candidate Thesis Declaration

I declare that this thesis, which I submit to RCSI for examination in consideration of the award of the higher degree Doctor of Philosophy (PhD) is my own personal effort. Where any of the content presented is the result of input or data from a related collaborative research programme this is duly acknowledged in the text such that it is possible to ascertain how much of the work is my own. I have not already obtained a degree in RCSI or elsewhere on the basis of this work. Furthermore, I took reasonable care to ensure that the work is original, and, to the best of my knowledge, does not breach copyright law, and has not been taken from other sources except where such work has been cited and acknowledged within the text.

Signed _____________________________________________________

Student Number ______________________________________________

Date ________________________________________________________
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Abbreviations

CDC  Centre for Disease Control
CCGHR  Canadian Coalition for Global Health Research
COHRED  Council on Health Research for Development
CIOMS  Council for International Organisations of Medical Sciences
DALY  Disability Adjusted Life Years
DfID  Department for International Development
DANIDA  Danish International Development Agency
EDCTP  European and Developing Countries Clinical Trials Partnership
ESSENCE  Enhancing Support for Strengthening the Effectiveness of National Capacity Efforts
EU  European Union
GDP  Gross Domestic Product
GFHR  Global Forum for Health Research
HIC  Higher Income Countries
HIRO  Heads of International Research Organisations
HPSR  Health Policy and Systems Research
KFPE  Commission for Research Partnerships with Developing Countries
LMIC  Lower and Middle Income Countries
MDP  Microbicide Development Programme
MoH  Ministry of Health
NEPAD  New Partnership for Africa’s Development
NGO  Non Government Organisation
NHRAC  National Health Research Advisory Committee
NHRAZ  National Health Research Authority of Zambia
NHREC  National Health Research Ethics Committee
NHRS  National Health Research System
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<thead>
<tr>
<th>Acronym</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>NUFU</td>
<td>Norwegian Programme for Development, Research and Education</td>
</tr>
<tr>
<td>PI</td>
<td>Principal Investigator</td>
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<tr>
<td>RCS</td>
<td>Research Capacity Strengthening</td>
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<tr>
<td>RCSI</td>
<td>Royal College of Surgeons in Ireland</td>
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<tr>
<td>RCT</td>
<td>Randomised Controlled Trial</td>
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<tr>
<td>R&amp;D</td>
<td>Research and Development</td>
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<tr>
<td>REC</td>
<td>Research Ethics Committee</td>
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<tr>
<td>SIDA</td>
<td>Swedish International Development Cooperation Agency</td>
</tr>
<tr>
<td>TDRC</td>
<td>Tropical Disease Research Centre</td>
</tr>
<tr>
<td>UNZA</td>
<td>University of Zambia</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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<td>ZAMFOHR</td>
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Summary

Health research between lower and middle income countries and higher income countries can lead to important ethical questions at different stages in the research cycle. To date, research in the area focuses primarily on either:

- **micro research ethical issues**: incorporating traditional definitions of research ethics such as research ethics reviews processes, informed consent and community engagement.
- **macro research ethical issues**: though generally not designated as ‘ethical’ matters, these studies include broader issues of the politics of the research process, from agenda setting to capacity building, to authorship, and how research actors and institutions function and interact.

The overall study aim is to undertake a situated ethics analysis of international academic public health research between the global north and the global south, using Zambia as a case study, to develop an understanding of the different *ethoses* of north-south health research. A situated ethics analysis allows micro and macro research ethics issues to be debated in tandem, and recognises power and culture as being central to international health research. The study focus is on the lens of researchers - both north and south - identifying them as the most important stakeholders in defining, shaping and executing the research study. A situated ethics of health research conceptual framework is developed to analyse the findings.

Primary data were collected through in-depth interviews with: Zambian researchers (n=20), Zambian national stakeholders (n=8) and northern researchers who had been involved in public health research collaborations involving Zambia and the global north (n=25). An inductive iterative process of thematic analysis was conducted. Findings were grouped around micro and macro research ethics issues, and the ethics of researcher relationships. Power imbalances and cultural issues emerged as the central key issues. Two heuristic devices were used to analyse the findings according to the situated research ethics framework around power and culture: Bourdieu’s theory of *Power and Practice* (1977), and a model of cultural competence adapted from Papadopolous & Lees (2002).
This thesis has broadened the scope of ethical reflection to encourage the broader ethics of north-south health research. The overall study contribution is that through developing an understanding of the different ethoses of north-south health research, power imbalances may be identified and uncovered, which could ultimately lead to a shared community of partnership, or a shared ethos of partnership. Through transcending the dichotomy of micro and macro research ethics, with macro research ethics issues considered on a par with micro, this will enable an ethos of north-south health research to emerge.
Acknowledgements

It is often said that a PhD journey is along a lonely and solitary path. I found that this could not be further from the truth. I would not have been able to come this far without my PhD supervisors, family, work colleagues and friends.

To my supervisors, Professor Ruairí Brugha and Doctor Elaine Byrne, who encouraged me to tackle the topic head-on. I have really enjoyed the journey with them over the last number of years, and have valued their guidance, support, patience and encouragement every step of the way. My gratitude also goes to Professor Gill Walt, for encouraging me to embark on this journey and for general guidance. I would like to acknowledge the support of Irish Aid, for partly funding this PhD, from 2009-2011, through the Global HIV/AIDS Initiatives Network.

My sincere appreciation goes to my Zambian collaborator, Chishimba Mulambia, for going above the call of duty to help me during the Zambian data collection for this study. Thanks to her, and Joseph Simbaya, for providing me with valuable contextual and insider information into the Zambian health (research) system, as well as helping me gain some cultural competence of the Zambian way of living. Thanks to each and every one of the participants in this PhD study, who openly and honestly shared their experiences with me.

To my buddies in Room 20, Niamh and Sara. I would not have got through this without your words of encouragement and advice, particularly over the last year; and, of course, the breakfast buns, ginger cake and macaroons. I would like to thank all my work colleagues for their support, in particular Regien, Tracey, Carlos, Fiona, Lisa and Anne Matthews. Sincere gratitude goes to Dad, Bridget and Sarah, who gave up their valuable time to proof read the thesis.

A special mention must go to my friends, particularly Ailbhe, Alacoque, Bridget, Caoimhe, Gill, Jenny, Kev, Paili, Sarah, Tanya and Ted, for easing the pressure, by phone, and weekend counselling sessions. A massive thanks to Joanne McCarthy for much needed lunches and texts to avert meltdowns.
To Mum and Dad, Orla, Ronan and Niamh for support throughout. Orla, your phone calls, particularly in the last few miles have been a wonderful source of sustenance. Mum and Dad, you have behind me throughout my academic career to date, always providing warm words of encouragement, even though at times, I asked you to dissuade me from embarking on this path. I have especially enjoyed Sunday lunch time study breaks over the last number of months. I would not have been able to get this far without Laoise taking weekly Saturday trips to Grannie and ‘Grandand’.

A special thank you to Gerard, for solid and honest advice. To Anne and Laura, for happy times spent together in Boksburg and Victoria Falls, during weekend data collection breaks from Lusaka.

To Laoise and Anú. I started this journey before you both came into the world, and sometimes doubted whether I would be able to continue with it after you arrived. You have enabled me to continue my studies, particularly through marathon sleeping sessions, and have provided a welcome breath of fresh air and perspective when it all got too much.

Finally, to Dean. I simply cannot express how much your support has meant to me throughout this journey. You have been by my side, pushing the boulder up the hill every step of the way. Hopefully we can free wheel down the hill together soon.
Chapter 1: Introduction and study rationale

“It is confirmed that buried deep within the DNA of international collaborative research is a recognition that cultural, linguistic and social differences between collaborators pose critical challenges to the success of research partnerships. Similarly, differences in the respective political histories of countries, just like the differences in the distribution of prosperity and poverty, will inevitably impact ethical reflection.” (Meslin et al., 2013)

1.1 Study aim, objectives and research questions

The starting point for this PhD study is that international academic north-south public health research between lower and middle income countries (LMIC) and higher income countries (HIC) raises ethical issues at each stage of the research process, including: what types of research will be conducted, how data are collected and analysed, research ethics approval mechanisms, and researcher relationships. While it can be said that all health research raises ethical questions, research between LMIC and HIC raises unique ethical concerns. Ethics in this study is defined as ‘situated research ethics’ (see Section 1.2) within which the core components are power, culture, and researcher identity. A situated research ethics recognises that research ethics is integral to the entire research process, from funding to agenda setting, research design, data collection, analysis and outputs.

The overall study aim is to undertake a situated ethics analysis of international academic public health research between LMIC and HIC, using Zambia as a case study, to develop an understanding of the different ethoses of north-south health research.

Specific research objectives are as follows:

1. To identify, from existing literature, ethical issues in international academic north-south health research (Chapters 4 & 5). The research question to be

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1 The terms LMIC and HIC, (global) north and (global) south will be used interchangeably throughout this thesis. This is explained further in Section 1.4
2 Another key stage of the research process is getting research into policy and practice which has been deemed beyond the scope of this study.
addressed is: what are the ethical issues that arise when academic health research is undertaken between the global north and the global south?

2. To develop (Chapter 2) and utilise (Chapters 6, 7, 8) a situated research ethics framework for analysing micro and macro research ethical issues in international academic north-south public health research.

3. To explore the role of power in international academic north-south health public health research (Chapter 9). The research question to be addressed is: how does power influence international academic north-south public health research and why do power imbalances exist and persist?

4. To undertake an analysis of the role of culture in the health research process in international academic north-south public health research (Chapter 10). The research question to be addressed is: how does culture influence north-south health research and how aware are researchers of their culture in relation to the research process?

The overall study contribution is that through developing an understanding of the different ethos of international north-south health research, power imbalances can be identified and addressed. A situated ethics analysis of research - an analysis of micro research ethics, macro research ethics, power and culture - will allow for the different ethos of contemporary collaborative research to be explored. Through this, a better understanding of the different ethical dimensions of research will be developed. This research ethics analysis may ultimately result in a shared ethos, a shared frame of reference, a community of partnership for research collaborations. This is discussed in detail in Chapter 11.

1.2 Study rationale: what is and why a situated research ethics analysis?

The value of international research collaborations has been well documented and studies evaluating these partnerships primarily focus on what constitutes best practice, the politics of research priority setting, and research capacity strengthening (Bradley, 2007, Maselli et al., 2006, Lairumbi et al., 2011). However, there has been less attention to other stages of the research process such as research design and research
study implementation. A north-south divide dominates evaluations of north-south health research. Some reports suggest that a shift has occurred in recent years where power is being transferred from the north to the south (Jentsch and Pilley, 2003), with an increasing number of projects led by southern institutions, a trend towards more equally shared budgets, and opportunities for research capacity strengthening (Bennett et al, 2010). Others report that the fact that funding is primarily routed through northern research institutions, ensures that power remains with the north (Costello and Zumla, 2000). Benatar (2002) states that “research and action priorities, as well as methodological standards typically comply with cultural and scientific traditions of northern institutions along with their prevailing ideological perspective” (Benatar, 2002).

A review of the literature on ethical issues in health research between LMIC and HIC (Chapters 4 & 5) confirms that power imbalances and inequities exist at each stage of the research process: from funding, to agenda setting, data collection, analysis and research outputs. The literature identifies and explains the nature of these inequities and power differentials, but often does not explain in detail why they exist and persist. Some of these imbalances are structural (such as funding) and some are related to imbalances in relationships, though both are interlinked.

Inter-country collaboration on health dates back centuries, as far back as the Plague. However, the field that came to be described as international health began with colonisation, at the end of the nineteenth century (Rowson et al., 2012). Until relatively recently, people in LMIC received little benefit from the results of research (COHRED, 2007). The central message contained in the 2013 World Health Report is that evidence is needed from research to ensure universal health coverage (WHO, 2013). Lower and middle income countries suffer from limited financial resources to self-fund health research, and a low priority is given to their national health problems by the global research community (COHRED, 2000).

To date, studies analysing research collaborations between the global north and the global south have either focused on:

1. micro research ethics issues: incorporating traditional dimensions and aspects of research ethics such as research ethics review processes, informed consent,
community engagement and the benefits of research to communities, with a focus primarily on research participants and relationships between researcher and research participant (see Chapter 5).

2. **Macro research ethics issues**: the broader issues of the politics and power of the research process, from agenda setting to capacity building, to authorship, and how research actors and institutions function and interact. For the most part, the literature generally does not designate these topics as ethical issues (see Chapter 4).

Inequities and power imbalances between researchers in LMIC and HIC are often considered outside the immediate remit of research ethics, resulting in researchers, funders and institutions ignoring the more fundamental ethical issues of the politics and inequity of research in LMIC (Molyneux and Geissler, 2008, Geissler and Molyneux, 2011, Robinson-Pant and Singal, 2013). These authors have proposed that both micro and macro research ethics should be regarded as complementary and dependent on one another. They call for a consideration of the processes of collaboration between the north and south and the ethics of inequitable international relations as ethical concerns. This includes attention to both research ethics principles, and the political economy and social relations of research. Considering these issues in tandem allows a situated ethics of research to emerge, which analyses:

“the relevance and application of ethical principles and guidelines for different studies and contexts, and takes into account the realities of complex individual, institutional and national imbalances in power and resources. Thus, it potentially brings together the micro and macro level perspectives.” (Molyneux and Geissler, 2008)

Central to a situated ethics analysis is a consideration of social and cultural contexts, and unequal power relations at both the micro and the macro levels (Molyneux and Geissler, 2008, Geissler and Molyneux, 2011, Robinson-Pant and Singal, 2013):

“We are concerned that issues of ethics should be seen as integral to the whole research process, rather than adopting a bolt-on approach. We suggest that researching ethically is not just a matter of understanding and adapting
research tools to specific social and cultural contexts, but also about researchers interrogating and responding to unequal power relations at both micro and macro levels.” (Robinson-Pant and Singal, 2013)

This PhD study undertakes a situated research ethics analysis (Molyneux and Geissler, 2008, Geissler and Molyneux, 2011, Robinson-Pant and Singal, 2013) of north-south academic public health research, through the lens of researchers, identifying them as the most important stakeholders in defining, shaping and executing the research study. The study uses Zambia as the country of focus. Situated ethics can be analysed on diverse levels of scale: global, national, institutional and individual. This PhD study will pay particular attention to the national and individual level, whilst also providing context from the global level.

1.3 Power, culture and researcher identity in international health research ethics

In order to undertake a situated research ethics analysis of north-south public health research, two heuristic devices are used in this study: (i) power and (ii) culture, both of which are considered to be central to developing an understanding of situated research ethics. Much of the literature recognises the unequal distribution of power in north-south health research (see Chapters 4 & 5), however the nature of this distribution has not been analysed in detail. Bourdieu’s theory of Power and Practice (1977) helps to explain, how power is distributed and why imbalances exist and persist between the north and the south. This is described in detail in Chapter 2 and analysed in relation to the research findings in Chapter 9.

Culture is the second key component of situated research ethics, because of its relevance to research collaborations that involve stakeholders from more than one country. Recognising that cultures are not homogenous, the focus of this PhD study is on the common elements of northern and southern culture, within which, rules and

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3 The reasons for choosing Zambia are outlined in Section 1.4
4 In social science, a heuristic device is a model or a concept that, while not necessarily portraying things as they really are, nonetheless help us to understand them POOL, R. & GEISSLER, P. W. 2005. Medical Anthropology, Berkshire, Open University Press
meanings are shared (Keesing and Strathern, 1998). This study has identified the following definition of culture as being the most useful for the purpose of a situated research ethics analysis.

“The values, norms and traditions that affect how individuals of a particular group perceive, think, interact, behave and make judgements about their world.” (Chamberlain, 2005)

This PhD study employs a cautious approach to using culture as an analytical category, as outlined by Pool and Geissler (2005):

‘A culture is always a composite, an abstraction created as an analytical simplification. We make such a simplification in order to capture and describe as a system, the shared elements of socially distributed knowledge. But there is a danger of taking this abstraction we have created as having a concreteness, an existence as an entity, and causal agent ‘it’ cannot have. (Pool & Geissler, 2005)

Culture will be analysed from two angles in this study. Firstly, it will be analysed in relation to power, particularly using Bourdieu’s perspective on cultural capital and power (see Chapters 2 & 9). Secondly, cultural competence has been chosen as a useful model to analyse the role of culture in international academic public health research between the global north and the global south. Chapter 2 will define cultural competence and outlines the framework used to assess cultural competence, which is an adaptation of a model developed by Papadopolous & Lees (2002). Surprisingly, no model has been found to address cultural competence in research collaborations that involve researchers from LMIC and HIC, with most models focusing on health care provision (health provider to patient interaction). Limited studies have been undertaken in relation to cultural competence in research, and where they do exist, the focus is primarily on clinical trials or on community based participatory research (Harvard, 2010).

Researcher relationships and researcher identity are also key to north-south health research and will be analysed across micro and macro research ethics, and power and culture. Guillemín & Guillam (2003), Simon & Mosavel (2011) and Madiega et al.
(2013), highlight the central importance of researcher identity in the ethical conduct of global health research. Researcher identity is defined as the “identities that researchers ascribe to themselves, or have ascribed to them in their places of research” (Simon and Mosavel, 2011). Reflexivity will be essential to the analysis of this PhD study, from the position of the interviewees in the study, and also the PhD researcher. Within a situated research ethics analysis in this thesis, culture and power are considered to underpin researcher relationships, identity and reflexivity.

1.4 Circumscribing the PhD study

The field of north-south health research is immense. An initial broad literature search yielded tens of thousands of results for studies, reports and evaluations in this broad arena, therefore it was deemed necessary to circumscribe the units of analysis for this study.

- **International rather than global health research**: Recent decades have seen a distinction between *global health* and *international health*. Global health is considered to focus on issues that affect all countries, across LMIC and HIC. On the other hand, international health is centred on health problems in LMIC (Rowson et al., 2012). This PhD study focuses on international health research because most north-south health research continues to focus on health problems in LMIC.

- **Public health research**: this study started out by circumscribing the research to health policy and systems research (HPSR) collaborations involving Zambia and the global north. However, it became clear that most of the researchers involved in these collaborations aligned their research broadly within the public health research definition (see Box 1), rather than the field of health policy and systems research. Fourteen health research collaborations were included in the study; 6 of these were categorised as HPSR projects/collaborations, while 8 were considered to be in the broader field of public health, including 3 Randomised Controlled Trials (RCTs).
Global north and south: this study will use the term ‘southern’ to denote researchers primarily based in low and middle income countries (LMIC) and the term ‘northern’ to denote those working predominantly in higher income countries (HIC). As Bradley (2007) notes, the division is not so clear cut in practice: “many researchers from the developing world were trained and work in the north. By the same token, many researchers from the north have relocated to the south”. Moreover, some countries in the geographic south, for example Australia and New Zealand are considered to be part of the global north. The terms southern/lower and middle income countries, and northern/higher income countries will be used interchangeably throughout the thesis. While it is recognised that some of these terms have limitations, they also “have certain currency and are generally understood” (Bradley, 2007).

Stages of the research process: This study focuses on the ethics of the following elements of the research process that are considered knowledge

<table>
<thead>
<tr>
<th>Box 1: Definition of public health</th>
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<td>It is helpful before defining public health research to differentiate between medicine and public health. Medicine focuses on the treatment or diagnosis of individuals. In contrast, public health focuses on a community or population, rather than an individual. Public health incorporates the interdisciplinary approaches of epidemiology, biostatistics and health services, environmental health, community health, behavioural health, health economics, public policy (Nuffield Council on Bioethics, 2007). It can be defined as:</td>
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<tr>
<td>“…one of the efforts organised by society to protect, promote, and restore the people’s health. It is the combination of sciences, skills, and beliefs that is directed to the maintenance and improvement of the health of all the people through collective or social actions.” (The Dictionary of Epidemiology, 2001)</td>
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production: funding, partner selection, priority and agenda setting, data collection, data analysis and research outputs. It is recognised that getting research into policy and practice is an important stage in the research process. However, the number of studies in this area is immense and encompasses a different set of issues to the other stages of the research process, therefore considered to be beyond the scope of the study.

- **Academic research**: The focus of this thesis is academic research between Universities and research institutions. An abundance of evidence exists relating to the ethics of health research involving communities, non-government organisations (NGOs), private-for profit research (such as issues relating to patents) and/or policy makers, raising distinct ethical issues which are beyond the scope of this thesis. This study focuses on researchers understanding of north-south health research, placing them at the centre, as key stakeholders in shaping and executing the study.

- **Legislation and legal issues in north-south health research**: this PhD study does not examine in any significant way the legal issues which arise in north-south health research. Legislation governing research in Zambia is detailed in Chapter 6. Legislation governing research in northern countries is not analysed in detail, primarily due to the fact that the case study is Zambia. Many diverse legal/regulatory systems exist in the northern countries that were involved in this PhD study, which would be too complex to cover in a superficial manner.

- **Why Zambia?** Zambia has been chosen as an ideal country to explore the ethics of health research between the global north and the global south. According to the Zambia Forum for Health Research (ZAMFOHR), health research in Zambia is fragmented and underfunded (Leininger, 1995). Health research priorities in Zambia remain disease focused in outlook and priority setting is not representative and inclusive (COHRED, 2008). External donors fund up to 90% of health research and over 90% of the University of Zambia’s (UNZA) funded research work in 2005-2006 consisted of collaborative work involving northern partners (COHRED, 2008). A formal health research priority setting exercise was undertaken in 1999 by the Ministry of Health (MoH), which has not been updated (Kwibisa, 2009). Recent years have witnessed attempts to establish a
national health research system, including legislation and regulation in 2013 (National Health Research Act, Zambia, 2012).

- **Defining research partnerships**: Many definitions and types of partnerships exist (Rosenthal, 1998, Bradley, 2007, Maselli et al., 2006). A number of studies in north-south health research relate to the research partnership itself, in terms of processes of the collaboration and evaluations of the collaboration (see Chapter 4). This study will use the terms interchangeably, “to indicate the wide variety of arrangements that link researchers and research institutions in the global north and south” (Bradley, 2007), and will not focus on the organisation or partnership elements of north-south health research. Comprehensive characteristics of partnerships are provided by the Canadian Coalition for Global Health Research (Mason, 2002), see Box 2.

**Box 2 Characteristics of research partnerships**

Canadian Coalition for Global Health Research (2007)

a) They support a relationship between players and structures (institutions, organisations, social entities).

b) are based on the principles of equality and shared responsibility.

c) are governed by a comprehensive and inclusive perspective, geared towards strengthening governance in global/local health and health research by seeking equality in health.

d) promote synergetic actions and initiatives which favour autonomy, an expansion of networks and an increase in the capacity and potential to strengthen governance in health and research.

Partnerships can involve different networks of actors such as individual researchers, to more complex forms, such as institutional partnerships, research networks, public–private partnerships and multilateral international research centres (Jacobsen, 2009). They can range from single research projects with clear objectives and a limited timespan to more long-term networks for exchange and collaboration, or into larger
research programmes. A useful typology of partnerships is identified by Maher et al. (2003) who identified three types of partnerships: obligatory, imposed and natural. The focus on international north-south academic public health research in this PhD study will often be abbreviated throughout the thesis and referred to as ‘north-south health research’. The terms LMIC/HIC; (global) north/(global) south, will be used interchangeably throughout this thesis.

1.5 Defining health research ethics

Definitions of research ethics vary according to discipline. This is important to state from the outset, as it is central to the conceptual lens for this study. Much of the discussion, particularly from philosophy and biomedicine, focuses on research ethics as issues of morality and social justice. Ethics is sometimes translated as custom, referring to customary ways of behaving in society and “norms for conduct that distinguish between acceptable and unacceptable behaviour” (Calhoun et al., 1993). One definition of research ethics is: “the analysis of ethical issues that are raised when people are involved as participants in research” (Walton). The vast majority of literature on health research ethics is biomedical in focus. Public health ethics has begun to develop frameworks separate to medical ethics and can be said to be either practice based or theory based (Schwartz, 1997). However, their primary focus is not research. It has been argued that ethical principles (see Chapter 5) see individuals as “theoretical entities rather than as concrete persons working in institutionalised environments” (Bourdieu and Wacquant, 1992). Business and engineering ethics have also discussed micro and macro ethics, with micro referring to the individual level, and macro referring to the level of institutions, government and cultural traditions (Jenkins, 2002). It is also helpful to outline a sociological definition of ethics, as this PhD study is based on a social science study of research ethics:

“... of ethics being historically and culturally located; of ethics working in association with key social institutions... of ethics defining particular social

5 Obligatory: core group of initial stakeholders identified; imposed: by donors, based on their agenda rather than those of partners; natural: usually based on past partnerships (Maher et al, 2003)

6 http://www.researchethics.ca/what-is-research-ethics.htm
groups, such as genders, professions, communities, or sexualities; of ethical values being both reflective and constitutive of the self.” (Haimes, 2002)

Based on the definitions of: Haimes (2002), Molyneux and Geissler (2008), Geissler & Molyneux eds. (2011), and Robinson-Pant & Singal (2013) (see Section 1.2), this study will encompass a broad definition of research ethics as an overall lens for the study, rather than focusing on issues of morality or justice.

1.6 Models for international north-south public health research

A number of models for north-south health research are described in the literature: (Mason, 2002, Bradley, 2007, Costello and Zumla, 2000). These models are consolidated here to encompass four broad types of models: i) parachute/safari model; ii) annexed site research; iii) north-south partnership model; iv) south-south, south-north partnership model. Elements of the different types of models can be present in any given research project and as such they should not be considered as separate, but often overlapping. Parachute/safari models and annexed site models are generally perceived to be less equitable than partnership models.

1.6.1 Parachute and Safari models

Postal or parachute models of health research have been described by a number of authors (Binka, 2005, Bradley, 2007, Gonzalez-Block et al., 2011, Geissler, 2013). This model sees researchers from the global north come to the global south with their own research interests, obtain the data or samples that they need, before returning to their Universities to analyse and write up their findings. Northern scientists come to an African country:

“take blood samples, then fly them out for analysis and publication with no further input from their African counterparts; and collaborations where consultants come to a country, make use of a considerable part of the research budget in a short period, get local expertise to contribute to their work but publish the results without acknowledging their local advisors.” (Binka, 2005)
Another similar semi-colonial model is referred to as the postal model, where southern partners courier biological samples or data to their northern partners (Tomlinson et al., 2006, Bradley, 2007). Although generally considered to be less common since the beginning of the 21st century, Costello and Zumla (2000) claim that this model is still practised. These methods have been described as ‘research colonialism’, following the links of political colonialism (Pearce, 2004).

1.6.2 Annexed site research

A number of large research sites have emerged in countries throughout Africa, linking local scientific institutions, Universities, or teaching hospitals, to northern Universities, research centres, or charities. They employ large numbers of staff, and often involve thousands of research participants from local communities, in various types of research, usually resulting in positive health impacts on the local community (Geissler, 2013). This type of research is often referred to as annexed site research. Critics of this model have stated that it has resulted in deteriorating standards in southern University Departments, hospitals and laboratories (Costello and Zumla, 2000, Tomlinson et al., 2006), due to a concentration of research into islands of excellence, rather than recognising and building capacity of the wider health research system.

“The combination of these factors—capitalisation and acceleration of global science and deprivation of local scientific and medical landscapes—results in the contraction of valid scientific inquiry into enclaves...as an archipelago of a few high-powered and well-resourced islands of global science, connected to one another and to the centres of scientific excellence and policy by long-distance flows of knowledge, materials, and resources.”(Geissler, 2013)

Other downfalls have been outlined: local staff are often paid higher salaries than those offered in local institutions, as a result attracting researchers away from national institutions. It is also argued that due to nature of northern control of the research, findings from these sites are less likely to become translated into policy in the host country (Costello and Zumla, 2000).
1.6.3 North-south partnership model

In the north-south partnership model, the research agenda is ideally negotiated with researchers from the host country, however, initiation of the collaboration in most cases remains with the northern partner (Bradley, 2007). International and local dissemination and outputs are arguably more balanced, and local research capacity building may be integral to the partnership (Edejer, 1999b, Costello and Zumla, 2000). Within the north-south partnership model, research is managed by local academic leaders, while northern researchers visit regularly to provide advice and technical support, and junior researchers within the country work with counterparts under the supervision of local academics (Costello and Zumla, 2000). European and Developing Countries Clinical Trials Partnership (EDCTP) and the INDEPTH network are specific examples of mutually beneficial north-south partnership models (Binka, 2005).

1.6.4 South-south, south-north partnership model

South-south, and south-north partnerships are usually initiated by southern partners, either to work jointly on common health issues or to share expertise and experience. In this model, southern partners pool resources and assume joint ownership, shedding the hierarchy of a dominant northern partner, with equality pervading (Bradley, 2007).

In reality, there are of course variations on each of these models described in this section, with some being more equitable than others (i.e. south-south/south-north more equitable than annexed site). All of the models, except for south-south, mirror development aid, with the northern partner often viewed as the donor and the southern partner viewed as the recipient.

1.7 Contribution of PhD study to original knowledge: how does it add to the situated research ethics debate?

Molyneux & Geissler (2008) posit that their work on situated ethics provides a starting point for further, joint thinking about an ethos of medical science in Africa. The authors hope that a growing body of work and discussion will ensue that will shine a light on the “complex individual, institutional and national imbalances in power and resources
within which all research is conducted” (Molyneux and Geissler, 2008). From a conceptual perspective, Molyneux & Geissler (2008), Geissler & Molyneux eds. (2011) and Robinson-Pant & Singal (2013), have laid the foundations for a situated research ethics analysis, which requires further development. Developing and testing a situated ethics conceptual framework to enable micro and macro research ethics issues to be recognised and debated in tandem to develop an understanding of the different ethoses of north-south health research, is the central focus of this PhD study.

To date situated research ethics has:

- focused primarily on biomedical research\(^7\). This PhD study focuses on public health research more broadly.
- has used ethnographic research methods which tend to focus more on researcher-research participant, and researcher-community relations\(^8\) (Dilger in (Geissler and Molyneux, 2011, McDonough and Polzer, 2012, Kamuya et al., 2013). An exception is Geissler (2013), who investigates relations between field staff. This PhD study analyses researcher to researcher relations from the perspective of both northern and southern researchers, across micro and macro research ethics. This study employs a case-study approach (Gilson ed. 2012) utilising in-depth interviews.
- while a situated research ethics concept explains the importance of micro and macro research studies, empirical studies under the umbrella of situated research ethics usually address either the micro or the macro level.

This PhD study develops, tests and utilises a situated research ethics conceptual framework to enable micro and macro research ethical issues to be recognised and debated in tandem, to develop an understanding of the different ethoses of north-south health research, through analysing power and culture as central concepts. Through this situated ethics analysis, power imbalances may be identified and uncovered, which could ultimately lead to a shared community of partnership, or a shared ethos of partnership.

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\(^7\) Robinson-Pant & Singal (2013) and Simons & Usher (2000) discuss situated research ethics in educational research. Simons & Usher’s understanding of the concept refers to situated ethics as being local and specific to each research context.

\(^8\) A small number of studies have analysed relationships between researchers and policy makers, although not under the situated research ethics banner.
This study examines the role of power and culture both at the macro and micro research ethics levels. Concepts from Bourdieu’s theory of *Power and Practice* (Bourdieu, 1977) are used to assist in understanding how power is distributed in north-south health research and why power imbalances persist (Chapter 9). A model of cultural competence is used to explain the role of culture in international academic north-south health research (Chapter 10). Based on a review of the macro research ethics literature (Chapter 4), it appears that macro research ethical issues have not benefited from an in-depth analysis based on power and culture. From the micro research ethics perspective (Chapter 5), power and culture have primarily concentrated on researcher – research participant relationships, rather than researcher to researcher, including power and culture within the micro research systems and structures, or differences in culture at the level of data collection, which is a focus of this thesis. Specific areas where the situated research ethics analysis will add to knowledge are detailed in Chapter 11, section 11.2.

### 1.8 Research methodology, methods and study design

This PhD study will analyse the situated ethics of north-south health research through a social science analysis of ethics (Haimes, 2002), which includes power and culture in ethical debates.

> “The social sciences see legal and ethical issues as primarily social issues, and because of this encompassing perspective, can contribute not only to the understanding of ethical issues, but also to the understanding of the social processes through which those issues become constituted as ethical concerns.”  

*(Haimes, 2002)*

Qualitative methods were selected for this PhD study, to understand and discover researchers’ (the participants in this study) interpretations and experiences. This is explained further in Chapter 3. A flexible research strategy was employed, which allowed the research to be modified while the analysis was underway.

The PhD researcher began by defining the broad research topic, a socio-cultural analysis of researchers’ experiences in academic north-south public health research,
with a focus on Zambia. This was followed by a search of the literature in this area and development of an initial conceptual framework in order to refine the research aims, objectives and research questions. Detailed macro and micro research ethics reviews were then undertaken. Data were collected in three phases: Zambian researchers (n=20), Zambian national stakeholders (n=8) and northern researchers who had been involved in public health research collaborations involving Zambia and the global north (n=25). The detailed conceptual framework and theoretical lens were then developed which led to further analysis and write-up of findings, according to: (a) concepts from Bourdieu’s theory of *Power and Practice* (Bourdieu, 1977); and, (b) a model of cultural competence for international health research (Papadopoulos and Lees, 2002). Chapter 3 provides a full discussion of methodology, methods and research design.

1.9 Thesis structure and outline

Chapter 2 outlines the conceptual framework for the study, including a description of the lens of power and culture in north-south health research. Chapter 3 presents the methodological approach employed by this PhD study, including a detailed explanation of the research design. The central position of reflexivity in this study is discussed, as well as sampling, data collection, and data analysis. Chapters 4 and 5 present the reviews of the literature that inform the PhD thesis. Chapter 4 discusses evidence that analyses north-south research from the macro research ethics perspective. Chapter 5 discusses evidence from the micro research ethics perspective.

Chapters 6-8 are the findings and initial discussion chapters of this PhD study. Chapter 6 presents findings from Zambia national level-stakeholder interviews and an analysis of policy documents relating to the national health research system in Zambia. Chapter 7 is focused on findings and discussion from qualitative interviews relating to macro research ethics, following the structure of the conceptual framework; while Chapter 8 focuses on micro research ethics also according to the structure of the framework. Each of these three chapters (Chapters 6-8) present the findings and discussion in light of existing literature, highlighting where findings are new, or where they provide a different perspective to what was detailed in the literature.
Chapters 9 and 10 present an in-depth discussion on the role of power (Chapter 9); and, culture (Chapter 10) in health research between the global north and the global south. Chapter 11 presents a conclusion to the study, paying particular attention to contributions of the study and conclusions/gaps, whilst also outlining the limitations of the study.
Chapter 2: Situated Research Ethics: a conceptual framework for north-south health research

2.1 Introduction

This chapter sets out the conceptual framework for this PhD study, a situated research ethics conceptual framework for international academic north-south public health research. It outlines the literature that exists in this area and how it feeds into the framework which the PhD study develops. The framework provides the structure and central analysis point for this thesis. Conceptual frameworks provide researchers with the ability to move beyond descriptions of ‘what’ to explanations of ‘why and how’ (Vaughan, 20089), as a filtering tool to scaffold the research (Taylor and White, 2000). They can also “provide the research with a common language, guiding principles and reference points from which to structure discussion and analysis” (Taylor and White, 2000).

While a situated ethics analysis approach was identified at the outset of the study, the conceptual framework described in this chapter was developed following initial analysis of the data and based on a review of the literature, therefore it is grounded in the empirical findings. It links the literature, core concepts and findings to the research aim, which is: to undertake a situated ethics analysis of international academic public health research between LMIC and HIC, using Zambia as a case study, to develop an understanding of the different ethoses of north-south health research. The framework was devised once an initial analysis of the qualitative in-depth interviews had taken place, following the development of codes, and once it became clear that within a situated research ethics analysis, power and culture were the central emerging issues.

As described in Chapter 1, the foundation for a situated ethics analysis has been laid by a number of authors (Molyneux and Geissler, 2008, Geissler and Molyneux, 2011, Robinson-Pant and Singal, 2013). However, a detailed conceptual framework has not

previously been developed and tested, which would enable micro and macro research ethics to be recognised and debated in tandem, to develop an understanding of the different *ethoses* of north-south health research. Ritzer’s micro-macro theory of social analysis (Finlay, 2002), was used as a starting point in developing an initial framework focusing on the various stages of the research process, from initiation of the project, to data collection, analysis and write-up (see Chapter 3, Methodology). This framework was then used as the topic guide for the semi-structured interviews. The themes emerging from the analysis of the data collected were the starting point for the development of the overall situated research ethics framework that guided the thesis. Chapter 3 Methodology, will explain this process in further detail.

This chapter begins by explaining why a situated research ethics conceptual framework is needed to analyse north-south health research, and then details the existing research and literature in this area. Each of the dimensions of the framework are then described in detail, from micro to macro research ethics, through the heuristics of: (a) power (concepts from Bourdieu’s *theory of Power and Practice*, 1977) and (b) culture, through a model of cultural competence, adapted from Papadopolous & Lees (2002).

### 2.2 Why a need for a situated ethics of international north-south health research? The evidence

White, in Geissler & Molyneux eds. (2011) argues that whether a particular procedure is ethical is secondary to the question of whether the whole political and epistemological process can be judged as ethical. Over the past two decades, the ethics of health research – primarily medical research - has emerged as an area of debate, in particular concerning transnational research collaborations (Molyneux and Geissler, 2008). Geissler & Molyneux eds. (2011), refer to the *ethos* of medical research as going beyond rule-set ‘ethics principles.’ They define *ethos* as being:

> “*shaped by historical and political-economic circumstances, and revealed by close attention to how different actors in different localities and times, produce scientific evidence in particular ways, how they express motivations and aims, take decisions, identify and solve problems, chose ways forward and evaluate past actions.*” (Geissler and Molyneux, 2011)
A number of authors claim that it is necessary for the ethics debate to include broader issues of the ethics of how institutions function, and the ethics of international relations: (Benatar, 2002, Benatar, 2004, Jentsch and Pilley, 2003, Molyneux and Geissler, 2008, Wight, 2008, Pratt and Loff, 2013, Marshall and Rossmann, 2011). Molyneux & Geissler (2008) maintain that taking global and local ethics into consideration is not enough. It is necessary to include a political assessment, including power and resources, in understanding health research ethics at both micro and macro research ethics levels:

“The call is to consider more centrally, as crucial ethical concerns, the wider interests of whole populations, the functioning of research institutions, the processes of collaboration, and the ethics of inequitable international relations.” (Molyneux and Geissler, 2008)

Their focus is on social and political processes, at individual, institutional and national levels, including the analysis of power relations at the various stages of the research process. This includes a consideration of: a) research ethics principles; b) power relations; and; c) culture and context in international health research. The authors express a fear that the narrow focus on micro research ethics prevents these kinds of debates, rather than viewing them as two sides of the one coin (Molyneux and Geissler, 2008). The definition of situated research ethics used for this PhD study is as follows:

“A situated ethics considers the relevance and application of ethical principles and guidelines for different studies and contexts, and takes into account the realities of complex individual, institutional and national imbalances in power and resources. Thus, it potentially brings together the micro and macro level perspectives.” (Molyneux and Geissler, 2008)

The need to consider power and culture as integral to the entire research process is also discussed by others (Kubanyiova, 2008) Ulrich (in Molyneux & Geissler eds. (2011), (Merriam et al., 2001). A small number of publications deserve special
mention here as they analyse health research ethics under the umbrella of a situated ethics of health research.

Firstly, Geissler & Molyneux eds. (2011) and contributors, analyse the interaction between global researchers in Africa, their institutions and participants, underpinned by political and economic inequities, through asking the question: how could research be conducted more equitably? The contributors to this volume share a focus on power and culture in international north-south health research relations that make up medical research, how evidence is produced and negotiated in medical research, including the politics and history of medical research and public health. Contributors focus on either micro or macro health research ethics issues.

Secondly, a Special Issue in Social Science and Medicine entitled ‘Ethics and Ethnography of Medical Research in Africa’ (Molyneux and Geissler, 2008), explores health research under the umbrella of situated health research ethics, through a focus on relationships between actors. These papers focus on relationships between communities/participants and research teams, and researchers and policy makers. The papers in this Special Issue do not focus on researcher to researcher relationships.

Thirdly, Robinson-Pant & Singal (2013), analyse situated ethics, focusing on micro research ethics and within the field of educational research, through exploring literature from the field of anthropology and health. In particular they investigate ethics to understand how ‘hierarchies of culture and power influence knowledge construction.’

Rather than adopting a ‘bolt on’ approach, we suggest that researching ethically is not just a matter of understanding and adapting research tools to specific social and cultural contexts, but also about researchers interrogating and responding to unequal power relations at both micro and macro levels”. (Robinson-Pant and Singal, 2013)

Many other empirical studies, reflections and opinion pieces analyse power and culture in international health research (discussed and analysed in detail in Chapters 4 & 5), however not specifically under the label of situated ethics.
As stated in Chapter 1, this PhD study undertakes a social science, situated ethics analysis of north-south health research. Hoeyer et al. (2005), state that there are different ideas of ethics in the social sciences and medicine. It is argued that the social sciences possess a greater awareness of and attention to conflicting interpersonal relationships and the power imbalances inherent in many research relationships (what can be termed macro research ethics), while medical or clinical research is more concerned with micro research ethics (Haimes, 2002).

### 2.3 A situated research ethics conceptual framework

Figure 1 illustrates a situated ethics of international north-south academic public health research conceptual framework. The aim of the framework is to assist in developing an understanding of the different *ethoses* of north-south health research. The two pillars that make up the situated research ethics are macro and micro research ethics. Macro research ethics are the focus of Chapter 4 (literature review) and Chapter 7 (macro research ethics results and initial discussion). Micro research ethics are the focus of Chapter 5 (literature review) and Chapter 8 (micro research ethics results and initial discussion). Researcher relationships, reflexivity, and identity are central to the study and are integral to both micro and macro research ethics.

The framework recognises the different levels of situated research ethics, at individual, institutional, national and global levels. This PhD study focuses primarily on the individual and national levels. The national health research system in Zambia is discussed in Chapter 6, using an analysis of policy documents and in-depth interviews with national level stakeholders. The two key central heuristic devices used in this study that make up a situated research ethics analysis are: power (Chapter 9); and, culture (Chapter 10), although elements of culture are also discussed within power. Each of the components of the framework will now be described.
Figure 1: A situated research ethics framework for international academic north-south public health research

- Macro Research Ethics
  - Research collaboration guidelines
  - Project Initiation: funding partner selection, priority & agenda setting
  - Production of knowledge
  - Capacity strengthening & career paths

- Micro Research Ethics
  - International guidelines for health research ethics
  - Procedural Ethics: research ethics review processes
  - Ethics in practice: data collection and community engagement

- Power
- Culture
  - Power
  - Cultural competence

Ethos of North-South Health Research

Researcher
  Relationships, Identity, Reflexivity
2.4 Micro research ethics: procedural ethics and ethics in practice

Micro research ethics in this thesis incorporates traditional definitions of research ethics, such as research ethics review processes, informed consent, community/participant engagement and benefits of research, with a focus on research participants and in particular relationships between the researcher and research participants/communities. Procedural ethics and ethics in practice, defined and described below, are considered to be the fundamental components of micro research ethics. A review of the micro research ethics literature in Chapter 5 analyses existing evidence in this area. Chapter 8 presents findings from in-depth interviews for this PhD study around micro research ethics and discusses these findings in light of the literature.

Guillemin & Heggen (2009), focus on the distinction between procedural ethics and ethics in practice. Procedural ethics refers to the formal regulations and review processes for research, such as research ethics review committees, including informed consent; while ethics in practice refers to the everyday ethical issues that arise in fieldwork: “and are not usually addressed in research ethics committee applications, nor are they events that are often anticipated when applying for approval” (Corrigan, 2003). In this thesis, the focus is on how data are collected, including different roles in the process and community engagement. These issues may not be regarded as ethical in the sense that they may not be dilemmas, or may not appear to be of great consequence. It has been defined as:

“ethically important moments where the approach taken or the decision made has important ethical ramifications but where the researcher does not necessarily feel himself or herself to be on the horns of an ethical dilemma.” (Corrigan, 2003)

A number of authors echo the point that RECs do not consider ethics in practice, but rather focus strictly on REC mechanisms: (Molyneux and Geissler, 2008, Lairumbi et al., 2011, Pratt et al., 2012b, Robinson-Pant and Singal, 2013). This has also been referred to as ‘empty ethics’ (Corrigan, 2003). One study situates research ethics review within
a larger system of power using Michel Foucault’s analysis of governance, focusing on a HIC alone, Canada (Guta et al., 2013), and discusses this from the perspective of ethics creep, which refers to the “increasing bureaucratisation of research ethics boards and the expanding reach of ethics review.” Chapter 5 reviews the micro research ethics literature and Chapter 8 presents findings in relation to micro research ethics and discusses these findings in light of the literature.

2.5 Macro research ethics: project initiation, production of knowledge, capacity building and career paths

A body of literature has begun to focus on the wider ethics of health research in developing countries, instead of the narrow focus on relationships between researchers and research participants. There is concern that the increasing refinement of guidelines, and the introduction of more and more accountability mechanisms for research may narrow the scope of ethical reflection and depoliticise ethical debates, rather than encouraging reflection of the broader ethics of scientific knowledge production, (Molyneux and Geissler, 2008, Geissler and Molyneux, 2011, Robinson-Pant and Singal, 2013).

Macro research ethical issues are defined in this thesis as the broader issues of the politics and power of the research process, from agenda setting to capacity building, to authorship, and how research actors and institutions function and interact. For the most part, the literature does not designate these as ethical issues. Chapter 4 reviews the macro research ethics literature. Chapter 7 presents in-depth interview findings in relation to macro research ethics and discusses these findings in relation to literature in this area.

2.6 The role of culture in north-south health research

As explained in Chapter 1, culture is a central heuristic used to analyse health research that crosses cultural divides, and the second component of situated research ethics. The relevance of culture in relation to situated research ethics in this PhD study is twofold: i) how does culture influence north-south health research and how aware are northern and southern researchers of their culture in relation to the research process?
(discussed in Chapter 10); and, ii) what are the power dimensions of culture that are relevant to a situated research ethics (discussed in Chapter 9). The ethical universalism versus ethical relativism debate which relates primarily to the discussion on micro research ethics is also discussed.

This thesis recognises that culture does not exist as a thing that independently causes behaviour (Pool and Geissler, 2005). This study focuses on northern and southern communities and the culture of science, however it recognises that there will always be local and individual differences within cultures. Keesing & Strathern (1998) caution against reifying culture as: “a thing, but rather that it can be used as an analytical simplification to capture and describe commonalities between individuals and/or communities” (Keesing and Strathern, 1998).

2.6.1 Cultural competence in north-south health research

Cultural competence in research has been defined as the ability of researchers to conduct high quality research that takes into account an awareness of culture and diversity when developing research ideas, undertaking fieldwork and analysis and exploring the applicability of research findings (Harvard, 2010, Clark, 2012). Forde et al (2008) identified characteristics of effective cross cultural researchers, see Box 3. (Leininger, 1995) points out, that without cultural awareness, researchers tend to impose their beliefs, values and patterns of behaviour upon cultures other than their own.

<table>
<thead>
<tr>
<th>Box 3: The responsive cross-cultural researcher:</th>
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<tbody>
<tr>
<td>1. Possesses self-awareness and self-understanding, is able to think honestly about personal views of race and cultural diversity and understands his or her cultural beliefs, values and norms and their influence on relationships with others.</td>
</tr>
<tr>
<td>2. Possesses awareness and understanding of the culture in which he or she is working.</td>
</tr>
<tr>
<td>3. Is socially responsive and responsible, working towards greater multicultural understanding in the larger society.</td>
</tr>
<tr>
<td>4. Employs techniques and strategies to promote effective intercultural interactions.</td>
</tr>
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(Forde et al, 2008).
Models of cultural competence tend to focus on health care provision, specifically health provider to patient interaction (Campinha-Bacote, 2002). Where cultural competence in research has been addressed, it chiefly relates to: a) researchers undertaking studies on a number of cultures; b) when researchers and study participants are from different cultural backgrounds; and, c) application of research questions and tools developed in one cultural context to another cultural group (Clark, 2012). Studies in this area focus mainly on clinical trials and community based participatory research (Harvard, 2010).

Papadopolous & Lees (2002) believe that culturally incompetent research is unethical research, because it can waste resources and may lead to inappropriate policies. This thesis adapts and refines a model of cultural competence in health research developed by Papadopolous & Lees (2002) and discusses its’ use for defining what constitutes culturally competent research between HIC and LMIC (see Figure 2). Additions to the model made for the purpose of this PhD study are indicated in red text in Figure 2 and explained further in Chapter 10.

Figure 2: A model for cultural competence in international academic north-south public health research (adapted from Papadopolous & Lees, 2002)
1. **Cultural awareness:** begins with the researcher examining and challenging their own values, perceptions and behaviour in relation to how these can affect research, in particular the data they collect (Papadopoulos and Lees, 2002). This PhD study asked researchers to reflect not only on how their values affect the data they collect, but how they affect the entire research process ranging from priority setting, to data analysis, to relationships with other researchers. This relates also to cultural identity and researcher identity (see Section 2.7) (new addition to the model) in terms of whether researchers see themselves as being: i) northern; ii) southern; iii) a scientist/researcher, based on a culture of science; or, iv) a combination of these. Ethnocentricity is an element of cultural awareness, defined as “the assumption that your own culture, values... are the only or best or the most valid ones” (Pool and Geissler, 2005). This will be examined to ascertain if northern or southern researchers display ethnocentric propensities.

2. **Cultural knowledge:** is needed to understand similarities, differences and inequalities in health research (Papadopoulos and Lees, 2002). It is achieved through contact with people from different cultural groups as well as from many disciplines. Central to cultural knowledge is the avoidance of essentialism which assumes that there are essential cultural differences between people which supersede other aspects of their being (Papadopoulos and Lees, 2002). In analysing the ethics of north-south health research, it is important not to reduce all issues to a north-south dichotomy. This thesis seeks to explore to what extent multiple identities exist amongst researchers.

3. **Cultural sensitivity:** according to Papadopolous & Lees (Papadopoulos and Lees, 2002), this is achieved by considering participants in research as true partners, particularly in terms of trust, empathy, communication skills, and respect. This PhD study adds cultural sensitivity towards other researchers as being essential, that is whether researchers in a collaboration consider other researchers as true partners, thereby challenging unequal power relationships (Papadopoulos and Lees, 2002).

4. **Cultural competence:** “requires the synthesis and application of previously gained awareness, knowledge and sensitivity” (Papadopoulos and Lees, 2002), therefore can be viewed as the cumulative effect of the process. This thesis
analyses cultural competence in relation to the degree to which researchers in this study have displayed cultural competence in relation to the research process and researcher relationships.

(Dean, 2010) questions the notion that one could become competent in the culture of another, instead proposing a model in which maintaining an awareness of one’s lack of competence is the aim, rather than the achieving competence. This thesis recognises that exploring cultural competence will not result in a remedy that single-handedly eliminates imbalances in north-south health research, but opens up a dimension that can inform more ethical research relationships, instead of stereotyping and oversimplification of culture (Betancourt, 2004). In developing a model of cultural competence, it is also important not to reduce culture to a technical skill of “do’s and don’ts” (Betancourt, 2004). Culture in this PhD study is not seen as homogeneous or static. It is not a single variable but rather is linked to power and set within a situated ethics of north-south health research. This thesis recognises that cultural processes frequently differ within the same group – for example between northern and southern researchers - because of differences in age cohort, gender, political association, class, religion and ethnicity. Chapter 10 will apply this model of cultural competence to PhD study findings.

2.6.2 The false debate between ethical universalism versus ethical relativism
There is a longstanding and on-going deliberation surrounding the applicability of ethical principles across countries and cultures. This is generally known as the ethical universalism versus ethical relativism debate, that is, whether research ethics principles should be universally applied (ethical universalism) or whether they are relative to time and place, due to cultural and contextual differences (ethical relativism). It is pertinent to highlight this debate in this PhD study that analyses research processes and ethics across cultural and geographical divides. Fundamental to this discussion is whether researchers, north and south, have similar perceptions of what is ethical in north-south health research or whether a more contextual approach to ethics emerges? A larger debate exists on ethical universalism versus ethical relativism from a moral perspective, which is beyond the scope of this study.
There is a growing realisation that abstract principles are difficult to apply in practice: history, geography, culture and economic status can have important implications for the way in which ‘universal’ ethical principles and guidelines are prioritised and applied in different contexts. Ethical relativists contend that a universal set of ethical principles is inappropriate, due to cultural variations between countries. Anthropologists introduced this term in the late 19th century and it is linked to a perception of Western cultural imposition on developing countries (Leontis, 2006), and Western cultural imperialism (Newton and Appiah-Poku, 2007, Widdows, 2007). Other authors refer to this as ‘moral imperialism’: “the aim of imposing, through different forms of coercion, moral standards from specific cultures, geopolitical regions and countries on other cultures, regions or countries” (Garrafa and Lorenzo, 2008). Ethical relativists contend that it is not correct to “blindly apply” Western research ethics principles without considering local context and culture (Harrowing et al., 2010). Simons and Usher (2001) also challenge universal ethics, “arguing that all ethical acts are situated in socio-political contexts that require the researcher to make complex and sensitive decisions in particular cases and settings”.

An initial scoping of literature in this area found that many authors appear to advocate ethical universalism. However, the degree of rigidity with which they apply it differs, with none fully backing the extreme universalist argument, that is, without allowing any consideration of cultural context. Benatar (2002, Benatar, 2004) suggests that there is overall acceptance of a need for universal ethical standards, however the challenge is to differentiate between universal and imperialistic beliefs with the acknowledgement of the relevance of contextual issues, without resorting to ethical relativism.

A number of other authors also advocate the middle ground, recognising that while undisputed ethical universal principles exist, these need to be adapted and embedded in specific contexts: (Tangwa, 2004, Emanuel et al., 2004, Harrowing et al., 2010, Ruger, 2012). Emmanuel et al.’s (2004) principles and benchmarks for undertaking research in developing countries, conclude that adaptation and balancing of these principles are relative to risk, resources and social practices. Macklin (2005) concludes that ethical standards can be applied across national borders by distinguishing
between substantive and procedural ethical requirements. Substantive ethical requirements are stated as fundamental principles of research ethics as stated in the Belmont Report (1978): respect for persons, beneficence and justice. Procedural requirements, those relating to research ethics procedures, such as whether informed consent documents should be signed, may vary according to cultural and contextual differences in multinational research (Macklin, 2012). International research ethics guidelines such as those from the Nuffield Council on Bioethics (2002), also acknowledge that principles must be translated into practice and made relevant to local context, with input from both sponsoring and host country.

A critical point in this argument is that “failure to distinguish between substantive standards and procedures may give rise to a perception of ethical conflicts when none really exist” (Macklin, 2012). The contention is that substantive issues in ethical regulations are stated so generally, that interpretation is required before they can be applied in practice. This debate is relevant to this thesis within the lens of cultural competence, i.e. do researchers advocate ethical universalism, relativism or do they adopt the middle ground? This will be particularly pertinent in relation to procedural ethics (REC review processes) and ethics in practice (data collection and community engagement) and will be discussed in relation to the findings in Chapters 8 and 10.

2.7 Researcher relationships, identity and reflexivity

This thesis places the researchers’ experiences at the centre of the situated research ethics analysis. Researcher identity refers “to the identities that researchers ascribe to themselves, or have ascribed to them in their places of research” (Simon and Mosavel, 2011). Reflexivity implies that the orientations of researchers will be shaped by their socio-historical locations, including their values and interests (Mason, 2002). Reflexive research “means that the researcher should constantly take stock of their actions and their role in the research process and subject these to the same critical scrutiny as the rest of their data” (Mason, 2002). Guillemin & Guillam (2003) argue that reflexivity is a helpful conceptual tool for understanding the nature of ethics in research.

Reflexivity will be central to the analysis of this study, both from the position of the PhD researcher and the interviewees in the study. This PhD study has centred on
researchers’ reflexivity in relation to each stage of the research process as a whole, including researcher relationships. Reflexivity will be discussed further in Chapter 3 in relation to PhD researcher reflexivity. Within a situated research ethics analysis in this thesis, culture and power are considered to underpin researcher identity and reflexivity.

Guillemin & Guillam (2003), Simon & Mosavel (2011) and Madiega et al. (2013), highlight the central importance of researcher identity in the ethical conduct of global health research, particularly from the perspective of power. They analyse the ethics of researcher identity in international health research, however, from the researcher to research participant perspective only. The ethics of researcher identity in relation to relationships between researchers (north and south) has not been analysed to date.

Simon and Mosavel (2011) also introduce the concept of symmetry and asymmetry in how researcher identity is perceived. Symmetry refers to when communities/research respondents perceptions of who researchers are corresponds with their own perceptions. Asymmetry is when perceptions do not accord with one another. This PhD study will explore if southern and northern researchers’ perceptions of one another are symmetrical or asymmetrical, particularly within the context of cultural competence (Chapter 10).

2.8 Power in north-south health research
Power is a central component of situated research ethics, across micro and macro research ethics issues. Many definitions of power exist. A useful broad definition considered appropriate for this study is “the capacity or ability to direct or influence the behaviour of others or the course of events.” Analysis of the findings of this PhD study show that concepts from Pierre Bourdieu’s theory of Power and Practice (Bourdieu, 1977) provide a useful lens to view the power dimensions in this study, as a major component of situated research ethics. The use of Bourdieu’s concepts in this thesis are in accordance with Bourdieu’s philosophy, for while Bourdieu was considered a theorist, he rejected pure theory that lacked an empirical base. However,

http://www.oxforddictionaries.com/definition/english/power

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he also disagreed with pure empiricism as an approach to be used in a theoretical vacuum (Calhoun et al., 1993). This section will outline the central concepts to this theory of *Power and Practice* (1977) including why these concepts are considered appropriate to analyse power in international academic north-south public health research. Chapter 9 will discuss results within this theory to provide a deeper understanding of power in academic north-south public health research, in particular why it exists and persists.

Bourdieu contends that power is at the heart of all social life (Schwartz, 1997). At the centre of Bourdieu’s analysis is the question of why social inequalities persist without powerful resistance. Bourdieu’s complete theory of *Power and Practice* (Bourdieu, 1977) conceptualises action as the outcome of a relationship between *Habitus, Capital and Field*. These concepts will now be introduced.

### 2.8.1 Field

Bourdieu contends that society is a system of fields, each with its own structure: an accumulation of history, logic of action and forms of capital - economic, social, symbolic and cultural, which are semi-autonomous and set within a larger field of power. Fields are structured spaces of dominant and subordinate positions that are organised around specific types of capital or combinations of capital; and where actors struggle to accumulate these different kinds of capital (Bourdieu and Wacquant, 1992). It is possible for actors situated outside of specific fields (the outsiders’ view) to grasp a clear perception of the interests or capitals struggled over in those fields. In this study, the arena is the field of international academic north-south public health research. The occupants of positions within a field may be either agents (in this case researchers) or institutions (Universities or research institutions) which are constrained or enabled by the structure of the field (Bourdieu and Wacquant, 1992). The field is a ‘*competitive marketplace*’ in which the various kinds of capital are employed and deployed (Schwartz, 1997). *Nomos* are the laws that govern practice in the field (Bourdieu, 1977), which in this PhD study are: research ethics guidelines and research collaboration guidelines.
Bourdieu defines three different types of field strategies that will be useful in understanding particular actions within north-south health research.

- Conservation strategies: pursued by those who hold dominant positions and enjoy seniority in the field;
- Succession strategies: attempts to gain access to dominant positions in a field, generally pursued by new entrants;
- Subversion strategies: those who expect to gain little from the dominant groups. (Bourdieu and Wacquant, 1992).

For the field of international north-south public health research to continue, all actors must share a common interest in preserving the field itself, even if they are sharply divided on how it is to be controlled (Bourdieu, 1977). In order to enter the field, the unspoken rules of the game must be accepted. An issue of paramount importance in Bourdieu’s theory is that actors misrecognise power relations, therefore contributing to the maintenance of the social order/structure of the field (Schwartz, 1997). This will be analysed in relation to whether northern and southern researchers are aware of power dynamics and their implications within north-south health research.

Bourdieu wrote at length about intellectuals, academics and the Scientific Field (Schwartz, 1997). For this PhD study, the scientific field can be perceived to be the field of international academic north-south public health research. Bourdieu speaks of the ‘universal’ value of a mode of understanding, discovery and communication, which he calls the rules of science. This will be explored from the perspective of whether there are universal rules in academic/research disciplines to which researchers all conform?

### 2.8.2 Habitus

A central focus of Bourdieu’s theory is *habitus*, which is acquired as a result of a long-term occupation of a position in a social world and provides the principles by which people make choices (Bourdieu, 1977). These choices result from early socialisation experiences, where broad parameters and boundaries of what is possible or unlikely for a particular group in a stratified social world are developed (Schwartz, 1997).

*Habitus* refers to the lifestyle, values, and expectations of particular social groups that
are acquired through involvement in everyday life. Essentially, it is our comfort zone, where we do not need to look for clues to know how to participate (Schwartz, 1997). *Habitus* focuses on habit rather than consciously learned rules and principles (Jenkins, 2002). Similarities can be drawn between definitions of *habitus* and culture (see Chapter 9, Section 9.3). The terms ‘cultural unconscious’ and ‘habit forming force’ (Schwartz, 1997) have also been used. *Habitus* is considered to shape individual action so that existing opportunity structures are perpetuated and it is resistant to change, often generating ‘self-fulfilling prophecies’, that reproduce the structure of life chances (Schwartz, 1997) and therefore the status quo is maintained (Jenkins, 2002). Bourdieu highlights the collective basis of *habitus*, individuals who internalise similar life chances, share the same *habitus*. The concept of *habitus* is particularly useful for explaining northern and southern positions in health research between HIC and LMIC, in particular for explaining why power imbalances exist and why the status quo remains unchanged, despite an impetus for change at the global level, in terms of building capacity for health research leaders in LMIC.

*Habitus* has moments when it is out of phase, particularly when a field undergoes a transformation that changes its rules. A structural lag can occur in these circumstances, or ‘hysteresis effect’ between aspirations and changing opportunities (Bourdieu, 1977). Because the habitus has a tendency to reproduce itself, some agents:

“*may have difficulty generating practices that correspond with the new order... The notion of hysteresis highlights the disparity between the new opportunities associated with field change and agents whose habitus leaves them unable (temporarily at least) to recognise the value of new positions.*” (McDonough and Polzer, 2012)

The *hysteresis* effect is a useful lens through which to analyse why power imbalances remain ingrained in north-south health research, despite efforts to redress this balance by many northern and southern stakeholders. Bourdieu does not however view *habitus* as governing all behaviour. He describes it as being most useful for explaining behavioural patterns in situations where normative rules are not explicit and where
domination relies on interpersonal relations rather than institutions (Calhoun et al., 1993). The rules of international north-south health research are often not made explicit (see Chapters 4 & 5), therefore showing the usefulness of habitus in explaining north-south power imbalances.

### 2.8.3 Capitals

According to Bourdieu, individuals and groups draw upon a variety of resources to maintain and enhance their positions in the social order (Schwartz, 1997). The capital that people accumulate defines their social trajectory (Calhoun et al., 1993). Bourdieu identifies four types of capitals which are used in this thesis to explain power in north-south health research; that is, the amount of each capital that researchers in the north and in the south possess. These are economic, social, symbolic and cultural capital. There is relatively little documented in the literature explaining each type of capital.

**Economic capital**

Economic capital is defined as "immediately and directly convertible into money" (Bourdieu, 1977), and can take various forms, such as intellectual property, shares and finance capital. Little detail is given on the nature of economic capital, from either Bourdieu or writers on his theory. Economic capital is considered to be the capital which assumes prime positioning, above social, symbolic or cultural capital. Access to research funding is a major issue in international north-south health research, therefore will be explored from the perspective of economic capital in Chapter 9.

**Social capital**

Social capital refers to collaboration between individuals and groups. Bourdieu sees it from the perspective of producing or reproducing inequality, “demonstrating how people gain access to powerful positions through the direct and indirect employment of social connections" (Bourdieu, 1977). Collaboration between researchers and research institutions is at the centre of international health research, therefore how researchers utilise social connections and social capital within north-south research partnerships will be an important point of inquiry.
Symbolic capital

Bourdieu refers to symbolic capital as the resources available to an individual on the basis of honour, prestige or recognition. “Individuals seek, individually or collectively, to safeguard or improve their position and to impose their position and to impose the principle of hierarchisation most favourable to their own products” (Bourdieu and Wacquant, 1992). Symbolic capital is based on dichotomous distinctions such as rare/common, good/bad, and inside/outside (Bourdieu, 1977). Inherent in international research between LMIC and HIC are a number of dichotomies, including north and south, and outsider and insider. Scientific capital is a form of symbolic capital, based on the prestige of the University one attends, publications, membership on editorial boards, grant committees and institutes (Calhoun et al., 1993). Both northern and southern partners could possess symbolic capital in similar or different ways in north-south health research.

Cultural capital

Cultural capital is identified by Bourdieu (1977) as existing in three different states.

- **Internalised**: refers to dispositions that are internalised by the individual through socialisation and that constitute patterns of understanding. This will be analysed as: (i) national health research culture in Zambia; and (ii) north-south culture of researchers.
- **Objectified**: referring to objects, such as books, works of art, and scientific instruments that require specialised cultural abilities to use. This will be investigated as the culture of science, specifically in health research.
- **Institutionalised**: the educational credential system, namely qualifications, degrees or titles (Schwartz, 1997). This will be examined as educational culture and work culture in north-south health research.

According to Bourdieu, cultural capital is a major source of social inequality. He contends that sharing similar forms of cultural capital with others creates a sense of collective identity and group position (Bourdieu and Wacquant, 1992). Cultural capital plays a major role in research partnerships that transcend cultural and geographic divides and will be analysed in Chapter 9. It is recognised that there are overlaps between power and culture. Placing cultural capital within the discussion of power in
Chapter 9 is partly to facilitate clarity and structure for the thesis. The significance of power in relation to culture will be drawn together in the concluding chapter, Chapter 11.

2.9 Conclusion

This chapter has highlighted the various elements of a situated research ethics conceptual framework for north-south health research, focusing on power and culture as lenses through which to analyse research ethics across each stage of the research process, both micro and macro research ethics issues. Macro research ethics have not been analysed in detail from the perspective of power and culture. Within micro research ethics, power has only been considered from the perspective of relationships between researcher and researched, not researcher to researcher power and cultural dynamics, including power within micro research systems and structures. With the exception of Chapter 3, that provides an overview of the methodology adopted, the remainder of this thesis will be organised according to this conceptual framework and will provide a structure through which to develop an understanding of the different ethos of international academic north-south health research.
Chapter 3: Methodology

3.1 Introduction to the research journey

This chapter describes the research journey for the PhD study (see Figure 3), each stage of which will be described in detail. The PhD researcher began by defining the broad research topic through an initial search of the literature – international academic public health research between the global north and the global south. A broad literature search was conducted, followed by the development of an initial conceptual framework, based on the research process. The research aim, objectives and questions were then developed. Detailed literature searches followed: i) macro research ethics (Chapter 4) and; (ii) micro research ethics (Chapter 5), followed by development of interview guides and REC approval in both the Royal College of Surgeons in Ireland (RCSI) and the University of Zambia (UNZA). Fieldwork was conducted in three stages, followed by initial data analysis. The situated research ethics conceptual framework was developed following the literature reviews, data collection and initial data analysis. Detailed data analysis was undertaken based on the framework, followed by write-up of findings, discussions and conclusions. Each stage of data analysis led to further refinement of research aims, objectives and questions, showing the iterative process. This chapter describes each of the stages of the research journey in detail, beginning with a description of how reflexivity has been integral to the process.
3.2 Reflexivity in the research process

Researchers are members of cultural communities, where values, dispositions and attitudes from the researchers’ background needs to be brought to the research, with a critical awareness of how this background may shape and influence the research (Mason, 2002). Reflexivity cross-examines previously taken for granted assumptions about these positions (Taylor and White, 2000), and is considered an integral part of the research process (Finlay, 2002). Reflexivity is a valuable tool to:

- “examine the impact of the position, perspective and presence of the researcher,
- Promote rich insight through examining personal responses and interpersonal dynamics,
- Open up unconscious motivations and implicit biases in the researcher’s approach,
- Empower others by opening up a more radical consciousness,
- Evaluate the research process, method and outcomes,
▪ Enable public scrutiny of the integrity of the research through offering a methodological log of research decisions” (Finlay, 2002).

Bourdieu & Wacquant (1992) suggest that this critical awareness will enable the researcher to be more successful in gaining objectivity on the research topic to the extent that he or she is able to identify those personal dispositions and interests that penetrate his or her own concepts, choice of research topic, and methods. The PhD researcher is a northern researcher, a PhD student, has undertaken research in Zambia with Zambian colleagues over a number of years, and who has a commitment to equity and fairness in international north-south health research.

Since the PhD researcher began undertaking research in international health in 2006, she has had an interest in north-south researcher dynamics and in particular power imbalances between LMIC researchers and HIC researchers and the effects that northern researchers have on research in the global south. Her first experience of this was as a researcher travelling to Tanzania to give training on research tools and methods. Throughout the visit she was surprised at the extent to which the lead researchers, often medical doctors and Professors looked to her to tell them how their research project should be run, what questions ‘were they permitted’ to ask, and how should the budget be spent, even though she did not have control over the funds. This was not a once off experience, and subsequent trips to Zambia revealed similar experiences. She spent regular periods of time in Zambia, where she worked closely with Zambian colleagues, allowing for an understanding of the pressures experienced by Zambian researchers to be developed. For a number of studies she travelled to the community level and participated in fieldwork, gaining an understanding of the role of the northern researcher in the data collection process. Her research position has led her to this specific research topic, yet it needs to be ensured that her “positionality does not preordain the findings of the research” (Marshall and Rossmann, 2011).

The suggestion that north-south imbalances play a role in north-south health research was proposed from the beginning of the research, yet the PhD researcher did not have pre-conceived ideas about why this was the case, and this was a proposition that the researcher set to explore. To address potential biases reflection notes have been taken
throughout the PhD process. “The challenge for the researcher is to use personal revelation not as an end in itself but as a springboard for interpretations and more general insight.” (Finlay, 2002). However, it was also necessary not to get “lost in endless narcissistic personal emoting or interminable deconstructions of deconstructions where all meaning gets lost” (Finlay, 2002). Recent studies of insider/outsider status have acknowledged that the two positions are not very clearly delineated. Being an insider can mean easy access, the ability to ask more meaningful questions and read non-verbal cues. However, insiders can be too close to the culture to be curious enough to raise provocative questions. “The outsiders advantage lies in curiosity with the unfamiliar, the ability to ask taboo questions and being seen as non-aligned with sub-groups this often getting more information” (Merriam et al., 2001).

Bourdieu rejects value-neutral objectivity in research, contending that reflexivity is necessary for undertaking good science (Schwartz, 1997) and states that there is no point outside the system from which a neutral perspective can be obtained. “Bourdieu necessarily operates within what he analyses; he is both an analyst of science and society, and an actor in these fields” (Jenkins, 2002). This is particularly relevant for the perspective of the PhD researcher, who is both analysing the field of north-south health research, but is also an actor (researcher) within the field. In keeping with the spirit of ethical north-south health research, a Zambian collaborator was enlisted to work with the PhD researcher. Both researchers had worked together over a period of five years researching health systems issues in Zambia. The Zambian collaborator assisted with setting up interviews, provided contextual and cultural understanding and sat as an observer in a number of national level interviews. She also assisted in the interpretation of findings relating to the national health research system in Zambia, contained in Chapter 6.

### 3.3 Research Design

#### 3.3.1 Methodological approach

The research study design for this PhD study was question driven rather than method driven. A key starting point is that all research is influenced by the researchers’ understanding of what knowledge means (Gilson, 2012). This study is considered to be
rooted in the knowledge paradigm of relativism (or interpretivism/social constructivism), the other two broad knowledge paradigms being positivism and critical realism (Gilson, 2012). The relativist paradigm focuses on the social processes, including power relations that influence actors’ understanding and experiences. This is a fit for the PhD study research question which seeks to undertake an in-depth analysis of the ethics of international academic north-south public health research. It is suitable to a qualitative inquiry, as it aims to understand and discover researchers’ interpretations and experiences (Sarantakos, 2013). It is subject centred; normative (involves a value laden inquiry); and reflexive (it values the self-awareness of the researcher).

“Research grounded in this tradition focuses on people’s intentions, beliefs, values, reasons and how they make their meaning. It acknowledges that the researcher also constructs knowledge through how they interpret what they hear and observe.” (Gilson, 2012)

This study employs a case-study approach (Gilson ed. 2012) utilising in-depth interviews. An ethnographic study could have been one possible alternative methodological approach for this study. Ethnography usually involves researchers actually living in the communities of the people being studied for extended periods of time (Pool & Geissler, 2005). It would have been inappropriate to adopt this approach, because although the PhD researcher spent periods of time in Zambia, at no stage was she in a position to actually reside there for a prolonged period of time.

A flexible qualitative research strategy was employed for this PhD study, allowing the research to be modified while analysis was underway (Silverman, 2011, Sarandakos, 2013). This explains the process in Figure 3 where research design was further refined following data collection and initial data analysis, particularly around the lens of Bourdieu and cultural competence to explain a situated research ethics.

“Interpretive researchers are thus more likely than deductive researchers to change their view of the theory or literature as a result of the analysis of...
collected data and so they require greater flexibility to modify the boundaries of their subject as they go along.” (Bryman and Burgess, 1994)

3.3.2 Development of initial conceptual framework
An initial conceptual framework was developed following a broad literature search, in order to inform the research aim, objectives and research questions. Most studies on health research collaborations put the collaboration itself at the centre of the study, focusing on the processes and structures of collaborations. This study places the researcher at the centre of the analysis (inner circle of conceptual framework). Within this inner circle lies the researchers that together make up the research collaboration and/or the academic research community. Surrounding the researcher/research community in the centre are the actors which are involved in shaping researchers experiences of research collaborations, i.e. other researchers, policy makers, communities, research funders and donors.
The four boxes which link to the inner circle are the four components of social analysis based on Ritzer’s micro-macro theory of social analysis (Ritzer, 1990) which provided a useful macro starting point to situate the study. This starting point was a socio-cultural analysis of the ethics of researchers’ experiences of international north-south health research. Ritzer (1990), posits that there are four major levels of social analysis:

i) **macro-objective**: the structural aspect of the collaboration, including infrastructure, bureaucracy, human resources, access to knowledge, resources and technology.

ii) **macro-subjective**: which encompasses cultural elements such as norms, values, customs, ideologies, traditions and language.
iii) **micro-objective:** which includes patterns of behaviour, action and interaction.

iv) **micro-subjective:** has been named as social cognition, and is the personal sphere, including identity, perceptions, attitudes and beliefs.

These four elements of social analysis developed into micro and macro research ethics once it emerged that power and culture were emerging strongly from the findings.

The diamonds contain the two broad geographical areas that researchers fall into and at which culture is played out: a) the global north (HIC, including Europe, US and the global level) and b) the global south (LMIC and in this specific case, Zambia). The stages of the research process are placed within the outer circle. These stages provided a structure for the interview guides, with the exception of getting research into policy and practice, as already mentioned, was considered to be outside the scope of this study. The boxes outside the circle contain the contextual elements, the wider issues that affect health research collaborations, such as globalisation, development, Millennium Development Goals, science, the political sphere, the legal and economic sphere.

### 3.3.3 Ethical approval

Ethical approval was granted by RCSI Research Ethics Committee in December 2010 and the UNZA Zambia Humanities and Social Sciences REC in February 2011. UNZA REC approval contained the following standard request:

- that clearance be obtained from the MoH before proceeding to carry out the research;
- after six months, a Report Form be completed and sent to the REC;
- a full copy of the results be deposited with the Secretariat upon completion of the research.

The UNZA REC also requested that the UNZA logo and details of the Department of Research and Graduate Studies be placed in a prominent position on the participant information sheet and the informed consent form. Zambian Ministry of Health
clearance to conduct the study was granted on 5\textsuperscript{th} March 2011, on the conditions that:\footnote{11}{The conditions formed part of a standard letter which the Zambian Ministry of Health use to grant research study clearance.}

- the relevant Provincial and District Directors of Health where the study is being conducted are fully appraised;
- progress updates are provided to MoH quarterly from the date of commencement of the study;
- the final study report is cleared by the MoH before any publication or dissemination within or outside the country.

3.4 Literature Review

“If one thing must be realised about conducting and reporting a literature review, it is that the stages for conducting and reporting a literature review parallel the process for conducting the primary research. Instead of human participants, for example, the units in a literature review are the articles that are reviewed.” (Randolph, 2009)

The gap between narrative and systematic reviews is beginning to narrow, as some of the procedures associated with systematic reviews are incorporated into narrative reviews (Bryman and Burgess, 1994). The literature review undertaken for this study can be described as taking a systematic approach to a narrative review (Petticrew and Roberts, 2006). This approach included the method of incorporating systematic review processes into the narrative review. An initial decision to undertake a systematic review was reversed due to the unsuitability of the review questions to the method, primarily due to the literature review topics being broad (Petticrew and Roberts, 2006). A systematic approach to the narrative review emphasises features such as transparency about how searches are conducted and comprehensiveness in the literature search. The use of tight quality assessment criteria has sometimes been rejected because too few studies end up being included in the review, that if included would add to the understanding of a topic (Glasby and Lester, 2004).
Following an initial broad literature search on health research between LMIC and HIC, two detailed literature review research questions were identified:

- What are the macro research ethical issues that arise when academic public health research is undertaken between the global north and the global south? (Chapter 4)
- What are the micro research ethical issues that arise when academic public health research is undertaken between the global north and the global south? (Chapter 5)

Following piloting of search terms relating broadly to north-south health research, the PhD researcher searched four databases: Web of Knowledge, Pubmed, Global Health, and Scirus. These were deemed the most suitable databases for the topic, following consultation with an RCSI librarian and other experts in international health. Search strings were also discussed and tested with the RCSI librarian. See Appendix 1 for search terms/strings used. From the beginning of the study, to write up, the PhD researcher collected documents that she was alerted to through emails from databases, and a weekly update from Pubmed and Web of Knowledge, based on the search terms. Both peer reviewed and grey literature were included. The following inclusion criteria were applied. For the macro research ethics review, it was compulsory for 1-5 to apply in order to be included. For the micro research ethics review, it was compulsory for 1-6 to apply.

2. Research to involve at least two countries.
3. At least one of the partners must be a LMIC (any region).
4. Academic research: researchers working in Universities/research institutions (for example community/policy partnerships not included).
5. The project/collaboration process must be detailed, rather than an exclusive focus on results of the research.
6. Focus on: research ethics, or ethics committees, or situated research ethics.

Literature searches resulted in the identification of the following relevant references for each literature search:
• macro research ethics review: 8,000 potential relevant references, 239 of which fitted the criteria for inclusion.
• micro research ethics literature review: 4550 potential references, 360 of which fitted the inclusion criteria.

300 duplicate references were identified, i.e. references that covered both micro and macro searches. For both literature reviews, all abstracts were read, and short listed articles fitting the inclusion criteria were read in detail. Relevant articles were imported into Nvivo 10 qualitative data analysis software, to enable the organisation of literature themes. The main themes and codes arising from both the macro and micro literature reviews combined are included in Appendix 2.

Wallace and Wray (2006), distinguish between the following types of literature: theoretical, research, policy and practice. Most of the literature for this study falls into the practice and research categories. A number of questions were considered for each article (Wallace and Wray, 2006). Once the literature was broken down into themes and analysed using Nvivo software, questions were asked of each theme, which broadly followed Bryman (1994).

3.5 Sampling and recruitment

In total, 53 interviews were undertaken (see Table 1). Twenty of these were Zambian researchers, and 8 were national level stakeholders who had been involved in setting up the Zambian national health research system. Twenty five northern researchers were included in the sample, 4 of whom were considered to be north-south researchers: 3 of these were northern researchers who had lived in Zambia for a long period of time; and 1 South African researcher who was involved in a multi-country

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12 Written by informed professionals who evaluate others’ practice and by practitioners who evaluate their own practice (Wallace & Wray, 2006)
13 Why am I reading this? What are the authors trying to do in writing this? What are the authors saying that is relevant to what I want to find out? How convincing is what the authors are saying? In conclusion, what use can I make of this? (Wallace & Wray, 2006)
14 What is already known about this area? What concepts and theories are relevant to this area? What research methods and research strategies have been employed in studying this area? Are there any significant controversies? Are there any inconsistencies in findings relating to this area? Are there any unanswered research questions in this area? (Bryman, 1994)
collaboration involving Zambia was also included in the sample\textsuperscript{15}. A purposive sampling strategy was employed, which involved selecting participants on the basis of their characteristics, roles and experiences in north-south health research.

The primary inclusion criterion was public health researchers involved or recently involved (up to 5 years ago) in academic public health research involving Zambia and a HIC. Researchers from a range of academic backgrounds were included: nationality, career path stages/research experience and gender were taken into consideration for the sample. Exclusion criteria included academic public health researchers that had not been involved in public health research involving Zambia and the global north; and research projects/collaborations that had been operational for less than one year at the time of data collection.

An overall respondent sample size of 50-60 was an initial estimate of the number of qualitative interviews required in order to identify and thoroughly explore the key issues arising for understanding researchers’ experiences of north-south health research, i.e. to reach the point of data saturation – that is the point where an appropriate sample size has been reached with no additional perspectives or issues emerging from additional interviews (Mason, 2002). This is in keeping with estimate sizes of good practice for qualitative studies (Morse, 2000). The aim was to select participants based on their characteristics, roles and experiences, and not to generalise across the population, but to shed light on the range of issues relevant to the research questions. Therefore, exact numbers were not rigidly fixed prior to the commencement of the study (Mason, 2002). Saturation began to emerge in the final 2-3 interviews in all three phases of data collection.

\textit{“There is a point of diminishing return to a qualitative sample – as the study goes on more data does not necessarily lead to more information. Qualitative samples must be large enough to assure that most or all of the perceptions that might be important are uncovered, but at the same time if the sample is too large data becomes repetitive and eventually superfluous.”} (Mason, 2002)

\textsuperscript{15}The South African researcher was placed in the ‘north-south’ category. South African researchers are often considered to be northern by other African researchers, but considered to be southern by most northern researchers.
3.5.1 Interview phases

**Phase 1: Zambian researchers:** Sampling was conducted by undertaking a systematic mapping exercise of Zambian health researchers\(^\text{16}\), which identified 70 eligible researchers. The search was initiated using the Zambia Forum for Health Research (ZAMFOHR) database and a COHRED study mapping the national health research system in Zambia (2008). The mapping exercise also included internet searches of staff listed on the websites of the main Zambian research institutions. A Google search of ‘health research Zambia’ returned one additional organisation. Selection was based on a mix of interviewees across a range of academic backgrounds, gender, career stages, and research collaboration experience. Researchers were excluded where they have been involved in north-south health research studies that have been operational for less than one year at the time of sampling, and where research studies had completed more than five years prior to the commencement of the PhD study data collection.

**Phase 2: Zambian national stakeholders:** The Zambian PhD research collaborator provided details of those who had been involved in setting up the national health research system in Zambia, in particular the Zambian National Health Research Advisory Committee (NHRAC) members (n = 13). All members were approached to participate.

For the Zambian researcher and national stakeholder interviews (phases 1 & 2) emails were sent to potential researchers requesting an interview, approximately two weeks before the PhD researcher travelled to Zambia, in early 2011. The email summarised the background and aim of the study and attached the participant information sheet. Prior to travelling to Zambia, 10 interviews had been arranged. Senior researchers were more responsive to initial emails and were more eager to be interviewed than junior researchers. Once in Zambia, follow-up phone calls were made by the PhD researcher and the Zambian research collaborator, who also contacted many of the national level stakeholders to arrange interviews. Snowballing also occurred, where other researchers were nominated from a given collaboration. Of the identified

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\(^{16}\) Mapping included the following information: researcher, institution, project/collaboration, years of project/collaboration, topic, discipline(s), seniority.
researchers that were contacted, through initial selection and snowballing, a number of these did not respond to emails, and some were unavailable for interview due to work pressures. Two interviewees did not show up at the scheduled interview time, and a number were not contactable on follow-up.

**Phase 3: Northern researchers:** there were two sources for sampling northern researchers:

i) A systematic mapping exercise of northern researchers, involved in the 14 research collaborations that the Zambian researchers were involved in, which identified 60 researchers. Mapping involved similar information to that gathered for Zambian researchers.

ii) Snowballing: at the end of each Zambian interview, the interviewee was asked if they could recommend northern researchers that they had partnered with, also being mindful of the possibility that this could be biased, i.e. only northern researchers that the Zambian interviewee viewed as having a positive relationship with might be revealed.

Emails were sent to potential northern interviewees in mid-2011, following initial analysis of Zambian interviewees. As with the Zambian interviewees, there was a high initial response rate. In some cases, follow-up emails were sent. A number of interviewees were not available due to work pressures. Two of the northern interviewees were also involved in setting up the national health research system in Zambia.

**3.5.2 Interviewee attributes**

Table 1 summarises the attributes of the interviewees in the study. For institutional affiliation, most are classified as working in Universities, as this PhD study focuses on academic research. The research institutions all had affiliations with Universities. The NGOs were also research oriented and were often perceived as research institutions, with interviewees mostly holding a dual affiliation with a University. Throughout the thesis, the term ‘research institution’ as often used to encompass University or research institution. The background of the researcher has been split into biomedical
or social scientist, which is a crude split. In reality, many interviewees with a biomedical background – primarily medical doctors and nurses – had moved into social science research. Social science covers anthropologists, economists, sociologists and political scientists. Fourteen research collaborations were included in the study. Sampling included both a northern and southern representative from each of these collaborations. Six of these were classified as health policy and systems research collaborations, while 8 were in the broader field of public health, 3 of which were RCTs. Eight of these collaborations were multi-country research studies involving more than one northern and more than one southern country. Six were bilateral studies between Zambia and a northern country.

<table>
<thead>
<tr>
<th>Table 1: Interviewee attributes</th>
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<tbody>
<tr>
<td>Geographic location</td>
</tr>
<tr>
<td>North</td>
</tr>
<tr>
<td>Zambian</td>
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<tr>
<td>North-south</td>
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<tr>
<td>Sex</td>
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<tr>
<td>Male</td>
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<tr>
<td>Female</td>
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<tr>
<td>Institutional affiliation</td>
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<td>University</td>
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<td>Research institution</td>
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<td>Government</td>
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<tr>
<td>NGO</td>
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<tr>
<td>Career level</td>
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<tr>
<td>Junior-middle level</td>
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<tr>
<td>Senior</td>
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<tr>
<td>Background/training</td>
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<tr>
<td>Biomedical</td>
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<tr>
<td>Social science</td>
</tr>
</tbody>
</table>

### 3.6 Data collection

#### 3.6.1 In-depth interviews and interview guides

Interviews are the most widely used method of data collection in qualitative research (Bryman and Burgess, 1994). It is considered that research questions that focus on experiences are suitable to in-depth interviewing (Bryman and Burgess, 1994; Morris, 2015).
“The interview gives the researcher access to interviewees’ thoughts, reflections, motives, experiences, memories, understandings, interpretations and perceptions of the topic under consideration.” (Morris, 2015)

Interviews for this study were in the form of the in-depth, semi-structured interview, where the interviewer has a list of questions and topics to be covered. However, the interviewer has the flexibility in how to ask questions and does not have to follow the question order (Bryman and Burgess, 1994). The interviewer has been described as a miner, whose role is to “dig nuggets of knowledge out of subjects pure experiences” (Kvale and Brinkmann, 2009). Obtaining quality information is dependent on a high level of trust between the interviewee and interviewer (Marshall and Rossmann, 2011). There can also be problems with recall or memory bias. This was addressed by only including researchers who had been involved in health research between Zambia and the global north within the five years prior to the commencement of the study. Due to the fact that interviewees were themselves researchers, there was a risk that they might take control of the interview process (Marshall and Rossmann, 2011). However, this did not prove to be the case in any of the interviews, perhaps because interviewees respected the interview process itself as a method.

Two pilot interviews were conducted (January 2011) with northern researchers that have been involved in public health research with the global south. Interviews were transcribed and interview guides were amended slightly. The Zambian national level interview guide was developed from an initial analysis of national level policy documents relating to health research in Zambia and the macro research literature review. The Zambian and northern researcher interview guide was developed from the initial conceptual framework based on the research process and the literature reviews. The northern researcher interview guide was modified to include some results from the Zambian researcher and national level interviews. Appendix 3 details the two interview guides for the study. The main topics included in the researchers’ interview guides - north and Zambian - were researcher’s experiences of north-south health research at the various stages of the research process, with a focus on socio-cultural issues as per the initial conceptual framework (see Figure 4). Certain researchers had experiences in both: a) the setting up of the national health research system; and, b)
experiences of north-south health research collaborations. In these cases, both sets of questions were asked.

- Background and introduction questions: professional background and research career
- Motivations: personal motivations and incentives for involvement in north-south health research; roles, responsibilities and relationships within the research project/partnership
- Research agenda setting
- Research design and implementation: research design, data collection
- Research ethics processes
- Research analysis and outputs.

Each topic probed issues around north-south differences where they arose. The main topics included in the national health research stakeholder interviews were as follows:

- Key health research priorities in Zambia
- Process of setting up the national health system in Zambia
- National Health Research Advisory Committee
- National Health Research Ethics Committee
- Perspectives on north-south health research
- Future of health research in Zambia

### 3.6.2 Interview process

Twenty six of the 28 Zambian interviews were conducted face to face, with two taking place over the phone. Five of the 25 northern interviews were conducted face-to-face in London, one in Dublin, and the remainder over the phone. Telephone interviews can provide a number of advantages, such as extended access to participants, lower expenses, opening up to more sensitive issues than via face-to-face (Opdenakker, 2006). Interview guides were semi-structured. As the PhD researcher became more familiar with the topic guide, a one page guide listing themes/sub themes to be covered was followed. However, as the interview stage progressed, fewer questions were asked, with more probes, and interviewee responses guided questions in later interviews. This became an important source of testing and triangulating information.
obtained from other sources and interviews. In many interviews, claims made by previous interviewees were put to the current interviewee, a method described in the methodological literature (Marshall and Rossmann, 2011).

Not all topics were relevant for all interviewees, for example some researchers were not involved in the research from the inception of the study, therefore were not familiar with project initiation processes. The PhD researcher found that due to the fact that respondents were all researchers themselves, in many cases they were keen to check their transcripts (see Section 3.6.3) and asked questions in relation to steps to be undertaken to ensure anonymity. This occurred more for the Zambian researchers than the northern researchers.

Twenty six of the 53 interviews were transcribed by the PhD researcher (13 Zambian and 13 northern), with 27 being transcribed by a transcription company that had been used previously by RCSI and where assurances of confidentiality had been obtained. The researcher found the process of transcribing useful for the first set of interviews, to immerse herself in the data. All interviews were listened to at least twice by the PhD researcher. However, transcription was a lengthy process and it was decided that following immersion in the data, time would be better spent initialising the coding process. The transcription company were also quicker in completing the transcription than the PhD researcher. Following receipt of each transcript from the transcription company, each one was read thoroughly by the PhD researcher, for any gaps in the text, and incorrect interpretations of language, which in a small number of instances changed the meaning of sentences. The quality of these transcriptions was deemed to be high.

3.6.3 Interviewee Transcript Review
All transcripts were cleaned, anonymised and sent to interviewees for review, of which 3 responded with only minor edits. Transcripts were password protected and a text message sent to interviewees containing the password to unlock the transcript. Studies have shown mixed reports of interviewee transcript review (Hagens et al., 2009). It has been suggested that the advantages to its use may be relatively small,
particularly in relation to the added time and effort required for interviewees (Hagens et al., 2009). However, in this study, giving interviewees the opportunity to review their transcript appeared to assist in establishing trust between interviewer and interviewee.

3.6.4 Reflection on the data collection process
Interviews were generally formal but open, with rapport between interviewer and interviewee generated easily in most interviews. The PhD researcher could empathise with many of the issues raised by interviewees – in relation to her own research career, frustrations of research partnerships, particularly undertaking research in Zambia, and educational background (3rd level, PhD candidate). Face-to-face interviews usually took place in the interviewees own office, and always in a private room. The professional background/career to date questions were useful icebreakers for both northern and southern interviewees. Most spoke very articulately and at length for each question. Two Zambian interviewees had initial apprehensions about the interviews being recorded, but following an explanation by the PhD researcher that recordings would not result in a loss of confidence or anonymity, they agreed. It is the PhD researchers’ view that the opportunity given to review the transcript was the deciding factor. A comparison of face-to-face and telephone interview transcripts for this PhD study showed that there was no noticeable difference in the responses of the two methods. This corresponds with literature in the area (Novick, 2008).

The PhD researcher prepared an interviewee profile document, with information relating to each interviewee, to recap on collaborations the interviewee had been involved in, as well as other background information that had been gathered (journal articles authored, reports and biographies from research institution websites). For the Zambian interviews, the Zambian collaborators provided supplementary insider information where she was familiar with the work of the interviewee, particularly for the national level interviews. The PhD researcher began each interview by introducing herself, her background and previous research conducted in Zambia. Ensuring correct use of titles is very important in Zambia, i.e. the researcher needed to ensure that she addressed interviewees as Professor or Doctor where applicable. This was not the case
for the northern interviewees, most of whom requested to be addressed by their first name.

Structuring the interview around the research process (i.e. agenda setting to research implementation to analysis and outputs) ensured a natural progression from one topic to the next. The PhD researcher probed by quoting some of the literature i.e. “some studies in this area have said agenda setting in north-south partnerships is unequal…” and, as interviews progressed, “other researchers have said…” Contrary to some northern interviewee perceptions that Zambian interviewees may not be forthcoming with north-south issues, it was surprising that many respondents were so open. An example was the interviewees making frequent references to ‘you muzungus’.

At the close of the interview, many interviewees expressed an interest obtaining a summary of the PhD study results, particularly the Zambian national level interviewees. Some interviewees conveyed that the interview was useful for them, allowing them a space to reflect on previous research partnership involvement in order to inform future choices about whether or not to participate. The Zambian research collaborator took part in three national level interviews in a listening capacity. One of these interviewees did not give some detail about the national level which she was involved in and the Zambian research collaborator wondered if this was because of her presence at the interview.

Because many interviewees had been involved in a number of research collaborations, they were asked to focus on one recent (within the previous five years) health research project/partnership. Nevertheless, many broadened their experiences to other projects they had been involved with. With the exception of two research studies, both a northern and a southern researcher were included from the same collaboration.

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17 Literally translated from Bantu, the term muzungu means ‘aimless wanderer.” It is now used in Eastern and Southern Africa to refer to someone from foreign descent. [http://swahilitime.blogspot.ie/2013/02/the-meaning-of-word-mzungu-maana-ya.html](http://swahilitime.blogspot.ie/2013/02/the-meaning-of-word-mzungu-maana-ya.html)
3.6.5 Informed Consent

For the face-to-face interviews, some interviewees had read the participant information sheet and informed consent form in advance (see Appendix 4 and Appendix 5). However, many had not, therefore a hard copy was handed to them at the beginning of the interview, summarising the aims of the study, details of who was conducting the study, and how the study aims to add value. Interviewees were given some time to read the sheet before the interview commenced, followed by an opportunity to ask any questions. All interviewees kept a copy for their own records. All Zambian interviewees slowly went through each question of the informed consent form in detail, whereas northern interviewees generally ticked the boxes without giving them too much attention. For the telephone interviews, a copy of the informed consent sheet was sent to interviewees in advance via email. Their return email was taken to be consent to participate in the interview, a process that was cleared by both UNZA and RCSI Research Ethics Committees. The informed consent form questions were read out at the beginning of the interview and ticked as appropriate by the PhD researcher. A consent check was performed again (double consent) at the close of the interview, for both face-to-face and phone interviews.

3.7 Data analysis

3.7.1 Analysis approach

In qualitative research, there is often a lengthy description of how the data will be gathered, with only a few lines dedicated to how the data will be analysed (Bazeley, 2009). This section undertakes a thorough description of the data analysis process undertaken for this PhD study. Themes were arrived as both inductively – obtained gradually from the data - and deductively – at the beginning of the research, informed by existing literature and studies in the field (Pope et al., 2000). Data analysis was undertaken on an ongoing basis throughout each of the three phases of data collection, as the researcher familiarised herself with the research themes as they emerged. Further familiarisation took place after data collection, via analysis of interview transcripts. Thematic analysis was deemed the most appropriate for the study, as it was not tied to any pre-existing theoretical framework (Braun and Clarke,
at the outset of the study. It involves a method for identifying, analysing and reporting patterns (themes) within the data.

Braun and Clarke (Braun and Clarke, 2006) identify six phases in thematic analysis, see Box 4, which this PhD study has followed. With a semantic approach, themes are identified within surface meanings, and the researcher does not look beyond what a participant has articulated (Braun and Clarke, 2006). The latent approach identifies "underlying ideas, assumptions and conceptualisations – and ideologies – that are theorised as shaping or informing the semantic content of the data" (Braun and Clarke, 2006). It has been suggested that decisions will need to be made around whether to conduct either semantic or latent analysis (Braun and Clarke, 2006). This PhD study takes the view that both are necessary for a full and thorough analysis of data. The semantic approach is used to describe phases 1-4 and the latent approach for phase 5. The importance attached to a theme was not necessarily dependent on how many times it appeared, but rather on whether it captured something in relation to the overall research question (Braun and Clarke, 2006).

**Box 4: Phases of Thematic Analysis**

1. Familiarise yourself with your data: transcribe, read and re-read.
2. Generate initial codes: code data in a systematic fashion.
3. Search for themes: collate codes into potential themes.
4. Review themes: check if the themes work and revise if necessary.
5. Define and name themes: move from semantic to latent, using a) conceptual themes; and b) theoretical themes.
6. Produce the report.

Adapted from Braun & Clarke (2006)
**Phases 1 – 4: Semantic, explicit levels**

Phases 1-4 can be described as descriptive/semantic. The emphasis was on issues raised by respondents rather than the PhD researcher’s interpretation of them (King and Horrocks, 2010). This produced 43 codes (see Appendix 6) which were a mix of ‘in-vivo’ codes where the terminology of the respondent is used and ‘socially constructed codes’, terms devised by the PhD researcher (Braun and Clarke, 2006).

Topic coding is the coding of material into a subject-based structure and is recommended as the first step in the formal analysis of newly gathered data. This has been described as the ‘hack work of the qualitative researcher’ (Richards and Morse, 2013). Initially, content was coded for as many potential themes as possible, with each line of every transcript examined and labelled with a code. Attributes and characteristics were also coded (gender; north or south or north-south; institution; research background; level of research experience). *Nvivo 10* qualitative software was used for systematic analysis of the data “to ensure rigorous justification for findings with evidence and an audit trail of analysis and findings” (Bazeley, 2009). Appendices 6 & 7 detail the codes and themes for phases 1-4, for both researchers (north and south) and national level stakeholders.

**Phase 5: Latent level**

The latent level (phase 5) was interpretative and defined overarching themes using: i) the conceptual framework; ii) concepts from Bourdieu’s theory of *Power and Practice*; and, iii) a model of cultural competence. To supplement the analysis in the phases proposed by Braun & Clarke (2006), the researcher engaged Bazeley (2009) three step formula ‘describe- compare -relate’. This involved describing the data, comparing whether themes occurred more or less frequently for different groups, whether they were expressed differently by different groups, and relating the theme to other themes. Divergent views and outliers were given particular attention.

Phase 5 was divided into two stages, the first was applying the results to the conceptual framework, which was developed from the results (inductive-deductive, see Appendix 8). The second stage was applying the results to Bourdieu’s theory of
Power and Practice, (Appendix 9); and to the model of cultural competence (Appendix 10).

Table 2 demonstrates the process of data analysis from semantic to latent levels, for one of the themes (research ethics). Columns 1 and 2 refer to the initial semantic levels of analysis (phase 1-4) as outlined in the results chapters of the study (Chapters 6-8). These were then categorised according to whether codes were micro or macro research ethics (phase 5, column 3). These themes and codes were then used to undertake phase 5 latent analysis, based on: a) Bourdieu (phase 5, column 4) with analysis and interpretation presented in Chapter 9; and, b) cultural competence (phase 5, column 5) with analysis and interpretation presented in Chapter 10. In order to move from phase 4 (semantic) to phase 5 (latent), this involved a reanalysis of the findings from levels 1-4, rather than a re-analysis of the raw data.
### Table 2: Data analysis process

<table>
<thead>
<tr>
<th>Theme (phases 1-4)</th>
<th>Individual code (phase 1-4)</th>
<th>Application to situated research ethics framework (phase 5)</th>
<th>Application to Bourdieu theory of Power and Practice (phase 5)</th>
<th>Application to Cultural Competence model (phase 5)</th>
<th>Example of quote</th>
</tr>
</thead>
</table>
| **Research ethics** | Ethics approval processes – north and south | Micro: procedural ethics – research ethics review processes |  | - Cultural knowledge  
- Cultural awareness | “You get to a point where people are now beginning to look at Zambia and say ‘we don’t know if we could get anything out in time’”  
(northern researcher) |
| Microbicide Development Programme Trial & Lujo Virus | Micro: ethics in practice. National level |  | - Cultural capital  
- Scientific capital | - NA | “And it seemed like they were coerced. It’s very difficult really to establish what happened, but there was allot of misunderstanding between the communities and the researchers and people didn’t seem to respect people’s rights.”  
(Zambian researcher) |
| Perceived unethical research | Micro: procedural ethics and ethics in practice | - Symbolic capital | - Cultural knowledge  
- Cultural awareness | | “…And so they wave their ethics approval, from Washington and say “look this has been approved from NIH.” And then they start doing all sorts of things, which we would normally have stopped if they had gone through our processes. The people who think they are doing everything ethically but not in the context of the country and how the country looks at it.”  
(Zambian national stakeholder) |
3.7.2 Data protection and management

Data integrity and respect for participants have been maintained at all times throughout the study and practices have been bound by the RCSI Division of Population Health Sciences, Research Data Handling Guidelines, 2009. These guidelines comply with the Irish Data Protection Acts 1998 and 2003 and the Irish Data Protection Commissioner (2007) Data Protection Guidelines on Research in Health Sector.

Personal details have been safeguarded, digital recordings securely archived and stored in a protected folder on the RCSI server, with transcriptions pseudonymised, meaning that participants can only be identified by a number. Personal details have been omitted from transcripts to ensure confidentiality, while key characteristics that arose in the interview process to make them identifiable have been changed, for example, research institution. Participants were informed that information generated by the study may be published, but that confidentiality would be maintained and no personal details would be divulged. Participants were informed that their involvement was voluntary and that withdrawal was permitted at any time, without having to give a reason and without personal consequence.

3.8 Conclusion: Quality of PhD study design and findings

Lincoln & Guba (1985) devised a set of criteria for evaluating qualitative research studies, based on trustworthiness, which is comprised of four components:

1. **Credibility:** this can be achieved through two mechanisms: ensuring the research was carried out to best practice, and discussing research findings with some or all of respondents, known as research validation (Lincoln and Guba, 1985). Best practice in this PhD study is evidenced by two RECs (Ireland and Zambia) granting approval for the study; and the Zambian research collaborator being involved at different stages of the process. In terms of research validation, respondents were asked to clarify any ambiguous issues, at the time of the interview. In addition, transcripts were sent to all interviewees giving them the opportunity to review it. All respondents will be sent a summary of findings once completed.

2. **Transferability:** whether the findings of the PhD study are generalisable to populations outside those studied. The scope of the thesis could have potential
relevance and application to southern Africa - with the exception of South Africa - for example power differentials between southern Africa and HIC, and the utilisation of a model of cultural competence. It must also be recognised that there may be differences between Anglophone and Francophone countries, particularly around academic development and research infrastructure.

3. **Dependability:** how reliable the research process employed in a research study was. Lincoln and Guba (1985) suggest taking an audit approach to the research process in order to achieve reliability of the process. To comply with this approach, complete records of all phases were kept, both in Word and in *Nvivo*. Frequent meetings were held with PhD supervisors, where verbal and written updates were provided.

4. **Confirmability:** a reflexive approach was employed, as described in section 3.2.
Chapter 4: Macro research ethical issues in north-south health research: a review of the literature

4.1 Introduction: north-south health research and the research process

A preliminary broad scoping of the literature relating to health research between LMIC and HIC led to an initial conceptual framework for this study which focused on the stages of the research process (see Chapter 3). This chapter seeks to identify from contemporary debates in the literature, what are the macro research ethical issues that arise when health research is undertaken between the global north and the global south? (Research Objective 1). A focus on the macro research ethics process encompasses the following themes: research collaboration guidelines; project initiation- funding, priority and agenda setting; production of knowledge; and, research capacity building and career paths. Relationships between researchers will also be explored as a cross-cutting issue (see Figure 5). This literature review seeks to identify whether cultural differences exist at the level of macro research ethics and if so, what effect they have on north-south health research. It also seeks to understand if power imbalances are evident. Chapter 5 will seek to explore micro research ethical issues, from contemporary debates in the literature.

Figure 5: Macro research ethics
Studies and evaluations of international north-south health research are more abundant than is frequently bemoaned (Bradley, 2007). As was detailed in Chapter 3, 8,000 potential references were identified, 239 of which fitted the inclusion criteria. An abundance of commentaries and debates exist, and where empirical research exists, it is overwhelmingly in the form of self-reflection and self-evaluation (13 evaluations, of which 9 were self-evaluations) which usually focus on one aspect of the research partnership or research process, for example research capacity strengthening or authorship in north-south health research. Ninety-four empirical studies were identified through the literature search, 57 relating to macro research issues, and 37 relating to micro research ethical issues (detailed in Chapter 5). The breakdown of topics covered by empirical macro research ethics studies as follows:

- Evaluations of north-south health research collaborations (13)
- National health research system (10)
- Research capacity strengthening (15)
- Bibliometric analysis of north-south authorship (9)
- Researcher identity (3)
- Broad north-south issues (2)
- Situated research ethics (2)
- Intellectual property (1)
- Agenda setting (1)
- Research consultancies (1)

Bradley (2007) undertook what is probably the comprehensive review of north-south research partnerships, neither health specific, nor limited to academic research. Her review focused on issues relating to the macro research process, including actors, landscape, motivations, capacity building, and getting research into policy and practice, as well as the ethics and politics of research collaborations. The literature review in this chapter of the thesis critically reviews the quality of the evidence and highlights in particular where literature exists that goes beyond viewpoints and personal reflections. Gaps in the literature are identified which will then be addressed.
in this PhD study through empirical research. It is important to note that although there is often an implicit recognition of north-south research leading to ethical issues, most of the literature does not explicitly designate these issues as ethical concerns.

The structure of the chapter follows the stages of the research process that are defined in this study as being macro research ethical issues.

- Research collaboration guidelines
- Project initiation: funding, partner selection, priority and agenda setting
- Production of knowledge: data analysis and outputs. Data collection is designated a micro research ethics issue, and is discussed in Chapter 5.
- Research capacity building and career paths
- The ethics of researcher relationships in north-south health research, relating to macro research ethics. Relationships relating to procedural ethics and ethics in practice are discussed in Chapter 5.

4.2 North-south research collaboration guidelines

Many articles and reports have outlined key principles and guidelines for successful north-south research partnerships. Some of these are specifically health related, and some deal more broadly with north-south development research. Perhaps the most developed and frequently cited principles for research collaborations are the Swiss Commission for Research Partnerships with Developing Countries Guide for Transboundary Research Partnerships (KFPE, 1998, KFPE, 2012), see Box 5. This guide consists of 11 principles and 7 questions to trigger debate on organising research collaborations effectively. The guide is intended for the broad range of stakeholders who might be involved in intercultural research: researchers, funders, policy makers, development and international organisations. Each principle contains issues, main challenges and steps to application. It is recognised however that research partnerships have different requirements and that the principles may need to be selectively applied.
Other guidelines selected from the literature by the PhD researcher as being amongst the most useful, are as follows. Further details relating to these guidelines are outlined in Appendix 1.

- **COHRED (2007)**: This document outlines steps to ensuring vertical research programmes are more responsible. In addition to outlining what LMIC governments should do, a comprehensive list for researchers and research programmes is provided.

- **Tomlinson et al., (2006)**: based on the authors experiences of a research partnership between South Africa and the north, they developed guidelines for research collaborations.

- **The Montreal Statement on Research Integrity in Cross-Boundary Research Collaborations (Draft 2013)**: identifies responsibilities of individual and institutional partners, including: overall collaboration responsibilities, responsibility in establishing and maintaining the collaboration, responsibility for the outcomes of collaborative research. A number of countries have established research integrity regulators through legislation, including Croatia, Denmark, Norway, Poland, UK and the United States. (Dyer, 2011).

- **Costello & Zumla (2000)**: outline four broad principles for research partnerships

- **Njelesani (2013)**: analyses how a Canadian and Zambian research partnership have used principles for global health research partnerships presented in the Global Health Research Initiative framework.

- **The Netherlands Development Assistance Research Council (RAWOO) principles of fruitful partnership (1999)**

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1. Set the agenda together
2. Interact with stakeholders
3. Clarify responsibilities
4. Account to beneficiaries
5. Promote mutual learning
6. Enhance capacities
- De-Graft Aikins (2008): identified five “key ingredients” required in order to sustain their partnership.

While many of these guidelines differ in terms of their detail, all highlight the importance of: aligning agendas with southern country interests, capacity strengthening, trust and equity, and getting research into policy and practice. KFPE (KFPE, 2012) recognise that these principles will need to be adapted depending on context and circumstance. Despite the fact that these guidelines are widely documented, it is clear from the literature that inequitable research collaborations remain the norm. This could be because: a) these principles are not widely used; and/or, b) different perspectives exist as what these principles/guidelines mean in practice, and how they are translated into action. It would be useful to examine to what extent these frameworks are merely referred to by research partnerships, or to what extent they are actually used. The guidelines described in this section highlight the broad macro ethical issues relating to north-south health research, but do not cover the specific micro research ethical issues. Neither do any of these guidelines designate these issues as actual ethical concerns.

4.3 Project initiation

4.3.1 Funding for north-south health research

Funding for north-south health research is a topic that is frequently discussed in the literature (28 references retrieved). The main discussions are around models and sources of funding; amounts of funding for international health research; and sustainability of funding support.

It is well documented that the majority of funding for health research in LMIC comes from northern sources: (COHRED, 2000, Gonzalez Block and Mills, 2003, Ijsselmuiden et al., 2010). Health research funding is provided primarily by northern countries, multilateral or regional entities such as the European Union (EU) or World Health Organisation (WHO), while the burden of disease lies mostly in the southern countries. Southern countries find themselves “hostages to foreign financing” (Garrafa and
Lorenzo, 2008), while Edejer (1999a) states that the “north-south axis in health research funding is tilted, reflecting the rich-poor divide in an equally dramatic way.”

The Global Forum for Health Research reported that in 1992, despite the fact that 93% of the global burden of premature mortality was attributable to diseases in developing countries, 95% of global expenditure on health research was on diseases of developed countries. This became known as the 10-90 Gap (Davey, 2004). Despite strategies to increase research resources for LMIC, estimates in 2000 were similar to those in the early 1990s (COHRED, 2000). Global investments in health research and development (both public and private sector) reached US $240 billion in 2009. However, clinical trials investigating diseases of relevance to HIC were undertaken seven to eight times more often than diseases of burden in LMIC (Rottingen et al., 2013). In 2008, funding for international research in LMIC made up 1.6% of total global health research expenditure (Havemann, 2008).

In 2001, the Commission on Macroeconomics in Health proposed that the international community’s research funding for ‘diseases of the poor’ should be substantially increased to US$3 billion per year by 2007. It was recommended that this funding be split evenly between investments in new intervention development, by international research programmes, and priority research needed by health systems in LMICs. The 2001 Commission also recommended that LMIC should spend 2% of their budget on essential national health research and that donors should allocate 5% of their health assistance to support health research (Davey, 2004). In 2006, the African Union pledged that African countries would aim to spend 1% of their Gross Domestic Product (GDP) on research and development. In Tanzania, between 1991 and 2000, 100% of health research project funds came from foreign sources and in Zambia the estimates were over 90% COHRED, (2008).

Forty two per cent of global spending on health research and development is made by the pharmaceutical sector (Havemann, 2008). Some claims have been made that there has been an increase in funding for vertical programmes, when there is a need for an increase in HPSR funding (COHRED, 2007, Pratt et al., 2012a). Pratt & Loff (2013) report that the US National Institutes of Health spend 73% of their funding on basic
and clinical research. Two studies sought to calculate funding for health policy and systems research (HPSR) (Gonzalez Block and Mills, 2003, Adam et al., 2011). Gonzalez-Block and Mills (2003) estimate that international HPSR funding accounts for 10.3% of overall health research funding.

Most global health research funding continues to be allocated through northern mechanisms (Ijsselmuiden et al., 2010). The Global Ministerial Forum on Research for Health in Bamako (2008), called for better alignment and harmonisation of research funding to countries in line with the Paris Declaration on Aid Effectiveness (Rottingen et al., 2009). Some emerging initiatives to track funding for health research have been initiated, such as the annual G-FINDER survey, which collects data from over 800 funders of research on 33 neglected diseases; and World RePORT, which provides an overview of biomedical research funding in sub-Saharan Africa. In 2013, the WHO agreed a plan to develop an observatory for health research and development. However, this is likely to be an ambitious project, given that two thirds of countries do not report any health R&D information (Rottingen et al., 2013).

The last decade has seen some moves by research funders to coordinate their activities. Examples include: a) Heads of International Research Organisations (HIROs) and b) the Enhancing Support for Strengthening the Effectiveness of National Capacity Efforts initiative (ESSENCE). HIROs brings together government and philanthropic funding institutions for biomedical research, including major funders such as the US National Institutes of Health and the Bill and Melinda Gates Foundation. However, little information exists publically on its aims and objectives (Viergever, 2011).

ESSENCE is an initiative between funding agencies to improve the coordination and harmonisation of research and capacity investments in line with the principles of both the 2005 Paris Declaration on Aid Effectiveness and the 2008 Accra Agenda for Action. However, to date, there has been no agreement on a harmonised agenda for research funding (Rottingen et al., 2013). COHRED plans to host Colloquium 2014 to set up a research-based index to boost research collaborations by providing a recognised global benchmark for data sharing and ownership, capacity building and technology transfer.

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A number of articles have called for an independent global coordination body for global health research. (Kok et al., 2012) suggest that a stream of research is needed that is independent from established global health funders and policies. Findings from this study indicate that donors, policy makers and research funders in the global health community are closely intertwined, and can sometimes dilute controversial research findings. Rottingen et al. (2009) call for a new Global Partnership for Research for Health to be set up within WHO. In May 2010 the World Health Assembly adopted a resolution setting out WHO’s roles and responsibilities in health research and endorsing the WHO Strategy on Research for Health. It has been lamented that there has been little effort to identify common approaches to data gathering, and benchmarks to manage, organise or evaluate the global research portfolio (Terry and van der Rijt, 2010).

The most common models of funding emerging from the literature can be summarised as follows:

- **Northern funder to northern researcher/institution**: who then distribute funds to southern researcher/institution. This is the most common model, on which there are some variations. In some cases the funding for each southern institution is clearly ring-fenced; in others it may be at the discretion of the northern research institution or Principal Investigator on the Project.

- **Northern funder to southern researcher/institution**: such as the Alliance for Health Policy and Systems Research. This model is relatively uncommon, although it is increasing in popularity in attempts to address north-south inequities in health research funding.

- **South to south funding**: for example where a southern entity, for example NEPAD, distributes funding to southern partner. This model is not common.

Four main types of funding sources exist: bilateral and multilateral donors, government commissioning, private commissioning, and institutional research funding.

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19 The Council on Health Research for Development (COHRED) was set up in 1993 as an international NGO with the responsibility of supporting developing country efforts to invest in establishing and strengthening sustainable systems for health. COHRED and the Global Forum for Health Research merged in 2010 to synergise their work. However, COHRED does not play the role of global coordinator.
Bilateral funding is recognised as the most common (Gonzalez-Block, 2004). The source of funding will have different implications for the agenda or the manner in which findings are written and communicated. Considering that multilateral funding is primarily disbursed through government accounts, it is likely to be reported as ‘government funding’ (Gonzalez-Block, 2004).

It has been suggested that the policies and practices of donor agencies promote competition between northern academic institutions and reinforce the north and south divide (Costello and Zumla, 2000). The effect that direct funding through northern institutions has on potential partnerships is discussed by Habermann (2008), who suggests that this model of funding results in the ‘partnership’ being perceived as charity, with southern partners considering themselves to be the ‘beneficiaries’, therefore reinforcing the aid dependency model. The number of organisations involved in European Framework Sixth Framework Programme (FP6) has decreased by a factor of 2.5 compared to the Fifth Framework Programme (Katsouyanni, 2008). The authors states that this may result in the formation of an "elite" of LMIC institutions. This could be interpreted as meaning that the number of LMIC partners has decreased. However, it could also indicate that there is more money available elsewhere which is more attractive as it is less complicated than coordinating EU projects.

It has been suggested that many donors and development agencies had scaled down their support for networks by 2001, and therefore self-sustainability of funding support became essential (COHRED, 2007). There is no evidence to show whether this has actually occurred more than a decade later. De-Graft Aikins (2008) discusses sustainability in terms of a ladder of progression from small-scale projects to large scale projects. However, the small size and low capacity of most institutions would not be conducive to receiving larger grants (Gonzalez Block and Mills, 2003). Boutilier et al., (2011) show that research partnerships have been successful in attaining sustainability beyond the lifetime of one project.
4.3.2 Partner selection

The process of partner selection for international health research is under-examined in the literature. While 10 sources were identified that discuss partner selection in the collaboration process, only two empirical studies assess partner selection in detail (Maher et al., 2003), Chuang et al., 2011). Maher et al. (2003) identified three types of partnerships: obligatory, imposed, or natural and reported that obligatory and imposed partnerships impeded the collaborative process. Molyneux & Geissler (2008) point out that there is a concentration of international health research in a small number of collaborative research centres, often annexed sites (discussed in Chapter 1). This implies a cycle where because these institutions already have adequate capacity, they are the ones who are successful at obtaining grants.

Funders were reported as often dictating what types of partnerships should be developed. An example is the requirement for the participation in European and Developing Countries Clinical Trials Partnership (EDCTP) which stipulate a minimum of two European and two African countries must be included (Mgone and Salami, 2009). Twinning is another recently documented method where a researcher in the north is twinned with a researcher in the south in order to obtain a grant (Carr-Hill, 2008).

In a qualitative study to identify barriers and enablers to local investigator-initiated trials in Ethiopia, Franzen et al., (2013) reported that “many researchers would like to lead their own studies and had important questions, but were often unsure of how to go about doing this.” The authors conclude that a local and international online networking facility could be developed, detailing research interests, expertise, projects and resources. However, this is a broad recommendation and it is not detailed how and who would develop this facility. Freier et al. (2005) described key elements in the development of collaborative international HIV prevention research. This study assumes that northerners will be in control and is written with a language of northern dominance, for example: “an important preliminary task of working in an international setting is to identify local collaborators and investigators and their capacity to be directly or indirectly involved with some aspects of the research process.” Crane (2010) maintains that northern researchers are required to name African researchers/institutions to validate their application, suggesting that collaboration is often not a genuine partnership.
Evidence shows that personal links between researchers were the primary means through which partners were selected, such as longstanding links based on trust between institutions. Interestingly, only two studies identify common research interests as being central in partnership selection, de-Graft Aikins (2008), (Maher et al., 2003). The evidence shows that even with the personal links, the northern partner almost always initiated the contact due to knowledge of funding opportunities.

4.3.3 Priority and agenda setting

Bradley (2007) maintains that while many authors call for greater southern engagement in setting the collaborative research agenda, the issues surrounding this have not been adequately studied. Contrary to Bradley, this literature review found agenda setting in international health research collaborations to be extensively profiled (53 sources retrieved). The main issues arising from this review are as follows: northern dominance in agenda setting; topics/type of health research; motivations for becoming involved in north-south health research; social value of research and benefits to communities. The focus is primarily on north-south imbalances in the process. Priority setting at the national level will be discussed in Chapter 6.

Sieber & Braunschweig (2005) analysed project selection processes applied in north-south health research partnerships and developed a practical manual to help design and implement effective project selection processes in such partnerships. The manual illustrates how to involve relevant actors, how to weight selection criteria and how to genuinely incorporate southern perspectives at various steps of the selection process. It also suggests suitable priority-setting methods. The selection process is determined by: a) actors involved; b) criteria applied including scientific quality, development relevance, and capacity strengthening; c) methods used for processing information about project proposals; d) project proposals submitted. No evidence was found in the literature to show processes for agenda setting at the level of partnership, or that processes such as those identified by Sieber & Braunschweig (2005) have been utilised.

Habermann (2008), asks a question that has been raised but not been answered by the literature: “how does the mantra that partnerships should be mutually beneficial fit in
with the oft-repeated view that they should prioritise southern needs and agendas?”

The process through which the agenda is set receives the most attention in the literature, showing clear power imbalances, with most projects involving southern and northern partners being initiated by the latter (Jentsch and Pilley, 2003). The authors maintain that: “research and action priorities as well as methodological standards typically comply with the cultural and scientific traditions of northern institutions along with their prevailing ideological perspective”. These cultural and scientific traditions have not been examined in detail in the literature. Agenda setting in north-south health research has been described by others as ‘semi colonial’ (Caceres and Mendoza, 2009, Provenzano et al., 2010).

There is a contradiction between donor requirements that research fits in with national agenda/priorities whilst simultaneously releasing a call for funding in particular health areas. Bradley (2007) records that donors such as the Danish International Development Agency (DANIDA) are upfront about the fact that Danish-funded development research partnerships must support Danish policy-making processes. Stephen and Daibes (2010), in a self-evaluation of 14 global health teams, concluded that “donors, require a more narrow focus for their investments and global health research priorities are often chosen by assessing burden of disease”. Over half the US and international respondents in a study by Hyder et al., (2007) consider that research priorities of funders are not in line with priorities in-country. Tomlinson et al., (2006), describe the elements of an equitable model of research agenda in a mother to child intervention project in South Africa. This study is a self-evaluation, therefore assessing equity is from the perspectives of those within the partnership. The study shows that despite attempts to make the study locally situated and relevant, it was still seen perceived by the local community to be externally imposed.

The influence of the international agenda on what is researched in LMIC, rather than the national agenda has been conveyed (Gonzalez-Block, 2004, Kok et al., 2012, COHRED, 2007). This presumes that national research agendas exist in the global south. Chapter 6 illustrates the challenges associated with developing a national research system. There seems to be a need at a broad level to define a research area
that is in keeping with national and funder priorities, but that there is room within that to define a narrower research area that is more in line with local needs.

Not all studies found evidence of north-south inequities in agenda setting. Swingler et al., (2005) assessed whether randomised controlled trials conducted in Africa with partners from outside Africa “were more closely associated with health conditions that have a burden of disease that is of specific importance to Africa than with conditions of more general global importance or with conditions important to developed countries.” The study reported that relevance to Africa was not adversely affected by collaboration with non-African researchers. However, in the same study, funding from private industry was associated with a decreased emphasis on diseases relevant to Africa.20

A small number of studies examine topics and types of international health research. A common theme reported in the literature is the extent to which health research in LMIC is disproportionately focused on a small number of high profile conditions, to the neglect of other health problems such as non-communicable diseases (Chuang et al., 2012). Chuang et al (2011), in a bibliometric analysis of public health research in Africa between 1991 and 2005, reported ‘HIV’ and ‘tuberculosis’ to be amongst the top keywords in the East and South regions but not in the North or West. COHRED (2007) report that health research in LMIC countries is focused on six conditions: HIV/AIDS, malaria, diarrhoeal diseases, tuberculosis, maternal conditions and tropical diseases, which account for 31% of the disease burden, but more than 80% of their research output. Terry & van er Rijt (2010) report that “84% of WHO’s research budget is allocated to type I diseases (communicable, maternal, perinatal and nutritional diseases) that accounts for 40% of estimated DALYs. 4% of the research budget is allocated to type II non-communicable disease that accounts for 48% of estimated DALYs”. This may be changing in recent years with an increasing global health focus on non-communicable diseases (Horton, 2013). There is also a recognition that pharmacological interventions receive a large proportion of the budget (Geissler, 2013, Pratt and Loff, 2013), to the neglect of health systems research.

20 Diseases categorised as being specifically African diseases were those that were important to Africa in both absolute and relative terms. Burden of disease >500,000 DALYS and burden of disease in sub Saharan Africa >50% of global burden of disease.
There is a growing call for international health research to demonstrate greater relevance to local needs (Benatar, 2002, Bhutta, 2002, Macklin, 2012) (Marshall, 2005) (Ijsselmuiden et al., 2010), (Hunt and Godard, 2013), Benatar and Singer (2010). Even though it is assumed that southern researchers are more in tune with local health problems, a southern led research study is not sufficient to ensure relevancy to local health issues (Ijsselmuiden et al., 2010). It has been argued that institutional research ethics committees are dependent on research overheads and therefore are not in a position to reject proposals that might not be valuable to developing countries. The role of RECs in relation to agenda setting is discussed in Chapter 5. Inequities in funding may also lead local researchers to research topics that northern researchers deem important rather than on what is important at the community level (Provenzano et al., 2010).

A number of articles and commentaries discuss motivations for becoming involved in north-south health research (17 sources retrieved), however none of these empirically examine motivations. Motivations have been reported by a number of authors as being altruistic, meaning aspirations to contribute to poverty alleviation, strengthen research capacities; ensuring that research gets into policy and practice; and a desire to reduce global health inequalities (Rosenthal, 1998, Pinto and Upshur, 2009).

“A desire merely to explore an exotic part of the world is obviously not sufficient and contributes to wasting limited resources for global health work. Students should consider honestly whether the expense of transporting them to the research site is truly money well spent, as opposed to creating an opportunity for students and researchers in the developing world. It is also important to be very aware of one’s own privilege, whether based on class, ethnicity, gender or education, and understand how this affects one’s motives.” (Pinto and Upshur, 2009)

Geissler (2013), in an ethnographic study, explains how expatriate staff see their research as breaking away from the legacy of colonialism. Leong and Lyons (2010), consider that there are two motivational levels: those researchers whose motivations are to generate knowledge, and on the other level, those who are concerned with
vulnerable participants. However, it is more likely that multiple motivations exist. Ruger (2012), discusses a model where actors shape institutions, policies, and programs in the interests of their own countries and organisations, rather than the overall goal of health equity.

Katz and Martin (1997) claim that it is not often possible to establish researchers’ specific motivations for entering into collaborations. Through a literature review, the authors identified ten factors that account for the increase in multiple-authored papers in the experimental sciences. One of these factors is researchers’ desire to increase their scientific popularity, visibility and recognition. The other factors are primarily around self-interest or promoting academia. Maselli et al. (2006) and McCoy et al. (2008) highlight a number of motivators for researchers to be involved in partnership, including increased visibility and attractiveness, increased access to new fields of research; and enhanced research connections. More personal reasons for entering into north-south research collaborations are also cited in the literature, such as desire to travel and to learn about other cultures (Habermann, 2008).

4.3.4 Conclusions: project initiation

Funding inequities are sometimes viewed as an ethical issue (Pratt et al., 2012b, Pratt and Loff, 2013, Ijsselmuiden et al., 2010). The effects of funding mechanisms on north-south inequities and power imbalances and inequities are strong, as are the links between funding and agenda setting. There is a lack of available data for health research funding both globally and at the country level, either by topic or by discipline. It remains to be seen if ESSENCE will be successful in encouraging donors to align health research funding in LMIC, which will be essential if funding mechanisms are to become more equitable. Structural inequities in relation to funding are well documented. However, the effect that this has on agenda setting has not been examined.

Evidence shows partner selection to be overwhelmingly northern dominated. A more in-depth examination of partner selection would be useful including empirical examples of the barriers that exist for southern researchers in initiating a study. Agenda setting has been extensively covered in the literature, focusing on north-south
inequities and power imbalances. The links between funding and agenda setting have been made. Are there other reasons why inequities exist and persist? Do northern and southern partners see this as an ethical issue to be addressed? Are there different views north and south?

Individual motivations for researchers to become involved in health research have not been empirically tested, particularly from the perspective of researchers having multiple identities - researcher background, discipline, and personal characteristics - rather than the dichotomy of a northern/southern researcher. Do southern and northern researchers have similar or different motivations? What is the perception of northern researchers of southern motivations and vice versa? Imbalances relating to partner selection and motivations are generally not perceived to be ethical concerns in the published literature.

4.4 Production of Knowledge

4.4.1 Data analysis

The data analysis process within north-south health research has not been explored in detail in the literature. Where it does exist, the primary focus is on the politics and ethics of data ownership and intellectual property (Hunt and Godard, 2013, Sack et al., 2009), suggesting that it is common for research funders to claim data/sample ownership even though the materials have been collected by southern researchers.

“Exclusive data ownership was often claimed by the funder even though data were collected by the Centre. This was especially a problem with multisite studies where only the funder had access to the complete data set.” (Sack et al., 2009)

The authors place donor agencies, research councils, multilateral agencies, Public Private Partnerships and research institutions all under the banner of ‘stakeholder and funder’ which is not helpful. Disaggregating by funding source would be useful in illuminating differences between these very diverse stakeholders. Jentsch and Pilley (2003) maintain that north-south research partnerships’ “neo-colonialist aspects” come to the fore most for data ownership, and acknowledgement of contributions to
research outputs. Parker (2007) suggests that when negotiating research contracts, researchers need to consider ownership, control, access, storage, management and use of data and advocate that institutional data sharing and access policies should be developed. They also advocate that secondary users of data are obliged to assume the ethical responsibilities that come with the privilege of accessing shared data. However, it is not clear what these ethical responsibilities are, or if researchers consider use of data in terms of an ethical responsibility (Hunt & Godard (2013).

Sayogo and Pardo (2013) present researchers willingness to share data in a quantitative study. They report that historically, sharing of research data sets occurred on a one to one basis, based on mutual interest. They claim that data is sometimes connected to personal glory and recognition. It is unclear whether this suggests an emerging trend of suspicion amongst researchers, or increasing knowledge and debate over the rights of ownership of data in cross country partnerships.

A gap exists in the literature surrounding how data analysis is actually undertaken and by whom in north-south health research partnerships. Context and culture are crucial in local data interpretation. Where this is absent, there can be issues of validity in research (Smith, 2002, Freier et al., 2005, Sayogo and Pardo, 2013). Vasquez et al., (2013) describe how even though co-production is frequently cited: “research in Vietnam is a hierarchical practice, with questions and instruments developed in Washington or New York and data frequently translated back into English for analysis by professionals with little sense of the local context.” It is surprising that such little attention is paid to the role of culture and power in data interpretation. If the agenda is set by northern researchers, and they dominate at various levels, there is a gap in the literature on this dominance and inequity at data analysis stage.

Muula-Bengo (2006) is one of the few authors to investigate the transfer of samples from south to north for analysis. He underlines that while exporting samples can be justified if there is a lack of expertise or equipment in a LMIC, countries need to develop guidelines around ownership and access. If a research project plans to operate in an area for a significant period of time, funding should be provided for capacity building through transfer of equipment (Muula-Bengo, 2006).
4.4.2 Research outputs: the politics of authorship

Reports of north-south imbalances and inequities in authorship of peer reviewed articles across LMIC and HIC are plentiful. Research outputs are extensively documented in the literature (28 references retrieved) primarily through quantitative, bibliometric analyses. The focus is primarily on peer reviewed articles, with other types of outputs not addressed. There is a substantial body of literature on research to policy, which as previously mentioned, was one of the exclusion criteria for this literature search. However, co-authorship is only a partial indicator of the depth of international research collaboration (Costello and Zumla, 2000). Often a lead author is based temporarily or long term in the northern research institution, or may have dual affiliation. Surnames may be a hint, but may also be misleading.

Studies in this area show clear inequities in favour of northern researchers in north-south authored papers. All of these studies focus on quantitative indicators, with only one study (Jentsch and Pilley, 2003) exploring these inequities in further detail. Jentsch and Pilley (2003) report that northern researcher efforts are often overstated, while southern contributions are sometimes overlooked. In their study, southern researchers’ emphasis was demonstrated to be on the policy and practice value of research, which contrasted with northern eagerness to publish results in papers, perhaps due to a more encouraging publishing climate in the north.

“Who is given the opportunity to contribute, and thus potentially qualify as an author, is important. It is easy for research co-ordinators to exploit their central role, reserving for themselves the preparation of the most promising publications. In our collaboration, more publications were proposed by Northern researchers.” (Jentsch and Pilley, 2003)

Marusic et al. (2011) in a systematic review on issues in cross-disciplinary authorship conclude that power and ethical issues in authorship were common to all disciplines\(^\text{21}\). This prevalence of ethical problems in authorship is more than 10 times greater than

\(^{21}\) This study does not focus exclusively on north-south research.
the 2% prevalence of research misconduct of fabrication, falsification or data modification, reported. Smith (2002), suggests that authorship guidelines do not address specific authorship issues that can occur due to power differences between northern and southern researchers.

4.4.3 Conclusions: production of knowledge

The data analysis and research outputs process is the most neglected in the literature in terms of north-south power imbalances and cultural issues associated with analysing data across cultures. COHRED (2013) and Hunt and Godard (2013) discuss the ethical responsibilities that come with accessing shared data. It is not clear if researchers consider these to be ethical responsibilities, or what the roles of the various partners are in data analysis. If analysis is undertaken in the north, as is suggested by the literature, what effect does this have on understanding context and culture and on interpretation of research findings?

Quantitative bibliographic analyses point to north-south inequalities in authorship. Further investigation of the issues surrounding authorship of papers from northern and southern perspectives to explain this inequity is required. Some of the reasons mentioned by Jentsch and Pilley (2003) are: a) a more encouraging publishing climate in the north; and, b) southerners emphasis on the practical application of the research. However these have not been explored in detail.

4.5 Research capacity strengthening and career paths

Research Capacity Strengthening (RCS) constitutes the most literature on any topic related to north-south health research. Much of it is empirical, and as with the other literature, primarily comprises self-evaluations. Literature that focuses on individual capacity building and inequities between researchers is comparatively scarce, with most focusing on institutional and national research capacity imbalances. Resources on RCS include analytical documents, tools, training materials and guidelines (Nuyens, 2007). Research capacity strengthening relating to the national health research system is examined in Chapter 6. Contrary to the assertion by Pratt & Loff (2013), that most capacity building programmes focus on epidemiology and clinical research with HPSR
being neglected, this current review found a disproportionate amount of literature focusing on HPSR, as compared to other disciplines.

Research capacity strengthening is considered to be an ethical issue to be explored in north-south health research because, despite decades of research capacity building programmes, there remains a shortage of capable health researchers in Africa (Nchinda (2002). It is considered to be important to assist in achieving the Millennium Development Goals (Manabe et al., 2011). The role of research benefits in capacity building is recognised in the Council for International Organisations of Medical Science International Ethical Guidelines for biomedical research, which states that research sponsors have an ethical obligation to ensure that capacity is strengthened (CIOMS, 2002).

Estimates show that four-fifths of working scientists of all disciplines, including health, are concentrated in the Western industrialised nations, Japan and to a much lesser extent, some of the larger Asian countries. Africa, Latin America and the Middle East together have only 13% of the world’s scientists (UNESCO, 1996). In 1990, the Commission on Health Research for Development identified the strengthening of expertise in research as “one of the most powerful, cost effective and sustainable means of advancing health and development” (Nuffield, 2002). It is recognised that while capacity for undertaking multi-country studies in LMIC is low, disparities in research capacity also exist in the north (Gonzalez-Block (2006).

“Externally-supported research that does not address this issue of development of capacity in research may greatly limit the long-term value of the research. In many respects such research is the equivalent of food aid, which does not provide the tools and skills to help the local population to become self-sufficient in growing their own food.” (Nuffield, 2002)

Divergent definitions and types of research capacity strengthening permeate the published literature (Bates et al., 2011) Bennett et al, 2010, (Vasquez et al., 2013) 2013), (Nuyens, 2007). Several authors consider three levels of research capacity: i) environmental and network capacity ii) organisational/institutional capacity, iii)
individual level capacity (Lansang and Dennis, 2004, Nuyens, 2007, Manabe et al., 2011). The importance of linking the various levels of capacity strengthening has been stressed (Manabe et al., 2011). In addition to the three levels, Manabe et al., (2011) highlight a foundation level, “local context,” which outlines the need for capacity building to recognise cultural factors, alignment with local and national policies and strategies, trust between development partners, and local ownership. Jones et al. (2008), claim to take a holistic view of research capacity building, and are interested in: i) different levels; ii) all phases of the knowledge generation and knowledge translation cycle; and iii) the relational dimensions of capacity building. Bennett et al.’s (2010) systematic review on RCS found that capacity development initiatives focused on one level without taking links to other levels into account.

Nchinda (2002), in a literature review of research capacity strengthening, highlights principles for RCS, including: the nurturing of sustainable institutional capacities for research; each partner must have an independent capability for carrying out its own research to the same high level of quality; and the importance of northern researchers spending time in the south to gain a better idea of the context and the constraints faced by southern institutions.

4.5.1 Individual and mutual research capacity strengthening

Literature relating to individual RCS focuses on training models, particularly for MSc and PhD programmes. Davies et al. (2000) found that scientists in the UK have nearly 1,000 times more opportunities to study for a PhD than do researchers in LMIC. The study also found that 65% of PhD training awards for African malaria researchers were funded externally and over half of postgraduate qualifications were obtained wholly or partially overseas.

The different models of PhD training for LMIC researchers is discussed in the literature. The traditional PhD training model involves training abroad at an affiliated institution working with a researcher with linkages to the country where the student originates (Manabe et al., 2011). The sandwich PhD (SIDA model) has become more popular
recently, whereby most of the training occurs in the LMIC, with short periods of time spent abroad for particular courses.

The earlier literature on RCS emphasised northerner’s role in building capacity with southern researchers at the receiving end, displaying north-south inequities in the process. In recent years, it has been documented that it is often the northern researchers whose capacity is enhanced, as they learn from their southern colleagues how to deal with different cultural contexts, and how to adapt research methodologies. Here, RCS is seen as a two way collective process (Jentsch and Pilley, 2003). To what extent this is a model that is now being utilised, has not been explored.

4.5.2 Institutional challenges to research capacity strengthening

In an extensive review of the literature on research capacity strengthening, Vasquez et al., (2013) found inadequate research infrastructure in many southern institutions, including Information Technology issues, financial management and personnel. Institutional support has been identified as being critical to the implementation of health systems research capacity development initiatives (Bennett et al., 2010). The authors highlighted a number of areas to strengthen capacity and sustainability in health policy analysis institutes, such as securing multiple funding sources and longer term grants, and avoiding short-term contracts with high administrative burdens. Institutions in LMICs can struggle to negotiate mutually beneficial research contracts due to a lack of legal expertise and financial know-how (COHRED, 2013).

Southern Universities and research institutions often do not have budgeting capacities, and as a result they are at risk of underestimating the full cost of research. ESSENCE carried out a survey of its members, and found that rates set by research institutions in LMICs range from 8 to 35%, (averaging 15%), which are lower than other parts of the world, for example the US is 51% and UK is 60% of salaries and wages (ESSENCE, 2012). Nchinda (2002), (Manabe et al, 2011, Bates et al., 2011) have identified and developed a standardised evaluation and accountability process which enabled the universities to develop and monitor their own capacity strategies and also enabled
them to monitor inputs by external funders. The authors conclude that this internally controlled accountability promotes better ownership.

4.5.3 Evaluations of research capacity strengthening
A number of studies evaluate research capacity strengthening at various different levels, most focusing on self-evaluations of a particular project or initiative. Recommendations from these evaluations are broad, and could be said to apply to research partnerships more generally rather than specifically to RCS:

- Engage appropriate stakeholders from the start of the research;
- Strengthen existing processes and environment;
- Ensure local ownership and continuity of support;
- Use generic indicators.

There has been one systematic review of RCS initiatives at national, institutional, and individual level (Bennett et al., 2010), one comprehensive literature review (Vasquez et al., 2010), and case studies to analyse indicators for sustainable RCS and evaluations of RCS programmes (Bates et al, 2011, Bates et al., 2014).

4.5.4 Career paths
Career paths for researchers and research consultancies are relatively well covered in the literature, with some issues explored relating to brain drain, salaries and consultancies. Discussions surrounding brain drain are focused on: a) in-country brain drain; b) external brain drain and low retention rates; c) brain drain from healthcare to research. Difficulties for LMIC in the retention of skilled human resources for health research has been extensively described (Bennett et al., 2012, Ezeh et al., 2010, Lansang and Dennis, 2004). It has been reported that staff often move to better paid positions elsewhere having acquired skills and experience, leaving remaining senior staff with heavy workloads. Internal brain drain, where researchers work vertically with their northern partners through annexed research sites is reported by a number of studies, Costello & Zumla (2000) Bennett et al (2012) (Geissler, 2013). It is perceived that these sites use higher than local salary scales, and often attract researchers with
the most capacity. Bennett et al. (2012) suggest merging these sites with national partners.

Even when studies are locally relevant, there may be ethical concerns due to health care staff being drawn away from providing health care and into research, when there is such a shortage of health workers in Africa (Ijsselmuiden et al, 2010a, White 2007, Franzen et al., 2013, Manabe et al., 2011). “An ethical dilemma arises when one clinical trial in Malawi can recruit as many nurses to be trial staff as are produced annually by the national university, while Malawi already has a significant nursing shortage” (Muula, 2007). On the other hand, it is argued that researchers from LMIC should not be denied the rights to work in areas where there are greater opportunities (Nchinda, 2002). This places the onus on the developing country to commit more resources to attract researchers to remain at home.

Salary imbalances between the north and the south are addressed, which report little concrete evidence, but perceptions of differences (Ridde and Capelle, 2011). One study reports material differences between expatriate staff and locals to be common, which leads to “them and us” feelings, which are rarely articulated (Geissler, 2013). There is an absence of researcher’s opinions on this and how these imbalances should be addressed.

“…an expatriate scientist is unlikely to know much about the intricacies involved in local colleagues’ business activities, agricultural investments, or building projects, crucial for long-term security but sometimes interfering with other commitments; and a local scientist, in turn, has little idea about tax-free mail-order services and the origins of the North American colleagues’ muesli bars or the same colleagues’ mortgage payments and educational saving needs. This may well be because such issues are private, or irrelevant to the other group, but, as undiscussed observations, these facts feed into mutual perceptions.” (Geissler, 2013)

Poor career opportunities for southern researchers as compared with northern researchers have been reported by a number of studies (Nchinda 2002, Davies et al., 2000, Franzen et al. 2013).
“Insufficient staff motivation, isolation from peers, poor access to literature, very low salaries all compound the problem and prevent the few trained researchers from responding rapidly to ever-changing demands and needs of their countries. Finally rewards for productivity are hampered by non-merit considerations in appointments and promotions of senior staff and by restrictions in personnel policies.”(Nchinda, 2002)

Franzen et al. (2013), in a study investigating the barriers and enablers to the implementation of local investigator-initiated clinical trials in Ethiopia, found that altruistic incentives such as community health improvement and organisational development existed for researchers, however, personal career incentives were weak, such as poor salary and heavy workload. A lack of research career options discouraged students from entering into research after studies or caused them to migrate for work. Researchers in this study also reported little recognition for research and that promotion could be achieved without undertaking research. Mayhew et al. (2008), identified an absence of incentives and career structures as the biggest institutional challenge by both LMIC partner countries.

Research consultancies have been accused of inhibiting research capacity (Wight, 2008, Vasquez et al., 2013). Participants in Wight’s study accepted that consultancies should be contracted with institutions, rather than individuals, with overheads of approximately 30%, which could fund initiatives to strengthen research capacity. The practice of individual consultancies threatened sustainability of a University-based system of independent research (Vasquez et al., 2013), by diverting staff from academic research (Wight, 2008). Institutional consultancy arrangements are already practiced by the University of KwaZulu-Natal in South Africa and the REACH Trust in Malawi (Theobald et al., 2009).

Knowledge gaps exist on work ethics and culture in the north-south health research literature. Just three studies reference these issues, (Crane, 2010, Martin-McDonald and McCarthy, 2008, Maher et al., 2003). Maher et al. (2003) demonstrate the distinct layers of culture within and between different institutions and disciplines, and
highlight the importance of learning different organisational cultures and structures, both north-south and north-north. These layers are not explained in detail in the study.

4.5.5 Conclusions: research capacity strengthening, career paths and work culture

Research capacity strengthening has been extensively covered in the literature, particularly from the perspective of north-south inequities. Knowledge gaps exist on work ethos and culture, which would require further investigation of work ethos and work culture around differences/similarities in work practices, north and south; perceptions of career paths and equity; and differences between expatriate staff, local staff and southern and northern researchers. The published literature shows an abundance of research capacity strengthening initiatives, which are beginning to recognise RCS as being a two-way process. Despite these initiatives, power imbalances remain. The reasons for this, despite significant investment in these initiatives will be explored in the empirical research for this PhD study.

4.6 Researcher relationships in north-south health research

Many types of actors participate in international health research. In this PhD study, the focus is on academic researchers, in particular their roles, identities, relationships and motivations to participate in the research. These issues are relatively well addressed in the literature. The theme of power imbalances between actors in north-south health research cuts across both micro and macro research ethics issues (39 sources retrieved). However the nature of these power imbalances and how they play out is not discussed in detail. As with other topics, most of the literature is authored by northern researchers. The main debates are centred on power asymmetry, trust and researcher identity. Literature relating to researcher identity has been presented in Chapter 2 (see Section 2.7), as being central to a situated research ethics conceptual framework. Issues relating to community perception of researchers (from the perspective of researchers) and fieldwork relationships are discussed in Chapter 5.

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22 The various actors involved are: i) individual southern and northern researchers and research teams; ii) southern and northern research organisations (Universities and NGOs); iii) individuals and communities directly affected by the research issue; iv) policymakers (local, national and international); v) international organisations; vi) donors (bilateral donors, foundations, etc.) (Bradley, 2007).
4.6.1. Power asymmetry between researchers in north-south health research

Power asymmetry between researchers in north-south health research is frequently acknowledged. A number of authors (Costello and Zumla, 2000, Jentsch and Pilley, 2003, Lansang and Dennis, 2004, Nurse and Wight, 2006), posit that even with the best of intentions, and with similar values of equality and respect, power inequities are inevitable, where it is the case that the northern partner is the grant recipient. Power imbalances may be beneficial when they favour the southern partner and if the aim is to reduce inequalities in health and health research, partnerships should maximise benefit for LMIC (Jentsch and Pilley, 2003, McCoy et al., 2008). Molyneux & Geissler (2008) note that real partnerships will only be achieved when relationships between researchers are balanced in terms of knowledge, interest and power.

According to Horton et al. (2009) issues of power and equity are not common in definitions of partnership. This PhD study literature review shows that this is not the case, and although power and inequity is not explored in detail, it is at least mentioned in many studies. KFPE (2012) principles for transnational research partnerships suggest that research collaborations are exposed to the ‘dividing forces’ of participating actors. However, none of these dividing forces are unpacked in these principles, and they start from a negative standpoint, i.e. ‘dividing’, seeing actors in opposition to one another. The link between power inequities in relationships and the legacy of colonialism has been discussed (Ogden and Porter, 2000, Preston, 2008, Maselli et al., 2006), including northern researchers assuming responsibility for agenda setting, budgets, data analysis, while southern researchers are responsible for data collection. Kilama (2009) describes what could be considered to be the stereotypical role of the northern researcher:

“Foreign researchers want to break the code, analyse the results usually at a foreign location, and publish the findings hopefully in a very prestigious international journal, address seminars and workshops based on their experiences abroad, hold interviews with the international press and media, prepare and make presentations at international conferences, and in the process gain international recognition and accolades.” (Kilama, 2009)
Research institutions are also considered to be symbols of power, with links to colonialism permeating:

“So the institution—its name and reputation—has and “embodies” power. It also, like any other institution, has rules, structures and procedures, which lie outside the personal control of any single researcher working within its walls. These two factors—the symbolic and active power of the institution plus its rules and structures—are central to the creation of international research collaborations.” (Ogden and Porter, 2000)

Preston (2008) identifies neo-colonialism as being present in their north-south research partnership and that junior Andean researchers felt that their research was not held in the same regard as their European colleagues.

“Anger was palpable as junior Andean researchers (mostly women) told of acting as tour guides for uninterested European undergraduates and contributing to the glory of established European scholars, without equivalent opportunity or esteem for their own research. The neo-colonialist suggestion that Europeans should coordinate the post-project publications left transatlantic colleagues speechless.” (Preston, 2008)

Two empirical studies challenge the oft-reported north-south inequities in research between the global north and the global south: (MainaAhlberg et al. (1997), (Tomlinson et al., 2006). Maina Ahlberg et al., (1997) reported that socio-cultural conflicts and authorship disputes were not common in their research collaboration. However their study reports northern researchers’ perspectives only. It is unknown whether interviews with southern researchers would yield similar results. Tomlinson et al., (2006) point to the neglect of within-country, or within-research group dynamics, where power issues may also be at play.
4.6.2 Trust and respect between researchers

Trust and respect between partners are considered to be key principles to ensuring a successful partnership (Vasquez et al., 2013; de-Graft Aikins 2012; Preston 2008). de-Graft Aikins (2008) reported that “bonding social capital” was essential to the success of the partnership. However, there is little evidence of how trust should be established and few guidelines on how to develop it (Horton et al., 2009). Jentsch and Pilley (2003) in an empirical qualitative study, emphasise that when northern authors report on their experiences in north–south research partnerships, they tend to emphasise principles of partnership, such as ‘equality’, ‘capacity building’, and the ‘sharing of responsibilities’. Whether this is similar or in contrast to the southern perspective has not been explored.

Though in principle, trust and respect are discussed in the published literature, most of the studies dealing with this topic are self-evaluations, which raises the independence and hence reliability of self-reported studies. Maher et al. (2003) empirical self-evaluation, found that obligatory and imposed partnerships present the most barriers to collaboration. Natural partnerships, which are based on prior working relationships, are the most likely to succeed. It has been recognised that relationships are not black and white in research collaborations (Preston, 2008), demonstrating trust and distrust, enthusiasm and hostility within the one partnership, in relation to gender and seniority, as well as north-south.

“Intra-team harmony, but historical departmental strife also replayed itself, with gendered tensions over pay and status between junior and more senior participants, and the loss of enthusiasm and eventual withdrawal of those unpaid. Inter-organisational relations revealed fundamental trust between those who had previously co-operated and sometimes open hostility towards the two new teams.” (Preston, 2008)

In an ethnographic study, Geissler (2013) highlights inequities between northern and southern researchers and demonstrates that often these inequities are not openly discussed, due to claims of equality in north-south partnerships and a desire to move
away from colonial legacy. The author discusses this as a process of ‘unknowing’, which is similar to ignoring or denial.

“Hierarchy and dependence are distinctly unpopular ways of rendering difference, partly because of their connotations of colonial hegemony but also because such hierarchies can imply responsibilities and lasting commitments for the dominant party and moral entitlements for its subjects.” (Geissler, 2013)

Molyneux & Geissler (2008) warn that “efforts to establish ‘good relations’ should not be considered a panacea to the ethical and political dilemmas of transnational collaborative research”. Exposing inequality amongst researchers can lead to frustration due to an inability to alter the situation due to structural inequalities (Geissler, 2013). Geissler appears to hint that advocating equality in research partnerships without providing the means to achieve it, allows northern researchers to evade responsibility for inequality. The key message from the literature is that addressing relationship inequality is sensitive and is sometimes constrained by inequalities at a structural level.

4.7 Overall conclusions and gaps in the evidence on macro research ethics

Most of the literature relating to macro research ethical issues is focused on north-south inequities and power imbalances. Power, culture and politics, including the legacy of colonialism are frequently mentioned as being important in international health research. Many of the published documents relating to north-south health research are self-evaluations and self-reflections. Exceptions have been discussed in this chapter. While researchers documenting their experiences should be encouraged in terms of reflexivity, this is potentially problematic considering that the authors of these empirical studies often do not state their positionality in relation to the study. Studies usually report either the northern or southern perspective, usually northern, and usually a northern position on what the southern perspective is. However, in recent years, the southern voice is emerging more strongly.
There is a growing recognition that the binary oppositions of north versus south may be simplistic and that there is a need to develop more complex views on culture and ethics (Tomlinson et al., 2006). The published literature typically focuses on one partnership, rather than placing the researcher at the centre and many focus on structures and processes of collaboration. Issues relating to culture, power and researcher identity are emerging, but have not been explored in detail. This provides the basis for the empirical research in this PhD study.

This chapter has sought to partly address Research Objective 1: to identify from existing literature, macro ethical issues in international north-south health research. The literature does not provide sufficient insight into why power imbalances persist and the effects of culture on the research process and research relationships. There is also a risk that power imbalances from the perspective of self-evaluations may underplay inequalities in north-south health research. The gaps identified in this chapter were explored empirically with researchers and are presented in Chapter 7.
Chapter 5: Micro research ethical issues in north-south health research: a review of the literature

This chapter seeks to partly address Research Objective 1: to identify from existing literature, micro research ethical issues in academic north-south health research. Many of the studies use ethnographic methods, and focus primarily on biomedical research. The structure of this chapter follows the micro research ethics element of the conceptual framework, according to: a) procedural ethics: international guidelines for health research ethics, REC review processes and mechanisms; and, b) ethics in practice: data collection and community engagement, see Figure 6. This chapter also deals with the overarching area of researcher relationships relating to micro research ethics. A strong central common force in the evidence is the role of north-south cultural differences. This literature review seeks to identify whether cultural differences exist at the level of micro research ethics and if so, what effect they have on north-south health research. It also seeks to understand if power imbalances are evident. The literature search identified 39 empirical studies relating to micro research ethics, on the following topics.

- REC processes north and south (10)
- REC capacity (8)
- Informed consent (7)
- Community engagement and community perception of north-south health research (4)
- Social value/benefits of research (6)
- Perspectives on research ethics (2)
- Research ethics associated with data collection (2)

As detailed in Chapter 3, the micro literature search identified 4,550 potential references, 360 of which fitted the inclusion criteria.
5.1 International guidelines for health research ethics

A plethora of international guidelines for health research ethics exist. The existence of so many guidelines and codes can mean that collaborative researchers are sometimes faced with applying multiple and conflicting research ethics codes (Parker, 2007). The guidelines have been developed exclusively for biomedical research, however some of these state that they can be applied to all types of health research. Recently, there has been recognition that guidelines for other types of health research need to be considered (Hyder et al., 2014). It has been claimed that it is likely that these guidelines reflect primarily the beliefs and principles prevalent in the developed world (Caballero, 2002), although it has not been empirically tested if this is the case. This section summarises the principal international guidelines for health research ethics.
The first attempt to develop an international code for health research ethics was the *Nuremburg Code (Nuremburg, 1949)*, which was drawn up in the wake of the gruesome experiments carried out by German doctors on prisoners during World War Two. The code has 10 principles addressing voluntary consent, benefit to society, and avoidance of harm.

Figure 7: International codes/guidelines for health research ethics

The World Medical Association *Declaration of Helsinki (1964)* made its’ first appearance in 1964, with seven revisions since then, the latest in October 2013, and two notes of clarification. The Declaration has emphasised written informed consent, the following of a protocol, and independent research ethics review. The Declaration has been the subject of much criticism and debate. Emanuel (2013) asserts that the Declaration “reads like a haphazard list of articles without an overall logical framework”. Article 4 of the Declaration claims that it only “binds the physician”, however Article 30 includes ethical obligations of authors, editors, and publishers who are frequently not physicians. Emanuel (2013) also claims that the Declaration should be a statement of broad ethical principles with details of their application to be undertaken by national laws and regulations. The Declaration has also been criticised as being simply a ‘declaration’, which has no enforcement mechanisms and no sanctions for non-compliance (Macklin, 2012). A detailed comparison of English, Spanish and French versions of the Declaration discovered a number of ways in which wording could potentially be interpreted differently, which could be considered significant in their ethical relevance (Carlson et al., 2007).

The *Belmont Report (1979)* incorporates three core principles: i) respect for persons: duty to respect autonomous persons, their choices and their information and duty to protect those less than fully autonomous; ii) beneficence: duty to protect the welfare of participants; iii) justice: duty to distribute benefits and burdens fairly. It has been
criticised for being a one size fits all document and for not specifying how the principles should be weighted (Shore, 2006).

The Council of International Organisations of Medical Sciences (CIOMS) Guidelines (2002), were first published in 1983 and there have been various revisions up to 2002. It was the first code to explicitly consider less developed countries as a central concern. The CIOMS 2002 text contains a statement of general principles and 21 guidelines. The guide particularly considers low-resource countries in defining national policies on the ethics of biomedical research, and applying ethical standards in local circumstances. The guidelines state that “the challenge to international research ethics is to apply universal ethical principles to biomedical research in a multicultural world”. The Code highlights that research must be responsive to health needs of the host country and that there must be agreement in advance that products will be made reasonably available once the research has been completed. The 2002 revision was conducted primarily to address medical research in LMIC, with a redrafting group from Africa, Asia, Latin America, and the US (CIOMS, 2002).

The UNESCO Universal Declaration on Bioethics and Human Rights (2005), has claimed that it adds value by being the first international legal, though non-binding, instrument that deals with the link between human rights and bioethics (Andorno, 2007).

“Regardless of the weaknesses inherent to this kind of instrument, the very fact that virtually all states reached an agreement in this sensitive area is in itself a major achievement” (Andorno, 2007). Other documents such as the Declaration of Helsinki and CIOMS do not have this status because they have been issued by NGOs.

Perhaps the most detailed document to guide the ethics of research related to health care in developing countries is the Nuffield Council on Bioethics: ‘The ethics of research related to healthcare in developing countries’ (2002). The report outlines a framework for considering ethical issues raised by externally sponsored research with a focus on social and cultural context. It highlights four main themes: standard of care, consent, research ethics review, and what happens once the research has been completed. The Nuffield Report also concerns itself with the institutions and procedures through which these principles are put into practice. Four principles are applied:

1. the duty to alleviate suffering;
2. the duty to show respect for persons;
3. the duty to be sensitive to cultural differences;
4. the duty not to exploit the vulnerable.

Recommendations are primarily to guide external sponsors of research related to healthcare, but it is asserted that they can be equally applicable to internally funded, national research. Uniquely the guidelines consider the differing motives and “the disparity between the resources and power of the external sponsor of the research and the developing country has been central to the discussion” (Nuffield, 2002). There is also recognition of the potentially different cultural perspectives between funders/northern researchers and southern researchers and participants. The guidelines claim that “the existence of cultural diversity does not lead to moral relativism” (Nuffield, 2002) and provide a framework as opposed to a strict prescription of conduct. The importance of developing national guidance to go with these guidelines is underlined.

Emanuel et al. (2004) developed a framework of 8 principles (originally 7 principles in 2002) as well as a series of benchmarks for conducting clinical research in developing countries. The overall focus is on biomedical research, even though the authors state that the principles and benchmarks can be applied to all health research. The principles are: collaborative partnership, social value, scientific validity, fair selection of study population, favourable risk-benefit ratio, independent review, informed consent, and respect for recruited participants and study communities. These principles can be said to address both micro and macro ethical issues, however only one principle addresses the macro ethical issues. This framework is created from the premise that the research is initiated by northern researchers, with a starting point of justifying research in the global south (Emanuel et al., 2004). The framework has also been criticised for not including individuals from resource-poor countries as authors (Kuritzkes, 2004). Differences in health, economic, social, and cultural aspects of a research setting will affect application of the framework.

The European Union has a number of directives relating to health research ethics. The EU Directive on the implementation of good clinical practice in the conduct of clinical
trials on medical products for human use (2004), was incorporated into law for EU member states in 2004. Some organisations have developed their own guidelines to address ethical issues raised by research in developing countries, such as the Joint UN Programme on AIDS (UNAIDS), the UK Medical Research Council, the Wellcome Trust and the National Institutes of Health. Many of the guidelines have been criticised in recent years for being too general.

Specific ethical issues have arisen relating to clinical trials in LMIC, which have provoked fierce debate since the 1990s. The main issue is the need for low cost alternatives, in particular for HIV/AIDS treatment, that resource poor countries could afford. There were opposing arguments. One side promoted intervention trials that might be less effective and less expensive than treatment available in HIC research context should be considered by local decision makers, and decisions should not be made “paternalistically” by HIC (CIOMS, 2002). The other side argued that such trials risked exploiting LMIC and was inherently unethical. Higher income countries (and in particular pharmaceutical companies) have the capacity to make the most effective treatment available and that economic factors should not influence ethical considerations (WHO, 2008). Reports of ethical misconduct in international health research have contributed to heated debates over issues such as the use of placebos in clinical trials, obligations to research participants during and after an investigation, and informed consent (Marshall, 2005).

The question of who should benefit from research has provoked a considerable degree of debate in the north-south health research ethics literature. The debate follows a continuum, ranging from individual (micro), to social/societal value (macro). Three primary forms of benefit have been identified: the responsiveness of research to: i) host country needs and health care priorities; ii) capacity building; iii) benefits to participants and host communities during and after a study is completed (Whyte, 2007). It is proposed that international guidelines should be revised to establish a guarantee for LMIC to secure benefits from hosting research. Another claim is that research is skewed towards the interests of scientists, funders and interest groups, instead of the health needs of populations (Kok et al., 2012). Broader macro benefits, such as the social value of research; and adding to knowledge have been emphasised.
(Lairumbi et al., 2011, Lairumbi et al., 2012). COHRED (2007) Guidelines on Responsible Vertical Programming, recommend that all stakeholders active in health research should benefit at micro and macro levels.

Lairumbi et al. (2011) examine the recommendations from international and national research ethics guidelines regarding responsibilities of benefit sharing and conclude that “ethical guidance for global health research has taken a shift from a focus on protecting research participants, to a more holistic remit for securing community and host nation interests” (Lairumbi et al., 2011). There appears to be a growing recognition that research funders should make development of local expertise in healthcare an important component of research proposals and responsive to the health needs of a country.

Lairumbi et al. (2011) suggest that different stakeholders, are likely to make decisions on their responsibilities based on the research ethics guidelines that most suit their preferences. Nuffield (2002), CIOMS (2002) and Emanuel et al. (2004) provide the most comprehensive ethical frameworks for undertaking research in developing countries. However they encompass primarily micro research ethical issues. There remains no overall framework to analyse micro and macro ethical issues in north-south health research. Benatar (2004) puts forward the idea of a neutral global arbitrator (e.g. a Global Commission) to consider, and to adjudicate, on the ethics of how institutions operate (Pang, 2002).

Different legal traditions such as Common Law\(^{23}\) and Civil Law\(^{24}\) systems may affect how legislation relating to research ethics is developed and applied\(^{25}\). National legislation affects health research and research ethics, in particular, legislation governing data protection, freedom of information and human rights. Some northern countries have introduced legislation specifically in relation to health research ethics, such as Denmark and the United States. In Europe, the Council of Europe’s Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the

\(^{23}\) United Kingdom and some of their historical colonies, including Zambia

\(^{24}\) Continental Europe and some historical colonies of Spain and Portugal

Application of Biology and Medicine, develop their authority through treaty obligations (Nuffield, 2002).

5.2 Procedural ethics: research ethics review processes

“The establishment and maintenance of research ethics committees is just as much an essential ingredient in the proper conduct of research related to healthcare as the functioning of political institutions is essential to the proper conduct of government. An ethical analysis does not concern itself only with identifying and setting out appropriate general values and principles. It also has to concern itself with the institutions and procedures through which these principles are put into practice.” (Nuffield, 2002)

The existence, roles and functioning of RECs is the topic that receives the most empirical coverage in the research ethics literature, with articles either partly or completely dedicated to investigating research ethics review in lower and middle income countries. Although north-south cultural differences and power imbalances between RECs are frequently mentioned, the exact nature of these differences is not explored. The comparative evidence for REC processes is between the US/Canada and LMIC with no focus on other HIC. The main discussions in the literature are around:

- Inadequate REC review mechanisms
- Roles and composition of RECs
- Guidelines for REC review
- Divergent views between northern and southern RECs
- Research ethics training and capacity
- Informed consent

5.2.1 Inadequate research ethics review mechanisms

A number of empirical studies highlight the absence or inadequacy of research ethics review mechanisms in the south. van Teijlingen and Simkhada (2012) put forward possibilities as to why researchers from the north may choose not to apply for ethical approval in the south. These include: (a) assumption that a developing country does
not have an ethical review system; (b) belief that applying for ethical approval in a country is expensive and/or time consuming; (c) perceptions of certain research being exempt; or, (d) arrogance or paternalism that ethical approval from an institution in a developed country is sufficient or even superior. Box 6 summaries the empirical evidence in relation to inadequate REC review.
Some RECs were believed to rubber stamp REC authorisation in order to obtain international funding and southern RECs may sometimes be viewed as merely a ‘formality’ (Kass et al, 2007), Nuffield (2002) and Marshall (2005). Bribery may be an accepted practice in some countries (Klitzman, 2012), but it is important to note that these are researcher’s perceptions and there is no evidence to confirm that this is actually taking place. REC “shopping” Klitzman, (2013) was also considered to be an issue, where researchers could submit their protocol to a second REC if it was rejected by a first. The evidence shows an absence of or inadequacy of REC review processes and mechanisms in the global south. The implication of this is involvement of northern RECs in the process, the consequences of which will be explored in the empirical research in this PhD study.

5.2.2 Roles and composition of RECs

A number of authors examine the composition of RECs in the global south. (Hyder et al., 2007), in a study on the structure and function of RECs in Africa, reported RECs ranged from 9 to 31 members. Most committees comprised clinicians, social scientists, economists, nutritionists, pharmacists, statisticians, pastors, and lawyers. Ten out of twelve committees had lay or non-scientist members and 5 out of 12 RECs had paid staff. In some countries, it is considered an advantage to have a majority of lay members on a research ethics committee who are not professionals in the fields covered by research, to reflect the values of the local communities and the local and national culture (Nuffield, 2002). However, this does not often occur (Ateudjieu et al. (2010).

Rwabihama et al., (2010) investigate the process of establishing RECs in 25 African countries and compares them with the US and Canada, to assess their independence. The study concludes that generally the committees are not independent enough due to the history of how they were established, primarily to conduct northern research projects in southern countries. As previously mentioned, this ignores the trajectory of these committees since establishment, which may have resulted in RECs demonstrating more independence over time. Another primary role of RECs is to
monitor and audit research. This role is relatively absent in the literature, with the exception of Rwabihama et al. (2010), who report that none of the RECs in their study made any follow-up to the research, even though annual reviews were required, CIOMS (2002) suggest that RECs in the sponsoring country review scientific methods, and committees in the host country should “determine whether the objectives of the research are responsive to the health needs of the country, and assess the ethical acceptability of the research in light of the local community’s customs and traditions.” (CIOMS, 2002).

Formal ethics review could expand to consider wider health and socio-economic benefits, including intellectual property rights, technology transfer, institutional capacity strengthening and other ways of sharing the benefits of research (Ijsselmuiden et al. 2010). The authors recognise however, that it may be a challenge for local committees to achieve this, and an alternative body with an ethics-policy mission may need to be created to take on this agenda at the national level. One might ask how realistic this is in the short to medium term, considering the difficulties that developing country research ethics committees face.

5.2.3 Guidelines for REC review

According to the results of a study undertaken by Ateudjieu et al. (2010) in Cameroon, Mali and Tanzania, the Declaration of Helsinki was the most frequently named (22.5%) research guideline that was followed for in-country research ethics evaluation. Only respondents from Tanzania reported using national guidelines. Hyder et al., (2004) study found that 95% of developing country researchers reported that US ethical guidelines ensure high ethical standards in research, and more than two thirds of the researchers agreed that developing country collaborators rely on US ethical regulations for guidance.

In their ethical guidelines, Nuffield (2002) concludes that research ethics review should be separated from scientific review of research which may require the establishment of separate committees. In contrast, the Declaration of Helsinki, and CIOMS (2002) do not require a separate committee for review. A study by Kass et al., (2007) reported
that four RECs reviewed science, ethics, and budget equally, while another four reviewed science and ethics, but not budget; two spent little time on ethics, another focused almost exclusively on ethics, and another committee reviewed science only. According to Hyder et al. (2007) reviewers were often not trained to review from an ethical perspective, which led to an overbalanced focus on science. It is recommended by some guidelines that ethical review be undertaken in both the sponsoring and the host country (CIOMS 2002, Nuffield 2002). Kass et al., (2007) report that while seven RECs required all protocols to be reviewed, the other five committees only reviewed research when required by the funder.

Research ethics guidelines primarily reflect biomedical ethical frameworks, whose primary focus is to assess risk to individuals rather than to communities (Flicker et al. 2007). In many countries these came to be extended to all types of research over time. It has been argued that different types of research such as health systems research require diverse ethical considerations to those of biomedical research (Hyder et al, 2014). The ethical and practical implications of southern RECs using international guidelines has not been explored. Globally, a fear has been expressed that ‘ethics creep’ is occurring, that bureaucratic regulations, policies and procedures may remove the issues that are most significant to research (Guta et al., 2013), though not specifically in relation to research between HIC and LMIC.

5.2.4 Divergent views between northern and southern RECs
The literature points to divergent views between northern and southern RECs. Evidence shows that RECs reach diverse conclusions when reviewing the same study, including disagreements between host and sponsoring country RECs, primarily due to culture (Kass et al. 2007, Dovey et al 2011, Klitzman 2012, Nyika 2009). Although values may be held in common, how these values are interpreted and applied in judging a research project is influenced by historical and cultural contexts in which individual ethics committees perform. HIC interviewees in a study by Nyika and colleagues (2009), often recognised that they did not have enough contextual information about LMIC circumstances. There was recognition that both HIC and LMIC faced difficulties, particularly in interpreting principles and regulations. The authors
also perceive a need to harmonise ethical review in Africa and see double ethical review as a positive step, which leads to the strengthening of protection for participants. Hyder et al (2004) found that 83% of developing country researchers considered that US review committee regulations were insensitive to local culture and more than half (57%) agreed with the statement that US RECs were more concerned with politics than with protecting the interests of research participants. The nature of this politics is not described. It is interesting to note the perception of political preoccupation is equally considered to be an issue in southern RECs.

A study conducted with national REC members in Malawi, to ascertain their views on international relations found that when southern researchers were asked how international researchers perceived their RECs, many maintained that the RECs were seen as “police officers, blocking research and delaying scientific progress.” (Henderson et al., 2007). Members expressed concern that no mechanisms were in place for communication between international RECs and the Malawi REC. The authors recommend that REC members from both HIC and LMICs need to gain a better understanding of how each committee reviews protocols and of local research environment. Hyder et al.’s (2004) study reported 17% of respondents claimed that they had to abandon the research project because they could not get developing country approval; in contrast, only 6% reported abandoning their project because it was impossible to obtain US REC approval.

A reflection piece by Meslin (2013), reported that while there was agreement that a joint ethics committee would be approved for their north-south health research partnership, the Chair of the Kenyan National Bioethics Committee insisted that it would not happen because the Kenyan University had sufficient capacity to undertake research ethics review and that it was “perceived to infringe on Kenya’s national autonomy” (Meslin, 2013). This shows a desire on the part of Kenyan researchers to move away from HIC involvement in REC review.
5.2.5 Research ethics training and capacity

Research ethics training and capacity strengthening is extensively documented in the literature, with clear north-south inequities reported, including a lack of financial and human resources for RECs in the global south, insufficient training, inadequate standard operating procedures and no mechanisms for protecting conflict of interest (Hyder et al., 2007) (Klitzman, 2012) (Nyika et al., 2009, Ijsselmuiden et al., 2012, Hyder et al., 2013, Ateudjieu et al., 2010). Nyika et al. (2009) claim that many RECs in their study are not yet sufficiently multidisciplinary or multisectoral and that half of the respondents in their study had not received any training in research ethics review. In terms of finances for REC, all trainees in Hyder et al. (2007) study identified funding for RECs as being a challenge, and three committees had no operating funds. Hyder et al (2014) developed a framework to assess an organisation along eight domains in research ethics. This is a practical method which could be utilised by institutions in LMIC.

Capacity issues are not unique to African RECs. Increased attention has been given to ethics review capacity development in HIC and research sponsoring agencies, and in particular training on specific ethical issues relating to research in LMIC (Ijsselmuiden et al., 2010, Caballero, 2002, Camp et al., 2009, Hyder et al., 2007). The relevance of research ethics capacity training to Africa given that it is delivered primarily from HIC institutions has been questioned (Ateudjieu et al., 2010). Training on how to interpret ethics principles in light of local norms and the creation of mechanisms to facilitate communication between developed and developing country RECs, could help solve this situation (Hyder et al., 2004). One study recommended that an ongoing procedure for bilateral exchange between northern and southern RECs should be developed, and that a proficiency in international research ethics should be demonstrated by both HIC and LMIC RECs, with “development of harmonised policies and procedures for oversight of international collaborative research.” (Sidle et al., 2006).

26 Basic values and identity; structure and ability to carry out activities; relevance of activities to stated goals; capacity of staff and management; administrative, financing and accounting systems; relations with target groups; national context (Hyder et al, 2014).
The importance of evaluating research ethics capacity from the systems perspective to build capacity at national, institutional and individual levels has been emphasised, to avoid focusing solely on isolated programmes (Nuffield, 2002). Many global and regional initiatives exist to strengthen capacity for research ethics review. The majority of initiatives are focused on bioethics, and are organisation specific, multilateral and regional. Appendix 12 details research ethics capacity strengthening initiatives at a global and regional level.

5.2.6 Informed Consent: individual autonomy and communitarianism

The literature review for this PhD study has found informed consent to be one of the most discussed topics in the literature on international health research ethics, and focuses primarily on biomedical research. It is not the aim of this section to review all the published literature in relation to informed consent, but rather to focus on issues that arise in informed consent in north-south health research, primarily around cultural issues and its position in REC review process and guidelines. Studies focus primarily on debates over individual versus community consent and despite the dearth of empirical studies, theoretical debate on the appropriateness of applying a northern approach to informed consent in developing countries is plentiful.

Issues raised in the literature focus on the appropriateness of the northern informed consent processes for inclusion in research in Africa. The debate is that northern society is individualistic and thus ethics focus on the individual, whereas in more collectivist societies, community consent may be needed. The importance that most authors attach to the process of community consent is to add to the process of individual consent, rather than being a substitute for it. A number of authors express the importance of a multi-step consent process, beginning with community consent to undertake a study, followed by individual consent to participate in the study, thus respecting both individualism and communitarianism, showing compatibility between the two is possible (Molyneux et al., 2005, Doumbo, 2005, Diallo et al., 2005), Frimpong-Mansoh (2008). Doumbo (2005) places this in the context of northern researchers lack of understanding of the process and that individual and community consent should be seen as part of the one process.


“We cannot separate them in our countries, and this reality should be understood by sponsors and funding agencies and northern research institutions. We need to think about the protection, safety, risks, and benefits of individuals and of the community at large. We have learned in particular that the initial focus and discussion should be with the leaders of the community, rather than individuals. By approaching individuals first, one is likely to introduce social conflict in the village, and this could be unethical.” (Doumbo, 2005)

Caballero (2002) and Camp et al. (2009) go one step further to question the concept of individual consent in cultures where pre-eminence is given to the community. International research ethics guidelines also comment on individual and community consent. CIOMS Guidelines (2002) include a requirement to respect customs such as “obtaining permission from a community leader, a council of elders, or another designated authority”. Nuffield (2002) Guidelines claim that in many LMIC, concepts of respect for the family and community are equally as important as, or more important than, concepts of individual autonomy and rights.

Krogstad et al. (2010) and Tangwa (2004) conclude that there is no reason to insist that informed consent be identical in countries with markedly different cultures, social traditions, and literacy. On the issue of confidentiality, Macklin (2012) gives the example of how public posting in medical clinics of highly personal information about individual’s health status, inoculations, women’s menstrual cycles and other data is commonly practiced in some LMIC, whereas this would be considered unethical in most Western cultures. Stewart and Sewankambo (2010) case studies reveal the local view of informed consent in Uganda, which show that Ugandan’s sense of individual autonomy is not subordinate to the common identity:

“It is clear that the concept of individual autonomous consent is a strong one in Uganda both for daily life and in research, and it appears to conform closely to Euro-American ideals of autonomous consent. The broad process of informed consent is also generally well understood. This suggests that ideas of the autonomy of the individual in decision-making are deeply embedded in a
Informed consent forms are usually designed in HIC, serving to satisfy the legal side of the process, which are then translated and back-translated, often resulting in imprecise meanings, making it difficult for participants to ascertain the risks and benefits of participating in studies (Bhutta (2004), Krogstad et al. (2010) and Gikonyo et al. (2008), Doumbo (2005). Many potential research participants in LMIC are wary of complex consent forms because they are perceived as carrying legal risks such as court proceedings, or as a way of protecting researchers (Gikonyo et al., 2008, Doumbo, 2005). Camp et al. (2009) study reveals that El Salvadorian participants considered a US designed 20 page consent document too lengthy, where a typical local informed consent document usually only ran to one page, due to low literacy rates. The association of low literacy levels with difficulty understanding informed consent was also expressed by Doumbo (2005).

The concept of *Ubuntu* is closely linked to the debate on individual and community consent. It can be considered to be a code of ethics and behaviour which focused on the individual existence as being inseparable from the collective (Swanson, 2007) and is embedded in African culture (Nussbaum, 2003). It has been defined as the following:

> “Ubuntu is not a concept easily distilled into a methodological procedure. It is rather a bedrock of a specific lifestyle or culture that seeks to honour human relationships as primary in any social, communal or corporate activity.”

(Nussbaum, 2003)

The core values of *Ubuntu* are defined as communalism, interdependence, humanness, sharing and compassion (Brooklyn, 2008). The term is short for the Nguni proverb *Umuntu ngumunti ngabantu*, which literally translated means “a person is a person through their relationship with others” (Swanson, 2007). It is seen as being in contrast to the more individualistic and Western codes of living.
This PhD study literature review finds diversity in terms of individual autonomy associated with northern countries versus communitarianism. It would be important to explore what effect north-south health research partnerships have on this in terms of research ethics review processes, particularly in relation to informed consent. It would also be interesting to investigate whether different viewpoints exist between northern and southern perspectives on the consent process. There may be legal requirements for consent and confidentiality on the part of those who participate in health research, such as the right to confidentiality, as enshrined in the UN Universal Declaration of Human Rights, Article 12, (United Nations, 1948) and the Charter of Fundamental Rights of the European Union, Articles 7 & 8 (European Union, 2009).

5.2.7 Conclusions and gaps: procedural ethics
The literature shows that there are clear inequities in terms of REC capacity, with the global south lagging behind the global north. This creates a reliance on HIC systems procedures, which can result in tensions, primarily due to cultural differences. While research ethics review processes are extensively covered in the literature and despite reports of north-south cultural differences in research ethics review mechanisms and procedures, the exact nature of these differences has not been explored. All comparative evidence for REC processes between HIC and LMIC is between the US/Canada and the global south. There are no comparisons with RECs in other parts of the world, such as Europe. Evidence shows that cultural differences exist between northern and southern RECs, however these differences have only been quantitatively reported and the nature of these cultural differences remains hidden. This PhD study will undertake an in-depth examination of REC processes and mechanisms in order to gain a picture of the power differentials and cultural elements of these processes. Specific questions to be investigated (in Chapter 8) are:

- what are the processes for REC approval in north-Zambian health research and what are northern and Zambian researchers’ perspectives on this? Does conflict ever exist between RECs, and if yes, what is the nature of this?
- Are there examples where approval is not obtained in Zambia, as some of the literature has suggested, and what are the reasons for this?
While it is reported that some committees lack independence, the history of RECs has not been traced, nor the trajectory of how they have evolved over time. This PhD study traces the history of the REC process in Zambia. The national research ethics system has not been examined in detail - with the exception of Ijsselmuiden et al 2010 - nor the contextual issues through which these systems operate, for example, does external research have an influence on the national health research ethics system - regulations and functioning - as Meslin et al. (2013) suggest?

There are some reports of REC shopping and a culture of corruption amongst some RECs. This PhD study will ask if this is occurring in Zambia.

5.3 Ethics in practice: data collection and community engagement

Much of the health research ethics literature focuses on the ethics of data collection and is presented here in relation to past and present involvement of northern researchers in the data collection process. Most of the literature relates explicitly to power differentials between researchers and research participants/communities. A recurring theme in the literature on health research ethics relates to community engagement in research conducted in LMIC, however issues relating to the effects of HIC involvement are relatively neglected, particular relating to power, culture and researcher identity. The main areas discussed are: i) the historical legacy of data collection in north-south research and community perceptions of research; and, ii) the roles played by northern and southern fieldworkers in data collection.

5.3.1 Historical legacy of north-south research and community perceptions of research

There is a dearth of literature relating to how communities perceive research studies which are undertaken in collaboration with international partners\(^\text{27}\). Where literature exists, issues relating to trust and suspicion come to the fore, based on the legacy of

\(^{27}\) It is important to recognise that not all public health research is conducted at the community level. For example, research can encompass health facility, hospital level, district or national level. Published literature pertains primarily to the community level.
colonialism. It has been claimed that historically justified mistrust from the local community regarding involvement with northern researchers may interfere with community-researcher partnerships, causing distrust and refusals (Stenson et al. 2010), (Casale et al., 2013). Reports include being:

“chased out of communities and even labelled ‘Satanists’. We are still not clear as to the origin of these accusations, but believe they were simply a result of misunderstandings around the nature of research, and fear and distrust toward outsiders.” (Casale et al., 2013)

Community perception of research studies have found issues relating to ‘Satanism’ and blood stealing relating to biomedical research, which appear to be linked to outsiders undertaking research in the south. Whether this has knock-on effects for other types of north-south health research has not been explored. In a study which analyses how internationally supported medical research is understood and interpreted by research participants. (Fairhead et al., 2006) report that while a positive community perception exists that Medical Research Council provides health benefits through medicine, there is a belief that it “steals good, African blood that, people speculate, they send to Europe or America for transfusions and to make medicines” (Fairhead et al., 2006). The perception of blood and organ stealing is reinforced by Kingori et al., (2010) who claim that communities link blood stealing to colonial interventions in Zambia.

“European doctors, fat administrators, prospectors, surveyors, and tourists were highly suspected of being Banyama (vampire men). Rumours were also fuelled by appeals for and witnessing of blood donations or transfusions or seeing pictures of either, and by stories of mysterious disappearances of people in a given area. These rumours, which though unverified were believed and spread by many in a distorted form, bred fear and insecurity.” (Kingori et al., 2010)

Madiega et al. (2013) explained how blood sample collection, evoked rumours about practices such as ‘devil worshippers’ or ‘blood suckers’.
Simon and Mosavel (2011) recount how, as US researchers, their nationality had the potential to affect participants’ perception of them, particularly because they conducted their research in South Africa at the beginning of the US invasion on Iraq. This necessitated disclosure of their identity and a discussion on their views on the invasion in order to obtain trust. Tomlinson et al. (2006) found that the UK research team in their collaboration were sometimes viewed with less suspicion by the community than the white South Africans. The authors argue that these issues may be overlooked by examining only north-south differences. This point is often debated in qualitative research methodological literature where outsiders can often obtain richer information, due to the fact that they are outsiders (Ganga and Scott, 2006, Merriam et al., 2001). However, this was the only study that reported ‘outsiders’ being trusted more than ‘insiders’, though this could be an area to further explore.

The importance of international researchers being aware of local power structures within communities has been outlined in a number of studies. Jentsch & Pilley (2003) report that northern researchers insistence that a culturally sensitive research project could be carried out if enough rapport could be established, resulted in the community rejecting the project and leading to the southern partner’s organisation being excluded by the community. Tomlinson et al. (2006) recounted a community perception of cultural imperialism in South Africa, and “there would have been no possibility of our working in the area as community members felt imposed upon inappropriately.” Martin-McDonald and McCarthy (2008) report a literature review where ‘whiteness’ in research partnerships with indigenous Australian health workers, participants and community members impacted relationships within their study. They highlight the role that colour and colonisation played in delivering automatic power and privilege.

“As we are white, middle-class women, our knowledge of indigenous health is always partial, racial and socially constructed. We have become aware that our whiteness, which is invisible to us, is always visible or ‘marked’ to indigenous peoples and that we have privilege and power conferred on us through colonisation.” (Martin-McDonald and McCarthy, 2008)
As has been introduced in Chapter 2, Simon and Mosavel (2011) consider researcher and community perceptions of a researcher’s identity from the perspective of being in agreement (symmetrical) or in conflict (asymmetrical) in relation to fieldwork. Researchers claim to have an overarching identity of ‘researcher’, but have elements of their identity ascribed to them by research participants, which may be in agreement or different to their own perceptions. The authors recommend a practice called ‘ethical mindfulness’, to encourage awareness around researcher identity. They suggest that “researcher identity is a lens through which research communities and participants actively call attention to the ethics – and particularly the justice – of global health research”. Madiega et al. (2013) reported that due to suspicions towards researchers and the need to preserve confidentiality, research staff invented alternative identities of relations or friends. However, there are a number of identities held by researchers based on class, education and life experiences, which will be empirically examined in this PhD study.

It is well documented that northern researchers take the lead in most elements of the research process in north-south health research collaborations, but it is unclear who takes the lead for community engagement and whether this has effect or not on the research findings or on the community they are researching. Based on this evidence the questions of whether or not it is ethical for northern researchers to be involved in community engagement and whether it leads to suspicion and mistrust will be explored with PhD study respondents.

5.3.2 Northern and southern fieldworkers in data collection

A number of studies examine researcher relationships in the field, primarily between researchers and participants and to a lesser extent between northern and southern researchers (Kingori et al., 2010, Geissler, 2013, Kamuya et al 2013, Molyneux et al, 2013). In a Special Issue of Social Science and Medicine, Molyneux and Geissler (2008) report on a conference which explored the ‘trial community’ in medical research in the south. A qualitative study in this Special Issue, on vaccine trials in Kenya and Gambia recognise the importance of everyday relationships in the research process:

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28 research participants, researchers, funders, academics, health providers, government representatives and members of the public (Molyneux and Geissler, 2008).
“fieldworkers who are based in ‘the field’ do not simply neutrally observe and adhere to formal externally derived ethical rules, but instead play a vital, creative, and under-recognised role in research and ethics practice.” (Molyneux & Geissler, 2008). Many studies describe how ‘insider’ researchers used their knowledge of local culture to adapt ethical procedures in the field, to fit with local contextual situations as they arose (Molyneux et al, 2013, Robinson-Pant & Singal, 2013) recognising that everyday social relationships are not easily tested by ethics committees (Gikonyo et al., 2008). Geissler (2013) describes the deeper complexities of relationships, rather than merely a simple north-south divide, through dividing northern researchers into expatriate staff and short term visitors.

The positioning of researchers vis-à-vis research participants, in terms of differences between the fieldworker and interviewees in race, class, nationality, gender or education has been analysed (Geissler (2013), Geissler et al. 2008, and Molyneux et al. (2009), Kamuya et al., 2013). A malaria vaccine trial in the Gambia (Geissler et al., 2008) took a different approach, where fieldworkers lived with volunteers in their villages. The authors describe how fieldworkers combined the theory and practice of research ethics, suggesting that research ethics in the field is of critical importance, which is not easily assessed or monitored by research ethics committees.

“While scientific observation and formal ethics try to exclude face-to-face relations, the Malaria Vaccine Trial fieldwork drew upon these and the associated ethics of relatedness, underneath and intertwined with the neater order of the protocol.” (Geissler et al., 2008)

Using local staff to collect data was highlighted as central to the data collection process, particularly from the cultural perspective, Casale et al (2013), Kamuya et al (2013). The 2002 Nuffield report on the ethics of research related to healthcare in developing countries, explains how local researchers are likely to be more knowledgeable about traditional health practices than non-local fieldworkers and have an ethical obligation to discourage harmful practices. Three studies (Molyneux et al., 2012, Molyneux et al., 2009, Molyneux et al., 2013), underline the importance of fieldworkers as essential members of a research team, acting as cultural brokers. Inequities between northern and southern fieldworkers (insider and outsiders)
emerged as an issue in two studies. Geissler (2013) provide ethnographical insight into insider and outsider fieldworkers in a transnational field research site in Africa, suggesting that material and historical differences result in divisions between field staff.

“Because of short-term postings in Africa, mundane practical continuities, such as where one lives, shops, or goes to school, are not charged with particular significance by most expatriate visitors. By contrast, such material realities and historical continuities are not lost on local staff, and comments about “them and us” and material differences between the two are common in informal conversations among peers.” (Geissler, 2013)

In another study, the northern colleague was described (by the southern manager of a development organisation) “as having made sacrifices, such as staying in a simple house and sharing a room” (Jentsch & Pilley, 2003). This implies a division in ‘comforts’ between northern and southern researchers. Cultural orientation by visiting researchers was deemed important with the assistance of a ‘cultural interpreter’. The authors recommend that northern researchers should visit often and for as long as possible, with extended stays in the rural areas in order to build relationships with the communities (Jentsch & Pilley, 2003).

5.3.3 Conclusions: ethics in practice

Studies focus primarily on north-south power imbalances and cultural differences in terms of data collection between researchers (north and south) and communities. Imbalances between northern and southern researchers has rarely been examined, particularly from the perspective of northern researchers lack of understanding communities, and their roles in data collection. The role of northern researchers in data collection will be explored in detail in this study and will be presented in Chapter 8. The importance of going beyond the usual ‘binary oppositions’ of ‘coloniser’ and ‘colonised’, ‘first’ and ‘third’ world and ‘black’ and ‘white’ to develop more complex views of in-country dynamics, politics and identities has been espoused by Tomlinson et al. (2006)
“It is important to note, as we have suggested, that just as there are complex layers of being inside and outside, there are gradations of cultural knowledge. Who, within any group, can be seen to stand for, represent, and advocate on behalf of the cultural norms of that group assuming, incorrectly, that cultural norms are static and uncontested, or that communities are homogeneous?” (Tomlinson et al., 2006)

Two empirical studies and one debate probe the notion of what can be described as a ‘global research identity’, which is based on a culture of science or a culture of research (Tomlinson et al., 2006, Caceres & Mendoza, 2009). Tomlinson et al., (2006) concluded that LMIC researchers are often very different from other people in their country, in terms of education, status, and financial position. It is common for these researchers’ identity to be closer to researchers from higher income countries. Crane (Crane, 2010) in a literature review and qualitative case study, states that it is difficult to state who can speak for Africa regarding the ethics of research design and practice, because ‘sameness’ can also be associated with marginalisation. The author claims that:

“researchers from ‘resource-poor settings’ must often walk a tightrope between claims of difference from the global north and assertions of sameness, in which a claim too forceful in either direction can undermine the ethical — and thus scientific — legitimacy of their research.” (Crane, 2010)

5.4 Overall conclusions and gaps in micro research ethics

This literature review has sought to partly address Research Objective 1: to identify from existing literature, the micro research ethical issues relating to academic north-south health research. Each of the studies included in this PhD study literature review is written from: a) a particularly disciplinary perspective; and, b) discusses the ethics of a particular type of research, i.e. clinical trials, health systems research, and epidemiology; and, c) from a northern or southern perspective. A number of gaps have been identified which the empirical research in this study will address.
This review shows that cultural issues are at the centre of micro research ethics: both procedural ethics and ethics in practice. The data collection process has been relatively neglected in the literature on north-south health research, particularly from the perspective of the researcher. Involvement of northern researchers in fieldwork has had effects on the data collection process, primarily due to historical inequities. Are researchers sensitive to the local culture of research participants? Where community sensitisation and fieldwork is undertaken by northern researchers, what effect did this have on communities? Do researchers have similar or different views of micro research ethics? Chapter 8 will provide empirical evidence to answer these questions, which will be interpreted in Chapters 9 and 10 around power and culture, through analysing both procedural ethics and ethics in practice.
Chapter 6: Zambian National Health Research System

6.1 Introduction

As described in Chapter 1, Zambia has been chosen as a suitable country to explore the ethics of public health research involving the global north and the global south. According to the Zambia Forum for Health Research (ZAMFOHR), research in Zambia is fragmented and underfunded (ZAMFOHR, 2009). Health research priorities in Zambia remain disease focused in outlook and priority setting is not representative and inclusive (COHRED, 2008). External donors fund up to 90% of health research and over 90% of the University of Zambia’s (UNZA) funded research work in 2005-2006 \(^{29}\) consisted of collaborative work. A formal health research priority setting exercise which was undertaken in 1999 by the Ministry of Health has not been updated.

A Report on the Zambian Consultative Process for the International Conference on Health Research for Development (Ndubani et al., 2000) concluded that up until 2000, health research had not made a substantial impact on the Government, resulting in the lack of a clear policy framework and a fragmentation of national research activities. Efforts to develop a National Health Research System (NHRS) in Zambia gathered momentum in 2009, culminating in the establishment of the National Health Research Authority of Zambia (NHRAZ) and the National Health Research Act (2013) which provides a legislative framework for health research in Zambia.

This chapter presents the first findings from the PhD study. It: a) sets out the history, evolution and structure of the national health research system (NHRS) in Zambia and; b) analyses the national health research system in Zambia. This is achieved through an analysis of national level policy documents relating to the health research system, and through perspectives of national level stakeholders (n = 8) who have been involved in setting up the national health research process in Zambia since 2008. This chapter

\(^{29}\) More up to date data is not available.
partly addresses Research Objectives 3 & 4: to explore the role of power (Research Objective 3) and culture (Research Objective 4) in academic north-south public health research. It also sets the context for the other results chapters (Chapters 7 & 8). Interviews were undertaken with 8 key national level Zambian stakeholders who were involved in the evolution of the NHRS in Zambia and 2 northern stakeholders who were also involved in the process.

6.2 National health research system as a concept

A WHO Report on National Health Research Systems (2002) examines the national health research system (NHRS) as a concept. It begins by describing the health system in terms of principles, values and ethics that lead to strong health research systems including:

“equal opportunity, horizontal team work, decentralisation of decision making in research (at both national and global levels), greater transparency in what research has been carried out, in how research is funded, and on the impact of research; and a balance between excellence and relevance.” (WHO, 2002)

This WHO Report discusses how a health system interacts with other societal systems such as historical context, political climate, socio-economic factors and culture (WHO, 2002). The framework used in this report usefully identifies stakeholders in the health research system: research funders, researchers and research users, all of whom are guided by their own set of roles and functions, values and capacity (WHO, 2002). COHRED’s manual on building and strengthening national health research systems (2006) defines a NHRS framework in terms of its functions, processes, institutions and lines of authority. They define a systems perspective based on the various components of the research cycle: from needs assessment to research project to impact, and claim that this approach is useful, allowing stakeholders to locate their roles at the different stages of the research cycle (2006).

The literature search found 10 empirical studies relating to national health research systems, 2 of these relating to Zambia, 3 relating to research ethics review systems, 1 focusing on research priority setting, 2 relating to guidelines for research contracting,
and 2 broadly analysing national health research systems. None of the studies focus on the NHRS in relation to issues relating to situated ethics, that is, power and culture across micro and macro research ethics. In a mixed method study, (Sombie et al., 2013) describe the research for health environment within the Ministries of Health of the Economic Community of the West African States. Findings show that 50% of countries in the region had established directorates for health research in January 2011 and only 7% of the directors of research units were trained in research management. 57% of the countries had some form of strategy for research development and half of the countries had developed national research priorities.

Pang et al. (2003) constructed a framework to analyse national health research systems, which will be used in this chapter to organise and analyse PhD study findings from national level stakeholders and policy level documents. The framework includes four functions of a health research system: stewardship, financing, creating and sustaining resources and producing and using research. Operational components are described for each function (see Table 3). This framework will form the structure for this Chapter. Published literature relating to the national health research system is also included as appropriate.
Table 3: A framework to analyse national health research systems (Pang et al., 2003)

<table>
<thead>
<tr>
<th>Function</th>
<th>Operational component</th>
</tr>
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<tbody>
<tr>
<td>Stewardship</td>
<td>- Define and articulate a vision for a health research system</td>
</tr>
<tr>
<td></td>
<td>- Identify appropriate health research priorities and coordinate adherence to them</td>
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<tr>
<td></td>
<td>- Set and monitor ethical standards for health research and research partnerships</td>
</tr>
<tr>
<td></td>
<td>- Monitor and evaluate the health research system</td>
</tr>
<tr>
<td>Financing</td>
<td>- Secure research funds and allocate them accountably</td>
</tr>
<tr>
<td>Creating and sustaining resources</td>
<td>- Build, strengthen and sustain the human and physical capacity to conduct and absorb</td>
</tr>
<tr>
<td></td>
<td>and utilise health research</td>
</tr>
<tr>
<td>Producing and using research</td>
<td>- Produce scientifically valid research outputs</td>
</tr>
<tr>
<td></td>
<td>- Translate and communicate research to inform health policy, strategies, practices and</td>
</tr>
<tr>
<td></td>
<td>public opinion</td>
</tr>
<tr>
<td></td>
<td>- Promote the use of research to develop new tools to improve health</td>
</tr>
</tbody>
</table>

6.3 Stewardship

Stewardship of the NHRS as defined by Pang et al. (2003) includes the following components (see Table 3): define and articulate a vision; identify appropriate health research priorities; ethical standards; and, monitoring of the health research system. Findings from this PhD study broadly fit into these categories.

6.3.1 Vision for the health research system and setting national health research priorities

Two studies outline useful processes for determining research priorities at the national level (COHRED, 2000), (Sieber and Braunschweig, 2005). A review of health research priority setting in LMIC found most of these exercises were conducted at the global level (Kok et al., 2012).
COHRED (2000) Working Group on Priority Setting, found that the countries in their review used one or more criteria from the following categories: i) magnitude and urgency of the problem; (ii) extent of previous research and the potential contribution of research; iii) feasibility of carrying out the research; (iv) expected impact of the research. They also proposed topics for evaluation of priority setting such as: whether research priorities were implemented; which and to what extent were stakeholders involved, and: whether the research priorities address equity in health. Essential National Health Research (ENHR) priority setting approaches, developed by COHRED, have been attempted in several developing countries, including Kenya, Guinea and South Africa. This paper (COHRED, 2000) discusses lessons learned from the experience of all the countries throughout Asia, Latin America and Africa. A framework for priority setting is presented to define the overall approach. The Working Group reported on the outcome and impact of these priority-setting exercises in the developing countries had not yet been completed, at the time of publication of this report in 2000. It is not clear if over a decade later this has yet occurred.

In a report examining ethical issues that arise when undertaking research in developing countries, Nuffield (2002) do not consider it necessary that all externally-sponsored research must fit with national priorities. However, they recommend that if research is proposed which falls outside the national agenda, those proposing the research should justify the research topic to RECs in both sponsoring and host countries. Guidelines for determining research priorities at the national level have been outlined, but it is not clear if these have been utilised, and if not, what the barriers are (COHRED, 2006). A qualitative study of the evolution of the NHRS in Guinea Bissau shows that international research can actually constrain the setting up of a national health research system, therefore they claim there is a need for donors to align funding to national priorities (Kok et al, 2012).

A national level stakeholder who has been involved in health research in Zambia for many years, described the history of health research in Zambia as follows. In 1959, the then Federal Government surveyed the organisation of healthcare in Zambia, Zimbabwe and Malawi. This resulted in the Report of the Commission of the Inquiry into the Health System of Zambia (1959), which reported that health research in Zambia was weak, and recommended that all health institutions should be involved in
some form of research to bring them to “the frontier of knowledge” (national stakeholder). Soon after Zambia gained independence in 1964, the Government created the National Council for Scientific Research, which became effective in 1967. This was followed by the National Council for Science and Technology, which had a mandate to conduct all research, including health research. However, according to this national level stakeholder, the focus was primarily on agricultural research, resulting in a side-lining of health research.

A Report on the Zambian Consultative Process for the International Conference on Health Research for Development (2000) outlined that most of the health research undertaken in Zambia was initiated by northern institutions, which have greater access to the resources required for research. The document recommended that Zambian researchers should be encouraged to initiate research on national health priorities. No guidelines however were documented as to how this might be implemented. The absence of updated national research priorities encourages non-priority research as opposed to needs-driven health research (MoH, 2008). The National Health Research Act (2013) tasked the National Health Research Authority of Zambia (NHRAZ) - see Section 6.3.2 - with the development of mechanisms for setting national health research priorities and strategies, and recommending national health research priorities to the Minister. However, as of December 2014, NHRAZ is not active, and National Health Research Advisory Council (NHRAC) continues to function as the coordinating body for health research in Zambia. In identifying its priorities, the 2013 Act states that the NHRAZ should take into consideration:

- burden of disease;
- cost effectiveness of interventions aimed at reducing the burden of disease;
- availability of resources for the implementation of an intervention at the level closest to the affected communities;
- health needs of special groups;
- health needs of communities;
- emerging public health problems (National Health Research Act, 2013).

The National Health Research Act 2013, also stipulates that researchers and research institutions must align their research to the national health research strategic plan.
Reportedly, a 2014 national health research strategic plan has been drafted, although not yet publically available, therefore the most recent published plan covers the period 2008-2011. This Plan recognised that while there has been a process to identify research gaps, there is no system for regularly updating and coordinating research priorities. The national health research priorities were published only once in the *Zambia National Health Research Agenda: National Health Research Priorities and Recommendations for Action: 1999-2001*. These are in the areas of: integrated child health and nutrition; integrated reproductive health; HIV/AIDS, sexually transmitted infections, and blood safety; Tuberculosis (TB); malaria; epidemics control and public health surveillance; and environmental health and food safety. According to interviewees, there has been no action plan to monitor and evaluate whether researchers adhere to these priorities. There is no indication that research priorities have been updated since they were first documented in 1999, despite the fact that the Strategic Plan dictates that research priorities should be developed by June 2009 and updated every two years. The first national health research conference was organised in 2002, and even though informally research priorities were updated biannually at the end of every national health research conference, in reality these were not formalised.

In 2008, it was recognised that “*funding opportunities and sources, rather than nationally identified health research priorities, tend to be the main determinants of health research in Zambia.*” (MoH, 2008). In a situational analysis of the health research environment in Zambia (Kwibisa, 2009), most of the respondents argued that research is biased towards infectious or communicable diseases, mental health and HIV and AIDS, with other areas such as non-communicable diseases not receiving much focus. Stakeholders in a COHRED study on harmonisation and alignment of health research in Zambia (2008) confirmed that the MoH is disease focused in its outlook, and that this influences research priorities.

> “The influence of donors was also cited as a problem that skews health research priorities. Current donor interest in certain conditions influences the availability of research funds. Currently, research funds are mainly available for TB, malaria and HIV.” (COHRED, 2008)
The predominant view of national respondents on the priority and agenda setting process echoes national documents that research priorities are set in the north, and in most cases are not aligned with Zambian priorities. The following quote encapsulates the perspectives of a number of interviewees:

“The fact of north-south collaboration is to distort the priorities for research. Because [X northern research institution] would come here and they are interested in a particular area. They will say, we have got some money, can we do research in this area? Researchers have said they welcome that money. And they welcome the opportunity to do research and collaborate with senior colleagues who could help them develop. So the process by which you are setting process is not a local process at all.” (national stakeholder)

There was a general sense of frustration that much of the health research carried out in Zambia is determined by donors, which some researchers perceived to be unethical.

“If Bill Gates makes a call say, okay there’s money today for disease specific research, then you would see a lot of this specific research start here, if the WHO said ‘ok health systems, something for human resources for health’, then you see a lot of it. So it really depends on what call is there. I tell you, you check the internet, see which health institution has a big call and you can almost predict what sort of proposals you are going to have in the coming months.” (national stakeholder)

However, one stakeholder saw this in a more nuanced way, where northerners are trying their best to undertake relevant research in Zambia with good intentions.

“...They [northern researchers] are not full of evil people who are saying how do we do this. They are full of people who say well we have a very refined idea of what we want to do, we really believe in what we want to do and we have got some money to exercise that. While objectively I have a problem with it, subjectively, I can see the merits of it.” (national stakeholder)
The blame was not always squarely placed with the north. It was posited that Zambians do not always fully exploit funding opportunities as they arise, partly due to Zambian work culture and that Zambian researchers do not often actively search for funding opportunities.

“We had gone through a period where the north came and told us what to do. When the time came to collaborate at par, we were still suspicious that these people have come to tell us what to do. And that remains our intellectual obstacle. As soon as you sit there and say ‘the way you could have done it is this’, I am straight away putting up my wall, to say ‘there she comes to tell me what to do.’ That complex stands between us and international collaboration. And I hope we can break that complex.” (national stakeholder)

A Zambian researcher claimed that the MoH technocrats have their own perceived set of priorities or issues they are likely to address, and see other research work as an unwelcome imposition. He continued to state that some research is merely academic and the MoH need to provide flexibility for that because not everything is a policy or a technical issue. Some stakeholders suggested that the MoH may not have the capacity to set research priorities as they do not always understand health research. One Zambian researcher explained how WHO priorities are adopted as priorities for Zambia and that this ensures that most of research has an impact on national health issues.

A number of national stakeholders, who had been involved in setting the national health research agenda between 1990 and 2010, recalled the process. They reported that the Zambian Government realised that there was a poor link between service delivery and health research. A project entitled Applied Research and Childcare (ARCH) with technical and financial support from Boston University, undertook to document health research in Zambia. Aside from what was published in peer reviewed journals, most of the results/reports were not traceable. The Zambian National Health Research Advisory Committee (NHRAC) approached the Canadian Coalition for Health Research (CCGHR), in 2011 to assist with a national priority setting process. A number of researchers were positive that when National Health Research Authority of Zambia (NHRAZ) is operational, Zambia will be in a position to decline projects that do not fit with its’ priorities.
Some stakeholders saw *ad hoc* priority setting as being the norm in Zambia. For these respondents, research priorities emerged from a traditional method of researchers themselves identifying what they consider to be important issues. For example, the Zambian Forum for Health Research (ZAMFOHR)\(^{30}\) current priorities are: human resources for health, mental health and reproductive health. However, these priorities arose through discussions with ZAMFOHR Fellows\(^{31}\) and their interests and do not necessarily align with MoH priorities. One interviewee stated that while they do not agree with this on a philosophical level, in Zambia “*given the dearth of researchers, you need to focus on what the stars want to do*” (*national stakeholder*). A number of respondents expressed concern that even though Zambia has laid out a set of research priorities, the process has not been undertaken in such a way that all stakeholders - in particular northern stakeholders - will buy into. This led one of these respondents to believe that if you have a set of priorities and there is nobody to enforce them or respect them, they are relatively meaningless.

“There are people who will tell you very strongly that Zambia has already identified its priorities and they are correct, however the way in which those priorities have been identified has been exclusive, and that process alone is ensuring that the priorities have not been respected.” (*national stakeholder*)

Some respondents reported that the commissioning of an inclusive Zambian priority setting exercise including all relevant stakeholders, will need to communicate clearly to northern donors and researchers how to ensure adherence to these priorities. However, there is currently no plan in place. According to others, NHRAZ ability to set health research priorities will depend on the willingness of NHRAZ and of Zambian institutions more generally to stand up to northern counterparts to say that it does not align with what has already been identified as a priority. NHRAZ has been tasked with setting national health research priorities, however, there is no evidence that this had occurred by the end of 2014, and as such the original priorities identified in 1999 are still in place. The influence of donors on health research priorities arises frequently.

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\(^{30}\) ZAMFOHR: an NGO, established in 2005, and plays a role in monitoring and harvesting health research in Zambia.

\(^{31}\) ZAMFOHR Fellows are considered to be leading or up and coming Zambian health researchers.
in both the policy documents and the interviews. The view is that their central role ensures that priorities are set either at the global level or according to what donors see as a being a priority for their programmes in Zambia, which either may not coincide with Zambian priorities or may result in duplication of research studies, particularly if others fund similar research in a similar district.

The MoH are considered by most respondents to be lacking capacity to set research priorities, a point that was disputed by the MoH representative stakeholder interviewed for this study. A number of stakeholders have mentioned that once Zambian research priorities have been updated, it will be possible to decline projects that do not fit with national priorities. In reality, this might not be feasible, considering the MoH/NHRAZ have only a token budget for health research. It can be argued that it is unrealistic to assume or expect that research projects with large budgets and the potential to provide employment for many researchers to be refused.

6.3.2 Monitor and evaluate the health research system in Zambia

In many countries, there is no national register of externally funded research and where this information is available, it often only covers clinical trials (COHRED, 2007). This often results in national decision makers being unaware of what research is being undertaken, making it difficult to provide leadership for the health research system (COHRED, 2007). A national level institution, with the mandate to monitor and coordinate all research activities, had been under discussion in Zambia since 1999 (Chanda-Kapata et al., 2012). There was limited movement towards this until 2008, primarily due to a lack of resources (MoH, 2008; Kwibisa, 2009).

"Currently, health research in Zambia is fragmented, ineffectively coordinated and inadequately monitored. There is a lot of collaborative research involving local and international researchers and institutions being undertaken in the country currently. However there is no institutional mechanism for knowing who is conducting what type of health research." (MoH, 2008)

A specific research unit was established to coordinate health research in the MoH in 2011. However, it consists of only one research officer and the Director. Kwibisa
(2009) reported that there was “unavailability of vital numerical data and specifically, figures and data related to monies budgeted for, allocated and utilised in respect to health research.”

There was almost widespread agreement amongst national stakeholders that there is limited monitoring and coordination of health research in Zambia. A number of Zambian researchers spoke about not being aware of Zambian studies that are being undertaken by international researchers, whose results were not always considered to be reliable. Sometimes Zambian researchers discovered these studies, at international conferences, or on the internet.

“There have been such cases where somebody does research and walks out with the data, and I am invited for a big international conference and I am sitting there and listening from these results from Zambia which are ridiculous, because somebody did not do a diligent work by trying to look at the baseline that is existing at national level.” (national stakeholder)

“The repository of research is bad. So sometimes you can get shocked, you are Googling something and you find a paper in a journal on Zambia and you say ‘what is this?’ You don’t even know the names, they are strange. You wonder when they came in and when they did it. People just come and go... and you just see it in a journal.” (national stakeholder)

In an attempt to deal with this lack of visibility and coordination of health research, UNZA made it mandatory that if any School within the University enters into collaboration with an outside University, it should be sanctioned by the Director of Research. This has resulted in the creation of an official registry of research at UNZA.

There is a “systemic lack of incentives for researchers to collaborate or at the very least share information with each other, and the often corrosive spirit of competition among researchers for scarce research funds” (Kasonde and Campbell, 2012). Most of the health research undertaken in Zambia remains unpublished and inadequately disseminated (MoH, 2008, Kwibisa, 2009). The MoH prescribe that results of research studies, including those initiated by and undertaken with external researchers to be
disseminated to the MoH, with approval for publication to be granted also by the MoH. (Kwibisa, 2009).

Stakeholders gave their perspectives on how northern researchers also should also play a role in monitoring and coordinating health research in Zambia. One northern stakeholder commented how he would like to see a day when global researchers/funders set up global structures to regulate their activities. However, this was not considered to be feasible.

“I think the scientific community needs to have more attention placed on these issues in very practical and real terms and so it would be great if you were to publish something punchy and short about this to really help to galvanise opinion on how we correct some of the flaws in the global research architecture... I think that’s your real role, so it’s not really to illustrate or to comment on Zambia. Zambia is a reflection of what happens at the global level, or within the interaction between north and south.” (northern stakeholder involved in Zambia national process)

Some researchers believed that while the situation of ‘foreigners’ undertaking parachute research is changing, it is evident that the country is still being divided up by northern researchers.

“I think it’s something that has become an iconic narrative again as well, that lamented every single key informant interview, which is these foreigners come in and take the data and run away with it and this is what happens. I think that is really changing. I think that unfortunately what happens in Zambia is that you’ve got the one very, very conscious of the way the country has been carved up by researchers and you know, you stay in a guest house and you’re aware that whatever, XYZ universities in the US and UK are kind of ‘oh what are you working on?’ and there is almost a cautiousness about, oh well stepping on someone else’s feet, and that is so incredibly omnipresent in Zambia. And I think people react to that obviously and so there is this sense of too many researchers.” (northern researcher)
A number of other respondents reiterated this, lamenting that there are still instances where researchers come to Zambia to undertake minor field studies for short periods of time, without always knowing the protocol to undertake research in Zambia, and as a result, arriving to districts without having received either REC or MoH clearance. The conclusion reached by a number of researchers is that the presence of northern researchers often leads to fragmentation and duplication of health research in Zambia.

**National Health Research Authority of Zambia**

The National Health Research Advisory Committee (NRHAC) monitored health research in Zambia from approximately 1998-2014\(^\text{32}\). However, it was an *ad hoc* committee with no secretariat and was not considered to be fully functional (COHRED, 2008). In 2009, the Zambian Government partnered with the Canadian Coalition for Global Health Research (CCGHR), with a grant from the International Development Research Centre (IDRC), to plan for the establishment of a health research body to manage, monitor and coordinate health research in Zambia. In the absence of the National Health Research Authority of Zambia (NHRAZ) being operational by the end of 2014, NHRAC continues to provide guidance to the MoH on the policy issues broadly regarding health research, but does not provide advice on health research priorities. One NHRAC committee member commented that it was difficult to assemble members for meetings. The Zambian Health Research Act, 2013, outlined the functions of the National Health Research Authority (NHRAZ) which are summarised in Box 7.

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\(^{32}\) The National Health Research Authority of Zambia had yet to become fully operational by the end of 2014.
Interestingly, some national level stakeholders stated that it will be the entity that governs north-south dynamics which some described as being relatively out of control in Zambia, and in need of regulation. Some national respondents considered that NHRAZ will have the authority to request international researchers to modify research proposals to harmonise with Zambian health research priorities. Discussions were underway at the time of the interviews between NHRAC and the Ministry to establish a

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**Box 7: Functions of the National Health Research Authority of Zambia**

The functions of the Authority are to:

- regulate research conduct and monitor and evaluate all health research in Zambia;
- facilitate research and development in health research and provide oversight and coordination of health research;
- promote the translation of health research outcomes into policy;
- identify and recommend to the Minister national health research priorities
- promote public-private partnerships in health research;
- register and accredit research institutions and health researchers;
- investigate reports of professional misconduct relating to health research
- facilitate the development of health research capacity of individuals, institutions and systems
- mobilise and disburse resources for health research;
- advocate for health research within society
- collaborate with health researchers and research institutions outside Zambia;
- promote multi-disciplinary and inter-sectoral research collaboration

The Authority shall, in performing its functions under this Act—

- develop and review accreditation guidelines for health researchers and research institutions;
- maintain a database of research undertaken and facilitate the dissemination of research results;
- establish and maintain a central health research repository; and
- maintain a profile of non-complying health researchers and research institutions.

*(National Health Research Act, 2013)*

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high level coordination position (with funding from Boston University) to develop a system for coordinating research in Zambia.

As is the case with many countries, health research in Zambia is poorly coordinated. The National Health Research Act (2013) aims to transform this. Despite discussions around registries of health research, the PhD researcher has not been able to locate any such public database by the end of 2014. The National Health Research Act, 2013, also stipulates that health research shall not be undertaken without the inclusion of a Zambian researcher. It is unclear however if all international researchers will need to officially approach NHRAZ as some stakeholders have suggested. Adequate resources – both human and monetary – will be needed to undertake the ambitious portfolio of work for the Authority.

6.3.3 Set and monitor ethical standards for health research in Zambia

National health research ethics systems have not been examined in detail in the published literature, nor have the contextual issues through which national research ethics systems operate been discussed. Currently five RECs review health research in Zambia.

- University of Zambia (UNZA) Biomedical Research Ethics Committee
- UNZA Social Sciences Research Ethics Committee
- Tropical Diseases Research Centre (TDRC) Research Ethics Committee
- Macha Research Ethics Committee
- Ethics Reviews Converge (ERES), which is a private research ethics committee.

There is ambiguity in terms of membership of committees and it has been alluded to that some committee members serve on other committees, which was reported to have the potential to cause conflict of interest.

In their article on the development of the national health research system in Zambia, Chanda-Kapata et al. (2012) claim that, in 2007, the Zambian MoH realised that most research in Zambia was being conducted without ethical approval. It is not clear if there is evidence for the authors to make this statement. The authors also reported
that there was no legal framework to deal with research misconduct. This led to the MoH placing a temporary ban on all new health research studies (Chanda-Kapata et al, 2012). The authors state that the primary concern was in the field of biomedical research, where it was perceived by the Zambian Government that blood samples were been sent abroad, including the collection of samples for future unknown studies. The situational analysis of the health research environment in Zambia (Kwibisa, 2009) highlighted concerns around the ethical conduct of research in Zambia including:

- “Lack of or inadequate supervision in the conduct of research; researchers, both local and external sometimes conducted studies without due regard for ethical considerations, especially where these studies involved people/human subjects;
- Insufficient controls to regulate external researchers ‘flying’ away with data and specimens (human materials);
- A number of instances where there was a variance between the manner in which researchers conducted research and what was presented and approved in their research protocols were not uncommon”. (Kwibisa, 2009)

This document also identified a number of ‘regulations/measures’ that were put in place to govern ethics in health research in Zambia. These include: that it is mandatory to have a local researcher in collaborative research efforts; data analysis must be undertaken in Zambia; publication of work conducted in Zambia requires local dissemination of findings at research sites and at the MoH (Kwibisa, 2009). However, the document does not state where these measures originate, and there is no record of where researchers could get access to these regulations. This is particularly relevant considering these measures are highly pertinent for external researchers.
The Zambian National Health Research Act (2013) outlines the functions of a National Health Research Ethics Committee (NHREC), contained in Box 8. The 2013 Health Research Act outlines the types of research to be reviewed by NHREC which includes the following: all clinical trials; multi-centre and multi-national collaborative health research; health research which is fully or partially initiated, financed and wholly or partly carried out by external donors or international agencies. This list implies that the vast majority of health research needs to be reviewed by NHREC. Some interviewees were concerned that NHREC had not yet started to function, and that there was ambiguity about what proposals should be sent to the Committee for consideration. A number of northern interviewees were concerned that NHREC would create barriers for northern researchers, creating an extra layer of control.

“I think, it sounds terrible, but I think there is a degree of jealousy, you know you are getting all this money and you must be making loads of money from doing this, therefore we are going to make it just that little bit more difficult for you.” (north-south researcher)

“Why should I get national clearance if I already have ethical clearance. What role do the Ministry play in control, is it just for the sake of control? I think it is an inefficient use of resources, adding a layer that is not necessary in the process.” (Zambian researcher)
It is required that researchers submit mandatory reports to the relevant REC, however, while the process is clear for the UNZA Biomedical REC, there are no contact details given to send reports to, nor is there a website to ascertain this information for UNZA Social Sciences REC.

It was claimed by a number of stakeholders that the MoH was challenged by international researchers in the past, with no law to prevent them from undertaking research in Zambia, or no law to “punish any offender” (national stakeholder). One of the challenges cited by interviewees was that if the study received ethical approval elsewhere, the MoH had difficulties rejecting it. The situation was seen to be exacerbated by the fact that some funders were said to not to be insistent on ethical approval in order for funds to be released.

Another challenge mentioned by a number of respondents was that to date there has been no monitoring of health research ethics in Zambia outside the initial institutional REC process. A number of national stakeholders stated that even though there is a stipulation that periodic study reports will be provided to UNZA RECs, this is rarely adhered to and as a result there is the risk that implementation of studies deviates from what is approved by RECs.

“I can guarantee that if you keep quiet (about the PhD research study) I don’t think you will get a letter from anybody. Because there are unanticipated things that will arise during fieldwork, which you are supposed to report back, if those have got ethical implications.” (national stakeholder)

It could also be the case that HIC RECs also do not monitor health research ethics outside the official institutional REC process. It was mentioned that monitors could be put in place at the district level to ensure that research is being implemented according to how it was approved by RECs. It was also hoped that the system can be decentralised, so that ethics approval can be given at the district level for studies that are local in nature.
6.4 Financing the health research system in Zambia

The operation component of this function within Pang et al.’s framework is to “secure research funds and allocate them accountably” (Pang et al., 2003). The National Health Research Strategic Plan (2008) recognised that: “Government budgetary allocations for health research have been inadequate and have been the major constraint against the acceleration of health research in the country.” Financial support from external sources is not coordinated; and there are no policy guidelines to provide direction with regard to which health research priorities should receive funding (MoH, 2008).

The international recommendation of 2% of government budget and 5% of cooperating partner budgets to be directed to health research had not been reached in Zambia by 2008 (MoH, 2008). In 2009, it was estimated that approximately 0.02% of GDP, approximately 5% of the required amounts, is considered to be directed towards research, with the MoH and Ministry of Agriculture accounting for two thirds of this (one third each). While it is generally recognised that external donors fund most of the research - approximately 90% - conducted in Zambia (MoH 2000, COHRED 2008), there are no figures on exact amounts. Poor donor coordination makes estimates of the inflow of funding difficult (COHRED, 2008). A function of NHRAZ is to mobilise and disburse resources for health research in Zambia (Health Research Act, 2013).

“Inadequate financing from Government, unavailability of funding to support research, the absence of a mechanism to source for and secure funding from other sources and the limited coordination of support from international partners in the health sector remain major challenges facing the growth and strengthening of health research capacity in Zambia.” (Kwibisa, 2009)

There was an assumption amongst some interviewees that northern governments set aside large sums of money for health research activities because of the value they attach to research to inform policies and programmes, which does not happen in the
south, where most of the funding goes towards service delivery. Until such a time that there is a change of mind set by policy makers to provide more funding for health research, it was considered that Zambia will continue to rely on funding from the north. One suggestion was that the government should insist more that donors contribute earmarked funds to NHRAZ. Some stakeholders were confident that the establishment of NHRAZ will ensure that the MoH will provide some funding for health research, which will then ensure that research priorities are funded. However, both northern national stakeholders disagreed with funding being a function of NHRAZ, stating that it is too big a task for it to add to its’ already massive mandate.

The inaction of the Zambian Government in respect to setting research priorities was frequently linked to the lack of funding for health research. Without a system for financing Zambia’s own health research agenda, it is very difficult to control priorities.

“They don’t recognise local resources. For you to get recognition you have to go in some form of partnership and in most cases you find that their agenda has been adopted. I will tell you as an individual I don’t think I can access funding for anything that falls within the priority of the Ministry of Health as an individual or as a group of locals. We would need to team up with outsiders. There is alot of room for abuse of resources because we really have limited capacity to deal with this.” (national stakeholder)

Some stakeholders considered it imperative for Government to fund the majority of health research in Zambia, because international donors and researchers interests are not necessarily aligned with Zambian priorities.

“Because of course their intentions are extremely good but the reality of the power they have, and because there is so much money there, so much money forcing it’s way and the repercussions are just extraordinary, and they’re not coming from within, and they are following this agenda that comes from without.” (national stakeholder)
6.5 Creating and sustaining resources

According to Pang et al.’s framework (2003), the component of this function is to: ‘build, strengthen and sustain the human and physical capacity to conduct and absorb and utilise health research.’ Globally, it is recognised that that lip-service has been paid to the need for national leadership of health system strengthening efforts, with a focus primarily on individual and organisational levels (Bennett et al, 2012, COHRED, 2007). Opportunities for research capacity strengthening and training initiatives in Zambia have been criticised for being “isolated, highly fragmented and cannot be relied upon in any attempts to address the deficiencies in national capacity for health research” (Kwibisa, 2009). The Health Research Act (2013) tasks NHRAZ with facilitating the development of health research capacity of individuals, institutions and systems by building quality human resources for health research. It has been recognised that there are major research capacity deficiencies at all levels of the system in Zambia, from MoH headquarters to the provincial and district levels (MoH, 2008, Kwibisa 2009).

There is just one member of staff to run the entire health research unit in MoH and this was considered not to be feasible. The Canadian Coalition for Global Health Research were reported to be in the process of building up the capacity of managers in the health system to be able to ask relevant research questions, and to interpret and use research. Concern was also expressed around inadequate capacity to undertake ethical clearance and project monitoring. The importance of building capacity at the decentralised levels was also discussed by interviewees, where there is currently no health research portfolio. Clinical officers and nurses could be trained, to understand how research findings can be utilised to help improve service delivery. There was a sense that there needs to be a move away from a culture of perceiving research to be an activity to be undertaken on an ad hoc basis, but rather that it is on-going and should be part of health service delivery. Some interviewees were hopeful that while full capacity has not yet been developed in Zambia to independently undertake research, a capable research cadre had emerged in recent years. It was reported that
through a directive from the Minister for Health, second and third level hospital medical workers were being trained in research methodology in all provinces.

6.6 Producing and utilising research

The components of this function according to Pang et al. (2003) are to: “produce scientifically valid research outputs; translate and communicate research to inform health policy, strategies, practices and public opinion; and promote the use of research to develop new tools to improve health” (Pang, 2003). As this PhD does not focus on using research, this section will focus on producing research and in particular how different components of the research are communicated to the public and to communities. The findings in this section will focus primarily on two events that stand out as being significant in: a) shaping the health research system in Zambia; and, b) the evolving perception of international researchers from within Zambia. These were the Lujo Virus incident and the Microbicide Development Programme Trial. As each interview phase progressed, it became apparent that both these events shaped the recent years of research in Zambia and had an impact on almost every health research project undertaken in Zambia. While the other sections in this chapter are primarily based on national level stakeholder perceptions, this section incorporates perspectives from both national level stakeholders and individual northern and Zambian researchers.

6.6.1 Lujo virus

A number of researchers described the recent history of the Lujo virus and how its’ emergence in 2008 shaped the research environment in Zambia, following a highly fatal outbreak of a viral haemorrhagic fever. Some interviewees recounted the events in detail, which can be summarised as follows: a travel agent living in the outskirts of Lusaka developed a fever and deteriorated over time. She was evacuated to Johannesburg for medical treatment, where she died. The paramedic who carried out the medical evacuation also died a week later, followed by a cleaner and two nurses in the hospital where she was treated. It was discovered to be a new form of viral

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33 The name originated from the first two letters of the names of the cities involved in the outbreak of the disease, Lusaka and Johannesburg, in September 2008.
haemorrhagic fever. Samples of the patients’ blood and liver were sent to the United States, where they were tested at Columbia University in New York and at the Centre for Disease Control (CDC) in Atlanta.

Reports following the removal of blood samples from Zambia show that northern and Zambian interviewees were often not on the same page regarding the virus. Some northern researchers viewed it as impressive how quickly the South Africans and Americans were able to identify the virus and create a test for it, which could not have been done within the existing facilities in Zambia. This view was not always shared by the Zambian researchers, some of whom stated that the samples should not have been taken out of the country without permission, which they considered to be unethical. One Zambian researcher commented that CDC in the US “flew in the big heroes” in public health to investigate the outbreak.

The Lujo virus outbreak and events that ensued were reported to have caused tension in the MoH. The case was brought to the Attorney General, who specified that there was no law in Zambia dealing with research relating to human subjects, only cadavers (dating back to 1948). This was interpreted by government that research undertaken on live humans in Zambia was illegal. As a result, national stakeholders reported that no new studies were permitted in Zambia from late 2008 to January 2011, until guidelines were developed to cover this grey area. This was not limited to clinical trials alone. In addition, no blood samples were permitted to leave the country during this time. It appears that studies that were already operational were permitted to continue, although one researcher stated that it could have implied that they should have paused their studies during this time period. Issues relating to biobanks were not mentioned by study interviewees. A possible explanation for this could be that only three of the research collaborations included in the study were clinical trials.

6.6.2 Microbicide Development Programme Trial
The Microbicides Development Programme (MDP) is a not-for-profit, African-European partnership between Imperial College London, the Clinical Trials Unit of the UK Medical Research Council (MRC) and funded by DfID and the MRC, which was established in
to develop vaginal microbicides to reduce the risk of HIV infection in women. MDP partners include 16 institutions in Africa and Europe. A clinical trial of the effectiveness of the anti-AIDS virus gel, Microbicide PRO 2000 showed no evidence of reducing the risk of HIV infection in women. The study involved more than 9,000 women in four African countries, including Mazabuka district in Zambia. This was the second Microbicide Trial to be conducted in Zambia, the other being a trial involving the US, South Africa, Zimbabwe and Malawi. The Trials were conducted in populations of women who were at a “natural risk of acquiring HIV” (Ministerial Statement, 2010).

The trial showed that PRO 2000 was not effective against HIV, nor was it harmful. The infection rates were similar to that seen in the general population, meaning that none of the products used in this study increased the risk of HIV infection (MoH, 2010). The Minister for Health made a Ministerial Statement on the Trial, maintaining that “the results of the MDP Mazabuka trial were disappointing but Government recognises that this trial was done with high scientific and ethical standards” (Ministerial Statement, 2010). He explained the process of study implementation, which took place between 2003 and 2009, including REC approval, community advisory boards and local sensitisation, a feasibility study and a safety and effectiveness trial.

According to a number of interviewees in this PhD study, even though the Microbicide Trial was seen to be well-run from a scientific perspective, it was mismanaged in terms of communication to the communities involved in the study, as well as the public and media. Some respondents reported that the MoH did not step in to defend the trial in a timely fashion, waiting eight months before responding to the negative media reports. By that time public opinion, particularly in Mazabuka district, was already enraged. Interviewees often blamed the MoH for not managing the process properly, in particular for failing to understand the trial in enough detail before it was announced internationally. For these interviewees, the media in Zambia ‘got the wrong end of the stick’ (national stakeholder) because communication was so poor and the message that ensued was that the trial infected people with HIV. One interviewee explained

http://www.mdp.mrc.ac.uk/

Microbicide PRO 2000: a topical compound that can be used to protect against sexually transmitted infections during intercourse, where the gel was administered to HIV negative women as a preventive measure against contracting the virus.
how it was a prevention trial, therefore all participants started off HIV negative. Over time it would be the case that some people would seroconvert because of their behaviour, and participants were offered counselling and condoms to help them maintain their negative HIV status.

According to many Zambian study interviewees, the community was not sensitised sufficiently to the trial. One respondent commented that sensitisation was so poor that even people who are knowledgeable about the research process, did not understand the study and its’ implications. It was viewed by some that the research team did not do a good job of ensuring informed consent, to the extent that participants did not think that they could stop participating in the study.

“And it seemed like they were coerced. It’s very difficult really to establish what happened, but there was alot of misunderstanding between the communities and the researchers and people didn’t seem to respect people’s rights. So they were riding maybe on their ignorance in terms of not knowing that they could stop participating in the study.” (Zambian researcher)

It is interesting that these perceptions were limited to Zambian interviewees. Northern respondents did not report problems with community engagement. Consequences of the MDP Trial for research in Zambia was discussed by interviewees, such as NHREC now being harsh on researchers, resulting in more scrutiny of research protocols since the trial, making it more difficult to get REC approval. Boxes 9 and 10 detail some Zambian media reports on the MDP Trial, showing misinformation relating to the trial, such as half the volunteers contracting HIV as a result of the trial, when actual numbers were 46/1000. The Programme Director declined to give details of the results during which time many rumours relating to the trial developed, at Government and community level and amongst the public generally.
Box 9: Media reporting of the MDP Trial – Zambia News and Information Service (ZANIS)
December 2009

Volunteers in Mazabuka clinical trial contract HIV (ZANIS)

“Half of the volunteers for the clinical trial of the Microbicide Gel conducted by the Microbicide Development Programme in Mazabuka are feared to have contracted HIV due to alleged failed efficacy of the drug. The drug called PRO 2000 Gel was administered on HIV negative women as a preventive measure against contracting the virus in a trial to determine the effectiveness of the drug. However, the Programme Coordinator has declined to give details of the outcome of the trial to ZANIS in Mazabuka. The sources revealed that the results of the trial have since been submitted to the Microbicide Development Programme by the Medical Research Council of the United Kingdom”.

Box 10: ZANIS report on MDP Trial - January 24, 2010

Mwanachingwala, Catholic Church welcome investigations into microbicide gel saga

“Chief Mwanachingwala and the Catholic church in Mazabuka have welcomed the decision by the Human Rights Commission to institute investigations into how the 46 women who participated in the Microbicide Gel clinical trial contracted the HIV virus. Chief Mwanachingwala told ZANIS in Mazabuka today, that the probe is welcome as it will expose a lot of information the organisation has been hiding from members of the public. Chief Mwanachingwala alleged that all the women who participated in the clinical trial have been banned from sharing their experience with outsiders especially the press.

None of them has been briefed on the outcome of the trials. Chief Mwanachingwala alleged that two days ago, a team of medical doctors who only identified themselves as researchers from the University of Zambia pleaded with him not to issue negative statements on the failed clinical trials when they visited him at the palace. He said MDP officials maintained the drug was effective and was the quickest remedy to HIV/AIDS. Efforts by ZANIS to get a comment from MDP Community Liaison Officer, failed as his mobile phone was switched off”.

http://www.lusakatimes.com/2010/01/24/mwanachingwala-catholic-church-welcome-investigations-into-microbicide-gel-saga/
Box 9 and 10 show an absence of knowledge, not only of this trial, but of trials more generally. It displays a lack of community, and general public sensitisation on the part of MDP staff and the MoH. Ethical concerns associated with Microbicide Trials have been reported internationally (Moodley, 2007, Vallely et al., 2009). Hasunira (2010) investigated experiences and perceptions of communities participating in a Microbicide Trial site in Uganda, which were echoed by the MDP Trial in Zambia. Some sections of the community felt left out of the trial process; not all volunteers received trial results promptly, and some key stakeholders at the national level seemed left out of the results preparation activities.

6.7 Conclusion
It is evident that northern researchers, northern research institutions and donors have had a profound impact on the NHRS in Zambia, from agenda setting to research capacity strengthening to ethics to communication of health research. Some of these effects have been positive, for example, funding for the NHRS, but some of the practices can be questioned, such as not adhering to research priorities. Zambia appears to be at a turning point in terms of taking charge of the system. However, with the bulk of funding continuing to originate from the north, it is unlikely that the balance of power will shift completely to Zambia. Northern donors and researchers must too play a role, though the practicalities of how they will adhere to priorities and coordination of research has yet to be detailed and communicated. Chapter 9 will further discuss the role of power at the level of the national health research system. Perhaps what is missing from the national level health research vision is the identification of the stakeholders and analysis of their roles. By ignoring the specific roles of these powerful external stakeholders - donors or northern higher education institutions - there is a danger that Zambia may fail to implement national policies in this area.
Chapter 7: Macro research ethics results

This chapter explores the ethics of north-south health research from the view of researchers’ experiences: in-depth interviews with northern (n=25) and Zambian (n=28\(^{36}\)) researchers, of power imbalances and culture, from the macro research ethics perspective (see Figure 8). This partly addresses Research Objective 2: to utilise a situated research ethics framework for analysing macro research ethical issues in international academic north-south public health research. The focus is on: a) project initiation: funding, partner selection, priority and agenda setting; b) production of knowledge: data analysis and outputs; c) capacity building and career paths. The ethics of researcher relationships is also presented in this chapter. Where researcher relationships relate to fieldwork and relations with communities, these are presented in Chapter 8, micro research ethics results.

Chapter 4 has established that power imbalances exist at the macro research ethics level in north-south health research, although the nature of these imbalances, including why they exist and persist, has not been analysed in detail. The effects of different cultures undertaking research in Zambia will be explored, as the second key component to a situated research ethics and as a gap identified in the literature. Chapter 4 concluded that the majority of published documents were self-evaluations and most presented either a southern or northern perspective. Results will be discussed with reference to findings from other studies where the findings are similar or provide a different perspective to what is presented in the literature.

\(^{36}\) Zambian national stakeholders (n=8) shared experiences of their experiences of being involved in north-south health research collaborations, in addition to perspectives on the national health research system.
7.1 Project initiation: Funding, partner selection, priority and agenda setting

The macro research ethics literature review identified north-south power imbalances in the project initiation phase of international north-south health research, with northern researchers and donors almost exclusively taking the lead (see Chapter 4). Interviewees were asked to describe the project initiation process, under the following themes: partner selection, funding, priority and agenda setting, in order to gain an in-depth understanding of the nature of these imbalances.

7.1.1 Partner selection: whose choice?

Partner selection in north-south health research was found to be under-examined, with only two empirical studies addressing the topic in any degree of detail. Maher et al.’s (2003) study is particularly useful in terms of categorising research partnerships according to whether they are: a) obligatory: a core group of initial stakeholders
identified, as those who should be in a partnership; b) imposed by donors, based on their vision and agenda rather than those of partners; or; c) natural, usually based on past partnerships, where there is a ‘logical fit’.

Findings from this PhD study clearly reveal that in all but one research collaboration, initiation stemmed from the north. Several mechanisms were mentioned: personal links, institutional links, funder initiation, or a combination of a number of these. Responses such as they “needed local partners” (Zambian researcher) and, “you know they want you because they need you, not for your science” (Zambian researcher), were typical. One northern institution sent a scoping mission to Zambia to find out what competencies existed to support them on their project. “It was partly convenience because they were looking for countries where they were confident that data could be found” (Zambian researcher). A number of interviewees voiced their unease about this, but accepted it as part of the status quo. “So much of the time we were not asking for reasons why we were being selected. It was rare to question. The northern researchers try to get these intelligent people who will do what is asked of them.” (Zambian researcher). One north-Zambian37 researcher positioned South African researchers in the same category as northern researchers.

“So it was very much a group of Western Scientists coming together. Well of course there was this collaboration with South Africa, so that is a southern... But South Africa is different isn’t it? It was very much with an Afrikaans paediatrician, so it didn’t feel as African as you would think of as an African scientist. So I think that was not at all collaborative.” (north-south researcher)

This theme of South African researchers being viewed as the northern partner arises in other stages of the research process, an issue that has not been highlighted in the literature.

A number of interviewees spoke about the collaboration being initiated due to personal links between researchers. The most common personal link was the southern collaborator being a former student at a northern University, either as a Masters or PhD student. One north-north personal connection involved a northern researcher

37 North-south researcher (n=4): a northern researcher who has lived in Zambia for a significant period of time. As described in Chapter 3, this also includes 1 South African researcher.
applying to another northern University to be a visitor on an academic exchange programme. Other personal links included a history of working together on previous projects.

Some respondents attributed collaboration initiation to existing historical links between institutions. The fact that these links centred around five institutions could be the influence of the sampling procedure for this study and/or historical links between a small number of northern Universities and Zambian research institutions. The nature of these links vary; two were straightforward University to University links, which have capacity building at their core, and three involve northern Universities setting up research institutions in Zambia in collaboration with Zambian researchers. The nature of the three northern institutions that set up research institutions in Zambia is indicative of the perception amongst Zambian researchers that these institutions are not “home grown” (Zambian researcher). This becomes apparent through comments such as “it is basically [X northern University] in Zambia. It is just an operational name” (Zambian researcher). Secondly, respondents made comments in relation to perceptions that these institutions were considered to be northern institutions with implications for negative findings around salary differences between north-Zambian researchers and Zambian researchers, and a lack of meaningful RCS. These institutions cannot be considered to be annexed sites in the sense that the model in Chapter 1 describes, and while it is clear from the findings that they are undertaking quality research, they have not succeeded in creating complete ownership for Zambian researchers.

When asked how partnerships were initiated, some researchers referred to the important role funders had played.

“There were certain demands from funding agencies of how these partnerships should work. I would get requests from colleagues saying: ‘Well here is a nice opportunity for funding proposals for Zambia but it has to be led by Zambian researchers.’ So high income countries can partner or collaborate, but we can’t be the ones leading the proposal, we shouldn’t be an official investigator named on the proposal.” (northern researcher)
One bilateral donor provided funds to the Zambian government to assist with the abolition of user fees and sought to assess the effects on service utilisation. Northern and southern partners had different perspectives on how this particular collaboration was initiated. A Zambian researcher stated that the donor wanted an assessment of the user fees removal, but that this was not on the radar of the MoH. A northern researcher involved in this research collaboration stated that the MoH had instigated the study.

A number of respondents highlighted the role played by funders in dictating the partnership format - the number of southern and northern institutions to be involved and whether the partnership would be led by the north or south. In terms of EU regulations, one claim was that the EU stipulated that the prime partner would be northern. Another stated that EU rules were that there would be 2-3 EU countries involved. One example was given where the Zambian government chose a northern research institution rather than a local one to carry out research, suggesting that it is not always international donors alone that will favour northern institutions.

“The Ministry of Finance recognises the gaps in information, M&E in the Ministries. So what do they do, they identify an international reputable organisation to do that, and this funding is coming from the World Bank, so whether there is pressure from the World Bank to source internationally is not known. So it’s an organisation from Canada came to do an assessment and then identified the local partners to work with. So even when the funding is locally available, well it’s not in the sense that it is coming from the World Bank, but at least through the Ministry of Finance, then they outsource in the North.”

(Zambian researcher)

This correlates with the category of obligatory partnerships described by Maher et al. (2003) and supports the argument both in the literature and from empirical findings from this PhD study that ownership rests with funders as opposed to with researchers, either north or south. Barriers that exist for southern researchers in initiating a study, or solutions as to how to change the status quo, were not discussed by researchers.
It is likely that partnership initiation is more complex, as even when initiation came from the north, there were frequent references to personal and institutional links, therefore suggesting that some collaborations could be placed in the ‘natural’ category described by Maher et al. (2003). However, given the multiplicity of actors and relationships, personal links might also be part of the imposed category, particularly given that initiation was almost always in the north. An overall picture of northern dominance in partner selection emerges, whether obligatory, imposed or natural.

7.1.2 Funding flows: north to south

Interviewees discussed funding inequities for health research in terms of funding flows and a lack of capacity to manage funds. Funding for north-south health research is covered extensively in the literature, particularly from the perspective of models of funding. Findings from this PhD study suggest that in Zambia – at least from this sample – funds still flow exclusively through northern institutions, corroborating what is reported in the literature.

For all but one collaboration in this study, funds flowed from donor to northern partner to southern partners. The exception was a collaboration were directed the funds went through a South African partner. It is clear from the data that some respondents felt that they could not source funding locally, due to an absence of MoH ring fenced funds for health research. This was attributed to a lack of understanding of the role of research by the Zambian Government. Literature suggests problems associated with the nature of short-term grants have led to an inability to sustain research collaborations, and insufficient time to build research capacity. Findings from this PhD study show that only two funders had included funds for research infrastructure or seed money for research.

Some references were made to recent changes in funding flows, with southern partners taking the lead in submitting bids. However, it was remarked that this will take some time to take effect. Researchers spoke about the need for capacity to be built to enable southern research teams to become competitive in applying for their own international funds and that it is the responsibility of northern researchers to
build this capacity. It was lamented that it was not possible to access international funds as local researchers, but rather that they always needed to team up with international researchers in order to be eligible for funding. A northern researcher observed differences between Anglophone and Francophone countries, whereby Francophone African countries were more dependent on support from the north, but Anglophone African countries wanted more control. This was attributed to colonial history.

One perspective was that donors did not trust southern researchers in relation to capacity to manage funds, and accounting for the research budget, placing more trust in northern partners. Some northern and Zambian interviewees spoke about southern partners being perceived as “risky in terms of funding” and that funders have suspicions about southern partners in terms of resource allocation and management. Placing money in the hands of northern partners, gives donors an element of security that funding will be utilised in the most effective manner, making it easier to hold them to account for spending. This was described as important for the donors, “to be assured that there is some amount of eyes and ears from northern partners, who provide comfort that the money will be used properly for the research that it was intended for” (Zambian researcher).

It was reported by some interviewees that Zambian partners lacked the capacity to manage funds. One northern researcher mentioned that they offered their South African partners to be the lead institution in a multi-country study, but they weren’t interested due to the large administration and financial burden that the University infrastructure would not be able to bear. However, there was one exception where South Africa managed the project finances. Another northern researcher adopted a laissez-faire approach when it came to fund management and would not get involved in details of how funds were spent in the Zambian institution. One northern researcher attributed a potential abuse of resources in their research collaboration to a lack of capacity to manage resources.

It is important to note that the absence of trust was linked to a capacity deficiency, rather than a suggestion that funds would be misappropriated by the Zambian partners. It must also be noted that the perception of Zambians being risky for funding
was attributed to the funders, but the researchers themselves did not believe this, nor indeed was this verified by the funders, as they were not included in the study sample. It is reasonable to interpret this as a distrust of southern institutions - lack of good or trustworthy research and finance offices – rather than of individual researchers. Some Zambian interviewees perceived there to be a north-south funding inequity. They often felt that they were being subcontracted rather than working in partnership and that they were disadvantaged because the funds were centralised, which enabled northern researchers to control how much money went to Zambia and under which categories the funds would be spent.

“Sometimes I did even expect that maybe people who hold funds would want the money to sit in the account for so long that they get some interest out of it, before they dispatch the money to everybody else.” (Zambian researcher)

A general perception was that funding inequities of resources originating in the north and channelled through the north ensures that the balance of power lies with northern researchers, despite other attempts at ensuring equity at other stages of the research process.

The Norwegian Programme for Development Research and Education (NUFU) programme and the Swedish International Development Cooperation Agency (SIDA) were described as being the most progressive funders for health research in Zambia. Interestingly, there were references to US research institutions being more controlling than European institutions, in terms of dictating what funding can be used for. This is an issue which is threaded throughout the findings of this study, but has not been raised in the literature, which tends to see northern researchers as homogenous.

7.1.3 Priority and agenda setting processes: a northern privilege

The literature review found the process of agenda setting in international north-south health research to be extensively profiled, revealing predominant northern agenda setting through what were often inequitable processes. However, the actual detail of these inequitable processes has not been explored. Interviewees were asked to discuss how research topics were prioritised and how the agenda was set in north-Zambian
health research. While there were a number of exceptions, overwhelmingly the research agenda was set by northern funders and northern research teams.

Examples were given where funders had set the agenda, sometimes reflecting the needs of southern partners and sometimes not. “They needed the African data to push their agenda forward. So in a way it was almost contract research. It was really their study idea but our study site” (north-south researcher). For many northern and southern interviewees, the research agenda was said to have been set by northern researchers and/or northern research institutions. Proposal writing primarily took place in the north without much, or in some cases any, input from Zambian researchers. While some articulated examples of northern researchers working in isolation, others spoke about northern researchers realising that they needed to work with locals to create ownership and to institutionalise the research. As referenced earlier, one interviewee put the South African research team in the same category as the northern research team and classified it as a “group of western scientists coming together” (north-south researcher).

Where northern researchers agreed that they had set the agenda, it was primarily attributed to an interest in a particular topic. “We were convinced that there was something going on with the traditional sector and HIV, and the MoH would not necessarily have had an interest in it” (northern researcher). Many Zambian researchers felt that an absence of MoH buy-in or knowledge about what studies are being undertaken, could result in duplication of study topics. Only one northern interviewee expressed the importance of engaging with Zambia MoH when setting the agenda. Northern researchers were often cast in the role of arriving with their own agenda, as articulated by one northern researcher:

“I don’t think there is always a role for X (northern institution). A woman I knew in South Africa used to joke about it being the X institution of Colonial Medicine. I think there is an element of truth in that. I would like to think that X institution could become a place that didn’t direct research in other countries. Because I think the dynamics of it are always ugly actually. I don’t think it was high on the agenda of the Ministry to find out the effect that user fees had.” (northern researcher)
The admission by northern researchers that they did not perceive a problem with pursuing a topic not identified as being on the national agenda, could be indicative of:
a) a lack of confidence in MoH to identify research priorities, which have not been formally updated since 1999, (see Chapter 6); b) confidence in their own ability to identify issues of importance; and/or, c) belief in the scientific autonomy of the researcher.

One Zambian researchers’ response was more positive, stating that it made sense for the northern researchers to take the lead in agenda setting due to their expertise in proposal writing. Another Zambian researcher spoke of Europeans being more inclusive of Zambian researchers in setting the agenda, while the US institution he works with does not take his comments into consideration. This is a reminder of the dangers of reducing researchers to the polarities associated with north-south identities. A number of Zambian interviewees placed the responsibility on Zambians themselves for not being more proactive in setting the research agenda, and not exploiting opportunities that arise, partly due to work culture and not actively seeking funding opportunities.

“When you are constrained financially, I don’t know whether it is because of poverty, there comes a point where you stop thinking what you can do. ... And so it is only when they actually see the money coming in, that is when they start to think. You are not going to a thought-out programme. You are making them say ‘now we are thinking what to do’. And so we find computers with dust on them, we have vehicles that have been used but have not done any research. So in that sense you can blame us as the southern, the poor people, in not having enough of this stimulus on our own. So although I go along with the suggestion that we are always being guided about what people from outside want, I think we have to do more to create the directions. So that when people come in, at least they find us with something we want to do. And then they can say we will fund it or not fund it. But to find us with nothing prepared, I think is our fault.”
(national level stakeholder)

There were some exceptions where it was suggested that although the agenda was primarily set in the north, Zambian partners were also included. Primary research
interests, and often the first draft of the proposal were said to have come from the north, with input from Zambian researchers being sought in subsequent drafts. However, it was reported by northern researchers that this opportunity was often not availed of. The reasons why opportunities to set the agenda are not availed of will be discussed further in Chapter 9.

Perhaps the most solid reference to joint north-south agenda setting was the NUFU programme. According to one interviewee, the model was established based on the values that there should be national ownership of research programmes. Examples of shared decision making came more from consortium type collaborations where funding was given for the collaboration and consortium, with broad priority setting coming from northern coordinators and all members collectively setting the detailed agenda. One consortium prioritised southern partner research ideas. For another, there were annual consortium meetings where the areas of focus were approved and consortium members had complete control. Perhaps the most sustainable example of collaborative agenda setting is the Department of Economics, UNZA which have a joint workplan with MoH. SIDA puts money into general budget support and the Department discusses a regular research workplan with the MoH.

Research findings concur with the literature in terms of a focus on a small number of diseases which is considered to be disproportionate to disease burden in Zambia. A number of interviewees mentioned that research funds were more readily available if HIV/AIDS was included in the proposal. Zambian interviewees again sometimes place the responsibility on local researchers, who may be as ‘guilty’ as northern researchers in terms of setting an agenda that is not in line with the needs of the local population. There may be four reasons for agenda setting focusing on a limited number of conditions that do not always accord with Zambian priorities: i) researchers – both north and south - not being aware of research priorities, though these are considered to be outdated (see Chapter 6) ; ii) MoH/RECs not wishing to decline research projects that bring in funding and employment for research in Zambia; iii) southern/northern researchers and donors following their own priorities, in terms of believing in their scientific autonomy, and/or; iv) donors setting the agenda according to global priorities that do not necessarily accord with Zambian priorities.
7.1.4 Research design

One of the challenges in multi-country studies\(^{38}\) was accommodating the contextual differences across the countries. Respondents shared their experiences on how the study was designed, ranging from complete standardisation across countries to tools being modified to suit country context. This PhD study found a gap in the literature on the research design stage of the research process. For a number of multi-country studies, there was complete standardisation of protocols and tools and it was reported that there was little room for manoeuvre within particular country contexts. One interviewee spoke about strict outcome tables that had to be adhered to which was foreign to the type of training he had undertaken. Others spoke about standard tools which were modified to suit country context and cultural requirements. In studies where standardised tools were ‘enforced’ (Zambian researcher), or where northern researchers were the principal drafters, there were frequent references to northern researchers lack of understanding of context in research design. For example:

“The fact that the questions were set I think limited us. When we were going to talk to the respondents that we were targeting at national level, as well as the other lower levels, you found that when you asked a question, listening to them then you thought we should have asked this other question and not necessarily the one that we were asking.” (Zambian researcher)

There were also instances where northern researchers would insist on standardised questions even though contextually they did not fit, or where it was hard to find suitable terms in the local language. Thomas (2007) noted that “lack of appropriate contextualisation may lead researchers to incorporate ethnocentric attitudes and perspectives into their studies... leading to false conclusions and consequent inappropriate policy implementation.” It was mentioned on one occasion by a northern respondent that despite the fact that each country were given the freedom to adapt tools to country context, research teams did not alter them. There is no doubt that this results in important knock-on effects for the other stages of the

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\(^{38}\) Eight collaborations that interviewees were members of were multi-country health research partnerships. Six were bilateral.
research process. It is surprising that even in bilateral studies in some cases the assumption was that tools will be drafted in the north and ‘adapted’ to the Zambian context. In other words, the Zambian partners were inputting rather than leading.

However, examples were also given of a collaborative process of developing methods, protocols and tools. Many examples were given of workshops and meetings to formulate protocols and tools. For others, there were no cultural differences in terms of the way the research was designed, due to standard methodologies and techniques that are adhered to internationally, though predominantly referring to Randomised Controlled Trials.

7.2 Production of knowledge

Power imbalances and some unethical practices in the production of knowledge in north-south research was identified by the literature. This section discusses findings around the data analysis process and research outputs. Ethical issues in the data collection process are discussed in Chapter 8.

7.2.1 Data analysis: a question of ownership and intellectual property

There is little published evidence to show how data are analysed in north-south health research. Therefore, this PhD study sought to answer the following questions: a) what are the roles of the various partners in data analysis and interpretation and can these be described as ethical?; b) when analysis is undertaken in the north, what effect does this have on understanding/reporting of context and culture, and ultimately the quality and reliability of the study? A number of published studies state that cultural issues arise, but do not analyse the implications in detail (Freier et al, 2005, Smith et al, 2008, Sayogo & Parado, 2013). Findings from this PhD study demonstrate that northern researchers dominate the data analysis process. Responses ranged from joint north-Zambian analysis to northern researchers taking the lead. Only two examples were recounted of Zambian researchers taking the lead in the analysis.
For a number of collaborations, respondents mentioned northern and Zambian researchers working together to carry out the analysis of the data. However, on closer inspection, in reality this meant northern researchers taking the lead with input from the Zambians. Analysis was undertaken by distance – email and teleconferences - and/or through workshops. One Zambian researcher stated that the coordinators took the datasets ‘home’, to London. Three Zambian researchers spoke of how northern statisticians held the data and worked on the analysis with the Zambian researcher but that the northern researchers were ‘the experts.’ One multi-country collaboration had a standard operating procedure whereby if a researcher wanted to carry out an analysis on the data, they had to apply to the central Steering Committee for access.

“All the data were sent to Sweden. They would store it and clean it. You had to apply to the Steering Committee if you wanted access to the data. I understand that there were a number of apprehensions, why should the data be locked up in Sweden? I could see some problems. There will be a time when we want to use the data for our own country. How do future researchers access the data after X partnership has folded? But it has not given a problem so far.” (Zambian researcher)

A major issue arising was Zambian researchers’ lack of capacity to take the lead in the analysis. This was primarily mentioned by northern researchers, particularly that even when Zambians were encouraged to take the lead in analysis with support and quality control, this was often not accepted. One of the reasons mentioned by a number of northern researchers for lack of capacity was Zambian researchers having multiple research commitments. It was suggested that the northern researchers needed to do more “to push” Zambians to carry out more data analysis (northern researcher).

The perception that many northern researchers showed a poor understanding of Zambian contextual and cultural issues emerged strongly in the interviews, resulting in an inability to undertake thorough and accurate interpretation of findings. Instances were recounted when northern researchers insisted on particular interpretations of the findings, even where they did not fully understand the Zambian context. There was a sense of frustration among some Zambian interviewees that northern researchers put African countries together as opposed to focusing on different country
contexts. One South African researcher spoke strongly and in-depth about being forced as a study coordinator to carry out analysis with the Zambian team, despite the fact that she had no input into research design, fieldwork or had no prior knowledge of Zambia. She stated that this was contrary to her research ethical principles:

“I had no input in the research design, how the questionnaires were developed, how the research was conducted, and then this mythical idea that I could come in and I could just look at the data and write-up, so really it was completely ridiculous. When I did raise that, first of all contextually to be working with three very different African countries in different contexts with very little understanding of the contexts, let alone of how the research was done, the fieldwork, to now have to just have outputs done was, for me, against every principle that I’d learned and felt in my heart about research. And so this is why it was pushed that I must go and spend time in each of the countries, get to know the people, the community. But there was actually less of an emphasis, it still perplexes me as to how people thought that I could just look at data and come in, didn’t know anybody, having not been at all involved, and from South Africa, a white South African, into which in itself come with politics, entering into these countries and saying ‘right we need papers on this, and that kind of theme’ which it still haunts me that this is what went on.” (South African researcher)

A small number of Zambian researchers pitted science against culture in research, stating that science does not take culture into consideration. For one Zambian researcher, there is an imperative to understand how people live, and to see how science can be adapted to benefit people who should continue living according to their traditions and culture. Therefore, the lack of understanding of cultural and contextual issues in Zambia is not just a characteristic of northern researchers. Zambian researchers are also part of a culture of science, which ensures they remain at a distance from the communities they study.

Some Zambian researchers spoke about northern researchers having a grasp of context and health issues in Zambia. It is explained that there is a need to take it case by case, by not putting all northern researchers together, but rather recognising that
multiple identities exist. One researcher commented that it depended on the individual and also on disciplinary differences, for example northern anthropologists have a better understanding of the cultural dimensions, than other disciplines. Another respondent mentioned that the contextual is easier to deal with in the quantitative analysis and that the qualitative analysis is more difficult when you have not lived in the country. However, it was also understood by some interviewees that it was difficult to analyse quantitative data - such as Health Management Information Systems and Living Conditions Monitoring Surveys - when one is not fully aware of the context. One interviewee also acknowledged that cultural issues are well addressed theoretically in international health training, and therefore the key is local collaboration to assist with the understanding. Culture was considered to be better understood by researchers who had experience of working in Zambia through multiple collaborations, or who had lived in Zambia.

Many examples were recounted of the ethics of ownership of project data between the north and Zambia. COHRED (2013) and Hunt and Godard (2013) discuss the ethical responsibilities that come with accessing shared data. Northern and Zambian respondents in this study referred to ‘parachute research’, ‘pick and run research’ and ‘helicopter research’, where the local researchers collect the data and the northern researchers bring it back to their research institutions for analysis. It was referred to by many northern and Zambian interviewees as being extremely unethical. One researcher stated that until recently, a northern institution insisted that data ownership was with them, but that this would no longer be tolerated by Zambian partners. The “arrogance of US researchers” assuming that they will have access to government data was mentioned by a Zambian researcher. US universities were accused by some as practicing helicopter research more than those from other countries within the global north.

“I think the issue and the tension comes with the arrogance [of a US research institution] of assuming that just because they are producing so much good research, they ought to have a carte blanche when it comes to access. Or that they shouldn’t have to continue to tow the line in terms of seeking Ministry
One South African researcher in a multi-country collaboration who had responsibility for assisting country researchers to produce publications, felt that she had to build up trust with local researchers before they shared data with her. Zambian Government policy (MoH 2009, Zambian Health Research Act, 2013) states that ownership of the data must lie with Zambian researchers. Zambian respondents were of the opinion that this has been emphasised in the National Health Research Act (2013) due to the history of parachute research in Zambia, and inequities in ownership and analysis of data. An example was given of a clinical study on neonatal survival where the team wanted to export data to the US, but the MoH refused. The analysis brings into view the importance that researchers - particularly Zambians - accord to data ownership and intellectual property issues. Literature claims that the parachute model is not as prevalent as it was in the past, however findings from this study illustrate that it remains a feature of the Zambian research environment, and/or in the consciousness and memories of Zambian researchers.

7.2.2 Research outputs: an ethical dilemma.

Published studies in the area of health research outputs focus largely on quantitative bibliometric analyses of published papers. However, quantitative analyses of authors can be problematic and are only a partial indicator of issues relating to whether research outputs are authored north or south. Issues include southern researchers based in northern research institutions, either short-term or long term, and dual affiliation, which is becoming increasingly common. Studies reveal that published papers relating to LMIC contain authors from HIC and also that the first author is likely to be from a HIC (Adams et al 2011, Gonzalez-Block 2006; Davies et al, 2000). This PhD study found empirical evidence on inequities in authorship of papers from northern and southern perspectives, and differences in incentives/disincentives to publishing north and south.

Authorship issues for publications featured as an important consideration for many researchers in this PhD study. For some interviewees, the process was seen as
equitable and ethical with both northern and Zambian researchers having equal opportunities to publish. Authorship was said to adhere to the international standards for contribution, i.e. to have played a significant role in collecting or analysing the data. Examples were given such as “a transparent and collective approach to writing”, establishing a publication team early on in the study, and papers published as a consortium. However, a number of northern respondents claimed that even though they do most of the writing, they cannot put themselves as first author.

“We end up doing most of the writing but because they are Zambian projects we cannot be first author. We need to be lost somewhere in the middle. This is fine if you are already a senior academic, but as a new researcher it is a challenge because you need papers to progress your academic career.”

(northern researcher)

If it was the case that northern researchers thought they would be first authors, some said they would rather not write a manuscript, but instead would write a report. Contrary to this, other researchers stated that it is the norm for the first and senior author to be non-Zambians and for the Zambians to be in the middle. One collaboration held an academic writing workshop, where everyone had to be first author on a paper in order to take part in the workshop and the lead author was paired with a more senior researcher who would give feedback on the paper. Another example of capacity building for writing was where one of the more experienced researchers came to Zambia to help identify papers and to bring literature. It was sometimes perceived that because Zambian researchers do not have experience in writing manuscripts, it is difficult to convince them to take the lead. It was mentioned by some respondents that northern partners have higher writing standards than their Zambian partners.

Several experiences of authorship being controversial and political were communicated, such as Zambian researchers being included as second authors when they had not been involved in writing the paper. Two northern researchers were taken off the authorship list in another collaboration as it was documented that their input was not substantial.
“The scientific committee decided in the end and of course they could not decide unethically. You have to create a culture in academia of being open and accepting that there are rules for co-authorship that are ethical rules. We have to decide who is worthy of being co-author.” (northern researcher)

Analysis of the data suggested that incentives to publish were important to interviewees, particularly northerners. For some northern researchers incentives to publish are not present in Zambia in the same way as they are in the north. One researcher was in the process of submitting a paper on behalf of her Zambian partner, because she suggested that if she did not submit, it would never get published. She expressed uncertainty about how ethical it was to submit a paper with someone else’s name on it first, and was concerned that she was the last author.

“So now I’m trying to submit a paper on his behalf, he’s the first author. I can’t even get hold of him to get him to agree that it’s ok, it can go in. But ultimately if there is a problem with it he’s the first author. And I’m not sure what the ethics of...should I submit a paper with somebody else’s name first? But if I put my name first that would be wrong.... I’m a bit not willing to do it but on the other hand I feel a bit concerned the other way around that I am the last author. It doesn’t seem quite right but I suppose maybe that’s the way these collaborations do work in the end.” (northern researcher)

Another northern interviewee shared the view that there was no publication culture in Zambia. She spent time in Zambia pushing people to write papers in a short space of time. However, by the end of the project, she considered there was more of a sense that publication does give ‘some kind of power in the world.’

“So that was why I think I was brought in because everyone was frustrated because people were sitting on data and not publishing and I think they thought there could be an easy fix getting in someone to focus on being a schoolteacher and whiplashing people about needing to publish.” (South African researcher)

Contrary to the literature, PhD study findings show that for the most part, inequity in terms of publishing favoured the Zambian researchers rather than the northerners, though exceptions were documented. The ethics of this can be questioned,
particularly when this does not adhere to internationally recognised authorship guidelines. This has the potential to lead to frustration amongst northern researchers, as evidenced by the data that they are under more pressure than Zambians to publish. Interestingly some researchers, north and south, saw this as being unethical, whereas other perceived it being important in terms of visibility and building capacity for southern researchers.

7.3 Capacity strengthening and career paths

North-south imbalances in capacity to undertake health research is extensively covered in the literature. Studies acknowledge the various levels of RCS: individual, institutional, and national. Interviewees in this PhD study did not discuss levels of RCS and linkages between them. It must be stated, however, that interviewees were not specifically asked about these links, as it was not the aim to cover capacity building as a major focus of the PhD study, but rather include it as one element exploring a situated research ethics of north-south health research.

7.3.1 Individual researcher capacity strengthening

PhD programmes were one common form of capacity building cited by respondents. One type of PhD programme mentioned was a sandwich programme, where all the research was carried out in Zambia, with travel to the northern country only for short periods of interaction with supervisors. The idea behind this type of programme was that students would not be uprooted from their home environment. Researchers mentioned that most PhDs currently run through collaborations and that it would be unusual for individual standalone scholarships to be awarded.

Another type of PhD programme mentioned was where the student from Zambia attends full-time at the northern institution. Davies et al.’s (2000) study reported that African researchers who obtain their MSc/PhD training overseas are often unwilling to return home due to poor salaries and infrastructure. This is contrary to findings from this PhD study where all researchers who had studied abroad had willingly returned to Zambia. One respondent expressed that she could not cope with living away from Zambia and returned home to complete the programme by distance learning instead.
Yet another PhD programme method was discussed where students would register with the northern University even though they are based at the Zambian collaborative sites, and that a northern academic would be at the site to supervise them. Some researchers recognised that the PhD pathway is underdeveloped in Zambian institutions. There was a sense that students preferred to qualify from a prestigious northern university rather than UNZA, because it is not seen as “glamorous or high quality” (Zambian researcher).

7.3.2 Unidirectional transfer of skills
Whilst literature has recently begun to focus on mutual research capacity strengthening (Bradley 2007, COHRED 2013, MacLaren et al 2012, Jones et al 2008), interviewees in this PhD study tended to associate capacity building as being unidirectional, i.e. north-south, with the north having a wealth of research experience to impart to Zambian researchers. This was primarily mentioned by the Zambian respondents. A small number of interviewees did mention capacity building as being bi-directional, with a need to foster south-south capacity building. A number of long term north-south capacity building initiatives were mentioned by respondents. The view was expressed that there is little point in building capacity if researchers whose capacity has been built are lost to international research organisations, therefore a system needs to be put in place to look after them when they come back to the University system in Zambia. This internal brain drain has been described in a number of studies (Bennett et al 2012, Ezeh et al 2012, Lansang & Dennis 2004).

7.3.3 Exposure to research in the guise of capacity building
Zambian respondents were frequently frustrated that so-called capacity building was in reality ‘exposure’ in the guise of capacity building, a theme which the literature has not reported. For some, this was considered to be patronising, more about enabling Zambian researchers to collaborate better with northern researchers:

“I think one has to look at the history and say at what point and how do you do capacity building that’s not patronising in nature, and it’s not just simply about
building up people’s capacity to collaborate better with Western researchers so that we get better data... I think there’s probably very few Zambian higher education facilities that would offer that breadth of exposure to theory say, so it’s a fallacy to say from the other end well, Zambian researchers should be at the same ability to compete with a UK researcher who’s had six years of University background, I think the discussion is sort of misplaced somehow.”
(north-south researcher)

One researcher insisted that northern researchers are very good at putting people in mid-level coordinator positions, “but in terms of conceptualising the research, analysing the data, and writing up, those three skills sets are still very much in the muzungu corner” (northern researcher). There was a sense of frustration that even though northern researchers often claimed capacity building as a motive for collaboration, this was disguising other motivations:

“They would say’ capacity this, capacity that’, but you find that when the data is collected you don’t participate in the analysis. You don’t participate in even writing an article or something. So how is that helping us? So we are thinking that they are benefiting more, of course they should benefit more, because they are probably putting the resources there but we are also putting human resource time there so we should also benefit. So for me the challenges are that we don’t know what the motive is for the interest in the collaboration, other than what they are telling us is the reason why they think we should be collaborating. And they are saying it’s capacity building, but sometimes we don’t feel this capacity building. So that’s the challenge.” (Zambian researcher)

Several interviewees singled out US collaborations as being the primary offenders of exposure, and an unwillingness to compromise the quality of the outputs:

“And I think of the American HIV programmes who are doing evaluations, of course it would be nice of them to involve Zambians, but their funders are interested in results to show that they have an impact. So they are not going to waste resources for the Zambians to do it themselves. So therefore I think you have to be clear, is that capacity building, or is it us trying to get nice things to put on our CV while we are in Zambia.” (north-south researcher)
A Zambian researcher viewed the situation in a practical light, stating that there is a shortage of skilled human resources for health research in Zambia, and therefore useful to have northern researchers to augment this paucity of personnel. He considered it to be very simplistic to think that Zambians can do it all alone. Blame for research capacity imbalances between the north and south was not always attributed to northern researchers. The Zambian education system was considered to be a bottleneck to building researcher capacity, due to the style of teaching at UNZA, which was likened to rote learning. This resulted in graduates being ill-equipped for a research career that demands analysis and interpretation skills.

7.3.4 Institutional capacity strengthening: the neglected institution

Most of the studies in the literature highlight the lack of investment by donors in institutional capacity strengthening - in particular research infrastructure – and an inability of southern research institutions to deal with the financial and legal aspects of research grants (Bennett et al 2012, Vasquez et al 2013). These frustrations were echoed by many respondents in this PhD study, who claimed that donors are typically not willing to support infrastructure development for research in Africa, instead focusing on individual capacity building. This is compounded by both an inability to identify indirect/institutional costs and overheads and/or a stipulation by donors that overheads will be lower than what is actually required. The same could perhaps also be said for HIC higher education institutions, although comparisons are not discussed in the literature or by study respondents. One researcher described the culture of research institutions in Zambia as colonial, which does not encourage Zambian researchers to take the lead, an issue which is not considered in the literature.

“It goes back to the different histories around developing a research culture in a country, and I think that has been very colonial, because the kind of culture of research institutions, particularly medical research institutions, is so colonial in nature, that getting to a point where you say okay you have a viable alternative and a strong institution that’s going to be able to lead. We’re still not quite there.” (northern researcher)
An analysis of findings therefore brings into view the need to combine individual and institutional RCS, and donor, northern and local initiatives that are not patronising in nature and aspire to break the glass ceiling which arguably northern researchers sometimes perpetuate.

7.3.5 Career paths: the impoverished Zambian versus the affluent northern researcher

Interviewees were asked to what extent researcher career paths were the same or if they differed north to south. Zambian researchers’ motivations were often expressed as being in the financial aspect of research rather than pursuing it as a career or an interest, which was perceived to be a “Western luxury” (Zambian researcher). It could be posited that there are many researchers in the north as well as the south that enter research as a career, primarily for the monetary aspect. One northern researcher stated that sometimes northern researchers speak about this in a judgemental way, but that it needs to be understood and not judged.

“When you talk about this you make it sound like it is so judgemental, because they are doing it in a different way, maybe with a different mind-set. So I don’t want it to come across that way from me. Because I don’t feel that way. That is part of doing research in a different country. You have to understand these things. And it is because I didn’t understand them enough, that is one of the reasons the research didn’t come out as good as it could have done. And I can’t blame the Zambians that they are only in it for the cash. I should have known that before trying to do research there.” (northern researcher)

Extended family pressures which were said to differ completely from the north were mentioned as a reason that Zambians take on too much work. The importance of providing for extended family was mentioned as a key consideration for Zambian researchers.
“Here even if I have to draw in my own money I’ll get food on my table. But if you have five children and an extended family, and then someone is dying from HIV and you have to take their children also. Then you have to draw in money for having food on the table and being able to pay your rent, and then you don’t have to give a s*** about publication.” (northern researcher)

Researchers at times perceived there to be differences in Zambian versus northern salaries. One northern researcher spoke of how there was an unfounded assumption that UK salaries would be higher, and this can create tension within the collaboration:

“I think people here would assume that all of us on [X northern University] salaries are getting paid a hell of a lot more than they are on [X southern research institution] salaries. In fact it is definitely not the case for me as a social scientist. I think when you become clinical, there is probably more of a gap, because of the way the [X northern University] pays clinical people a lot more than non-clinical. The gap is pretty small I think. But nevertheless the assumption that that is the case, that undermines the collaboration, definitely. And the more equality I think that you can begin to get in there, the better it would be for the collaboration. Someone like X would earn more than me as a consultant, because he is African, and I would earn less because I am not. But you know that is fine. I don’t have a problem with that, but maybe we should be earning the same. But at a certain point within research projects that can cause quite a lot of tension that can be manifested.” (north-south researcher)

Geissler (2013) ethnographic study found that material differences between expatriates and local staff exist, leading to ‘them and us’ feelings, that are rarely articulated. Findings from this PhD study have found that researchers both north and south discussed differences with the PhD researcher, but whether this was a topic discussed amongst themselves in the partnership was not raised.

Respondents discussed the need for greater economic security within the Zambian University/research institution. In the absence of this security, people will be lost to international agencies in Zambia or will go abroad. The ethical imperative to train researchers to have this choice was mentioned as being important. However, another
spoke about it from the perspective of ethically needing to build capacity to work in the health service, and not to train specialist health researchers. Internal brain drain is an issue which was documented by Bennett et al. (2012) and Costello and Zumla (2000). Findings from this study confirm that this is a feature of the research environment in Zambia.

Others reiterated that there is an absence of career paths for researchers in Zambia, and attributed this to the lack of research culture in the country and limited research training. The absence of postdoctoral positions was mentioned as a hindering factor, although the Wellcome Trust Initiative is attempting to introduce such opportunities. The typical role of a researcher was considered to be different north and south. It was reported that in contrast to HIC, because Zambians are often not full-time researchers and often have multiple roles in teaching and administration, this led to an inability to spend time analysing the data. Zambian researchers often get tied down in administration without having time to pursue their own research, whereas it was sometimes perceived that northern researchers do not take on such large administrative roles. For one northern researcher, it is an ethical dilemma because they don’t want to take over the project, but at the same time they see that their colleagues do not have the time or capacity to undertake the work.

Some researchers were concerned that motivations to research a particular topic is due to where the funding comes from, rather than a personal interest in the topic, or a belief that this is a topic of importance for Zambia. “You are interested in maternal mortality because it is being funded by the Belgians, or health equity because it is being funded by the UK” (Zambian researcher). This may well be true in the north also, but was not mentioned by interviewees.

Some respondents cited ways in which the career paths were similar north and south but that there are fewer opportunities in Zambia. There is also a smaller pool of researchers in Zambia meaning that the available pool spread themselves too thinly. One researcher mentioned that it takes too long to move from Grade 1 to Professor and how it is more difficult for Zambian researchers to build up in-depth expertise in a research area:
“Our colleagues from the north ground themselves very much in the literature, academic debates, so it is easier for them to move in the academic world. Whereas we are more on the practical end of things, go and collect data, where are the data? And then you are running to another study maybe because there is some money. So you find yourself working as a data collector for years and years without moving up in terms of a career progression” (Zambian researcher).

Connected to this, is the finding that only one Zambian respondent recognised that northern researchers also lacked stability of tenure. There were frequent references by Zambian researchers that northern researchers remain within a University following completion of a research project, or that it is not difficult to find another position. This was not reported by northern interviewees and can be interpreted as the historical culture of presuming that LMIC researchers will be at a disadvantage, as compared to their northern counterparts.

There was a view by some northern researchers that Zambian researchers were not as productive as their northern colleagues, particularly as they became more senior, due to the lack of emphasis on publishing once they received Professorship, and a degree of patronage around appointments. This was echoed by Franzen et al. (2013) who found that promotion could be achieved without conducting research. This points to a lack of a standardised global research career progression standard, which begs the questions as to whether there should be global standards, particularly as it is common for researchers to move north-south and vice versa. “So here you are a big fish in a small pond. If you were in the UK, you would be a very small fish in a big pond” (north-south researcher). A strong theme emerging from PhD study findings is the perception of impoverished Zambian researchers versus affluent northern researchers. It can be concluded that this is due to historical inequities and general north-south imbalances, which are perceived to have remained unchanged over time.
7.3.6 Research consultancies

There was fairly widespread agreement that research consultancies resulted in poor quality research, potential duplication of studies, and interfered with academic work. UNZA has introduced a consultancy policy whereby academics declare a certain percentage of their fees, which is in turn handed over to the University. Respondents from the Department of Economics saw this as positive and consultancies are actively encouraged because of the level of funding they bring to the Department. The Head of one Department involved in health research said that the researchers in their Department spend 10-20% of their time on consultancies.

It was agreed that consultancies can be demanding, with tight deadlines - therefore limiting time for in-depth analysis- strict methods of reporting and no quality assurance. One researcher commented that consultancy work used to be carried out without getting REC approval. It was also perceived that consultancies make too many demands on the same pool of experienced researchers.

'It was a constant frustration for us because we were always competing with consultancies for researchers’ time. This was in the late 90’s and so a hundred and fifty dollars a day for consultancy was a lot of money. We had a really difficult time trying to persuade people that a couple of good papers in international journals would be really good for their reputation. It would lead to more interesting things. It really had to do with the returns to an academic career, as all the money was in the data collection and people had relatively little substantive interest in the research questions.’ (northern researcher)

This is in line with the one published study on research consultancies (Wight, 2008) which concludes that they should be undertaken with institutions rather than individuals. Northern researchers were not reported to be under the same pressure to take on consultancies as their Zambian counterparts, creating potential inequities in terms of workload.
7.4 Ethics of researcher relationships within north-south health research

Ethics of researcher relationships is an issue which cuts across both micro and macro research ethics findings. The literature review exposed power imbalances, particularly north-south, amongst researchers in north-south health research collaborations (Jentsch & Pilley 2003; Molyneux & Geissler 2008). Studies highlight the need for researchers to engage in reflective practice and positionality regarding relationships in research (Simon & Mosavel 2011; Guillemin & Guillem 2004). This PhD study offered researchers the opportunity to do this. Questions around whether researchers openly discuss power imbalances and cultural differences in north-south research collaborations and whether there is a difference in north-south perceptions of what these imbalances are were raised. Individual motivations for researchers to become involved in health research have not been explained, nor have issues relating to multiple identities - researcher background, discipline, personal characteristics - rather than always assuming the dichotomy of a northern/southern researcher. This section discusses the ethics of researcher relationships within collaborations under the following themes: trust between northern and southern researchers; north-south differences in work culture and work ethos; and, the culture of aid and colonisation. Research relationships relating to ethics in practice (data collection and community engagement) are discussed in Chapter 8.

7.4.1 Trust between northern and southern researchers

While issues relating to trust and power imbalances pervade this entire thesis, they deserve specific attention in relation to researcher relationships. While a number of researchers – primarily northern - spoke of trust and equity amongst partners, many perceived relationships and roles to be inequitable with the power balance remaining with the north. Perhaps surprisingly, the analysis brings into view many negative examples of an absence of trust and inequalities, and on balance there were more negative than positive reports. For some researchers, equity is reached if there are shared values and shared motivations for research. Words such as “shared meaning”, “trust” and “respect” were articulated. A decision to build a research career was
mentioned as enabling trust and equity, “so if people feel the commitment in you and you can feel it in them, then in a way you are equal” (northern researcher).

Trust based on long standing partnership was an issue for some interviewees. This was primarily mentioned by northern researchers, though one Zambian interviewee said that trust was based on past interaction. One of the reasons that northern researchers mentioned that they kept returning to Zambia for studies was that they had built up trust with partners over a period of time. Not surprisingly, northern researchers who lived in Zambia for a period of time reported more trust and equity in north-south relationships.

Personal clashes within country research teams were cited as being an issue for some partnerships, rather than specifically a north-south issue. In one multi-country partnership, Zambia was seen to be very top-down from the PI to the research officers, whereas it was perceived that in South Africa relationships were more equal between different levels of seniority, and that researchers opinions were valued as much as the PIs. One researcher ascribed the lack of trust to muzungos coming to collect data and leaving the country with it, a theme which is threaded throughout the thesis.

For a number of northern researchers, even where friendships are made and respect is built, north-south inequities and power imbalances persist. These interviewees felt that the partnership may not be as genuine as presented at face value. One southern respondent perceived that southern colleagues undertake the majority of work, whilst northern partners wait in the wings for the writing stage of the research process. Another source of frustration in this regard was that even though the northern researchers were polite, they have their own objectives and motives which are sometimes not made clear.

Two northern researchers questioned the role of the northern researchers in north-south health research:

“I do always struggle with the role of northern partners. And for someone who wants to develop a career in global health but is affiliated with an institution in their home country, I find it a bit of a challenge. Because the results should come out of local researchers and we shouldn’t be doing parachute research. So
I think that is partly why I got into capacity building because that is different. That is a bit more a neutral territory and I feel more comfortable taking the lead on that.” (northern researcher)

“We have to look at ourselves as Western researchers as to ‘what are we doing here?’ We can’t deny, as far as I’m concerned, the negative things that we are doing, and also what we need to give away. I mean if you’re actually looking for equity and balance, somebody’s got to give away something, and it’s pretty clear who has to give away stuff.” (northern researcher)

It also became evident that active attempts to address power imbalances and inequities have not been successful. The first was where a northern research institution played a non-interventionist role in one north-south health research collaboration, because they did not want to be seen as the dominant partner. However, this laissez-faire approach led to a perception that they were not pulling their weight on the project.

“I think from their side, they felt that there’s a lot of feelings that northern partners come into these projects and play too much of a dominant role and take over and assert themselves and it’s driven by them, so they felt that they wanted to try to not play that role, but I don’t think they got the balance quite right because we hardly... had basically not done much within the project.” (Zambian researcher)

The other example was where the South African team played the role of coordinator in a multi-country collaboration. The intention was to create ownership in the south; however, the outcome was that they were seen as the new northern, colonial power.

The literature review found three empirical studies: Jentsch and Pilley (2003), Ogden and Porter (2000) and Geissler (2013) report differences in north-south perceptions of relationships. Considering that most studies are self-evaluations of collaborations, it is worth asking if these present an unbalanced understanding of relationships. This can be interpreted in light of Geissler’s (2013) study which suggests that inequities are often not openly discussed in a desire to break from the colonial past. However, this thesis has found that many references were made – both north and south – to power
imbalances and to the culture of aid and colonisation, which is perceived to remain a defining feature of north-south research. It is not clear if these power imbalances were actually discussed amongst researchers within the partnerships.

Some respondents were in line with Geissler’s (2013) findings and discussed how Zambians are guarded in their dealings with northern researchers. It was reported that the longer a researcher spends in Zambia, the more likely it is that trust will be built. If Zambians are guarded in their discussions with northern researchers, this could have implications for the reliability of this PhD study, in terms of whether Zambian researchers spoke openly and honestly to the PhD researcher (discussed also in Chapter 3). The role of the PhD collaborator was seen to be essential in terms of her perceptions that interviewees were open with the PhD researcher. One northern researcher reported that that many things happen behind closed doors that northerners do not have access to. He went on to state that he had a certain amount of access because he worked in Zambia for a long time, although discussions around setting up NHRAZ would have been more heated and there may have been more disagreement if there were no northerners involved.

Where respondents perceived there to be unequal relationships within partnerships, most of these were ascribed to north-south imbalances of power. A senior Zambian researcher remarked that the main problem he heard in relation to research at UNZA was of north-south relationships. Tensions “between the black and white researchers” were reported in one north-Zambian research organisation. It was sometimes considered that there were certain expectations of northern researchers within the collaboration. One example was given from a northern researcher going out socially with the Zambian researchers and it was assumed that the northern researcher would pay. “It’s just the whole thing of the muzungo pays. It’s so ingrained in the whole culture” (northern researcher).

Just one researcher brought up issues of gender imbalance, and again this was in the context of the north-south divide. This northern researcher explained how it is difficult to get the same type of respect or authority in Zambia, she would get in the north, being a white female. She found it challenging to be one female working with many males in Zambia and complained that when she raised issues, they were not listened
to. However, when her male middle-aged supervisor raised the same issue, it was considered to be a good idea. She added that she did not experience this in the northern research environment.

Researchers differed in their motivations to get involved in international north-south health research collaborations. An interest in research topics directly with relevance to the health needs of population was cited by many interviewees, both north and south. An interest in research generally was also discussed by many northern and southern researchers, which was perceived as bridging a gap between northern and southern researchers. This runs contrary to the contention by some respondents that most Zambian researchers are ‘in it for the money’, which was also mentioned by both northern and Zambian researchers. A number of northern researchers spoke of their interest in international health and working with different cultures. One northern researcher was more interested in researching African public health issues, than those closer to home:

“I think about this a lot because I have worked on Europe which is where I’m from and I just can’t get so interested about public health in Europe, I do not feel the same. And then recently I was at this WHO meeting and there was a US social scientist who focuses specifically on the NHS but also health systems in Europe and he was totally fired up about it. I think it is hard to prescribe what people are interested in.” (northern researcher)

7.4.2 North-south differences in work culture and work ethos

North-south differences in work culture and work ethos emerged as an important issue in relation to researcher relationships. Many interviewees spoke about Zambians being less direct in their partnership relationships than their northern partners. All but one of these statements came from northern researchers. The Zambian researcher shared that he “kept quiet just to be flexible, whereas our colleagues in the north spoke bluntly.” There was the view that a culture exists in Zambia of agreeing with whatever is presented by northern researchers and for some researchers this was due to them being polite and reluctant to evoke confrontation. According to one respondent, there
is a tendency for northern researchers to get frustrated with this, rather than accepting that this is the system of work:

‘I just think in Zambia quite often there is also a code when someone actually declines but doesn’t outright say ‘no’ and I think quite often I have also seen people from the north... who don’t understand that’s actually a no and that it’s then quite rude to push. I hope like I wasn’t too rude, but I’m sure there have been instances when I have been a bit brusque. But I mean I quite like it because it’s quite charming this song and dance and never actually saying ‘no’”. (northern researcher)

The politeness of the Zambians made one northern researcher feel that he was “quasi bullying”, stating that sometimes it was difficult to know if this was an exercise of restraint or a feeling of inferiority due to a historical legacy:

“Sometimes it’s quite difficult to gauge whether it is polite constraint and actually there’s potentially issues underneath or whether it’s a feeling of inferiority, i.e. we’re not really running the show here anyway, therefore go ahead, carry on and we’ll respond. It’s difficult to overcome because there are settings in which you come in much more as partners and there are other settings where it is kind of clear that there is an inbuilt power divide, which is very difficult to surmount, and no matter what one does about it, because it’s a historical legacy type of thing.” (northern researcher)

Despite these perceptions of north-south differences, two researchers stated that these were stereotypes and generalisations. It was considered difficult to bridge the gap unless one lives in Zambia for a long period of time. One suggestion offered by a northern researcher was to socialise with Zambian partners, but it was mentioned that it is not always easy for Africans to accept people into their own homes, due to differences in wealth and status. These issues of material inequities are echoed by Geissler (2013).

Many researchers, both north and south, referred to different work practices and work ethos north to south and that the determinants of what is considered to be hard work
(and what is a deadline) are different from north to Zambia. One researcher said that ethical and value systems should be similar, but in reality that this is not the case. A number of interviewees attributed differences in work ethos to the different value attachments to family which was reported to be stronger in Zambia, particularly due to a dependency on extended family and where the social issues surrounding work are very different. An example was given where a Zambian will take leave of work even when a distant relative becomes ill which is often not understood by the northern partners. Another example was of long queues for clinics in Zambia, which may result in an entire day being taken away from work for a perceived minor event, illness or injury.

It is surprising that the literature does not address the issue of work differences in detail, given that culture is deemed to be important in health research partnerships. Only two studies mention work culture in any detail. Crane’s (2010) study described the different ‘culture of organisation’ she confronted in her international work, which was ‘a battle’ for her every time she worked overseas. Martin-McDonald and McCarthy (2008) reported differences in work ethos between local and expatriate fieldworkers.

7.4.3 Culture of aid and colonisation

Some respondents – both north and south - linked the different work practices and approaches to the culture of aid and colonisation. This was sometimes attributed to Zambia receiving significant aid and that northern researchers are expected to come in to solve problems. It was stated that perceptions southern partners held about northern Universities goes back to colonialism. It was reported that the decision to designate South Africa as coordinators was made in order to change the traditional perception and to make southerners support one another. However, within Africa, South Africa is often considered to be northern, especially the former white Universities. One researcher felt that sometimes assumptions were made that he knew nothing because he came from the south.

While most of the power imbalance issues were designated broadly as north-south differences, there were some references to the US model of working being very
different to the European model. It was remarked that the Europeans are more accommodating, flexible, and easier to work with, compared with the US who are more controlling with tight deadlines, strict methodology and little space to manoeuvre within the country context. Other terms that were used to describe US research teams were ‘one sided’, ‘aggressive’ and ‘very little human side to work’ (Zambian researchers).

While most interviewees spoke at length about cultural differences in many aspects of the research process as well as in relationships, a small number of respondents spoke of the culture of academia overriding north-south cultural differences. It was mentioned that most Zambian researchers are educated in the north, therefore are aware of the nuances of northern culture. It was also mentioned that there are pressures for the internationalisation of research culture within scientific circles.

7.5 Future of international health research in Zambia

Some informants saw the potential for continued links with northern researchers and research institutions into the future, primarily to serve as a link with donor funding agencies, and to build capacity. However, the optimum end point was seen to be where the northern researchers would play more of a supervisory role, with colleagues in Zambia taking the lead. Some respondents considered a need for knowledge production to be seen as a global activity. Examples were given such as the link between northern and southern researchers being mutually beneficial, because the results benefit both north and south, particularly for challenges that are global in nature.

“An important point is the question is to what extent my research and the research that I am interested in has to do with Zambia, because it doesn’t really. It has to do with the global TB/HIV interface which happens to be worst in Southern Africa of which Zambia is an example. Now I want to work closely with Zambia and Zambians but I think the work we are doing extends far beyond Zambia, it is set by a global community that includes people from within the region and people within international agencies. It’s a very globalised world, the reason that the Gates Foundation wants to spend
money has nothing to do with Zambia, it has to do with TB and HIV, and the reason that we can win that money is because we happen to work with Zambia on TB and HIV.” (northern researcher)

Furthermore, it was suggested that multi-contextual and multi-geographical teams should be developed to bring a wealth of experience and knowledge to each individual project.

“So we can as researchers collaborate and see how all these things can fit to support the common way of living. In a way that is how I see global health initiatives should be. They should take into account as global citizens, it’s not about me pushing my way of thinking on you but it’s about how we can understand so that your way of doing things can also help me live my life better in some way. Not to say ‘you change, so that I live better’... So you do it with the spirit that we are sharing.” (Zambian researcher)

The importance of having the freedom to carry out research in a country other than ones’ own was reiterated by another researcher, not only due to the internationalisation of the cultures of communication, but also an internationalisation of the movement of researchers and how we learn from each other: north-south, north-north and south-south. The Canadian Coalition for Global Health Research has brought together Canadian Universities working in this field to see how they can work better together in the field of global health. A similar group exists in Europe, the European Academic Global Health Association, and in the US, the Consortium of Universities for Global Health.

However, many respondents - both northern and Zambian - were forthcoming in expressing the view that the ideal situation would be that northern researchers would not be involved in research in Zambia. The belief was that there needs to be a focus of research coming from within Zambia, due to the history of people writing about Africa as opposed to African people generating their own theory and new knowledge, coming from their own experience. While some researchers considered that it would be incorrect to come to the conclusion that people should not be permitted to cross
geographic borders to do research, there needs to be more awareness and sensitivity around its’ effects.

In summary, three different scenarios for the future of health research in Zambia were expressed in this study:

i) the potential for continued links with northern institutions, chiefly to serve as a link with donor funding agencies and to build capacity. It is particularly thought provoking that they did not look beyond this, potentially perceiving that the status quo will be maintained and that Zambian researchers will continue to rely on northern researchers for funding links and to build capacity. This will be discussed further in Chapter 9.

ii) Knowledge production was considered to be a global activity, where joint research should be undertaken for challenges that are global in nature, rather than to be seen as exclusively north or south. This suggests a focus more on global health research rather than on international health research (see Chapter 1, section 1.4). This was also seen from the perspective of being enabled to undertake research in a country other than one’s native country.

iii) Views that it would be desirable that northern researchers would not be involved in research in Zambia in the future.

7.6 Conclusion

This chapter has explored the macro ethics of north-south research from the perspective of researchers, and has related these to published literature in the area, particularly where findings have filled gaps in the literature or where they have provided different perspectives to those in the literature. The literature on researcher relationships in north-south health exposes north-south imbalances, however the nature of these imbalances is not explored in detail. Studies highlight the need for researchers to engage in reflexivity regarding the process, which this PhD study accords to both northern and southern researchers, and whether there are differences in terms of what these imbalances are.
Partner selection for north-south health research was found not to have been covered in the literature in any degree of detail. Findings from this PhD study show that initiation primarily stemmed from the north, with an overall picture of northern dominance, either by donors or researchers. While funding for north-south health research has been extensively covered in the literature, findings from this PhD study are analysed from the perspective of power. A general perception was that funding inequities of resources originating in the north and channelled through the north ensures that the balance of power remains with northern researchers, despite other attempts at ensuring equity at other stages of the research process.

The literature review found the process of agenda setting to be extensively profiled, and while it remains with the north, the detail of these inequitable processes has not been explored. Empirical findings from this study have helped to explain this, with an absence of updated priorities from the MoH, and Zambians not always exploiting opportunities that have been given to them to take the lead. Reasons for why these opportunities are not availed of are discussed in Chapter 9, through an in-depth analysis of power.

An absence of published literature in relation to research design in north-south health research led to a focus on this in the empirical research for this study. While some examples of collaborative processes of developing methods, questions and tools, there was evidence to show that northern researchers sometimes insisted on standardised protocols and tools which did not fit with the Zambian context and cultural requirements. The implications of this for the research will be discussed in Chapter 9 in terms of scientific and cultural capital; and, Chapter 10, from the perspective of cultural competence.

A gap the literature was identified around how the data are analysed in north-south health research, therefore the empirical interviews examined the roles of the various partners in data analysis. Where northern researchers lead, as was frequently reported, what implications does this have for the interpretation of the findings, particularly in light of northern researchers not understanding Zambian culture and context. Zambians themselves were also seen not to sufficiently understand community culture. Contrary to the literature, this PhD study findings show that for
the most part, inequity in terms of publishing favoured the Zambian researchers rather than the northerners, leading to frustrations, particularly amongst northern researchers.

While literature relating to RCS, has more recently begun to focus on mutual RCS, interviewees in this study primarily associated capacity building as being one way, north to south. Respondents were frequently frustrated that so-called capacity building was in reality exposure in the guise of capacity building, a theme which the literature has not reported. This requires further interpretation in terms of why this is the case, and is discussed in Chapter 9.

These issues will be taken forward for in-depth analysis relating to power and culture. This chapter shows that questions remain in terms of power in north-south health research, as to why these imbalances exist and persist. The structural reasons for these inequities (such as funding and RCS) have been relatively well addressed in this chapter, therefore the discussion in Chapters 9 and 10 will link the structural inequities to inequities at other stages of the research process, and particularly around researcher relationships. Addressing relationship inequalities is sometimes constrained by inequalities at the structural level. The application of concepts from Bourdieu’s theory of Power and Practice have a number of uses for highlighting new aspects of researcher relationships and inequities at each stage of the research process. Culture will be analysed in detail in Chapter 10, from the perspective of how culture influences north-south health research and how aware are researchers of their culture in relation to the research process.
Chapter 8: Micro research ethics results

This chapter explores the ethics of north-south health research from the view of researchers’ experiences of power and culture from micro research ethics processes (through in-depth interviews, 25 northern, 28 Zambian), focusing on: a) procedural ethics: research ethics approval processes; and b) ethics in practice: data collection processes (see Figure 9). The ethics of researcher relationships is also presented in this chapter, relating to fieldwork relations between researchers and between researchers and communities. (see Figure 9). The literature review concluded that power and cultural issues are key to micro research ethics, but the nature of these issues has not been explored. What effects do north-south differences have on research ethics approval and data collection processes? This will partly address Research Objective 2: to utilise a situated research ethics framework to analyse micro research ethical issues in international academic north-south public health research. The findings will be discussed with reference to findings from other studies, where findings are similar or provide a different perspective to what is detailed in the literature.

![Ethics of North-South Health Research](image)

Figure 9: Micro research ethics results
8.1 Procedural ethics: research ethics review processes

Procedural research ethics are defined in this PhD study as issues around formal health research ethics approval processes and mechanisms. PhD study respondents discussed issues relating to: their perspectives on REC approval processes; differing ethical considerations of northern and Zambian RECs; informed consent forms and the REC approval process; and, reported alleged unethical research practices.

8.1.1 Perspectives on the research ethics approval process north and south

The existence, roles and functioning of LMIC research ethics committees is a topic that receives much coverage in the literature (Hyder et al. 2004, Kass et al., 2007, Rwabihama et al., 2010) and while north-south cultural differences of RECs is frequently mentioned, the exact nature of these differences has not been explored in detail. A review of the literature located only quantitative studies and comparative evidence for REC processes between US/Canada and LMIC, with no focus on other HIC. The literature review found a reliance on northern REC approval systems due to a lack of capacity, which has implications for the location of and sequencing of ethical approval. This thesis attempts to address gaps in this area around what are the processes for REC approval between the north and Zambia; what are the perceptions of researchers - both north and south - on these; and, does conflict ever exist between Zambian RECs and HICs, and if yes, what is the nature of this?

Interviewees spoke at length about research ethics approval processes, and gave their views on the challenges of obtaining ethical approval. All but two of the north-south health research collaborations in this PhD study applied for research ethics approval in both the north and in Zambia. It was reported that the Zambian REC often carried more weight than the northern REC. In some cases, there was a requirement that the Zambian REC approved the proposed research first, in advance of the northern REC reviewing it. For multi-country studies, the norm appeared to be approval sought in all

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39 In one of these cases where the REC approval was not received in the north, there was a requirement to make a pre-application to the northern committee to get clearance that ethical approval was not needed for the study. In the other example, the northern REC only gave approval for research taking place in that country.
southern countries and in the northern coordinating institution. An interviewee with responsibility for health research in the Zambian MoH, stated that if a study is externally funded, the MoH require that there is approval from both/all countries involved. Research involving a US University was reported to be more complicated than Europe, with the process containing six different approval stages, only one of which was Zambian. It was stated that the US process is not merely rubber stamping, and that clarification will often be sought on many issues before approval is granted.

Many respondents discussed the lengthy delays which ensued from obtaining double ethical approval between the north and Zambia. One northern researcher, whose collaboration sought research ethics approval both in Zambia and in Ireland, declared he would “never do that again”. Their study was required to pay €700 to apply to the Zambian REC which they had not budgeted for. While the Zambian REC process was straightforward, the Irish REC “asked all sorts of questions, as if they had never reviewed a proposal like that before”. However, they were happy to let it through once the Zambian committee had passed it. This respondent viewed that a study should not be required to apply to more than one committee if, as he considered, the ethical principles are the same everywhere. Other examples were given where double ethical review resulted in delays of between six months and two years due to differences in country REC requirements.

Interviewees spoke about some of the difficulties associated with Zambian RECs, primarily UNZA Biomedical REC. It was described that this committee is overburdened with applications and that “you get to a point where people are now beginning to look at Zambia and say ‘we don’t know if we could get anything out in time’ ” (northern researcher). It was considered that in the past Zambia was perceived by northern researchers as a country that was conducive to research, not necessarily that it was unregulated, but that it was not bureaucratic.

The findings illustrate that some northern researchers viewed the process of applying both north and in Zambia as delaying the study, perceiving it to be an inconvenience, rather than ensuring due process. Delays were ascribed to differences in requirements of committees and to the northern committee lack of understanding of southern study
contexts. These findings are in line with the literature outlining little or no communication between LMIC and HIC RECs, as is suggested by Henderson et al., (2007).

Some international research ethics guidelines (CIOMS 2002, Nuffield, 2002) state that approval should be obtained in both the host and the sponsor country. However, a number of studies report research studies that have not undergone ethical approval in the southern country, (Kirigia and Wambebe, 2006, Hyder et al. (2004); Kass (2007). It is positive that this was not the case for the studies in this PhD study where all studies sought REC approval in Zambia. One could propose that this is due to increased capacity and visibility of RECs, both north and south. However two Zambian researchers claimed that research continued in Zambia which did not undergo ethical review.

Respondents reported that no studies were rejected by either a northern or Zambian REC. Hyder et al. (2007) study reported 17% of studies had to be abandoned due to an inability to get LMIC approval, as opposed to 6% in HIC. This could mean that a lack of in-depth knowledge of contextual issues leads to a proposal being approved and passed to LMIC, particularly as a number of northern interviewees stated that the Zambian REC approval process took precedence over the northern approval process.

Apart from one reference from a northern researcher to fluctuating capacity of UNZA RECs to undertake ethical review - attributed to the chairs interest in making the committee work and the committee being underfunded - there was little mention of REC capacity. According to Hyder et al. (2007), training should be delivered on how to interpret ethics principles in light of local norms and the creation of mechanisms to facilitate communication between northern and southern RECs. It is clear that this has not taken place either in Zambia or with the institutions that partner with Zambian institutions.

Some researchers spoke about their being a conflation of scientific and ethical review, which some did not view as being within the RECs remit. This is highlighted in international guidelines which state that the processes should be separated (WHO
2011, Nuffield, 2002). However Zambian REC review procedures cover both scientific and ethical elements of a study. Hyder et al., (2007) reported that reviewers were often not equipped to review from an ethical perspective which led to an over emphasis on scientific issues.

There was ambiguity for some northern researchers around which Zambian REC to apply to. It begs the question as to why the northern researchers could not get clarification from southern researchers. This could imply that northern researchers were leading the REC submission process or that the southern researchers in the partnerships were also equally at a loss. National guidelines/standard operating procedures are supposed to exist to inform researchers about the process of application, but an extensive search by the PhD researcher found that these are not readily available online. REC “shopping” (Klitzman, 2013) was not reported in this PhD study, although it was declared by some interviewees that it is easier to get approval from the UNZA Social Science REC than other RECs. An example was given where a northern interviewee was told by the MoH to apply to the new national committee, which they did paying $1000. However they did not get a response, so they applied with a more modest fee to UNZA Humanities and Social Sciences REC and received a timely response. Two northern respondents were suspicious of ERES Converge and considered that an ethics committee should reflect the institution where one is working. However, this presupposes that all research takes place in higher education institutions. An interviewee who works in a US institution stated that they now regularly apply to ERES Converge, which is registered in the US. It was reported by a number of Zambian and northern researchers to be more efficient than other RECs, often reviewing applications within six to eight weeks. It is not clear who runs this REC, or if it is recognised nationally in Zambia. Only one interviewee described ethical processes in relation to the actual partnership as opposed to the research study. This partnership has put together a formal document of partnership process ethical issues and steps to be taken if ethical issues arose.
8.1.2 Differing ethical considerations of northern and Zambian RECs

Only two studies report differences in ethical considerations of RECs\(^\text{40}\) (Dovey et al. (2011), Kass et al (2007)). Dovey et al. (2011) study focused on HIC alone and concluded that although values may be held in common, how these values are interpreted and applied in judging a research project is influenced by the historical and cultural contexts in which individual RECs perform. Kass et al. (2007) also report that many international studies found that RECs reach diverse conclusions when reviewing the same study. However, they do not explore what these differences are.

A key finding from this PhD study is that most respondents consider that, while principles of health research ethics are universal, how they are executed differs depending on research context and that there were differences in ethical considerations of northern and Zambian RECs. This means that RECs: a) start study reviews from different perspectives, and b) consider different issues when reviewing a study. It emerged that the role of the local Zambian REC was primarily to ensure cultural sensitivity, which it was considered would not be captured in the north. This echoes Hyder et al.’s (2004) findings that the majority of developing country researchers considered that US review committee regulations were insensitive to local culture, and Nyika et al. (2009), whose study participants recognised that they did not have enough contextual information about LMIC circumstances. However, some Zambian researchers objected to the way that RECs regulate issues that are, as one researcher put it, ‘philosophically grounded in another system.’ This shows a perception of difference, not just in standards, but also in basic research ethics principles. With reports of little contact between RECs, it is unlikely that these north-south differences will be understood by REC members. Participants in Nyika et al.’s (2009) study recognised that both HIC and LMIC faced difficulties, particularly in interpreting principles and regulations. This indicates that it is not appropriate to put HIC RECs on an ethical pedestal, as they too have difficulties in interpreting ethical principles. A number of researchers perceived that Zambian researchers had the same

\(^{40}\) Apart from different north-south views in relation to informed consent, which is extensively profiled in the literature.
perception as northern researchers of what is ethical. This was contrary to the view of a northern interviewee who teaches research ethics, insisted that it is striking how different cultures see research ethics differently on his ethics course and that international ethics meetings always bring up many arguments.

Findings illuminate that many northern researchers perceive the REC process as a hurdle which needs to be overcome as part of the overall research process, but without consideration for the substantive ethical issues and procedures, that research studies produce. This was perceived particularly to be the case in the case of data collection, where Zambians were reported to have a more innate sense of community. The issue of Zambians being “custodians of our own culture” (Zambian researcher) can be called into question by the fact that Zambian RECs were sometimes perceived to rubber stamp REC authorisation in order to obtain international funding. This is echoed in the literature where Kass et al (2007), Nuffield (2002) and Marshall (2005) claim that developing country RECs are sometimes viewed as a formality. If northern committees defer to Zambian RECs, and Zambian RECs merely rubber stamp, this could bring the entire REC process into disrepute.

It is debatable whether a process of only Zambian REC approval is needed. There appears to be tensions if ethics review is stipulated in both countries and issues are different. Perhaps, a) northern and southern RECs should assume different roles in relation to the process; and/or, b) contact between northern and southern RECs should be stipulated. However, it is likely that this is not very realistic, at least in the short term, given the dearth of capacity of southern RECs.

Some interviewees recognised that there was a long history of ethical review for clinical research in Zambia but that it is in its infancy for social scientists researching health issues. It was sometimes perceived that it is easier to get approval with the social sciences than with the biomedical sciences and that applications to UNZA Humanities and Social Sciences REC rarely come back with any comments. There was a general sense amongst respondents that social science research was not as sensitive as clinical research.
It is worth noting that Zambian RECs do not require that approval is obtained in the north, however, northern RECs require that approval is obtained in Zambia. For a number of Zambian researchers, the role that northern research ethics committees play in the Zambian research approval process is positive, with northern standards considered to be more rigorous than in Zambia. It is unclear as to whether this means that standards are actually more rigorous or whether application of international standards are more rigorous. It was claimed that double ethical review ensured a safety net that international standards are adhered to, rather than Zambian standards alone. One Zambian researcher stated that this gave donors the comfort of feeling safe that they are putting their funds into something that ‘is legal’, giving the impression that the Zambian process is not as rigorous as the northern process. Northern standards were sometimes considered to be more global in nature as compared to Zambian standards. This echoes Hyder et al. (2004), whose study reported that more than two thirds of researchers agreed that LMIC colleagues relied on US ethical regulations for guidance. van Teijlingen and Simkhada (2012) put forward possibilities as to why researchers from HIC may choose not to apply for ethical approval in the LMIC, one of which is arrogance or paternalism that ethical approval from an institution in a developed country is sufficient or even superior. Results from this PhD study reveal that this was not necessarily arrogance or paternalism on the part of the northern researchers, but rather it was the Zambians that sometimes held the view that the northern REC process was more robust.

8.1.3 Informed consent forms and the research ethics approval process

Differing north-south perspectives on the informed consent process was frequently raised by the interviewees, echoing the strong focus on this area in the published literature (see Chapter 5, Section 5.2.6). Generally, northern RECs were considered to be more concerned with informed consent forms than UNZA RECs. Several researchers reported how informed consent works differently in African countries where people often do not have a concept of informed consent as a procedure, meaning that at the community level, respondents would rather agree verbally to take part. It was frequently stated that the northern idea of informed consent was “over the top” and resulted in contention between northern and southern researchers. An
example was given of a US consent form which stretched to fifteen pages. One multi-country collaboration permitted different consent forms for each country to allow for different contexts. The quote below is typical of responses on informed consent.

“I think it is very important that you tell people what you are doing and that you make it very clear to them that they can withdraw and you tell them how it is going to be used. But I think there are lots of occasions where getting an informed consent form is very intrusive.” (northern researcher)

This finding is well supported by other research (Bhatta 2004, Krogstad et al, 2010, Gikonyo et al, 2008, Doumbo 2005, Molyneux et al. 2005, Nuffield 2002). Results from this PhD study have shown that consent forms continue to be designed in HIC. This begs the question as to why this continues to be the case despite the evidence to show that it poses problems for the informed consent process. This study uncovers diversity in views on individual autonomy in relation to individual consent versus community consent, while international guidelines are clear about community consent not being a substitute for individual consent. It is interesting to observe that the literature highlights northern researchers’ roles in insisting on individual signed informed consent, which was not always the case in this study, as evidenced by the above quote.

Most respondents considered that, while it was appropriate to gain initial consent from a chief for the study to be undertaken in a particular community, individual consent is a universal principle. Results from published studies vary in relation to the process: from questioning individual consent in cultures where primacy is given to the community (Caballero 2002, Camp et al., 2009) to the importance given to both individual and community consent. (Hyder & Wali 2006, Stewart & Sewankambo 2010, Frimpong-Mansoh 2008, Molyneux et al 2005. Doumbo (2005) places this in the context of northern researchers lack of understanding of the process and that individual and community consent should be seen as part of the one process. This can be related back to Ubuntu and northern researchers not being aware or having the capability to relate their research processes to it.
8.1.4 Unethical research practices: corruption and conflict of interest or lack of capacity?

There was a perception by a number of researchers both north and south, that unethical research was a feature of the Zambian research system, particularly in the past, and to a lesser extent in the present. A concern was expressed by some researchers that prior to the 1980s, a lot of the research carried out in Zambia was unethical, with trials carried out on subjects that were not permitted in northern countries. This reportedly led to the establishment of the UNZA Biomedical REC, which functioned for years in effect as a national research ethics committee. A recurring theme amongst both northern and Zambian researchers was the Microbicide Trial and the Lujo Virus, which were considered by many to have unethical elements. This has been discussed in detail in Chapter 6.

Three examples of unethical research were witnessed by northern respondents. The first was a northern researcher who was involved in a project where the research participants were being tested for sexually transmitted infections, but requested that they would not be tested for HIV. However these requests were ignored and the tests were carried out. The interviewee, who had been working closely with the community, was appalled and even though she informed the institution where he worked, no punitive action ensued:

“At local level it really mattered what he did but if you are more removed, like in Sweden or Norway, the implications are far less. I do think ethics are trying to catch up with that but I am sure it is not an isolated case.” (northern researcher)

Another northern researcher who had worked in a district hospital in Zambia in the 1990’s collected samples for a northern University, but he was not sure if the study had ever obtained ethical approval. The researcher “inherited it and just continued to send these bloods off into a black hole.” He imagined that there were many unethical practices occurring on quite a large scale, potentially in other district hospitals, but he felt that ethics became tighter with the HIV agenda in the early nineties. The third example came from a researcher who anecdotally heard that there may have been
some products tested in UNZA Medical School that did not have ethical approval, but he emphasised that this was not by external researchers. He added that he did not know the facts, so he did not want to cast aspersions on what occurred.

While most examples were given of unethical practices that happened in the past were for clinical research, one researcher claimed that the Zambian team he worked with did not anonymise their data and that the interview transcripts sat openly in offices. In this case the funders intervened, to remind them that research participants confidentiality needed to be respected.

For some northern interviewees, power and ambition issues among Zambian REC members was considered to be a factor in encountering difficulties in obtaining ethical approval. Findings from this PhD study highlight a small number of reports of conflict of interest in RECs and unethical research practices. A number of northern interviewees spoke about the lack of neutrality of some members of UNZA Biomedical REC, bringing into question the transparency and independence of the committee. It is interesting that this was mentioned by northern researchers only. This could mean that Zambian researchers did not perceive transparency and independence to be an issue, or that they did not wish to disclose these issues to an outsider. Examples were given where perceptions of political decisions being taken instead of decisions being based on scientific/ethical review and members of RECs approving projects when on its’ payroll. It can be hypothesised that there are issues around this institution being perceived to be an annexed research site or a semi-northern research institution.

Issues pertaining to conflict of interest were cited only for UNZA Biomedical REC. This suggests that UNZA Social Science REC might not be considered as making decisions based on political rather than ethical grounds.

One national level respondent spoke of her experience of northern researchers attempting to get a waiver from Zambian RECs, because they already had obtained northern approval. Interestingly, her perception of unethical research was from the perspective of not adapting/adhering to the Zambian context. This is in contrast to the perception of some Zambian researchers that northern standards are higher, or perhaps that while the standards that are higher, their application is not.
“Researchers who are in a hurry, will come from America, from Europe, and they come with a research project and it says you should send samples of blood to Washington. They don’t find a process through which they can do this quickly. And so they wave their ethics approval, from Washington and say ‘look this has been approved from NIH.’ And then they start doing all sorts of things, which we would normally have stopped if they had gone through our processes. The people think they are doing everything ethically but not in the context of the country and how the country looks at it. For us, someone taking a sample of blood is a serious issue, because of the political implications of what they are taking it for. Is it for propaganda? Is it for research? We don’t know. In my opinion, it is our system that needs to be streamlined, strengthened to perform it’s task.” (national stakeholder)

This could lead to two interpretations: (i) that northern standards are perceived to be higher, but lower when carried out in the south, or, (ii) that northern researchers perceive a different standard to be appropriate. The latter interpretation is given further weight by two Zambian researchers stating that correct policies and procedures for undertaking ethical research is a strong ethical issue for Zambian researchers but the models for funding north-south health research is at odds with this.

8.2 Ethics in practice: data collection and community engagement

The literature review found that the data collection process has been relatively neglected in the literature on north-south health research, particularly from the perspective of researchers’ experience of the process. Studies show that power imbalances and cultural differences exist: a) between researchers and communities (most of the literature concentrates on this): and, b) between northern and southern researchers (less of a focus on this area). Interviewees in this PhD study were asked to give their opinions on the interface between communities and researchers during fieldwork, and in particular if they thought there were differences in community perceptions of northern and southern researchers. A key issue emerging from the
findings is that cultural competence (see Chapter 10), and cultural capital (see Chapter 9), are the most important issues when it comes to data collection. The main discussions were around: roles in the data collection processes; community engagement and researchers understanding of communities; effects of northern researchers on data collection; and, discipline mix.

8.2.1 Roles in the data collection process

For many health research partnerships in this study, data collection was undertaken by the Zambian members of the collaboration, either completely, or with limited involvement from northern partners. Where northern partners did participate, it was often in the form of monitoring and evaluation visits, or for training/piloting. Northern researchers often played the role of data collection coordinators, so whilst they did not actually partake in the data collection themselves, they spent periods of time “in the background”, supervising and coordinating the data collection for quality assurance. However, there were also many cases where northern researchers played an active role in data collection with their Zambian colleagues.

Northern partners’ lack of understanding of the challenges involved at the data collection stage of a study, featured as a source of frustration for a number of Zambian researchers. This was primarily attributed to their lack of presence on the ground, so that they did not have an awareness of: a) the amount of work involved; and, b) the logistical challenges involved in undertaking fieldwork in Zambia:

“They fail to understand that it is expensive to move from point A to point B because fuel is expensive. They also fail to understand technological challenges, economic challenges, social and cultural challenges etc. You find data collection is probably planned for the rainy season when the roads are bad.” (Zambian researcher)

“I think also the fact that we are so far away and so when we are doing larger studies like this and we are not always on the ground where it’s happening, it leaves a lot of the work burden of the actual practical issues of running a study
on our Zambian colleagues. Sometimes I sense that they feel that we in the north have started something that leaves a huge burden on them in terms of work and time, especially in the data collection phase. So that could be one of the reasons for them not having so much time to allocate for the analysis phase because they have spent a lot of time in the data collection phase.” (northern researcher)

One northern interviewee detailed how the culture of research and interviewing is different from north to south, from the pace of the interview, to how she would have assumed that the interviewee has knowledge of the research culture. She articulated that there is an assumption in the north that the interviewee will know how to act as a research participant, which may not be the case in Zambia, where a research culture is only emerging.

“Whereas what struck me in the interview with X is that he didn’t make that assumption, and so it was on a different conversational level and I think I learned a lot from that. I learned that you cannot make the assumption that somebody understands what it means to be part of a piece of research. It ties into the whole notion of are you in a place which has a developed research culture, where people use the word research and it’s common currency and in other places it isn’t, or it comes to represent something else and in Zambia it may well come to have very negative connotations simply because of all the post-colonial scrambling around for a piece of the research cake. So I guess what I am getting at is that often by observing or working alongside and partnering with somebody, is that there is actually more to be learned from the grounded style of how you’re interviewing because he was very sensitive to that, perhaps not in a conscious way. It was something that struck me. I would be very impatient in my head and I would think, why isn’t he getting on with it, why is he detouring via here.” (northern researcher)
8.2.2 Community engagement and researchers understanding of communities:

*Ubuntu* and worldviews

Community engagement in research conducted in the global south is comprehensively covered in the literature. However, issues relating to the effects of northern involvement in the process of engaging communities are relatively neglected. This PhD study examines community engagement where northern researchers are involved in the process, or when they are involved in determining how the community will be engaged.

Northern and Zambian interviewees who had participated in data collection shared their opinions on the quality of engagement with the communities they were researching. A number of researchers were happy with how communities were engaged. One Zambian researcher posited that even though the study was developed abroad, the community had a say in how the study progressed, through a formative community assessment. Another northern researcher said they had learned – from a decade of research in Zambia - how to engage the community, through the formal health structures and through the chiefs. Yet another study started with the qualitative data collection and used this as a vehicle to gain an understanding of what the local setting was expecting and how to make it culturally acceptable to the community.

However, numerous examples were cited where north-south studies lacked appropriate engagement with communities. There were frequent references to the community not being sensitised properly and therefore not understanding the value of research. Some interviewees blamed international studies for the lack of community sensitisation, stating that northern researchers are not always respectful of communities. It was stated that sensitisation at the community level is a very strong ethical issue for people in Zambia, but that international studies are not set up in such a way to instil this. It is interesting that this view came from a northern researcher.

“This issue of overseas coming in with a perspective and being able to argue very clearly that it’s important but without any understanding of what the
priorities are for the community and whether they actually want this... other people might think it’s good for them but they might have completely different ideas. So I think that whole aspect of listening to what communities are wanting and then research following from that process is really important, and very difficult and doesn’t really fit in with the way international studies are created or funded.” (northern researcher)

One researcher stated that when a researcher from Europe comes to Zambia, it is imperative that they have an effective interface with the people, rather than assuming that they can engage with them in a culturally appropriate manner. This could imply that the northerners are the outsiders and that the local Zambian researchers will be that interface. Zambian respondents often viewed northern researchers as lacking capacity to fully understand the context and culture of local communities, particularly when their presence on the ground was for only a short period of the fieldwork. Interestingly this once again comes back to the concept of *Ubuntu*[^41], which some Zambian researchers spoke about in relation to the ethics of undertaking research in communities. These researchers believed *Ubuntu* is innately present in African researchers, but not understood by northern researchers.

Analysis of the findings show that the picture is sometimes more complex than a straightforward north-south divide. Zambian researchers who are not members of the immediate community were also reported to be removed from the community they study, particularly in terms of cultural distance, an issue which is highlighted by Geissler (2013). One such example was as follows:

> “Sometimes...I am corrupted too. When I was growing up... I knew my own language very well, I knew what the trees were, what functions they were doing, which fruits were there. But then as you grow up and you begin to go into English... I lose track, I can’t even know some of the trees now and what their functions are. I have lost all that and the way I think is different. But somehow I believe I am one of them. But I need to respect and understand my

[^41]: HARROWING, J. N., MILL, J., SPIERS, J., KULIG, J. & KIPP, W. 2010. Culture, context and community: ethical considerations for global nursing research. *Int Nurs Rev*, 57, 70-7. recommend the adoption of a communitarian ethical framework for global research. In this framework, the individual is seen as inseparable from the community to which he or she belongs. This is widely known as *Ubuntu*, which emphasises the importance of the collective/community over the individual.
people better because I have been out for a long time. So I need time to relearn what my society is all about. We as educated Zambian researchers should understand that we have gaps in trying to reach and understand our own communities as well.” (Zambian researcher)

Where fieldworkers spent lengthy periods of time in a community, whether north or south, it is reported that they were enabled to move from outsider to semi insider status. Jentsch & Pilley (2003) recommend that northern researchers should visit often and for as long as possible, with extended stays in the rural areas in order to build relationships with the communities. While numerous respondents in this study gave examples of north-south research lacking engagement with communities, northern partners were not always blamed for this. Some studies had to abandon research in certain communities, because community protocols for entry into that community were not followed, such as not approaching a chief or headman at the outset. Two interviewees attributed this to having no budget for community engagement. A Zambian researcher stated that they cannot blame the northern researcher for the lack of engagement, as it was their role to ensure that the cultural aspects of the study were taken into consideration.

“I think those things (community engagement) were downplayed. Which I think you can’t entirely blame the northern institutions for it, because we are supposed to be custodians of our own culture... But then what happened was, they actually just went in, there were mappers, just map out what areas we were doing so they would do in without informing the headman, just go there, who lives there, so most people got offended with that.” (Zambian researcher)

This is also highlighted in the literature where local fieldworkers were described as ‘cultural interpreters’ (Jentsch & Pilley, 2003) and ‘cultural brokers’ (Molyneux et al., 2009). It is important to note that this PhD study did not categorise fieldworkers as separate to researchers (Molyneux et al, 2009), and respondents did not usually make the distinction.
8.2.3 Effects of northern researchers on data collection: muzungos and Zambian outsiders

The literature review found an absence of research into whether northern researchers have a distinctive effect on the research when they participate in data collection. A notable exception is Simon and Mosavel (2011), who recount how, as US researchers, their nationality had the potential to affect participants’ perception of them. However, they also found that the UK research team were sometimes viewed with less suspicion by the community than the white South Africans, drawing attention to the nuances of national culture.

The association of muzungus undertaking research in communities was linked to an historical fear of colonial times and was expressed by many north-south respondents. Tomlinson et al. (2006) explain how research in South Africa in the mid-1990’s involved political negotiations, particularly for white researchers, where there was a community perception of cultural imperialism. One of the primary areas where muzungus were mentioned as having an effect on the data collection process – and in fact the research more broadly – was the association of drawing blood with Satanism. This was more obviously the case for clinical trials, however, it appears to have fuelled suspicion of all types of health research. Kingori et al. (2010) cites common rumours of ‘blood or organ stealing’, which reportedly have a lengthy history in Zambia, and were linked to colonial interventions. It is interesting that this perception is reported to be reserved more for northern researchers, although with the history of biomedical research primarily following the parachute or safari model, the face of these studies in the past was likely to have been the muzungo.

“Research in part has been associated with Satanism, especially research to do with the drawing of blood. So there were people that were very suspicious, especially each time they saw a white person coming in ‘why has this person come all the way from wherever they have come from just to come here to do research. I think that there is something that they really want from us.’”

(Zambian researcher)
Where northern researchers participated in fieldwork, interviewees spoke at length about the effect it had on data collection. Zambian respondents were forthcoming in expressing the view that northern researchers were far removed from Zambian communities and lacked the capability to fully understand their practices. This was often attributed to "outsiders coming in to run the show" for only a limited time. Africans were often considered to have much more of a sense of community, when it comes to issues of research, which is innately present and unique to Africa, particularly from the perspective of Ubuntu.

“What I find is if we are lucky enough to have representation from different continents, it’s strikingly different how they see things and when you get them to address an ethics issue of any kind it’s remarkably different. But for me the Africans particularly have a very strong sort of sense of community which is just sort of innately in there, and this is just my perspective, but it’s like when we start talking about community often they are silent, they don’t say anything because it seems like ‘what are you talking about, this is so obvious?’” (northern researcher)

The effects of northern researchers on the data collection process were said to have stemmed from cultural differences which meant that the northern researchers often stood out in the field. One researcher remarked:

“For the time-in-motion study I would sit in the registry for 8 hours a day, marking in the time. From that perspective you got a very good sense of how the clinic moved. For the first day everyone was very conscious of me and after that I was part of the woodwork and they would have their conversations in Nyanja. Quite often they were talking about and wanted to know about me, where I am from, whether I am married, whether I have children, what church do I go to.” (northern researcher)

It is interesting to note however, that while this northern researcher stood out initially, within a short space of time, she was seen to be ‘part of the woodwork’. Interviewees, both north and south, spoke about how the presence of a northern researcher creates expectations amongst the communities being studied. Expectations were created on a
number of levels and examples were given: a) that people would be provided with something in return for their participation in the research project; b) people felt “excited and important”, that someone has come to help them; and, c) beliefs that the “the white person” would be able to link them to sources of funding.

At the most basic level, this was described as being distracting when a foreigner is involved in data collection and that people will not open up to northern researchers. It was stated that communities will know the standard answers that northern researchers are happy with:

“We are used to a background where a muzungu comes and there has been fear that has been used in colonial times. Same with you, if you went into Zambian context, they will say ‘oh here is a muzungu, this woman what does she want, let’s tell her what will make her happy’. So much of the time the way they will answer will not be because of what they think, but they will say what is it that she wants to be happy with. So they will try to please you so that you come out and you feel good about what you have brought.” (Zambian researcher)

Another suggestion was that the presence of a foreigner leads to bias, and that “they will say yes just to get rid of you” (Zambian researcher). An ‘event’ is created when the northern researcher participates in data collection, such as district officials getting stressed and on alert. While most respondents mentioned this as being a north-south issue, some respondents believed that every researcher affects the field, “whatever colour you are” (Zambian researcher). However, when it was probed further, both northern and Zambian researchers described how in fact the perception that communities held of Zambian researchers was different, particularly when the Zambian researchers were from the same community/locale where the research was taking place. It was sometimes perceived – by northern and Zambian researchers – that Zambian researchers were closer to the community. This has been underlined in empirical research (Molyneux et al, 2013, Madiega et al, 2013).

“because of this element of ‘oneness’ and also because some of the research assistants were from the same communities as the research participants so they
looked at them as being part of the community rather than being an outsider who comes to collect information and then disappears.” (northern researcher)

Furthermore, it was mentioned that there were cultural differences in the way researchers address the community and in the style of dress. However this was not strictly seen to be a north-south issue, as it was remarked that local young people may also cause offence. Language barriers were also seen as interfering with the quality of the information. While it was not considered to be restricted to collaborative research - the same can be true of other places in Zambia where the interviewee may go and not speak the same language - it is more pronounced in international collaborations where people move from one culture to another.

One northern interviewee stated that it is quite common in Zambia for a northern researcher to be accompanied by an assistant or partner. This researcher felt that she gained respect within the MoH and the district because she did not use the system of ‘higher-up’ to make appointments, which northern researchers frequently do. “I did a lot of the appointment fixing myself and I think people found this a bit weird” (northern researcher). Another northern researcher noted that he had succeeded in moving from outsider to insider status and gaining credibility within the district, but considers that one will never completely become an insider due to differences in wealth. It is notable that the interviewee equates wealth with being an outsider.

Two northern interviewees that participated in fieldwork spoke of being aware that their presence may have an effect on the research. For the first, the research was taking place in a rural district, which was not frequented by many white people. The researcher discussed whether or not she should participate with the local research assistants, as she was concerned that her presence would influence the responses. However, they assured her that her presence would not affect the interviews, based on their discussions with the local community. The other researcher, who was in the field for four or five months, said that she was very aware of her role when in the field and she tried to take as much of a back role as possible. The team that she was leading explained the study in detail to communities and tried not to raise expectations. She did not consider that the results were biased because of her presence.
Northern researchers that had participated in data collection spent varying lengths of time in the field, ranging from a few days to five months at a given time. When sharing their experiences, both northern and southern researchers felt that there was a genuine need for northern partners to participate in at least part of the data collection, enabling partners, to give northern researchers grounding in the context. One northern interviewee considered that northern researchers do not spend enough time in the field, but that it might be perceived as being a drain on resources because international travel is so expensive.

Some northern interviewees saw northern involvement in data collection as adding to the quality of the results. For these respondents, outsiders may be perceived as being more interested in the mundane and more neutral, resulting in better access to information than for ‘insiders’, and because they look to the outsiders to solve their problems, they may open up more. Others considered that outsiders are needed in research to see things that insiders might seem ‘normal’ and to bring different perspectives to the study. This point is often referred to in the qualitative research methodological literature where outsiders can often obtain richer information due to the fact that they are outsiders (Ganga & Scott, 2006, Merriam et al., 2001), so perhaps these issues are not restricted to the realm of north-south research. One interviewee spoke about northern researchers that are accustomed to travelling to different countries on a regular basis, acquiring a skill to distil information in a nutshell without being in the country for too long, even though sometimes this might be shallow.

“The external vision is always important. People who are open are people who travel anyway I think. You can be a traveller and completely narrow minded and maybe too focused when you come to do your five or ten days. Maybe they do underestimate because we as northerners see different countries, different contexts, we do make an impression. It may be shallow and certainly not completely informed, but you do get an impression fairly quickly of what’s going on. You then rely on mediators who are the insiders.” (northern researcher)
8.2.4 Discipline mix and fieldwork

The published literature does not deliberate on the discipline mix in north-south health research partnerships. PhD study findings indicate that disciplinary differences are an issue for a number of respondents. All research partnerships discussed in this PhD study included more than one discipline, primarily medical doctors, anthropologists, economists, and sociologists. Some respondents articulated that interdisciplinarity worked well. There were frequent references to complementarity of skills and that even though it is often a challenge to work together, it is essential to have different skills and perspectives.

One northern interviewee articulated that as a social scientist, she was looked down upon in health research and that her role in clinical trials was considered to be marginal. She stated she believed in undertaking interdisciplinary work, but that multidisciplinary work is easier, when you work in parallel but not necessarily together. She considered that clinicians are rigid and do not spend much time in the field. She also considered that social scientists do not get the same respect or funds that the clinical scientists receive. She articulated this as follows:

“I find it distressing how little clinicians are in the field. How they train research assistants, send them out, and do very little observation on how they work and how the instruments work in the field. For example, last year we did a prevalence survey and I was probably in the field about one week a month managing four sites and the other sites were being managed by clinicians. One of them spent hardly any time in the field. The other two spent a bit more time, but compared to me, very little time. And that is very much the way they work. When the data comes, they spend loads of time on it, but actually in the collection of it I think there is shockingly little attention given to it actually.”
(north-Zambian researcher)

However, one respondent articulated the opposite view, that a certain researcher she worked with, found it easier to relate to the people on the ground, because she had a medical background. Two Zambian researchers made particular reference to northern anthropologists having a good understanding of cultural issues. One researcher
claimed that African clinicians understand social science quicker than northern clinicians as they have a natural empathy with it. On the other hand, one interviewee blamed the Zambian medical doctors involved in the research collaboration for the community engagement problem, stating that they did not understand the community dynamics, which are different in every community.

Some comments were made around the culture of academia being the same globally, and that there is pressure for the internationalisation of research culture. Others alluded to a merging of cultures, which were sometimes attributed to partners having worked in Zambia previously, and that many Zambian researchers were educated in the north. Findings relating to a culture of academia and discipline mix raises issues of multiple identities, and cautions against simplistic north-south dichotomies. This will be analysed in detail in Chapter 10.

8.4 Conclusion

This chapter has explored the micro research ethics of north-south research from the perspective of researchers’ experiences, which have been related to published literature in the area, particularly where findings have filled gaps, or where they have provided different perspectives to those in the literature. In terms of procedural ethics, a review of the literature located only quantitative studies. This chapter has sought to identify the perceptions of researchers on existing REC approval processes in the north and Zambia. A gap was also identified into what the northern and Zambian differences in ethical considerations are. A key finding from this PhD study is that most respondents consider that while principles of health research ethics are universal, how they are executed differs depending on research context. This will be explored in Chapter 10 in terms of how culture influences north-south health research and how aware are researchers of their culture in relation to the research process, through a model of cultural competence.

The literature review found that the data collection process in north-south health research was relatively neglected, particularly from the perspective of northern researcher involvement. Studies focus on power imbalances between researchers and
communities, with little empirical evidence on power imbalances between researchers, and also the effects of northern researchers’ involvement at data collection stage, has on the research process. While some PhD study findings point to a north-south divide, Zambian researchers were often perceived to have an effect on the fieldwork and to be distanced from communities, suggesting nuances to the north-south divide. These nuances will be teased out further in Chapter 9 through the lens of cultural capital, and in Chapter 10, in terms of a culture of science.
Chapter 9: Power in north-south health research

9.1 Introduction

PhD study findings have shown power imbalances to be at the core of international north-south health research. This chapter will analyse in detail the role of power in north-south health research, as a central component to understanding situated health research ethics, which is Research Objective 3 of this PhD study (see Figure 10). Power will be analysed through the lens of Bourdieu’s theory of *Power and Practice* (1977). His concepts of *Field, Habitus and Capital* are useful theoretical tools to assist in illuminating power imbalances in north-south public health research and to help understand why inequitable practices persist. The central tenets of this theory have been outlined in Chapter 2. This chapter uses the following steps – as set out by Bourdieu - to explain the power imbalances highlighted in this study of north-south health research.

i) According to Bourdieu (1977), the relationships of the *Field* in question must be traced and understood within the context of the field of power. The field of power is regarded as the dominant field of any society; it is the source of the hierarchical power relations which structure all other fields. The field in question in this PhD study is the field of international academic north-south public health research.

ii) Relationships between actors within the field must be mapped in order for *Capital* to be assessed. Dominant and subordinate positions must be identified for all the participants in the field. Each of the capitals – economic, social, symbolic and cultural - will be analysed in relation to north-south health research, identifying the dominant and subordinate positions of northern and southern researchers for each capital.

iii) The *Habitus(es)* of the agents within the field must be analysed, along with the strategies produced in the interaction between *habitus* and the constraints and opportunities which are determined by the structure of the
field. (Jenkins, 2002, Schwartz 1997). The *habitus* of research interviewees sampled for this study will be analysed in detail.

![Diagram: Ethos of North-South Health Research](image)

**Figure 10: Power in north-south health research**

### 9.2 Field of north-south health research

Interpretation of the findings from this PhD study point to power being at the heart of international, academic north-south health research, thereby following Bourdieu’s thesis that power is the dominant field in any society (Bourdieu, 1977). Bourdieu describes society as consisting of a system of fields, each one with its’ own structure – history, logic of action and capital – which is semi-autonomous and set within a larger field of power (Bourdieu, 1977). Within the field of academic international north-south health research, actors attempt to accumulate different forms of capital (Bourdieu & Wacquant, 1992) (see Chapter 2, Section 2.8.3). The point of departure for analysis of the field of north-south health research therefore, is that power is at the core of the field. Bourdieu discusses Science as being produced within a field. This PhD study
chooses to be more specific, by breaking down further the field of Science, into the field of international academic north-south public health research.

9.2.1 Field strategies

Chapter 2, Section 2.8.1, charted three types of field strategies, as outlined by Bourdieu: conservation, succession and subversion strategies. It can be argued that northern researchers lie primarily in the conservation field, through seeking to conserve the status quo, and maintain control of most elements of north-south research projects, for example agenda setting and data analysis. Succession strategies are pursued primarily by Zambians, both at individual researcher and at national level, as they seek to gain control of the different stages of health research undertaken in Zambia. At the national level, this is evidenced by the introduction of structures and regulations to manage the health research system, with frequent references to the importance of Zambian ownership of the research process. Neither northern nor southern stakeholders appear to fit the subversion strategists, except perhaps those who do not see a future for the field of north-south health research in Zambia. This is an interesting departure from Bourdieu, as he claims that all actors share a common interest in preserving the field, even if they are not in agreement on how it should be controlled. Not all respondents were in agreement that the field of north-south research in Zambia should be preserved, with some considering that northern researchers should not be involved into the future (see Section 7.5).

However, where there is shared consensus that there is a shared interest in a common field, according to Bourdieu, the rules of the game – nomos - must be accepted in order to enter the field. Within the field of north-south health research, two types of nomos exist: a) research collaboration guidelines (see Chapter 4, section 4.2) and, b) research ethics guidelines (see Chapter 5, section 5.1). These will now be discussed.

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42 Conservation strategies: pursued by those who hold dominant positions in the field (Bourdieu, 1977)
43 Succession strategies: attempts to gain access to dominant positions.
44 Subversion strategies: pursued by those who expect to gain little from the dominant groups.
9.2.2 North-south research collaboration guidelines

Only one health research collaboration in this PhD study had developed ethical guidelines relating to the partnership itself, however, plenty of examples of unwritten rules relating to agenda setting and authorship were given. Bourdieu contends that to enter the field of science, actors must play by the rules of science. For the most part, these rules of science have been broadly adhered to in the health research collaborations in this study, including for example the broad principles of honesty, accountability, professional courtesy, fairness and good stewardship, as outlined in the *Singapore Statement on Research Integrity* (2010) (see Appendix 11).

One area where the rules appear to be more loosely applied in many of the health research collaborations in this study is in the area of authorship. The Singapore Statement states that: "*researchers should take responsibility for their contribution to all public, funding applications, reports and other representations of their research. Lists of authors should include all those and only those who meet applicable authorship criteria*" (2010). While some respondents in this study considered that authorship adhered to standard norms and guidelines for contribution, many interviewees reported a bias in favour of including Zambian collaborators, sometimes as lead authors, even when they did not fulfil the requisite authorship criteria (see Chapter 7, Section 7.2.2).

9.2.3 Guidelines for health research ethics

Power is a dominant force within the REC approval process, albeit more subtly than in the overall field of north-south health research. It was assumed that researchers appreciated the importance of REC processes generally - although this was not discussed in detail at the interviews – however, respondents were divided as to whether northern RECs should also be involved in the process of approving research studies in Zambia (see Chapter 8, Section 8.1.1). For REC approval processes, *nomos* in this PhD study is interpreted as research ethics principles. In this thesis, results show how northern RECs are not always aware of the rules of Zambian RECs, nor are the Zambian RECs aware of the rules of the northern RECs; although in most cases, both
are dependent on one another for the study to proceed (see Chapter 8, Section 8.1.1 & 8.1.2) and the decisions of one impact the other. It is clear that the northern committees have not completely relinquished ultimate decision making to the Zambian committees. This could be due to a number of factors: i) the belief that Zambian standards are not as high as northern standards; and/or, ii) desire to remain in control of the process and maintain the status quo, iii) RECs not functioning due to lack of capacity; and, iv) duty and accountability of actors for research activity in Zambia.

An interesting departure from Bourdieu’s contention that the field is a place of struggle for power emerges from the findings that northern RECs often deferred to the decisions of Zambian RECs, hence showing a desire not to control the ethics approval process. On the other hand, there were some reports that the Zambian RECs rubber stamped approvals in order to obtain funding (see Chapter 8, Section 8.1.2). If this proved to be the case, it would bring Zambian REC approval mechanisms into disrepute. Both northern and southern RECs might benefit from assuming different roles in the process, at least in the short term. Chapter 10 discusses this issue in more detail through the lens of culture.

9.3 Habitus of researchers

Bourdieu’s concept of habitus provides a valuable tool to gain insight into why north-south inequities and power imbalances are perpetuated in north-south health research collaborations. Habitus refers to the values, dispositions, and expectations of particular social groups that are acquired as a result of a long-term occupation in a social world, and provide the principles by which people make choices (Ritzer, 2008). Habitus is often unconscious and defines what is possible within a certain group, generating a self-fulfilling prophecy (Schwartz, 1997). This PhD study demonstrates the existence of different habituses, north and south, which can further the understanding of the dynamics of north-south health research.

A lengthy history of north-south power imbalances exists, not only in research, but historically in the broader field of colonisation. The legacy of colonialism appears many times in the findings of this study, equally mentioned by Zambian and northern
researchers (see in particular Chapter 7, Section 7.4.3). There is evidence to show that Zambian researchers at times have accepted these inequities and have chosen to work within the confines of the structure of what is presented to them, for example accepting mid-level research positions, but not striving for leadership positions (see Chapter 7, Section 7.3.3).

Bourdieu’s conclusion that “the practices of the members of the same group are always better harmonised than the agents know or wish” (Bourdieu, 1977) can provide insight into the northern and southern interviewees in this study. North-south inequities were verbalised throughout the interviews by northern and southern researchers, and even when the multiple identities of northern and southern researchers and a shared culture of research were mentioned by some interviewees, it was usually in addition to, rather than in the place of, north-south imbalances. Therefore it is clear that the northern/southern habitus is deeply rooted in these relationships. Another example of habitus is when, in some situations, Zambian researchers considered it ‘natural’ for northern researchers to set the agenda. The assumption that data collection tools would be drafted in the north and adapted to the Zambian context, even in studies that were being undertaken in Zambia alone, illustrates an acceptance of the status quo, that this is how things have always been done (see Chapter 7, Section 7.1.4).

Despite the acceptance of the status quo, many respondents considered these imbalances to be unreasonable. Habitus is considered to be resistant to change and “considered to be more formative of internal dispositions than subsequent socialisation experiences” (Schwartz, 1997). This can provide an explanation for why the north-south divide is more ingrained than the culture of science, the latter being acquired later in life, primarily through third level education. Some examples were given by interviewees where opportunities to change the status quo have arisen slowly for Zambian researchers: namely, opportunities to input into the research agenda (see Chapter 7, Section 7.1.3), to lead data analysis (see Chapter 7, Section 7.2.1) and to lead on authorship of journal articles (see Chapter 7, Section 7.2.2). However, this study suggests that in many cases these opportunities have not yet been taken up, or that change is occurring at a slow pace.
Bourdieu’s *hysteresis* effect can provide a possible explanation for why this is the case. This is when a new opportunity arises within a particular field, but when the agents – in this case researchers - within that field may not immediately recognise these new positions (Bourdieu, 1977). Perhaps these changes in north-south health research are subtle and the changes emerging for Zambian researchers - such as opportunities to set the agenda, analyse the data and lead on research outputs - have not yet been taken on board by the many of them. There were also reports that Zambians often did not have their own research agenda prepared. For example, one researcher said he could not remember the last time he looked online for research funding opportunities. However, one should caution against placing the onus on Zambian researchers to be the sole agents of change, and instead recognise that northern researchers have a role to play in assisting to strengthen the capacity of Zambian researchers, to enable them to avail of these opportunities.

Bourdieu finds *habitus* most useful for explaining behaviour in situations where normative rules are not explicit (Bourdieu, 1977). As already outlined in section 9.2.2, the rules/principles of north-south health research partnerships are often not made explicit. This can lead to a different interpretation of how research partnerships should operate. Bourdieu claims that *habitus* works best in situations where domination operates through interpersonal relations rather than through institutions. Many of the health research collaborations in this study operate through a combination of interpersonal relations and research agreements between research institutions. It was reported by some researchers - north and south - that some northern researchers have an interest in maintaining the *status quo*, in terms of maintaining control over the research process. However, findings show that northern researcher motivations in many cases are altruistic, or illustrate a combination of securing career opportunities, progression and also altruism, in terms of improving health in Zambia, and capacity building for local researchers (see Chapter 7, Section 7.4.1).

A perception exists among some northern and Zambian researchers that northern Universities who have set up research institutions in Zambia, have not succeeded in creating ownership for Zambian researchers (see Chapter 7, Section 7.3.3). This could be due to: a) the expectation that northern researchers will lead on research projects; b) interest of northern researchers that the *status quo* will be maintained to enable
them to retain their academic positions within these institutions; and, c) *hysteresis* effect, because of a time lag between opportunity given to Zambians by northern researchers to lead these institutions, and opportunity taken by Zambian researchers.

In terms of capacity strengthening, many respondents saw this as exposure to research rather than capacity building in the real sense, with the capacity of Zambian researchers strengthened to reach mid-level positions only (see Chapter 7, Section 7.3.3). This could be viewed as the northern researchers’ method of maintaining the *status quo*. This is echoed by the finding that the culture of the research institution in Zambia remains colonial, instilling in Zambians a culture of taking the back seat in north-south health research. In addition, some Zambian researchers accused northern researchers of continuing to carve up the country for research studies, with post-colonial connotations.

In order to analyse REC approval roles and processes through the lens of power, it is essential to analyse the *habitus* of researchers. In order to obtain a complete picture of northern and Zambian RECs, it would be necessary to have interviewed institutional REC members. Ethics are proposed by Bourdieu as being part of the *habitus* (Schwartz, 1997), and it can be deduced that research ethics principles for a particular country might reflect the collective *ethos* of groups of people (Schwartz, 1997). Considering that *habitus* is rooted in the subconscious, it has been the role of this PhD researcher to look for evidence for the existence of different *habitures*, north and south, in relation to research ethics processes. An illustration of this is the attitude of northern researchers, not always expressed openly, that the REC process is an administrative hurdle to be overcome, but without viewing it a substantive stage of the research process that will assist with undertaking ethical research. This was also evidenced by the PhD researchers’ experience of administering the informed consent sheets for this PhD study. The Zambian interviewees were interested in talking through every line of the informed consent sheet in detail with the PhD researcher; however, the northern researchers sometimes perceived it to be an inconvenience and wished to proceed beyond this step as quickly as possible. This points to differences in perceptions of what is ethically important in the research process.

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45 Members of the National Health Research Ethics Committee were interviewed as part of the PhD study.
As has already been discussed, Bourdieu considers that *habitus* is most useful for explaining behavioural patterns in situations where normative rules are not explicit. In relation to the research ethics approval processes, as we have seen from the examples in this study, while research ethics principles are clear, there are differences in how these principles are interpreted. The nature of these different interpretations may not be apparent to the northern and southern RECs involved in the process. This will be discussed further in Chapter 10.

### 9.4 North-south imbalance in capitals

An understanding of the dynamics of power in north-south health research can be deepened through considering each of Bourdieu’s forms of capital. According to Bourdieu (1987), fields are organised around a combination of economic, social, symbolic and cultural capital. Researchers’ accumulation of capital can help us to understand their trajectory and in particular power differentials in the field of north-south health research. The following sections in this chapter analyse economic, social, symbolic and cultural capital, within the field of international academic north-south public health research. There are some cases where there is overlap between capitals, with study results fitting more than one capital. In some cases, these are dealt with in one section to avoid repetition, and in other cases they are included more than once to highlight a particular element of the capital.

#### 9.4.1 Economic Capital

Bourdieu contended that economic capital is “at the root of all other types of capital” (Bourdieu, 1986), thereby proposing it as the capital with the most influence. Economic capital is ‘*immediately and directly convertible into money*’ (Bourdieu, 1986). Findings from this PhD study show that research funds flowed almost exclusively through northern institutions (see Chapter 7, see Section 7.1.2) thereby instilling economic capital with the northern partners. Indeed, the primacy of

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*It should be noted that other models of funding exist, where funding is channelled directly south, such as the Alliance for Health Policy and Systems Research. This model was not discussed or represented within this study sample.*
economic capital was recognised by researchers themselves, many of whom concluded that as long as funding flows solely through the north, this will ensure that power remains with the north, no matter how much possession of other capitals shifts to either a state of equilibrium, or in favour of Zambian researchers.

A recurring theme was the reference to US research institutions being more controlling than European institutions (see for example Chapter 7, Section 7.1.2), in terms of dictating what funds can be utilised for, showing perhaps that some US institutions may use economic capital to exert control over other elements of the field, such as agenda setting and analysis. Not surprisingly, respondents repeatedly cited research donors as occupying the dominant position in terms of dictating both the broad agenda and the partnership format, showing that being in possession of economic capital secures a knock-on effect for control in other elements of the research process. Donors are in possession of the greatest amount of economic capital, followed by northern researchers, and lastly Zambian researchers. Reasons given for the direction of funding flows imply that unless capacity can be built for Zambian researchers to manage health research partnerships, it is unlikely that Zambian economic capital will be substantially increased in the short term. To add to the deficiency of economic capital of individual Zambian researchers, research institutions in Zambia also lack economic capital, through an unwillingness of donors to support them, in terms of building institutional capacity (see Chapter 7, Section 7.3.4).

There was also a hint at jealousies amongst Zambian researchers, reported by a senior Zambian researcher at UNZA, who stated that attempts to coordinate research within the University were met with suspicion that Departments within the University were trying to ‘grab one another’s money’. At the national level in Zambia, financial support from donors for research is not coordinated, nor are there policy guidelines to provide direction with regard to which health research priorities should be funded (see Chapter 6, Section 6.3.1 & 6.3.2). National level respondents also recognised the implications of economic capital resting in the hand of external researchers and donors, which can result in the Zambian government not paying due attention to study findings, because they are perceived to be imposed externally.
Perhaps the most interesting finding in relation to economic capital is the common perception, of poor individual Zambian researchers versus affluent individual northern researchers, and the belief that Zambian researchers choose a research career only for the salary. Choice due to actual interest in research or a particular research topic, was sometimes seen to be a northern luxury. For one research project, in an attempt to increase the economic capital of southern researchers, financial control was placed with a South African partner. However, because South Africa is generally seen to be somewhere in between the northern and southern camp, it resulted in them being viewed as the new colonial power.

One of the reasons given by Zambian researchers as to why research partnerships with the north should continue was high northern economic capital status, which would provide opportunities for Zambians as well as northern researchers (see Chapter 7, Section 7.5). It was hinted by some northern researchers that they have too much to lose (i.e. their careers) by relinquishing economic capital (see Chapter 7, Section 7.4.1). However, it is not always seen to be a straightforward issue in terms of northerners only considering their careers, in that many believe that they are using their access to funds to: a) undertake research on important public health problems in Zambia; and, (b) to increase Zambian researcher capacity. It was sometimes viewed that Zambian researchers ‘sell themselves’, accepting northern initiated research partnerships in order to increase their economic capital, even though the agenda did not accord with Zambian priorities (see Chapter 7, Section 7.1.3).

Zambian RECs were sometimes perceived to rubber stamp REC authorisation to obtain international funding. In another example, one respondent accused a REC member of approving projects that she was on the payroll of, thus contributing to economic capital for Zambian researchers. This fits with the concept of agencies seeking to maximise economic capital, as outlined in Bourdieu’s framework, which was recognised as being unethical by northern researchers, but was not mentioned by Zambian researchers.
9.4.2 Social capital

As explained in Chapter 2, Bourdieu refers to social capital to explain how people gain access to powerful positions through social connections (Ritzer, 2008). Bourdieu sees these connections as either producing or reproducing inequality, rather than as a way to promote equality. In terms of initiation of north-south research collaborations, it is clear that social capital is in abundance for both northern and Zambian partners in this study, as both used social capital – previous connections in the form of either personal or institutional links – to support attempts to gain economic capital, i.e. the research grant (see Section 7.1.1). While northern researchers generally have more direct access to social capital, due to connections with donors, both northern and southern partners need one another, though for different reasons. This is due to donor requirements to include certain countries in a research bid, because the focus of the research is in the south, but also because the National Health Research Act (2013), states that parachute research must no longer be undertaken in Zambia, stipulating that a Zambian must be a Principal Investigator or co-Principal Investigator on every study (see Chapter 6, Section 6.3.2).

Examples were given by a number of researchers that connections with Zambian researchers were used to steamroll agendas that northerners wished to pursue (see Chapter 7, Section 7.1.3). However, Zambians sometimes blamed themselves for not exploiting their own social connections to gain access to funding, and also with not being in tune with the needs of local communities. It might be suggested that the onus is partly on Zambian researchers to ensure that they make suitable social connections to fit with an appropriate agenda for health research in Zambia; that is, to seek out northern researchers who have an interest in health research topics of relevance in Zambia. However, it must be stated that eligibility for funding is often pre-defined and ‘tied aid’ is the norm, where European or US researchers have ring fenced access to their own national or EU research funding for pre-defined topics, and is therefore outside the control of Zambian researchers. Two Zambian researchers viewed Zambian researchers as showing authority when it came to agenda setting, and that they only accepted a proposal if it matched Zambian priorities (see Chapter 7, Section 7.1.3).

Paradoxically, the area of ‘capacity building’ was sometimes seen to benefit the northern researchers rather than the Zambians for which it was intended. This was
demonstrated through the contention that capacity building was in fact exposure to research, and with the purpose of enabling Zambian researchers to collaborate more effectively with northern researchers, rather than to undertake research under their own leadership. This may be framed as social capital playing a role in perpetuating inequality.

A strong perspective emerging from northern and southern researchers is that even where there are positive social connections between researchers, such as trust and respect, there was an overall view that north-south inequities and power imbalances continue to exist. Within an analysis of social capital, it could be attributed to the use of social connections to obtain and/or perpetuate this inequity. There were examples of northern researchers attempting to use their position to reverse their position of power, without success. The first example was where the northern researchers played a non-interventionist role in order not to be perceived as the dominant partner. However, rather than the desired result being obtained, they were perceived by southern researchers in the partnership as not pulling their weight. The other example was the attempt to shift social connections to the south, resulting in the South African partner being placed in the role of the new colonial partner.

9.4.3 Symbolic capital
Bourdieu contended that symbolic capital is a resource available to an individual based on prestige, recognition, and honour (Bourdieu & Wacquant, 1992). Scientific capital is classed as a form of symbolic capital based on the prestige of the University they are attached to and one’s membership of committees. It is within symbolic capital – and to a lesser extent, cultural capital - that the culture of science can be examined. Given the small number of northern research institutions that attract the bulk of research funding in Zambia, symbolic capital is closely related to and overlaps with social capital.

Bourdieu contended that symbolic systems are classification systems based on dichotomies such as inside and outside, and rare and common (1977). The dichotomy of north and south is well entrenched, not just in relation to research, but in respect to

47 Scientific capital is also directly linked to economic capital, particularly publications and citation ranks.
broader society. Scientists compete for scientific capital in the field of science (Schwartz, 1997), or in the case of the field of north-south health research, use it to support a competition for research capital.

There was a perception amongst many interviewees that Zambian research institutions did not have the capacity to manage funds and were seen by donors to be risky and suspicious, which was in contrast to northern researchers/institutions possessing the prestige to be viewed by funders as trustworthy. This could be attributed to the reputation - or symbolic capital and lack of it - which both north and Zambians have acquired over time. There are genuine reasons for considering Zambian researchers to be risky, due to lack of capacity to manage finances at the institutional level. The designation of Zambian researchers as being risky *per se*, bestows a stereotype on Zambian researchers which serves to their disadvantage. Effectively, symbolic capital here can be interpreted as dictating the weight of economic capital. US institutions sometimes possessed less symbolic capital than European partners in the eyes of a number of Zambian respondents, in terms of being seen as more controlling than European partners and less respected by Zambian researchers (see Chapter 7, Section 7.1.2). In compensation, they could often access economic capital (through tied research funds) more easily.

Examples of scientific capital are plentiful, particularly through reports that two northern respondents pursued a particular research topic, despite the MoH stating it was not relevant to the needs of the country. This can be interpreted as an example of a belief in the scientific autonomy of the researcher, whilst not adhering to local priorities (see Chapter 7, Section 7.1.3). The fact that it was possible for northern researchers to proceed with studies, despite it not being a priority issue, can be seen as due to scientific capital or *‘academic power’* (Jenkins, 2002), as well as the economic capital of the northern researcher. Zambians therefore can be seen as lacking, or not utilising, scientific capital through not being proactive in agenda setting. Their unwillingness to input into drafts of proposals could signify an absence of ownership of the research; and/or a lack of capacity to input, both of which can be interpreted as less (or less confidence in their) forms of scientific capital.
There was often an assumption that tools would be drafted in the north and adapted to the Zambian context (see Chapter 7, Section 7.1.4). This suggests that the weight of symbolic capital for northern institutions would appear to outweigh the cultural capital, which is more in abundance for Zambian researchers (see Section 9.4.4). The contradiction of northern researchers leading on data analysis, even though in most cases they were not leading on the data collection process (see Chapter 7, Section 7.2.1), can also be explained through the lens of symbolic/scientific capital. Even though northern researchers were often perceived to have a poor understanding of Zambian contextual issues – i.e. poor cultural capital, (see section 9.4.4) - scientific/symbolic capital seems to be stronger in northern Universities, who possess more capacity to undertake in-depth analysis. An example was given where a South African researcher was ‘forced’ to undertake research analyses, i.e. did so reluctantly, even when she had not been involved in the design of the study and lacked knowledge of the Zambian health system (see Chapter 7, Section 7.2.1). This can be attributed to symbolic/scientific capital of northern researchers, through their assumption that their capacity will be higher, due to their northern position.

An abundance of literature points to HIC researchers dominating the authorship process. However, results from this PhD study have shown that in many cases Zambian researchers were favoured in decisions around authorship of papers. This runs contrary to international authorship guidelines and was seen by some northern researchers to be unethical. Interestingly, this issue not raised by Zambian researchers. In this case, Zambian researchers can be seen to hold the majority of scientific/symbolic capital, making it appear that their dearth in capacity is advantageous when it comes to authorship. This sometimes led to frustration amongst northern researchers who reported that they were under more pressure to publish than Zambians (see Chapter 7, Section 7.2.2).

Most respondents discussed research capacity strengthening from a one-way, north-south perspective, suggesting that due to the symbolic (scientific) capital of northern researchers, there is an assumption that they alone have the knowledge and capacity to impart to the south. Another issue concerning an absence of scientific capacity was Zambian researchers lacking symbolic capital in the form of not being enabled to build
up expertise in a particular research topic due to a constant chase to follow funding opportunities.

The fallout of the Lujo virus outbreak, where blood samples were taken out of Zambia without permission (see Chapter 6, Section 6.6.1), can be interpreted as a lack of scientific/symbolic capital on the part of the Zambian government, resulting in the Government responding to power imbalances, and attempting to increase scientific capital and to gain power/control over the northern dominated research system (see Chapter 6, Section 6.2.1). Their response can be considered to be: i) a reaction to the history of parachute research in Zambia and an attempt to assert control and reverse the balance of power; ii) a genuine belief that this was unethical; or, iii) a combination of the two. Perhaps the most interesting finding in relation to the Lujo virus outbreak were the divergent views, north and south, on the response to the outbreak. Some researchers in the northern community heralded it as an exemplary example of north-south collaboration, however, the Zambian government and some Zambian researchers saw it as being unethical (see Chapter 10, Section 10.5 for further interpretation of this in relation to cultural competence).

A number of issues arise in relation to possession of symbolic capital in the arena of health research ethics approval processes. One MoH stakeholder with responsibility for health research was concerned about northern research institutions who expected to get an ethical waiver from Zambian RECs, due to the fact that they had already obtained northern approval. This displays a belief that their position as a northern institution that has received approval from a northern REC, automatically assumes an adherence to high global ethical standards without the need to apply to Zambian RECs. However, this was not the case for collaborations in this PhD study, all of which sought approval in both the north and Zambia.

A dominant theme is the perception by Zambian researchers that northern research ethical standards are more rigorous than those in Zambia, and that northern involvement in REC processes is a safety net to ensure that international standards are adhered to (see Chapter 8, Section 8.1.2). This is likely to be due to a shorter history of research ethics approval processes and lower REC capacity, although this was not specifically mentioned, in Zambia. This suggests that northern RECs possess more
symbolic capital than their Zambian counterparts. Another paradox emerges in that informed consent sheets are often designed in the HIC, and adapted to the Zambian context, again displaying the balance of symbolic capital to be more in favour of the northern researchers.

9.4.4 Cultural capital

According to Bourdieu (1977) three kinds of cultural capital exist:

- **Internalised**: referring to dispositions that are internalised by the individual. This will be analysed as: i) national health research culture in Zambia; and, ii) north-south culture of researchers.

- **Objectified**: such as scientific instruments. This will be interpreted as the culture of science.

- **Institutionalised**: such as educational credential systems, qualifications and titles. In this thesis, this will be interpreted as education and work culture.

An apparent irony emerged in the arena of cultural capital for agenda setting. Zambian researchers possess more cultural capital than northern researchers, yet, predominantly they do not set the agenda in north-south health research. Through the lens of Bourdieu, this displays the subordinate position of cultural capital to economic capital and symbolic capital combined. An example of this is that despite respondents’ views that northern researchers lacked understanding of context in agenda setting and research design, in some cases northern researchers insisted on standardised questions, even though they were not well suited to the Zambian context. (see Chapter 7, Section 7.1.4). It is difficult to understand why this should be the case in a position where the research was solely taking place in Zambia, and not as part of a cross-country study.

Taking institutionalised cultural capital as described by Bourdieu, a number of researchers mentioned that the culture of the Zambian research institution is colonial, therefore instilling Zambians to take a back seat in health research. This potentially shows cultural capital for northern researchers as being greater. Findings show a
paradox of northern researchers leading on data analysis, even though in most cases they were not leading on the data collection process (see Chapter 7, Section 7.2.1). Even though northern researchers were often perceived to have a poor understanding of Zambian contextual issues, i.e. poor cultural competence (discussed further in Chapter 10), scientific/symbolic capital is stronger in northern research institutions who possess more capacity to undertake in-depth analysis. Some northern researchers were acutely aware of this, expressing their discomfort with the situation, however others did not see this deficiency in cultural awareness as presenting a problem. This is another example of the symbolic/scientific capital of northern researchers overriding cultural capital, through their assumption that due to their northern position, their capacity to undertake data analysis will be higher.

Sometimes the culture of science (objectified culture) and community culture (internalised culture) were perceived by respondents as clashing, particularly as the culture of science ensured that researchers - north and south - remain distanced from the communities they study. To break this down further, within the culture of science, disciplinary differences exist, where northern anthropologists were seen to have a better understanding of cultural issues due to their training; and also that African clinical doctors were sometimes viewed as understanding social science more readily than their Western counterparts, due to a ‘natural empathy’ with it (see Chapter 8, Section 8.2.4).

A key finding from the study is that while broad ethical principles are universal, how they are applied differs depending on research context. It is clear from the findings (and perhaps obvious) that the Zambian REC has the monopoly on cultural capital vis-a-vis the northern REC. The primary role of the Zambian REC committees was seen to be in ensuring cultural sensitivity (see Chapter 8, Section 8.1.2). Delays in northern REC approval were ascribed to members’ deficient understanding of cultural and contextual contexts in Zambia. This was compounded by an absence of communication between northern and southern RECs. A solution for REC review would be to combine the most proficient of all the capitals, i.e. scientific (north in terms of capacity) and cultural (Zambian) in order for all RECs to play a role. In the long term, the ideal would be where the Zambian REC would have the capacity to review according to international standards, without northern committee involvement.
At the point of fieldwork, Zambian respondents often viewed northern researchers as lacking the capacity to understand the culture and context of communities (see Chapter 8, Section 8.2.2), therefore lacking cultural capital, particularly those who participated in fieldwork for only for short periods of time. Northern researchers seemed to be aware that their presence could have an influence on the research results, and as a result in some cases avoided involvement on the front line (see Chapter 8, Section 8.2.3). However some northern respondents felt that it was important that they take part in some of the data collection. This fits with the concept of them recognising the need to acquire some degree of cultural capital. Interestingly, even when they did participate, there was the perception that due to a different worldview, and to an absence of Ubuntu, (discussed further in Chapter 10) northern researchers will never be fully able to understand Zambian communities. This is particularly evidenced by the experiences of northern researchers leading the community engagement process in some studies, and ignoring community research protocols for engagement, resulting in studies being abandoned in these communities (see Chapter 8, Section 8.2.2). This is in contrast to the assertion that Zambian researchers need to be "custodians of their own culture”, suggesting they should have an innate closeness with the communities being researched, even when Zambian researchers were not considered to be complete insiders.

The Microbicide Development Programme Trial (MDP) trial is a fascinating example of north-south differences in opinion on appropriate community engagement. Even though some of the northern researchers considered that the communities involved in the trial were sensitised according to the highest appropriate local standards, it became clear that this was not the perspective of the Zambian researchers. It was clear also that the MoH was not sensitised properly in relation to the study, and perhaps lacked cultural and scientific capital and competence, as suggested by its delay of eight months before making an official statement in relation to the study. At this stage, the local community, and the Zambian public at large, were enraged at the process (see Chapter 6, Section 6.6.2). Cultural capital is the only capital that Zambian researchers possess more than northern researchers, in the field of north-south health research.
9.5 Conclusion

This chapter aimed to explain why power imbalances exist and persist in international academic north-south health research (Research Objective 3), using concepts from Bourdieu’s theory of *Power and Practice* (1977). The application of this theory has a number of uses for highlighting new aspects of researcher relationships and inequities at each stage of the research process.

Firstly, *habitus* helps us to understand the, sometimes, unconscious maintenance of the inequitable *status-quo* in north-south health research. This thesis illustrates that different *habituses* exist, north and south, which are central to understanding the dynamics of north-south health research. These are *habituses* of domination (northern) and subordination (Zambian) in relation to researcher relationships; and different perceptions of the application of research ethics principles, north and south. It is recognised that these are generalisations and stereotypes, used for typing and analysis of findings. However, the results showed a propensity among most respondents from each location to gravitate towards these identities.

Secondly, Bourdieu’s *hysteresis* effect provides a possible explanation for why power differentials continue to exist. In some cases, new opportunities have arisen for Zambian researchers; however, they may not immediately recognise and grasp them (Bourdieu, 2000). Perhaps these changes in north-south health research are subtle and the increasing opportunities for Zambian researchers (in agenda setting, data analysis and authorship) have not yet been fully taken on board by the Zambian researchers. Studies in the area of north-south health research consistently report a lack of capacity in the south as being one of the major reasons for north-south power imbalances. While this is undoubtedly the case - new opportunities without sufficient capacity strengthening will result in the maintenance of the *status quo* - Bourdieu’s concepts of *habitus* and *hysteresis* highlight other reasons for perpetuating power imbalances and inequity, other than those mentioned in the literature.

Thirdly, it allows us to explain how diverse resources – capitals – are used to explain these power imbalances, where northern researchers are often in possession of more economic, symbolic and social capital *vis-a-vis* Zambian researchers; while Zambian researchers possess more cultural capital, *vis-a-vis* northern researchers. There is a
degree of overlap between the four capitals, showing that findings do not always fall neatly under one form of capital. The literature illustrates that while power is regularly reported in north-south health research, it is rarely discussed in detail between research partners. A recognition of the different elements of power by northern and southern researchers could pave the way for more equitable partnerships. At the national level, Zambia is at a turning point in terms of taking charge of the national health research system. However it remains to be seen if the setting up of NHRAZ will result in national ownership of the health research system.

Bourdieu's work has been criticised for concentrating on the internal analysis of fields, which may encourage a loss of sight as to how fields are connected into broader society, and his framework stresses the propensity to perpetuate structures inherited from the past, rather than encouraging researchers to seek out forms of change (Jenkins, 2002). This thesis uses Bourdieu's analysis to highlight and understand the perceptions of researchers interviewed rather than to understand how the situation could change.

Bourdieu's theory is a useful heuristic to explain power in north-south health research, and is one lens through which to interpret the findings. However, the heuristic of power does not alone explain situated research ethics. Chapter 10 provides another lens to interpret the results, through culture. It is clear that power and culture are linked, as evidenced through cultural capital. In Chapter 10, cultural competence will discuss the other key element of a situated ethics analysis, as identified by the framework developed for this thesis. Together, these analyses will enable an understanding of the different ethos of north-south health research, which will be deliberated in Chapter 11.
Chapter 10: Cultural competence and ethical context in north-south health research

“To view other’s way of life in terms of our own cultural glasses is called ethnocentrism. Becoming conscious of, and analytic about, our own cultural glasses is a painful business. We do so best by learning about other people’s glasses. Although we can never take our glasses off to find out what the world is ‘really like’, or try looking through anyone else’s without ours on as well, we can at least learn a good deal about our own prescription.” (Keesing & Strathern, 1998)

Figure 11: Culture in north-south health research
10.1 Introduction

Within the conceptual framework for this thesis, culture is the second key component of situated research ethics. As has already been established in Chapters 1 and 2, culture is a central heuristic to analyse health research collaborations that cross cultural divides (see Figure 11). This thesis analyses culture through two lenses. Firstly, culture is analysed in relation to power, through the heuristic of Bourdieu’s cultural capital (Chapter 9). Secondly, this chapter uses a model of cultural competence as a tool through which to analyse the role of culture in north-south health research, addressing Research Objective 4 of this PhD study. The research question to be addressed is: how does culture influence north-south health research and how aware are researchers of their culture in relation to the research process? An adaptation of Papadopoulous & Lees’ (2002) model of cultural competence will be used to address this. The debate on ethical universalism versus relativism, which was introduced in Chapter 2, is returned to within a discussion on cultural competence to elucidate how this is interpreted within the Zambian micro health research ethics system. Some of the north-south dichotomies discussed in relation to power in Chapter 9 are broken down further, into a more complex discussion, particularly around researcher identity, where north-south differences are discussed in a more nuanced way.

This chapter also examines the cross-cutting issue of researcher identity, in particular if southern and northern perceptions of one another are symmetrical or asymmetrical within the context of cultural competence (Simon & Mosavel, 2011; Guillemin & Guillam (2004) (see Chapter 2). Symmetry refers to when other researcher perceptions of who they are corresponds with their own. Asymmetry is when perceptions do not accord with the other (Simon & Mosavel, 2011). This will be analysed from the perspective of whether northern researchers’ perceptions of who they are corresponds with southern perceptions of their culture; and whether southern perceptions of their own identity correspond with northern perception of their culture.
Figure 12: A model for cultural competence in international academic north-south public health research (adapted from Papadopolous & Lees, 2002)

An important qualifier in analysing culture, is to highlight that while this PhD study specifically analyses north-south culture, and to a lesser extent the culture of science, it is recognised that that there will always be variations and differences within and between cultures, including multiple identities. Culture is recognised as ‘an abstraction created as an analytical simplification’ (Keesing & Strathern, 1998). In this way, the chapter provides a critique of Chapter 9, in that there is more recognition of the complexity associated with north-south health research, with the avoidance of stereotypes and straightforward dichotomies.

There are two primary reasons for using culture as an analytical category in this PhD study. Firstly, culture is a term that has been used widely in the literature. Secondly, culture was a term that was used extensively by both northern and southern researchers during the interviews, and interviewees often considered a northern or southern culture to be dominant in research collaborations. The use of a model of cultural competence was not identified from the outset of the study. Once interviewees identified culture as being significant in north-south research
collaborations, cultural competence was chosen as an appropriate model to represent culture.

### 10.2 Cultural competence in north-south health research

This chapter utilises a model of cultural competence for research, adapted from Papadopolous & Lees (2002) (Figure 12)

[48], to analyse culture in north-south health research, under four themes: cultural awareness, cultural knowledge, cultural sensitivity and cultural competence. Chapter 2 has introduced the main components of this model including where it differs to that developed by Papadopolous & Lees (2002). Cultural competence is the ability of researchers to undertake research that takes an awareness of culture into consideration at each stage of the research process (Clark et al, 2012) and also in research relationships (Papadopolous & Lees, 2002). It is considered essential for the conduct of ethical research (Papadopolous & Lees, 2012). Where cultural competence in research has been addressed, it primarily has focused on: i) researchers comparing research topics across a number of cultures, ii) when researchers and study participants are from different cultures/backgrounds; and, iii) application of tools developed in one context to another context (Clark, 2012). No model was found to analyse cultural competence specifically in relation to research undertaken between researchers from the global north and global south. The cultural competence of both northern and southern researchers will be discussed in this chapter, as evidenced in the research findings (Chapters 7 and 8). However, considering the research collaborations in this study address research in Zambia, the focus will be more on levels of northern researcher competence in relation to Zambian culture.

### 10.3 Cultural awareness

Cultural awareness involves the process of reflexivity on the part of the researcher, that is, being able to reflect on how their own values, perceptions, behaviour or presence and those of the respondents can affect the data they collect (Parahoo,

[48] Text in red illustrates where the model has been adapted for this PhD study.
1997). The interviewer in this PhD study requested researchers to reflect not only on how their values affect the data they collect, but in relation to the entire research process, ranging from priority setting to data analysis, to relationships with other researchers.

PhD study findings illustrate that most researchers – in particular northern researchers - showed abundant self-awareness of their values in relation to undertaking research in Zambia. This is evidenced by a number of northern researchers openly questioning their roles in north-south health research, in terms of realising the power imbalances that exist. Many reported a degree of discomfort with the status quo of northern researchers dominating the research collaborations; and, in particular about the position of the northern researcher, which had post-colonial undertones (see Chapter 7, Section 7.4.3). This can be interpreted in light of Geissler’s (2013) study, which suggests that inequities are often not openly discussed in a desire to break from the colonial past. However, this study found that many references were made – both north and south – to power imbalances and to the culture of aid and colonisation, which they perceived as a remaining defining feature of north-south research. This was sometimes attributed, by northern and Zambian researchers (see Section 7.4.3), to Zambia receiving significant aid and where northern researchers are expected to come in to solve problems.

In terms of researcher identity49, it has been central to this PhD study to explore whether researchers view themselves as being: i) northern; ii) southern; iii) a researcher/scientist first and foremost; or, iv) a nuanced combination of these. Most perceptions of researcher identity (Simon & Mosavel, 2011) – introduced in Chapter 2 - were in relation to researchers identifying themselves as either northern or southern researchers, and in most cases, researchers raised these issues as being the most important issues within north-south research collaborations. However, multiple identities were sometimes highlighted, particularly in relation to: research discipline; length of time a northern researcher had spent in Zambia; or length of time a Zambian researcher had spent in the north. Overall, results show awareness on the part of northern researchers of their position of power in relation to the research process and

49 Researcher identity: “the identities that researchers ascribe to themselves, or have ascribed to them in their places of research” (Simon & Mosavel, 2011).
these perceptions are for the most part symmetrical, in that Zambian researchers also hold this view.

One of the elements of cultural awareness is ethnocentricity, “the assumption that your own culture, values, ways of doing things – the ones that you have learned and internalised – are the only or the best or the most valid ones” (Pool & Geissler, 2005). In general, northern or southern interviewees did not demonstrate ethnocentrism in their responses and reported practice. However, there is some evidence of this through the assumption in some cases that the agenda would be set in the north (see Chapter 7, Section 7.1.3) and that data analysis would be led by the northern researchers (see Chapter 7, Section 7.2.1), perhaps demonstrating a paternalism that northern researchers know best. However, this could also be interpreted as northern researchers being in possession of greater research capacity, or in a position to make decisions on the agenda (due to proximity to donors); and to undertake analysis, because of methodological expertise or back-up (for example in the form of biostatisticians). A strong theme emerging from the interviews was that many northern researchers showed a poor understanding and knowledge of Zambian contextual and cultural issues (see Chapter 7, Section 7.2.2). This was highlighted by both northern and Zambian researchers. Exceptions were noted however, where some northern researchers who had spent lengthy periods of time in Zambia were perceived to have greater cultural awareness, by both northern and Zambian researchers.

Whilst in some collaborations, tools were modified to suit country context, there were a number of references to tools and questions being ‘enforced’, even though they did not fit contextually. However, it was mentioned on one occasion that despite the fact that each country were given the freedom to adapt tools to country context, research teams did not alter them, perhaps also displaying a lack of cultural awareness or compliance on the part of Zambian researchers. This is discussed further in Section 10.3.

van Teijlingen and Simkhada (2012) considered that HIC researchers might display arrogance or paternalism and believe that ethical approval from an institution in a HIC is sufficient or even superior. Results from this PhD study reveal that this was not necessarily paternalism – or ethnocentrism - on the part of the northern researchers,
but rather it was the Zambian researchers that sometimes held the views that the northern RECs were superior. Relating this to symmetry/asymmetry, this illustrates that sometimes there was asymmetry in relation to the REC process. Northern researchers often considered the Zambian REC to be more important, while many Zambian researchers considered northern RECs standards to be more rigorous.

10.4 Cultural knowledge

Cultural knowledge is needed to understand similarities, differences and inequalities in health research. It is achieved through contact with people from different cultural groups as well as from different disciplines (Papadopolous & Lees, 2002). Of central importance to cultural knowledge is the avoidance of essentialism, which assumes that cultural differences supersede other aspects of their existence (Papadopolous & Lees, 2002). The adaptation of the cultural competence model for this PhD study focuses on disciplinary understanding and the avoidance of essentialism. Through discussing the ethics of north-south health research, it is important not to reduce all issues to a north-south dichotomy, and the findings in this study show that multiple cultures exist. A deficiency of cultural knowledge was not restricted to northern researchers alone. Many Zambian researchers considered themselves to be part of a culture of science, which ensured they remained at a distance from the communities they study, (see Chapter 7, Section 7.2.1) due to cultural differences, through being more educated, wealthier and urban dwelling, and with few opportunities for obtaining an adequate knowledge of rural community culture.

A small number of Zambian researchers spoke about some northern researchers having a good grasp of contextual issues in Zambia (see Chapter 7, Section 7.2.1) and the importance of recognising that multiple identities exist, incorporating individual and disciplinary differences. Northern anthropologists were generally seen as having a better understanding of the cultural dimensions of public health research in Zambia, while medical doctors were criticised by two respondents as not spending enough time in the field and not understanding community engagement dynamics (see Chapter 8, Section 8.2.3 & 8.2.4). The importance of different disciplines collaborating - to be able to view the research from different perspectives - was highlighted, guarding against
the dangers of reducing a lack of cultural knowledge to the polarities associated with north-south identities. There was a sense of frustration among some interviewees that northern researchers lumped African countries together, instead of focusing on different country contexts, therefore displaying a lack of cultural knowledge.

Whilst ensuring northern researchers are equipped with Zambian cultural knowledge is a stepping stone to working towards cultural competence, a Zambian understanding of northern culture is also critical if research partnerships are to succeed. A small number of respondents spoke of the culture of academia overriding north-south cultural differences (see Chapter 8, Section 8.2.4). Standardised global research methodologies and technologies were mentioned, although primarily in relation to Randomised Controlled Trials. Others attributed an absence of north-south cultural differences to partners who had worked in Zambia previously, or that many Zambian researchers were educated in the north, therefore displaying an awareness of the nuances of one another’s culture. It was also mentioned that there are pressures for the internationalisation of research culture within scientific circles. Furthermore, it was acknowledged that cultural issues are adequately addressed theoretically in international health training, and that local collaboration is key to assist with understanding. This emphasises that the onus should not always be on the northern researcher, instead recognising that both northern and southern researchers have a role to play in fostering appropriate cultural knowledge in collaborative research.

In terms of work culture, there was a general asymmetry between Zambian perceptions of northern work culture and their own. There were frequent references to northern researchers ability to remain in employment at a University following completion of a research study, with only one Zambian researcher recognising that northern researchers also do not have stability of tenure. This was in contrast to northern researchers often stating that a research career is not an easy path and often does not provide stability of tenure. Zambian researchers sometimes reported an absence of knowledge on the part of northern researchers of the culture of work in Zambia which was said to be influenced by extended family pressures and the need to undertake consultancies (see Chapter 7, Section 7.3.5), which was not present with northern work culture. However, on closer inspection of the findings, many northern researchers mentioned differences in work ethos, due to the different value
attachments to family which were reported to be stronger in Zambia; perhaps in some cases showing greater cultural knowledge than Zambian researchers gave them credit for.

The analysis suggests that many northern and southern researchers perceived that there were differences in ethical considerations of northern and Zambian RECs, meaning that RECs begin study reviews from different perspectives and consider different issues when reviewing a study. It is clear from the findings that most researchers adopt the middle ground between ethical universalism and ethical relativism as proposed by Macklin (2012) and Benatar (2002, 2004) (see Chapter 2, section 2.6.2), recognising that while universal research ethical principles exist, how they are played out in practice depends on culture and context. It is critical to note that while most researchers displayed a definite awareness of this, they did not necessarily possess the knowledge of what these differences are. With reports of little contact between northern and Zambian RECs (see Chapter 8, section 8.1.2), it is unlikely that reported differences in ethical requirements of northern and southern committees will be understood by REC members or researchers, at least in the short term.

It appears that in many cases, the Zambian REC approval process took precedence over the northern REC, particularly where there were differences in opinions, on whether certain parts of a study posed an ethical problem. This could mean that an acknowledgement of an inability to grasp an in-depth knowledge of contextual issues, can lead to a proposal being approved and passed to the Zambian REC.

**10.5 Cultural sensitivity**

Papadopolous & Lees (2002) state that cultural sensitivity is achieved through researchers considering participants in research as true partners. This PhD study adds other researchers to the model, that is, to what extent do researchers consider other researchers in the collaboration as true partners. Qualities associated with cultural sensitivity are: trust, empathy, communication skills, acceptance, appropriateness and respect (Papadopolous & Lees, 2002). The concept of Ubuntu (described in Chapter 5,
Section 5.2.6) has been included in the adaptation of the model of cultural competence, as a key emerging theme from the findings.

For some researchers, north and south, terms such as “shared meaning”, “trust” and “respect” were expressed, showing that a certain degree of cultural sensitivity exists. Many interviewees spoke about Zambians being less direct in their partnership relationships than their northern partners. All but one of these statements came from northern researchers. This might suggest asymmetry in relation to northern and Zambian perceptions of Zambian researchers, or it may display an unwillingness on the part of Zambian researchers to admit this to the northern PhD researcher. Some northern researchers expressed the view that a culture exists in Zambia of being polite and reluctant to evoke confrontation. Living in Zambia for extended periods of time was considered to be key to obtaining cultural sensitivity. Similarly, experience of conducting research in diverse cultural contexts meant an easier adaptation to the Zambian context.

It emerged from a number of interviews, that the role of the local Zambian REC was primarily to ensure cultural sensitivity, which was considered not to be captured in the north. This echoes Hyder et al. (2004) findings that the majority of developing country researchers considered that US review committee regulations were insensitive to local culture.

Interviewees in this PhD study were asked to give their opinions on the interface between communities and researchers during fieldwork and if there was a difference between northern and southern researchers, particularly in terms of culture. A key issue emerging from the findings is that cultural sensitivity - or lack of it in the case of many northern researchers - is the most important issue when it comes to data collection. This can generally be seen from the perspective of insider/outsider status (Ganga & Scott, 2006, Merriam et al., 2001).

Zambian respondents frequently viewed northern researchers as lacking the capacity to fully understand the context and culture of local communities, particularly when their presence on the ground was for only a short period of the fieldwork (see Chapter 8, Section 8.2.3). Interestingly, while this was discussed by both northern and Zambian
researchers alike, only Zambian researchers mentioned it in relation to Ubuntu\(^{50}\), (see Chapter 8, Section 8.2.2). The concept of Ubuntu was raised frequently by Zambian researchers, as being central to Zambian culture, and was portrayed as a code of ethics that is embedded in African culture (Nussbaum, 2003), a meaningful comprehension of which appears to be beyond the grasp of northern researchers. This displays not so much symmetry in relation to researcher identity, but rather an absence of awareness/knowledge of Ubuntu on the part of northern researchers, which is considered central in Zambia.

It was reported that the presence of a northern researcher creates expectations amongst the communities being researched, for example being seen as gateways to funding (see Chapter 8, Section 8.2.3), regardless of the degree of cultural sensitivity displayed by the northern researcher. This displays symmetry in relation to researcher identity, north and south. It was sometimes perceived by northern and southern researchers, that the perception was different for Zambian researchers, who were considered to be closer to the community, even if their background was different in terms of socio-economic status and education. This might suggest that even with the greatest degree of cultural sensitivity, northern researchers will be considered as outsiders. It is interesting that the perception of Satanism is reported to be reserved more for northern researchers, although with the history of biomedical research primarily following the parachute or safari model, the face of these studies in the past was likely to have been the muzungu.

However, a lack of cultural sensitivity can also be seen in relation to the MDP Trial, with the MoH not recognising the outrage of communities involved in the study and the general public, therefore perceiving a lack of cultural sensitivity on the part of the Zambian Government (see Chapter 6, Section 6.6.2). It could be interpreted from responses in relation to the Lujo virus, that a lack of sensitivity was displayed on the part of northern researchers, due to samples being exported to the US. It is clear from interpretation of the findings that exporting biological samples was not considered to be an ethical concern for northern researchers interviewed, yet it was an important ethical issue for many Zambian researchers and national level stakeholders. However,

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\(^{50}\) Ubuntu: where the individual is seen as inseparable from the community which he or she belongs, highlighting the importance of the collective over the individual (Harrowing et al, 2010).
the question must be asked, as to which response is more appropriate? i) a culturally sensitive response that results in people dying; or, ii) a culturally insensitive response that saves people’s lives? There may be times when the science is a matter of life and death, that it should take precedence over cultural sensitivity.

Generally, the northern RECs were considered to be more concerned with informed consent sheets than UNZA RECs (see Chapter 8, Section 8.1.3). Several researchers reported how informed consent works differently in countries where people do not have a concept of informed consent as a procedure. Results from this PhD study have shown that consent forms continue to be designed in HIC. This begs the question as to why this continues to be the case despite the evidence to show that it poses problems for the informed consent process. This was described by Zambian researchers in relation to an example of a lack of understanding of Ubuntu, but also points to an absence of cultural sensitivity on the part of the northern researchers and the lack of capacity or drive of Zambian researchers to design it themselves.

10.6 Cultural competence

“Cultural competence requires the synthesis and application of previously gained awareness, knowledge and sensitivity” (Papadopolous & Lees, 2002) and is discussed here in relation to the degree to which researchers in this PhD study have displayed cultural competence concerning the research process and research relationships.

Researchers, both north and south, generally showed an awareness of their own and others’ culture within their research partnership. It is also positive that in many cases there is a symmetry between researchers perception of themselves and that of their fellow researchers. However, exceptions were displayed, particularly around the REC process and north-south work culture. Simon & Mosavel (2011) highlight the importance of researcher identity in the ethical conduct of research, therefore it can be concluded that a first step to reducing inequalities is to recognise that differences exist, and that culturally sensitive research is required before moving on to reduce inequities.
Competence in cultural awareness, knowledge and sensitivity is needed to ensure cultural competence at each stage of the research process and within relationships. For example, respondents in this PhD study primarily advocated the middle ground between universalism and relativism, displaying cultural sensitivity, whilst recognising the importance and applicability of universal principles. However, neither northern nor Zambian researchers necessarily displayed knowledge of the different requirements or standpoints of the other REC. This thesis recognises that ensuring cultural competence will not single-handedly eliminate imbalances in north-south health research, but rather that it can contribute to more ethical relationships. It is also imperative that cultural competence is not reduced to a technical list to be achieved (Betancourt, 2004).

10.7 Conclusion

This PhD study has found north-south culture to play a pivotal role in international north-south health research. Northern and Zambian researchers generally show awareness and knowledge of the role their culture plays in the research process with varying degrees of cultural competence displayed. While a culture of science sometimes exists amongst north-south researchers, this is considered to be in addition to, rather than instead of, north-south divisions. Culture is entwined in political and historical relations (Anderson et al, 2007), which has been demonstrated within this study in terms of links to colonialism and links to the other key component of situated ethics, which is power. While this thesis does not investigate cultural or postcolonial theory, it is important to raise the issues in terms of the ‘other’, which in the case of postcolonial theory is usually the non-Western (Said, 2002). In the case of north-south health research, the ‘other’ is the northern researcher. Bhabha (1994) discusses a third (hybrid) culture which occurs when cultures mix. It is clear that multiple identities are important in north-south health research partnerships, for example in addition to being northern or southern, important differences emerged in respect to the culture of science. However, northern or southern culture is nearly always perceived to be stronger in this study.
Lynam et al. (2007) state that culture is not always viewed in the same way by all members of a cultural group. “While some may derive comfort and a sense of belonging from culture-related traditions, others may view traditions as constraining and limiting”. This thesis recognises that culture is not homogenous or static. In this PhD study, this is emphasised through the tension of Zambian researchers also being distant from communities: ‘we are supposed to be custodians of our own culture’, feeling the need to reconnect with communities. There may be a sense that some do not want to be seen to be part of the scientific culture, or the internationalisation of research culture. Similarly for northern researchers, they often sought to distance themselves from colonialism, and in particular from parachute research.

In relation to research participants, it can be taken for granted that the worldview and experience of privileged international researchers differs substantially from that of potential research participants from disadvantaged communities (Benatar, 2002). It can also differ from that of national colleagues with whom they are collaborating. Zambian researchers may also not be able to identify with the social and economic realities which characterise the poor or rural participant’s daily lives, but it is more likely that they will share more in common in terms of history and culture. It can be argued that cultural competence is needed on two levels: i) researcher to researcher; and, ii) researchers (both north and south) to community. It must be recognised that there are variable degrees of embeddedness in a particular culture (see Figure 13) and also that culture is linked to power and set within a situated ethics of north-south health research.

![Figure 13: Degrees of embeddedness in community and scientific culture](image)

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Chapter 11: Conclusion: towards an *ethos* of north-south health research

“We need to illustrate, put the spotlight on some of these north-south dynamics instead of saying these are Zambian issues. These are not Zambian issues, these are global issues and the more we understand those global issues the more we understand how northern countries set the terms for their interaction with southern countries. That’s the area that we just don’t know enough about.” (northern researcher)

11.1 Implications of PhD study for north-south health research

The starting point for this thesis was that health research between the north and south raises important and unique ethical questions at each stage of the research process. This chapter will highlight the key implications of the research findings as a result of undertaking a situated research ethics analysis, through the lens of power and culture, and how this leads to an understanding of the different *ethoses* of north-south health research. This chapter also discusses the contribution of this PhD study to original knowledge, limitations of the research, and areas for future research. An outline of the dissemination of research findings will also be described.

11.1.1 Objective 1: existing literature

Research Objective 1 was addressed in Chapters 4 & 5: to identify from existing literature, ethical issues in international academic north-south health research. The research question posed was: what are the ethical issues that arise when academic health research is undertaken between the global north and the global south? Power imbalances and cultural issues emerged from the macro (Chapter 4) and micro (Chapter 5) research ethics literature reviews. While power and culture have been analysed, studies usually address either power or culture, and either at the micro or macro research ethics level. A gap was also found in explaining why these power
imbalances exist and persist; and the role of culture in the macro research ethics process is rarely examined. There is also a risk that power imbalances from the perspective of self-evaluations may underplay inequalities in north-south health research.

11.1.2 Objective 2: a situated research ethics analysis: tandem of micro and macro research ethics
Research Objective 2 was to develop (Chapter 2) and utilise (Chapters 6-8) a situated research ethics analysis framework for analysing micro and macro research ethical issues in international academic north-south public health research. The importance of considering as ethical issues, not just traditional notions of research ethics, but also macro research ethics, has been central to the thesis. To date, studies in this area have focused on: a) traditional micro research ethics issues, with a focus mainly on research participants and relationships between researcher and research participant; and, b) macro research ethics issues, where power within the research process/research partnership is addressed, though without explaining why power imbalances exist and persist. Furthermore, the ethics of researcher relationships has rarely been discussed in detail. Culture and power were identified as two central lenses to undertaking a situated research ethics analysis. While a number of authors, (Molyneux & Geissler, 2008, Geissler & Molyneux eds. 2011, Robinson-Pant & Singal, 2013) have laid the foundations for a situated research ethics analysis, it has yet to be developed in detail.

A situated research ethics conceptual framework (Chapter 2) provided the central structure and analysis point for the thesis. The key to the framework was the identification of researchers as being fundamental to the research process, recognising them as being the most important stakeholders in shaping and executing the research study. While each component of the framework was broken down and analysed separately, there was a recognition of: a) the importance of seeing the pillars of micro and macro research ethics in tandem; and, b) to recognise how power and culture are intertwined. Similarly, the ethics of researcher relationships, including reflexivity and researcher identity cut across micro and macro research ethics, power and culture.
11.1.3 Objective 3: why do power imbalances exist and persist?

Research Objective 3 explored the role of power in international academic north-south public health research, and sought to answer the question: how does power influence international academic north-south public health research, and why do power imbalances exist and persist? This was addressed in Chapter 9. PhD study findings have shown power imbalances to be at the core of international north-south health research. Concepts from Bourdieu’s theory of Power and Practice (1977) were used to explain why power imbalances exist and why the status quo remains, despite an impetus for change at the global level, in terms of building capacity for health researchers in the global south. While a number of researchers spoke of trust and equity amongst partners, many perceived relationships and roles to be inequitable with the power balance remaining with the north, echoing the literature in the area.

This thesis illustrates the existence of different habituses, north and south, which can further the understanding of the dynamics of north-south health research. The application of concepts from this theory to the research topic has a number of uses for highlighting new aspects of researcher relationships and inequities at each stage of the research process. Firstly, habitus helps us to understand the unconscious maintenance of the inequitable status quo in north-south health research. These are habituses of domination (northern) and subordination (Zambian) in relation to researcher relationships. While it is recognised that these are generalisations and stereotypes, used for typing and analysis of findings, results show a tendency of respondents to gravitate towards these identities.

Bourdieu’s hysteresis effect provides another possible explanation for why power differentials exist. In some cases, new opportunities have arisen for Zambian researchers. However, many changes in north-south health research are subtle and have not yet been fully taken on board by the Zambian researchers. Studies in the area of north-south health research consistently report a lack of capacity in the south as being one of the major reasons for north-south power imbalances. This is undoubtedly the case and new opportunities, without sufficient capacity strengthening and

\[\text{footnote}{51\text{ Research findings displayed new opportunities, such as some new funding streams, opportunities to feed into the agenda and opportunities to lead on publications.}}\]
without funding flowing directly to Zambia, will result in the maintenance of the status quo. Bourdieu’s concepts of habitus and hysteresis highlight other reasons for perpetuating power imbalances and inequity, other than those mentioned in the literature.

Lastly, Bourdieu’s theory explains how diverse resources – capitals – are used to explain power imbalances, where northern researchers are commonly in possession of more economic, symbolic and social capital vis-a-vis Zambian researchers, and Zambian researchers being more in possession of cultural capital, vis-a-vis northern researchers. Northern researchers dominate north-south health research at each stage of the research process, with the exception of data collection. The literature shows that while power is regularly reported in north-south health research, it is rarely discussed in detail between research partners. A recognition of the different elements of power by northern and southern researchers could pave the way for more equitable partnerships.

The history and evolution of the national health research system in Zambia has been shaped by northern researcher involvement. Those involved in the national health research system are now at a turning point in terms of taking ownership of the system. However, with the bulk of the funding continuing to come from the north, it is unlikely that the balance of power will shift substantially to Zambia, at least in the short to medium term.

11.1.4 Objective 4: culture and ethical context in north-south health research

This thesis investigated culture through two lenses. Firstly, culture was analysed in relation to power, through the heuristic of Bourdieu’s cultural capital (Chapter 9). Secondly, a model of cultural competence was utilised as a tool through which to analyse the role of culture in north-south health research, addressing Research Objective 4 of this PhD study. The research question addressed was: how does culture influence north-south health research and how aware are researchers of their culture in relation to the research process? Throughout this thesis, there has been a recognition that cultures are not homogenous. The focus has been on common
elements of northern, southern, or academic culture, within which rules and meanings are shared. Two conclusions arose in relation to culture: firstly, while ethical principles are universal, how they are interpreted in practice differs from north to south; and secondly, researcher identity has arisen as an important ethical concern in north-south health research.

**Ethical universalism versus ethical relativism: north-south perceptions of ethics**

This study concludes that most interviewees adopted a middle ground approach to the ethical universalism versus ethical relativism debate, as advocated by Benatar (2002, 2004), Emanuel (2004) and Macklin (2012); which is, that while universal research ethical principles exist, how they are played out in practice depends on Zambian culture and context. While most researchers displayed an awareness of this, they did not necessarily possess knowledge of what these differences are. With reports of little contact between northern and Zambian RECs, it is unlikely that reported differences in ethical requirements of northern and southern committees will be understood by REC members or researchers.

Results show that northern researchers are more likely than their Zambian counterparts to consider macro research ethics issues as ethical and gave macro research ethics issues more weight, such as research authorship guidelines, research capacity strengthening, agenda setting. Some of the evidence points to Zambian researchers giving more weight to micro research issues, such as REC approval processes, when northern researchers saw these as formalities. Awareness of these differences is an important first step. However, an increased knowledge as to what these differences are is also needed, for the effective governance of research partnerships and specifically in relation to RECs. This thesis recognises that ensuring cultural competence will not necessarily eliminate imbalances in north-south health research, such as structural issues, but rather it can inform more ethical relationships. Results from this study show that even if the positions of power could be reversed, or become more balanced so that each actor had equal capital, considering cultural difference are so prolific, there will always be differences in ethical considerations in north-south health research.
**Symmetry and asymmetry in researcher identities**

This study has focused on researchers’ reflexivity in relation to each stage of the research process, as a tool for understanding the ethics of north-south health research. As the macro research ethics literature review established, most health research partnership evaluations have been self-evaluations, and while undoubtedly useful, authors often do not state their positionality in relation to the study. In terms of researcher identity (Chapter 10), it has been central to this PhD study to explore whether researchers view themselves as being: i) northern; ii) southern; iii) a researcher/scientist first and foremost; or iv) a nuanced combination of these. Most perceptions of researcher identity were in relation to researchers identifying themselves as *either* northern or southern researchers, and in most cases researchers raised these north-south differences as being the most important issues within these research partnerships. However, multiple identities were also evident, particularly in relation to: research discipline, length of time a northern researcher had spent in Zambia, or length of time a Zambian researcher had spent in the north. Many Zambian researchers consider themselves to be part of a culture of science, which ensures they remain at a cultural distance from the communities they study.

There was some evidence to show that some Zambian researchers do not wish to be associated with scientific culture. Northern researchers often sought to distance themselves from colonialism, and in particular from parachute research. This warns against ascribing a single dominant identity to the health researcher, from the north or south. This reinforces Crane’s 2010 statement that southern researchers:

> “must often walk a tightrope between claims of difference from the global north and assertions of sameness, in which a claim too forceful in either direction can undermine the ethical — and thus scientific — legitimacy of their research” (Crane, 2010).

Overall, results show awareness on the part of northern researchers of their position of power in relation to the research process and these perceptions are for the most part symmetrical, in that Zambian researchers also hold this view. Exceptions were noted, particularly around the REC process and north-south work culture. Simon &
Mosavel (2011) highlight the importance of researcher identity in the ethical conduct of research, therefore it can be concluded that a first step to reducing inequalities is to recognise that differences exist. Cultural competence is required at each stage of the research process and within research relationships.

The ethos of *Ubuntu* was raised frequently by Zambian researchers, as a code of ethics that is embedded in African culture (Swanson, 2007), but beyond the comprehension of northern researchers. This displays not so much symmetry in relation to researcher identity, but rather an absence of awareness/knowledge of *Ubuntu* on the part of northern researchers, which is considered to be of central cultural importance in Zambia. Once again, a sensitivity to *Ubuntu* is needed, even if it is not within the northern researchers’ grasp to fully understand it.

### 11.1.5 Overall aim: towards an ethos of north-south health research

The overall aim of this thesis has been to undertake a situated research ethics analysis of international academic public health research between LMIC and HIC, using Zambia as a case study, to develop an understanding of the different *ethoses* of north-south health research. It is hoped that the thesis has broadened the scope of ethical reflection to encourage consideration of the broader ethics of north-south health research. Situated ethics in this PhD study is the consideration of micro and macro research ethics issues in tandem, considering them to carry equal weight, avoiding assumptions that one - usually micro- carries more weight than the other. The overall study contribution is that through developing an understanding of these *ethoses*, power imbalances can be identified and uncovered. This could ultimately lead to a shared community of partnership, or a shared *ethos* of partnership.

“Commitments in the sense of ethos thus go beyond rule-set ‘ethics principles’. The latter distinguish right and wrong, an inside and an outside divided by a moral line. Such an apparently clear moral separation obscures the more political and economic struggles that shape medical science, and the society that it exists in and brings about. Discussions about the ‘ethos’ of science include interest and conflict into the purview of ethical reflection rather than
excluding them by the sanitising morality of principles. Ethical action can thus be anchored again from where it has been unmoored: if science is about truth and value... these are inseparable from power and resources.” (Geissler & Molyneux, 2011)

It is important to distinguish between situated research ethics and research ethos. In this thesis, situated research ethics is the actual analysis, which provides the vehicle through which one achieves an understanding of the different ethoses of north-south health research.

Three different scenarios for the future of health research in Zambia were expressed in this study, two of which included the continuation of the involvement of northern researchers, through funding and viewing knowledge production as a global activity, and, one which viewed it as desirable that northern researchers would not be involved in research in Zambia in the future. Due to the nature of funding for north-south health research, it is unlikely that the third scenario will arise in the short term, with co-dependency remaining. Therefore it is deemed important to address these power imbalances so as to achieve greater north-south equity, which could also lead to more rigorous and more culturally contextualised research.

As Chapters 4 and 5 have identified, a plethora of guidelines for north-south health research exist around: a) research partnerships and b) international guidelines for health research ethics. Only one health research collaboration in this PhD study developed ethical guidelines relating to the partnership itself, and whilst many references were made to health research ethics guidelines at the micro level, none of the established guidelines for health research collaborations, i.e. the macro level, were mentioned by respondents. If a shared ethos for north-south health research is to be developed, ethics in practice (Guillemin and Guillam, 2004) needs to be practiced, not only in relation to micro research ethics, but also in relation to the broader macro research ethics. Research collaborations could benefit from developing a process for identifying macro research ethics guidelines and for operationalising these.
This thesis has recognised the need to redress power imbalances and an assumption has been made that research partnerships should at the very least balance knowledge, interest and power in the short term, with the aim of maximising benefit for LMIC in the longer term. It is also essential to recognise that many of the imbalances are structural, rather than within the realms of researcher relationships. This means that even if relationships can be altered, structural inequities will triumph (for example economic capital in the form of research funding) over symbolic, social or cultural capital. Addressing relationship inequality is often constrained by inequalities at the structural level, which is within the hands of other actors in the research process, such as donors.

11.2 Contribution of PhD study to original knowledge within the debate on situated ethics

Molyneux & Geissler (2008) contend that their research on situated ethics provides an important starting point for further thinking about the ethos of medical science in Africa. The authors hope that a growing body of work and discussion will ensue that will shine a light on the ‘complex individual, institutional and national imbalances in power and resources within which all research is conducted’ (2008). From a conceptual perspective, Molyneux & Geissler (2008), Geissler & Molyneux eds. (2011), and Robinson-Pant & Singal (2013), laid the foundations for a situated research ethics analysis, which awaited further development. As has already been described, developing and testing a situated research ethics conceptual framework to enable micro and macro ethical issues to be recognised and debated in tandem across power and culture, so as to develop an understanding of the different ethoses of north-south health research, has been the primary aim of this PhD study.

To date, situated ethics has focused on biomedical research; used ethnographic methods; and, has concentrated primarily on researcher to research participant/community relations within micro research ethics, while including power as a discussion within the micro research systems and structures. While a situated research ethics concept explains the importance of micro and macro research studies, empirical studies under the umbrella of situated research ethics address either the micro or the macro level. This PhD study has developed a situated ethics conceptual
framework to enable micro and macro ethical issues to be recognised and debated in tandem.

Specific areas where the situated ethics analysis in this study has added to knowledge includes the following:

- Empirical evidence of both northern and southern voices, which lead to a more nuanced understanding of the dynamics of international north-south health research, particularly around power imbalances and the role of culture.
- To date, most studies of north-south health research collaborations have been self-evaluations. While this in itself is positive, often authors do not state their positionality in relation to the research.
- The may be the first attempt to explore the nature of differences between RECs in the global north and the global south and the effect that this had on research partnerships.
- A model of cultural competence has been developed and applied to research between LMIC and HIC, emphasising the importance of this for the ethical conduct of research. To date cultural competence has focused on: a) clinical care; b) clinical research or community based participatory research; and, c) when researchers and participants are from different culture, rather than when researchers themselves are from different cultures, which this thesis has addressed.
- This is the first known study to focus on the national health research system in relation to issues relating to situated research ethics, i.e. power and culture across micro and macro research ethics.

Certain elements of the study could have potential relevance and application beyond Zambia, particularly the concepts which have been utilised:

i) **Power differentials and cultural differences:**

- Both the macro research ethics literature review and the micro research ethics literature review concluded that power differentials exist (north to south), and that there are cultural differences between northern and southern researchers. The literature reviews scope was not restricted to
Africa, but rather encompassed all continents. It is recognised that there will be differences in countries and across continents that would need to be taken into account.

- The use of concepts from Bourdieu’s theory of power and practice could be used to explain power differentials in partnerships between other northern and southern countries.
- The use of cultural competence could also be applied to other northern and southern countries.

ii) **Situated research ethics analysis**: one of the key strengths of the PhD study is that this analysis could be applied to different types of research partnerships that encompass researchers from different contexts, i.e. north-north, south-south, researcher-community, researcher-policy makers.

### 11.3 Positionality of PhD researcher

It is important to discuss the identity of the PhD researcher in relation to interpretation of the findings from this PhD study, particularly as she is both an actor (researcher) in the field of north-south research, but is also analysing the field. The reflexivity and positionality of the PhD researcher has been discussed in Chapter 3. However, it is considered pertinent to the cultural awareness of the PhD researcher, particularly in relation to interpretation of the PhD findings. Since commencing a career in international health research in 2006, she had an interest in north-south researcher dynamics. She has spent regular periods of time in Zambia, where she worked closely with Zambian researcher colleagues, allowing for an understanding and empathy of the difficulties and pressures experienced by Zambian researchers to be developed. For a number of studies she travelled to the community level and participated in fieldwork, gaining a particular understanding of the role of the northern researcher in the data collection process. She observed, through personal experience, that north-south imbalances exist in north-south research, which could be said to have influenced interpretation of the findings, i.e. the researcher has a commitment to equity and fairness in international north-south health research, particularly in relation to interpreting north-south differences from the research analysis. However, this study has moved beyond personal reflection through this empirical study, exploring this
proposition, firstly within the literature and then through interviewing 53 northern and southern researchers. The role of the PhD collaborator was seen to be essential in terms of her perceptions that interviewees spoke openly with the PhD researcher.

One of the PhD study supervisors challenged these north-south interpretations, encouraging her to reflect a bit more on the findings, which led to a more nuanced interpretation of the findings, seeing less of an absolute north-south dichotomy with various degrees of power (particularly in the form of different capitals), cultural competence and the role of different disciplines and the culture of science.

11.4 Limitations of the research

Three main gaps/limitations have been identified in this PhD study. Firstly, this study highlights the perspectives of one set of actors - researchers - in the research process. It is recognised that other actors, such as research donors, research participants, communities and policy makers are key players in the research process. Secondly, dissemination and getting research into policy and practice stages of the research process have not been included, which would be desirable to gain a complete picture of power and culture across each stage of the research process. Both of these were deemed beyond the scope of a PhD study. Thirdly, the positionality of the PhD researcher as a northern researcher, could be seen as a potential limitation, perhaps having an effect on how interviewees discussed north-south issues. This could have had implications for the overall reliability of this PhD study in terms of whether Zambian researcher spoke openly and honestly to the PhD researcher. However, the PhD researcher was often surprised at the frankness of Zambian researchers in relation to north-south differences. The Zambian PhD study collaborator also confirmed openness and frankness following the interviews that she had been involved in.

11.5 Dissemination of study findings

Findings and conclusions from this PhD study will be disseminated in several ways. Firstly, once this thesis has been submitted, a summary of the key findings and conclusions will be sent to all interviewee participants. At the time of interview, most
respondents expressed an interest in receiving such a summary. Second, it is intended to write a number of journal articles based on this thesis, for publication in peer reviewed journals. Thirdly, it is anticipated that a number of policy briefs will be prepared for national level stakeholders in Zambia, which it is hoped will be presented by the Zambian collaborator on the PhD study. It is also planned to make these briefs available to global health research funders, both in Ireland, such as Irish Aid; and, globally, particularly through the Canadian Coalition for Global Health Research, who have been involved in establishing the national health research system in Zambia. As outlined in Chapter 1, PhD findings have been periodically presented at conferences, and it is the intention of the PhD researcher to continue to disseminate findings and conclusions through a number of fora: namely through the Irish Forum for Global Health and the Ethics of Health Systems Research Thematic Working Group of Health Systems Global Society, of which the PhD researcher is a member.

11.6 Future research on issues relating to north-south health research
This study illustrates the need for further research into north-south health research in the following areas:

- **Guidelines for health research collaborations**: this study found a plethora of existing guidelines for health research partnerships, it would be useful to explore if these guidelines are used by north-south health research partnerships. Considering the PhD study finding that micro research ethical principles are often interpreted differently by northern and southern researchers, is this also the case for macro research ethics guidelines? Linked to this would be a more explicit analysis of what researchers, north and south, consider to be ethical.

- **South-south perspectives**: given the potential limitations of a northern researcher leading the study, as outlined above, it would be interesting for a southern researcher to undertake a similar study to compare findings and particularly to ascertain if southern researchers are more open with one another.

- **Undertake a similar study in another LMIC**: The Zambian national health research system is at an early stage of development. It would be interesting to
compare with another country, such as Uganda or Ghana, whose national health research system is more developed, and where research capacity is stronger, to analyse if similar north-south imbalances exist.

- Microbicide Development Programme Trial: this PhD study has begun to explore the impact of the MDP Trial in Zambia. An interesting follow-up would be to analyse this as a case study, with a focus on the perceptions of the different stakeholders (communities, MoH, northern and southern researchers) in relation to how the study was undertaken, at each stage of the research process, through a situated research ethics analysis.

- Biobanks: biological samples and data transfer within and out of Africa is becoming increasingly controversial with the introduction of biobanks. This would be a worthy area for future research, analysing the various elements of legislation, and perspectives of different stakeholders – institutions, communities and individuals- as to how biobanks should operate both within Zambia (or another LMIC) and higher income countries.
References


BRYMAN, A. & BURGESS, R. 1994. Analysing Qualitative Data London Routeledge


COHRED 2013. Where there is no lawyer: Guidance for fairer contract negotiation in collaborative research partnerships Geneva Council on Health Research for Development


HARVARD 2010. Cultural competence in research MA: Harvard Medical School

HASUNIRA, R. 2010. COMMUNITY INVOLVEMENT IN HIV PREVENTION RESEARCH. Experiences and perceptions of communities participating in the MDP 301 microbicide trial in Masaka, Uganda. Global Advocacy for HIV Prevention


HORTON, D., PRAIN, G. & THIELE, G. 2009. Perspectives on partnership: a literature review Lima International Potato Centre


KING, N. & HORROCKS, C. 2010. *Interviews in Qualitative Research* London Sage


MARSHALL, P. & ROSSMANN, G. 2011. Designing Qualitative Research California Sage


MASON, J. 2002. Qualitative Researching London SAGE


MOH 2010 Ministerial Statement on Microbicides. Lusaka Ministry of Health


MOLYNEUX, C., WASSENAAR, D. R., PESHU, N. & MARSH, K. 2005. 'Even if they ask you to stand by a tree all day, you will have to do it (laughter)...!': Community voices on the notion and practice of informed consent for biomedical research in developing countries. *Social Science & Medicine*, 61, 443-454.


MORSE 2000. Sample Size and Saturation in PhD Studies Using Qualitative Interviews. *Qualitative Social Research* 11.


NUFFIELD 2002. The ethics of research related to healthcare in developing countries London Nuffield Council on Bioethics


NUSSBAUM, B. 2003. Ubuntu: Reflections of a South African on our Common Humanity


OPDENAKKER, R. 2006. Advantages and Disadvantages of Four Interview Techniques in Qualitative Research *Qualitative Social Research* 7.


RICHARDS, M. R. & MORSE, J. 2013 *Qualitative Methods* London SAGE


WALLACE, R. & WRAY, A. 2006. Critical Reading and Writing for Postgraduates London Sage


WHO 2008. Casebook on Ethical Issues in International Health Research, Geneva World Health Organisation


WIGHT, D. 2008. Most of our social scientists are not institution based... they are there for hire - Research consultancies and social science capacity for health research in East Africa. Social Science & Medicine, 66, 110-116.
APPENDIX 1: Literature Review Search Terms

A: Search strings/MESH terms for macro research ethics literature review

Final search terms for Pubmed and Web of Knowledge: (health OR medical OR medicine OR biomedical OR biomedicine OR clinical OR "tropical medicine") AND (partner* OR network* OR consort* OR collaborate* OR alliance* OR cooperate* OR co-operate*) AND (research) AND ((global OR international OR transnational OR multi-country OR (multi AND country) OR cross-country OR (cross AND country) OR (north AND south)) OR ("developing country" OR "developing countries") OR ((lower OR middle) AND income))

Search term pilot:

A. *ISI Web of Knowledge*

- Research partnerships / partnerships for research= 3975 results. Too broad.
- “Research partnerships” = 302 ✓
- “Partnerships for research” = 75 ✓
- Research partnerships for health and health research partnerships throws up 1203 results, which appear to be the same. ✓
- “Health research partnerships” = 5 results ✓
- ((global OR international OR regional OR north-south OR transnational OR cross-country OR African OR developing country OR multi-country OR collaborative) health research partnerships) = 527 results ✓ ? Some not very useful.
- ((global OR international OR regional OR north-south OR transnational OR cross-country OR African OR developing country OR multi-country OR collaborative) “health research partnerships”) = 4 results ✓
- ((global OR international OR regional OR north-south OR transnational OR cross-country OR African OR developing country OR multi-country OR collaborative) research partnerships) = 1570 results.
- ((global OR international OR regional OR north-south OR transnational OR cross-country OR African OR developing country OR multi-country OR collaborative) “research partnerships”) = 129 results, many relevant ✓
- ((global OR international OR regional OR north-south OR transnational OR cross-country OR African OR developing country OR multi-country OR collaborative) medical research partnerships) = 213 results
- ((global OR international OR regional OR north-south OR transnational OR cross-country OR African OR developing country OR multi-country OR collaborative) biomedical research partnerships) = 34 results
- (global OR international OR regional OR north-south OR transnational OR cross country OR African OR developing country OR multi-country OR collaborative) health research = 36,617. Much too broad.
- research (networks OR consortia OR alliance OR collaboration OR cooperation OR consultancies)) = 62,722 results. Far too broad
- health research (networks OR consortia OR alliance OR collaboration OR cooperation OR consultancies)) = 7,761. Too broad ????
- medical research (networks OR consortia OR alliance OR collaboration OR cooperation OR consultancies)) = 5,635 results. Too broad?
- Biomedical research (networks OR consortia OR alliance OR collaboration OR cooperation OR consultancies)) 737 results
- Research collaboration = 17,087 results. Far too broad
- Multi-country health research = 158 results
- Multi-country medical research = 73 results
- Agenda setting AND health research = 181 results
- “Research partnerships for health” = 2 results
- Partnerships for health research = 1203
- “Partnerships for health research” = 5 results
- Biomedical research partnerships = 73 results
- “Biomedical research partnerships” = 0 results
- Medical research partnerships = 493
- “Medical research partnerships” = 0 results
- “Health research networks” = 3 results
- “Networks for health research” = 1 result
- Health research alliance = 463 results.
- Health research consortia = 88 results. None relevant.

B. Global Health
- Research partnerships = 3,077. Too broad
- Health research partnerships = 924
- “Research partnerships” = 130
- “Partnerships for research” = 3 results
- (global OR international OR regional OR north-south OR transnational OR cross-country OR African OR developing country OR multi-country OR collaborative) health research partnerships = 885 results
- ((global OR international OR regional OR north-south OR transnational OR cross-country OR African OR developing country OR multi-country OR collaborative) medical research partnerships) = 184 results
- ((global OR international OR regional OR north-south OR transnational OR cross-country OR African OR developing country OR multi-country OR collaborative) biomedical research partnerships) = 21 results
- ((global OR international OR regional OR north-south OR transnational OR cross-country OR African OR developing country OR multi-country OR collaborative) research partnerships) = 2980 results. Many of these include agriculture research and research for development.
- (global OR international OR regional OR north-south OR transnational OR cross-country OR African OR developing country OR multi-country OR collaborative) "research partnerships" = 128
- health research (networks OR consortia OR alliance OR collaboration OR cooperation OR consultancies) = 6,358 results
- biomedical research (networks OR consortia OR alliance OR collaboration OR cooperation OR consultancies) = 189 results
- medical research (networks OR consortia OR alliance OR collaboration OR cooperation OR consultancies) = 1868 results
- Cross country research = 17,820 results. Too broad
- multi country health research = 755 results
- multi country medical research = 239 results
- multi country biomedical research = 10 results
Agenda setting and research = 540 results

C. Scirus
- (health OR medicine OR biomedicine OR clinical OR tropical medicine) research partnerships = 1,584,241 results. Therefore the need to refine.
- (health OR medicine OR biomedicine OR clinical OR tropical medicine) "research partnerships" = 41,230 results
- "health research" (networks OR consortia OR alliance OR collaboration OR cooperation OR consultancies) = 252,630
- "Research partnerships" = 67,350 results
- "Research networks" = 90,340

D. Pubmed
- Health research partnerships = 2188 results
- (Health OR medical OR biomedical OR clinical OR tropical medicine) research partnerships = 2,451
- (global OR international OR regional OR north-south OR transnational OR cross-country OR African OR developing country OR multi-country OR collaborative) health research partnerships = 995 results
- (global OR international OR regional OR north-south OR transnational OR cross-country OR African OR developing country OR multi-country OR collaborative) medical research partnerships = 315 results
- (global OR international OR regional OR north-south OR transnational OR cross-country OR African OR developing country OR multi-country OR collaborative) biomedical research partnerships = 103 results

B: Search strategy for micro research ethical issues in north-south health research literature review.

Final search terms (Filters, last 10 years, humans)

Pubmed:

**International health research ethics:** ("health"[All Fields] OR medical[All Fields] OR biomedical[All Fields] OR clinical[All Fields] OR tropical[All Fields] OR "medicine"[All Fields]) AND (("ethics, research"[MeSH Terms] OR ("ethics"[All Fields] AND "research"[All Fields]) OR "research ethics"[All Fields] OR ("research"[All Fields] AND "ethics"[All Fields])) OR ("Biomedical Research/ethics"[Mesh] OR "Ethics, Medical"[Mesh]) OR "Ethics Committees"[Mesh]) AND ("Glob Impacts"[Journal] OR "global"[All Fields]) OR transnational[All Fields] OR international[All Fields] OR ("developing countries"[MeSH Terms] OR ("developing"[All Fields] AND "countries"[All Fields])) OR "developing countries"[All Fields] OR ("developing"[All Fields] AND "country"[All Fields]) OR ("developing countries"[MeSH Terms] OR ("developing"[All Fields] AND "countries"[All Fields])) OR "developing countries"[All Fields]) AND ("2003/10/18"[PDat] : "2013/10/14"[PDat] AND "humans"[MeSH Terms]) 2314 results
Situated research ethics: (Situated[All Fields] AND ("ethics, research"[MeSH Terms] OR ("ethics"[All Fields] AND "research"[All Fields]) OR "research ethics"[All Fields]) OR ("research"[All Fields] AND "ethics"[All Fields]))) AND "humans"[MeSH Terms] 75 results

Situated ethics: (Situated[All Fields] AND ("ethics"[Subheading] OR "ethics"[All Fields] OR "ethics"[MeSH Terms])) AND "humans"[MeSH Terms] 172 results

Web of knowledge

International health research ethics: ((research ethics OR ethical research OR ethics committees) AND (international OR transnational OR global OR developing country OR developing countries)) 3231 results

Situated research ethics: (Situated research ethics) 123 results

Situated ethics: (situated health ethics) 56 results

The following search terms were piloted:

Pubmed

- Research ethics 43,717
- Ethics research 43,750
- Medical research ethics 38,713
- Health research ethics 20,162
- Health research and ethics 27,286
- Health research ethics and developing countries 865
- Transnational research ethics 48
- Global health research ethics 582
- International health research ethics 1,722
- International AND Health research AND ethics 2,140
- Research ethics committees Africa 132
- Research ethics committees Developing Country 201
- Politics and research ethics 1,139
- Africa AND health research AND ethics 831
- Health Research AND ethics and Developing Countries 1,071
- Situated research ethics 80 (16 potentials)
- Situated health research ethics 52
- Situated ethics 188
APPENDIX 2: Literature Review Themes and Codes from *Nvivo*

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APPENDIX 3: Interview Guides

INTERVIEW GUIDE – RESEARCHER

Study Title: A socio-cultural analysis of researchers’ experiences of international academic health research between Zambia and the global north

For each topic discussed, probe for:

- North-south differences
- Differences between disciplines

A – Background and introduction questions

Researcher background:

- Can you tell me about your [professional background]: education, research discipline, research experience, nationality, country of upbringing, institutional affiliations

Career:

- Can you tell me about your [career] to date - why did you become a health researcher? When did you begin to get involved in HRC?
- Have you ever [worked outside] Zambia/Europe/US? Probe: for type of work, experiences, how research community is similar/different to home country
- Broadly speaking, what [type of research] are you engaged in? [Probe: how do you define it, i.e. would you say you are a health systems researcher, a public health researcher, a health services researcher, or other?]
- What [health research issues] interest you?

Broad collaboration questions

- Can you tell me about this research collaboration: what are the [aims and objectives], topics studied, partners involved, funders, governance structures, who initiated it?
- Have you developed a [code of practice/ policy] to guide this collaboration?

B - Motivations

Personal motivations and incentives

- Why did you get [involved] in this collaboration? [Probe: financial, career path/promotion, personal].
Do researchers **career paths differ** from north to south? Do research collaborations contribute to or detract from this? Do you think similar **employment patterns** exist?

- Are there some **elements** of the partnership which you do not agree with? Which elements? Why did you get involved anyway?
- Do you think motivations **differ** between **northern and southern** researchers? Between **research disciplines**?
- Are there differences in the way northern and southern researchers view **health and illness** in the collaboration? [Probe: if yes, how does this affect the research?]
- Do all the research partners have the same **views** about the **purpose** of conducting the research? [Probe: how do they differ?]
- How were **partners selected** for this collaboration?

**Roles, responsibilities and relationships**

- What is your **role** in this collaboration?
- Do you think research partners **trust** one another? Are there any examples you can think of where trust between collaborators was **compromised**? [Probe: for all partners]
- How are **roles and responsibilities managed**? Were they discussed and agreed from the outset? Are they distributed **fairly** across the collaboration?
- Do you think typical ‘N-S’ roles are **changing** over time? Probe: in what way – positively or negatively? Should northern researchers remain involved in research in Zambia? In what roles?
- Who are you/your research institution **accountable** to in the partnership?
- Do you think there is an **equal power balance** between partners in this collaboration? [Probe: for an example of how unequal power relations have been played out]. How could they be more equitable?
- How do you **communicate** with others in the collaboration? Phone, email, face to face. Which works best?
- Are there some partners that you communicate better with? Why?
- Do **language differences** affect communication/relationships in HRC?
- Do **cultural differences** affect relationships within the collaboration? [Probe: north-south; culture of different disciplines]
- Is research **capacity strengthening** a component of this collaboration? Is the model appropriate?

**C - Agenda Setting**

**Processes and actors**

- Can you tell me how the **collaboration came about**? [Probe: can you talk me through the process?]
- How was the **agenda set** from the research proposal to the design of the research?
- Did you feel that your views were taken into consideration in **setting the agenda of research**?
Who was involved and what was the balance of influence across the constituencies:
- Communities, researchers (probe different disciplines and research institutions), policymakers, donors
- North versus south
- Global to local

Was the balance appropriate? Were there tensions? How were they reconciled?

Do you feel that your team/institution has received adequate funding to carry out the study? Is there a fair balance between north and south?

D- Research design and implementation

I would now like to move on to research design and the implementation of the study

What has been your role in research design for this collaboration? So the development of: research objectives, questions and tool development?

What methodologies are used? [Formal common protocols, tools and analysis plans to less formal]

Has this been appropriate to Zambia’s culture and traditions?

Did your research partners have appropriate roles in designing the study? Probe: differences and reasons for these:
- North-south.
- Across disciplines
- Within and across teams and institutions

Data collection

What is your involvement in data collection for this study? Role of other partners? How were you/they perceived by:
- communities
- other researchers
- policy makers

What effect does the involvement of northern researchers have on the research?

Are research partners sensitive to local cultures of research participants?

Ethics

How were research ethics negotiated for the study? Who was involved? At what stages?

Should ethical approval be obtained from Zambia alone or also in the partners countries?

Do all partners share common views on research ethics? How do these differ?
E - Research analysis and outputs

I would now like to move on to analysis of the results and research outputs

Research analysis - process and roles

- Who holds the study data?
- Can you take me through the process of how the findings have been analysed in this collaboration?
- What is your role/roles of the different partners in research analysis?
- Is analysis spread equitably across the collaboration? Where does the analysis take place primarily (North or in Zambia)?
- What are the challenges involved in data analysis? [probe: geographical distance, sharing of data/IP issues, translation issues, other cultural sensitivities?] North-south? Across disciplines?

Research outputs

- Do you think all partners have similar/different views of quality for research outputs? How does this differ a) north-south and b) research disciplines? Is there agreement on what the research outputs should be from research partners?
- Are research outputs appropriate for Zambia?
  - Appropriate balance at different levels? Cross-national, national, sub-national/community
  - Content appropriate for different audiences?
  - Types of outputs: policy briefs, reports, articles
- How are authorship issues managed in this HRC? Are they fair? [Probe: access to literature, technology etc.]
- Do you plan to publish in local/regional journals? What impact does this have on ownership of the research?
- Have you been an author on a peer-reviewed article within this HRC? How was the experience for you?

Closing questions:

- Looking back over your experience within this collaboration, would you change anything about it?
- How does it compare to other research collaborations that you have been involved in?
- How would you like to see health research evolve in Zambia over the next five years?
INTERVIEW GUIDE B - NATIONAL HEALTH RESEARCH KEY INFORMANT

A – Background and introductory questions

▪ Interviewee background: education, profession/discipline, research experience.

B - Health Research in Zambia

▪ What are the key health research priorities for Zambia today? How have these evolved/changed over the last 10 years?
▪ Does Zambia currently have a national health research priority setting process?
▪ Who is involved and how is it set? Can you take me through the process?
▪ Has this changed over time?
▪ What actors have enabled/constrained the establishment of the National Health Research system in Zambia? [Probe: how have they been involved? Any actors missing?]
▪ Does research capacity affect involvement in priority setting? [probe: access to funding, technology, infrastructure, research institution capacity]
▪ How does health research fit within the priorities of the MoH? Other Ministries that are involved in health issues?
▪ Who are the current champions for health research in Zambia?

C – National Health Research Advisory Council (NHRAC)

▪ What has your involvement been in setting up the National Health Research Advisory Council? [Probe: how long have you been involved in the process? How did you become involved?]
  ▪ When is NHRAC expected to come into existence?
  ▪ How does NHRAC propose to carry out each of its proposed functions?
    ▪ Oversee the research agenda (including priority setting mechanisms)?
    ▪ Develop effective resource mobilisation capacities?
    ▪ Develop capacities for health?
    ▪ Oversee research ethics in health?
    ▪ Monitor and coordinate national research activities?
    ▪ Develop capacities in knowledge management and translation?
    ▪ Disseminate research results and reports, and advocate for evidence-informed policies?
▪ What specific services will NHRAC offer? To whom?
▪ How will NHRAC be governed?
▪ How will it be funded?
▪ Who currently performs the functions that NHRAC will carry out?

C – Health Research Collaborations

▪ Is there a role for health research collaborations in the NHRAC?
- Is there an appropriate balance of collaborative versus non-collaborative research in Zambia?
- What role can north-south HSR collaborations play in enabling/inhibiting NHRAC to carry out its’ functions?
- How should ethical approval be managed in HSR collaborations? (from Zambia alone or also in the partner countries?)
- Do HSRC follow Zambia’s research priorities?

Closing question

- How would you like to see health research evolve in Zambia over the next five years? [Probe: health research collaborations]
PARTICIPANT INFORMATION SHEET

Study title: A socio-cultural analysis of researchers’ experiences of international academic health research between Zambia and the global north

Before you decide whether or not you wish to take part in this study, you should carefully read the information provided below.

PURPOSE AND FOCUS OF THE RESEARCH

Multi-country health research collaborations between academic institutions are a recognised mechanism for research. In addition to adding value to research outputs, they provide opportunities for capacity development. The aim of this study is to undertake a socio-cultural analysis of researchers’ experiences of international academic health research between Zambia and the global north. The objectives of the research are as follows:

A. To develop a typology of ‘north-south’ health research collaborations involving Southern Africa and the ‘global north’ (Europe and North America).
B. To explore researchers’ motivations for becoming involved in north-south health research.
C. To describe and analyse how the research priorities are set in international north-south health research.
D. To describe and analyse how research studies are designed and implemented in international north-south health research.
E. To examine how research findings are analysed and outputs produced in international north-south health research.

The results of this project will assist in filling the evidence gap in this area and will also provide guidelines and recommendations for researchers, research institutions and research funders to consider when committing to north-south research collaborations between lower income and higher income countries. Findings will be disseminated in the form of reports, presentations, policy briefs and journal articles.
WHO IS ORGANISING AND FUNDING THE STUDY?

The research is being conducted as part of a PhD study by a researcher (Aisling Walsh) in the Department of Epidemiology and Public Health, Division of Population Health Sciences, at the Royal College of Surgeons in Ireland (RCSI), under the supervision of Professor Ruairi Brugha and Dr Elaine Byrne. The study will be carried out in collaboration with Chishimba Mulambia, Research Fellow at the Institute of Economic and Social Research, at the University of Zambia and is being partly funded through the Global HIV/AIDS Initiatives Network (www.ghinet.org).

WHAT WILL THIS INVOLVE FOR YOU?

This study will take place between March 2011 and October 2012 and will interview participants from Zambia who have participated in public health research collaborations, as well as their research partners in other countries, especially in Europe/North America. We are asking you to participate in this research by answering some questions in an individual interview, which will last up to one hour, depending on your availability. This could be face-to-face or over the phone, depending on what is most convenient for you. Please carefully note the following:

- Your decision to participate is strictly voluntary, and you may decline to participate without giving any reasons.
- You are free to withdraw at any time, without providing a reason. Non-participation or withdrawal will be treated as a confidential action with no consequence for you.
- The interview will be audio-recorded and transcribed if you allow us to do so. All research notes will be kept confidential and information relating to your identity will not be linked to the transcripts.
- You are not waiving any legal claims or rights because of your participation in this study.
- You will not receive payment for your participation in the research.
- At the end of the interview we will ask you if we can contact you again should we need to seek clarification or to build upon points raised in the interview.

You have the right to review the transcript at a later date for clarification, to add to the transcript, or to indicate that part or all of it should not be used. If you wish to avail of this option, please tell me at the end of the interview, and your transcript will be made available on a protected site where you will be given username/password based access to your transcript. Neither the files, usernames, nor password will be exchanged via email.

Once the interviews have been transcribed and approval received from you if requested, the transcripts will be pseudonymised and stored securely for seven years before being destroyed. All information held by us will be protected by EU data protection and data handling laws and guidelines. This study has been approved by
the Royal College of Surgeons in Ireland Research Ethics Committee and the University of Zambia Research Ethics Committee.

CONTACTS AND QUESTIONS

Aisling Walsh: Tel: +353-1-4028657; Email: aislingwalsh@rcsi.ie

Chishimba Mulambia: Tel: +260 9777 02223  Email: chishimba.mulambia@unza.zm

Ruairi Brugha: Tel: +353-1-402 2424; Email: rbrugha@rcsi.ie

Elaine Byrne: Tel: +353-1-402 2769; Email: elainebyrne2@rcsi.ie

Thank you for your time and your interest in the study.
APPENDIX 5: Participant Informed Consent Form

PARTICIPANT CONSENT FORM

Study title: A socio-cultural analysis of researchers’ experiences of international academic health research between Zambia and the global north

PLEASE CIRCLE OR HIGHLIGHT THE APPROPRIATE ANSWER

Have you read the Research Information Sheet? Yes No

Have you had an opportunity to ask questions and discuss the study? Yes No

Do you understand that your identity will remain confidential at all times? Yes No

Do you understand all the information provided? Yes No

Have you received satisfactory answers to all your questions? Yes No

To whom have you spoken about the study? ______________

Do you understand that you are free to withdraw from the study?

- At any time Yes No
- Without giving a reason for withdrawing Yes No
- Without personal consequence Yes No

Do you agree to take part in the study? Yes No

Do you agree to the interview being recorded? Yes No
Have you been given a copy of the Research Information Sheet and Consent Form for your records?  

Yes  

No

Participant __________________

Signature and dated  

Name in block capitals

To be signed after the interview

Participant __________________

Signature and dated  

Name in block capitals

To be completed by the researcher:

I, the undersigned, have taken the time to fully explain to the above participant the nature and purpose of this study in a manner that (s)he could understand. I have invited the participant to ask questions on any aspect of the study that concerned them.

__________________

Signature  

Name in block capitals

Date

Study contact details

Aisling Walsh: Tel: +353-1-4028657; Email: aislingwalsh@rcsi.ie

Chishimba Mulambia: Tel: +260 9777 702223  Email: chishimba.mulambia@unza.zm

Ruairi Brugha: Tel: +353-1-402 2424; Email: rbrugha@rcsi.ie

Elaine Byrne: Tel: +353-1-402 2769; Email: Elainebyrne2@rcsi.ie
APPENDIX 6: Individual researcher themes and codes

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<tr>
<td>G</td>
<td>Governance</td>
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<td>29</td>
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<tr>
<td>H</td>
<td>Relationships &amp; communication</td>
</tr>
<tr>
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<td>30</td>
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<td>31</td>
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<tr>
<td>I</td>
<td>National level</td>
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<td>42</td>
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<td>43</td>
</tr>
</tbody>
</table>
## APPENDIX 7: National level stakeholder interviews themes and codes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub theme</th>
</tr>
</thead>
</table>
| **1 National priority and agenda setting processes** | Lack of government investment in research  
Priorities set in North, not aligned with Zambia priorities  
Priorities and agenda set in Zambia  
National health research agenda: process to 1998  
National health research priority setting process  
No priority setting process in Zambia  
Priority topics for health research in Zambia |
| **2 Monitoring and coordinating health research in Zambia** | Lack of coordinating and monitoring of health research in Zambia  
Zambia Forum for Health Research (ZAMFOHR)  
Role of the National Health Research Authority of Zambia (NHRAZ)  
Role of northern researchers in monitoring and coordination: global health research architecture and duplication of research |
| **3 Microbicide Trial and Lujo Virus** | Lujo virus and ban on research  
MDP Trial- misinformation and community reaction |
| **4 National Health Research Ethics Committee (NHREC)** | Lack of monitoring of health research ethics  
Role of NHREC  
Concerns around NHREC  
National Health Research Act and Ethics |
| **5 National and district level research capacity** | Need to build district level capacity  
HR issues: research cadre emerging  
Research units in universities needed |
| **6 Future of health research in Zambia** | Links with north should continue: capacity, donor link  
Links with north should continue: equal relationships, globalised world  
Look forward to a time when northern researchers not involved |
### APPENDIX 8: Codes applied to a situated research ethics conceptual framework

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-theme</th>
<th>Application to framework</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Priority &amp; agenda setting</td>
<td>Initiation of collaboration</td>
<td><em>Macro:</em> funding, priority &amp; agenda setting</td>
</tr>
<tr>
<td></td>
<td>Funding for collaboration</td>
<td><em>Macro:</em> funding, priority &amp; agenda setting</td>
</tr>
<tr>
<td></td>
<td>Priority and agenda setting process for collaboration</td>
<td><em>Macro:</em> funding, priority &amp; agenda setting</td>
</tr>
<tr>
<td>2 Research design &amp; data collection</td>
<td>Research design</td>
<td><em>Macro:</em> funding, priority &amp; agenda setting</td>
</tr>
<tr>
<td></td>
<td>Data collection</td>
<td><em>Micro:</em> community acceptability</td>
</tr>
<tr>
<td></td>
<td></td>
<td><em>Macro:</em> production &amp; flow of knowledge</td>
</tr>
<tr>
<td>3 Ethics</td>
<td>Ethics approval processes: north and south</td>
<td><em>Micro:</em> ethics review</td>
</tr>
<tr>
<td></td>
<td>Perceptions of unethical research</td>
<td><em>Micro:</em> ethics review Informed consent</td>
</tr>
<tr>
<td></td>
<td>Microbicide trial and Lujo virus</td>
<td><em>Micro:</em> community acceptability Informed consent</td>
</tr>
<tr>
<td></td>
<td>Community capacity to understand research (ethics)</td>
<td><em>Micro:</em> community acceptability</td>
</tr>
<tr>
<td>4 Data analysis/outputs</td>
<td>Data analysis process</td>
<td><em>Macro:</em> production &amp; flow of knowledge</td>
</tr>
<tr>
<td></td>
<td>IP issues</td>
<td><em>Macro:</em> production &amp; flow of knowledge</td>
</tr>
<tr>
<td></td>
<td>Outputs</td>
<td><em>Macro:</em> production &amp; flow of knowledge</td>
</tr>
<tr>
<td></td>
<td>Dissemination</td>
<td><em>Macro:</em> production &amp; flow of knowledge</td>
</tr>
<tr>
<td>5 Capacity building</td>
<td>Individual capacity building</td>
<td><em>Macro:</em> capacity building and career paths</td>
</tr>
<tr>
<td></td>
<td>Career paths</td>
<td><em>Macro:</em> capacity building and career paths</td>
</tr>
<tr>
<td></td>
<td>Consultancies</td>
<td><em>Macro:</em> capacity building and career paths</td>
</tr>
<tr>
<td></td>
<td>Discipline mix</td>
<td>?</td>
</tr>
<tr>
<td></td>
<td>Relationships: cultural differences</td>
<td>Relationships: note other themes also have relationships as a cross-cutting issue</td>
</tr>
<tr>
<td></td>
<td>Relationships: trust and equity</td>
<td>Relationships</td>
</tr>
<tr>
<td>7 Researcher background, motivation &amp; expectations</td>
<td>Motivation for involvement</td>
<td>Background</td>
</tr>
<tr>
<td></td>
<td>Expectations met</td>
<td>Background</td>
</tr>
</tbody>
</table>
### APPENDIX 9: Application of research findings to Bourdieu’s theory of Power and Practice

<table>
<thead>
<tr>
<th>Element of Bourdieu Theory of Power and Practice</th>
<th>Application to study research findings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Field:</strong></td>
<td></td>
</tr>
<tr>
<td>▪ agents and institutions and the network of relations between them</td>
<td>▪ Field of international health research</td>
</tr>
<tr>
<td>▪ competitive marketplace</td>
<td>▪ Agents/institutions: research funder/donors, research institutions (north &amp; south)</td>
</tr>
<tr>
<td>▪ <em>nomos</em>: laws that govern practice in the field</td>
<td>▪ Research ethics committees</td>
</tr>
<tr>
<td></td>
<td>▪ Nomos:</td>
</tr>
<tr>
<td></td>
<td>▪ Research ethics principles</td>
</tr>
<tr>
<td></td>
<td>▪ Guidelines for health research partnerships</td>
</tr>
<tr>
<td></td>
<td>▪ REC approval processes (north &amp; south)</td>
</tr>
<tr>
<td><strong>Habitus:</strong></td>
<td></td>
</tr>
<tr>
<td>▪ Lifestyle, values, dispositions, and expectations of particular social groups</td>
<td>▪ Researchers as northerners, southerners, northern and southern, different disciplines, male-female etc.)</td>
</tr>
<tr>
<td>▪ Principles by which people make choices</td>
<td>▪ Researcher understanding of communities</td>
</tr>
<tr>
<td>▪ Multitude of habitus possible</td>
<td>▪ Research Ethics Approval Processes</td>
</tr>
<tr>
<td></td>
<td>▪ Work ethos</td>
</tr>
<tr>
<td></td>
<td>▪ Culture of aid and colonisation</td>
</tr>
<tr>
<td>▪ <em>Hysteresis</em>: an inappropriate habitus, e.g. being uprooted from one society to another</td>
<td><strong>Hysteresis</strong>: some of the northern researchers in my study felt ‘awkward’ in research settings in the south and they also reported negative effects they had on data collection</td>
</tr>
<tr>
<td><strong>CAPITALS</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Economic capital:</strong></td>
<td></td>
</tr>
<tr>
<td>▪ Funding for collaboration: Funding flows; Lack of trust and capacity to manage funds</td>
<td></td>
</tr>
<tr>
<td>▪ Career paths</td>
<td></td>
</tr>
<tr>
<td>▪ Consultancies</td>
<td></td>
</tr>
<tr>
<td><strong>Social capital:</strong> how people get access to positions through social connections</td>
<td>▪ Initiation of collaboration (personal &amp; institutional links, funders call)</td>
</tr>
<tr>
<td>▪ Data collection processes</td>
<td>▪ Data collection processes</td>
</tr>
<tr>
<td>▪ Capacity Building (individual, exposure, institutional)</td>
<td>▪ Capacity Building (individual, exposure, institutional)</td>
</tr>
<tr>
<td>▪ Researcher relationships</td>
<td>▪ Researcher relationships</td>
</tr>
<tr>
<td>▪ Work practices</td>
<td>▪ Work practices</td>
</tr>
<tr>
<td>▪ Trust and equity</td>
<td>▪ Trust and equity</td>
</tr>
<tr>
<td>▪ north-south unequal relationships</td>
<td>▪ north-south unequal relationships</td>
</tr>
<tr>
<td><strong>Symbolic capital:</strong> Honour, prestige, recognition</td>
<td>▪ Priority and agenda setting processes</td>
</tr>
<tr>
<td><strong>Symbolic violence:</strong> mainly through cultural mechanisms</td>
<td>▪ Research Design</td>
</tr>
<tr>
<td>▪ Data analysis process</td>
<td>▪ Data analysis process</td>
</tr>
<tr>
<td>▪ IP issues</td>
<td>▪ IP issues</td>
</tr>
<tr>
<td>▪ Outputs</td>
<td>▪ Outputs</td>
</tr>
<tr>
<td>▪ Politics of authorship</td>
<td>▪ Politics of authorship</td>
</tr>
<tr>
<td>▪ Difficulties associated with Zambian research ethics committees</td>
<td>▪ Difficulties associated with Zambian research ethics committees</td>
</tr>
<tr>
<td>▪ Perceptions of unethical research</td>
<td>▪ Perceptions of unethical research</td>
</tr>
<tr>
<td>CAPITALS</td>
<td></td>
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<tr>
<td>----------</td>
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<tr>
<td>Cultural capital:</td>
<td></td>
</tr>
<tr>
<td>▪ Production and flows of knowledge</td>
<td></td>
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<tr>
<td>▪ Data analysis: understanding of cultural issues</td>
<td></td>
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<tr>
<td>▪ Perspectives on where ethical approval should be obtained</td>
<td></td>
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<tr>
<td>▪ Informed consent</td>
<td></td>
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<tr>
<td>▪ Lujo and Microbicide (showing lack of cultural capital)</td>
<td></td>
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<tr>
<td>▪ Community engagement</td>
<td></td>
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<tr>
<td>▪ Community perception of research</td>
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<tr>
<td>▪ Researchers understanding of communities</td>
<td></td>
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<tr>
<td>▪ Outsider carries advantages</td>
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</tbody>
</table>
## APPENDIX 10: Application of research findings to a model of cultural competence

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-theme</th>
<th>Application to model of cultural competence</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Priority &amp; agenda setting</td>
<td>Initiation of collaboration</td>
<td>Cultural sensitivity</td>
</tr>
<tr>
<td></td>
<td>Funding for collaboration</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>Priority and agenda setting process for collaboration</td>
<td>Cultural awareness</td>
</tr>
<tr>
<td>2 Research design</td>
<td>Research design</td>
<td>Cultural awareness</td>
</tr>
<tr>
<td>&amp; data collection</td>
<td></td>
<td>Cultural knowledge</td>
</tr>
<tr>
<td></td>
<td>Data collection</td>
<td>Cultural awareness</td>
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<tr>
<td></td>
<td></td>
<td>Cultural knowledge</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cultural sensitivity</td>
</tr>
<tr>
<td>3 Ethics</td>
<td>Ethics approval processes: north and south</td>
<td>Cultural awareness</td>
</tr>
<tr>
<td></td>
<td>Perceptions of unethical research</td>
<td>Cultural knowledge</td>
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<tr>
<td></td>
<td>Microbicide trial and Lujo virus</td>
<td>Cultural awareness</td>
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<tr>
<td></td>
<td>Community capacity to understand research (ethics)</td>
<td>Cultural sensitivity</td>
</tr>
<tr>
<td>4 Data analysis/outputs</td>
<td>Data analysis process</td>
<td>Cultural knowledge</td>
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<td></td>
<td>IP issues</td>
<td>NA</td>
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<tr>
<td></td>
<td>Outputs</td>
<td>Cultural awareness</td>
</tr>
<tr>
<td></td>
<td>Dissemination</td>
<td>NA</td>
</tr>
<tr>
<td>5 Capacity building</td>
<td>Individual capacity building</td>
<td>Cultural knowledge</td>
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<td></td>
<td>Career paths</td>
<td>NA</td>
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<tr>
<td></td>
<td>Consultancies</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>Discipline mix</td>
<td>Cultural knowledge</td>
</tr>
<tr>
<td></td>
<td>Relationships: cultural differences</td>
<td>Cultural awareness</td>
</tr>
<tr>
<td></td>
<td>Relationships: trust and equity</td>
<td>Cultural sensitivity</td>
</tr>
<tr>
<td>7 Researcher background,</td>
<td>Motivation for involvement</td>
<td>Cultural awareness</td>
</tr>
<tr>
<td>motivation &amp; expectations</td>
<td></td>
<td>Cultural sensitivity</td>
</tr>
<tr>
<td></td>
<td>Expectations met</td>
<td>NA</td>
</tr>
</tbody>
</table>
APPENDIX 11: North-south research collaboration guidelines

**COHRED: Steps to making vertical research programmes more responsible**

- Align their research activities in LMICs with national policies, priorities and strategies. If alignment is not possible, at the least, capacity building components of research programmes should be aligned with national capacity needs. Where necessary, support and input should be provided to priority setting and policy development for health research;
- Work through national governance and management systems – where these are functional – and coordinate activities with other research or complementary programmes active in the country. Where countries do not have these foundations work with stakeholders to develop them.
- Design capacity building, educational and training programmes in a generic way – so they serve the specific research programme, and research in other fields.
- Adopt ‘best practices in research partnerships’. This includes equitable benefit sharing and support for institution and system building.
- Include representation from low and middle income countries in programme governance structures.
- Promote the principles of responsible vertical programming among peers and colleagues.

*(COHRED, 2007)*

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1. Develop collaborations before extensive funding is secured, thus facilitating extensive local input into grant writing, program design, and early implementation.
2. Have a long-term view in order to develop meaningful relationships with partners in other countries.
3. Avoid parachute research.
4. Given the inevitable constraints more developed skills, technologies, and expertise on the part of the partner from the North, in the early stages of any collaboration, significant effort must be expended in terms of developing skills in the collaboration partner.
5. Throughout the life of the project, Northern researchers must be prepared to invest time and expertise in developing publication skills of the partners in the developing country.
6. Universities in the developed world should “twin” with academic and research institutions in the developing world.
7. Ownership of their skills by both parties is crucial. Researchers from the developed world generally have skills and knowledge and it is important that these do not some- how become denied or obscured in the interests of making all partners look equal.
8. Developing research collaborations in many parts of the world requires of researchers that they be politicians, managers, and social psychologists as much as being empirical scientists

*(Tomlinson et al (2006)*)
The Montreal Statement on Research Integrity in Cross-Boundary Research Collaborations (Draft 2013): recognises that collaborations present challenges for the responsible conduct of research, because there may be differences in regulatory and legal systems, organisational and funding structures, research culture and approaches to training. The Montreal Statement builds on the Singapore Statement on Research Integrity (2010) and identifies collaborative responsibilities of individual and institutional partners to include: overall collaborative responsibilities, responsibilities in establishing and managing the collaboration, responsibilities in collaborative relationships and responsibilities for the outcomes of collaborative research. The Singapore Statement does not deal specifically with research collaborations, but outlines principles and professional responsibilities, which are considered to be fundamental to the integrity of research throughout the world. The principles are: honesty, accountability, professional courtesy and fairness; and good stewardship.

Costello & Zumla (2000): outline four broad principles for research partnerships: mutual trust and shared decision making; national ownership; emphasis on getting research findings into policy and practice and development; development of national research capacity. The authors also construct a checklist to evaluate the principles of research partnerships in lower income countries.

Njelesani (2013): analyses how a Canadian and Zambian research partnership have used the principles for global health research partnerships presented in the Global Health Research Initiative (GHRI) framework.

1. Long-term and sustainable north–south partnerships
2. Interdisciplinary responses to complex issues
3. Participatory Action Research that grounds the research in its context
4. Research with a policy or practice impact orientation

Aikins (2012): identified five “key ingredients” required in order to sustain their partnership, which they claim can be applicable to research partnerships generally. They use Maselli et al (2005) to match partnership goals and criteria: social capital; measurable goals; administrative support; creative and innovative strategies; funding. Anderson & Metcalfe (2008) list similar
ingredients: leadership, integrity, setting joint goals, fulfilling promised commitments, intellectual property, funding, and evaluation strategies.

- **RAWOO Principles:** In 1999, the Netherlands Development Assistance Research Council (RAWOO) proposed three principles of fruitful partnership:
  
  o Strengthening the capacity for conducting socially relevant research should be a specific aim of the partnership
  o The Northern partner should be prepared to relinquish control and to accept considerable autonomy on the part of the Southern partner
  o A broad based consultative process, however painstaking and time-consuming it may be, should precede any programme
### APPENDIX 12: Global and Regional Research Ethics Capacity Strengthening Initiatives

<table>
<thead>
<tr>
<th>Initiative</th>
<th>Funder</th>
<th>Aim</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pan African Bioethics Initiative</td>
<td>WHO</td>
<td>To strengthen ethical awareness and discussion across Africa. Founded 2001, as an NGO [not clear if it is still operational].</td>
</tr>
<tr>
<td>Johns Hopkins Fogarty African Bioethics Training Program</td>
<td>Johns Hopkins</td>
<td>“Competitive selection of one African institution per year with existing strengths in bioethics to help the institution deepen its expertise in research ethics. This institutional approach strengthens the capacity of African Institutions to conduct sound research in public health”</td>
</tr>
<tr>
<td>WHO Strategic Initiative for Developing Capacity in Ethical Review</td>
<td>WHO</td>
<td>“A network of independently established regional fora for ethical review committees, health researchers and invited partner organisations. The primary objective is to contribute to human subject protections globally by developing local capacity for ethical review of research involving human subjects and for developing policies on the ethics of health research.”</td>
</tr>
<tr>
<td>Wellcome Trust</td>
<td>Wellcome Trust</td>
<td>Several fellowships aimed at training health professionals in LMIC in biomedical research ethics</td>
</tr>
<tr>
<td>South African Research Ethics Training Initiative</td>
<td>Funded by Fogarty International Centre Located in University of Kwazulu Natal, South Africa</td>
<td>“To build African capacity for the ethical review and implementation of relevant, appropriate and ethical health research, and to strengthen Africa’s institutional training capacity to achieve and sustain this aim”.</td>
</tr>
<tr>
<td>West African Bioethics Initiative</td>
<td>Partners</td>
<td>Programme for teaching, service and research in International Bioethics</td>
</tr>
<tr>
<td></td>
<td>University of Ibadan</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Fogarty International Centre</td>
<td></td>
</tr>
<tr>
<td></td>
<td>National Human Genome Research Institute</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Dominican Institute, Nigeria</td>
<td></td>
</tr>
<tr>
<td></td>
<td>University of Maryland, Baltimore</td>
<td></td>
</tr>
<tr>
<td>Initiative</td>
<td>Funder</td>
<td>Aim</td>
</tr>
<tr>
<td>------------</td>
<td>--------</td>
<td>-----</td>
</tr>
<tr>
<td>Global Forum on Bioethics in Research</td>
<td>Numerous partners including Wellcome Trust, WHO, COHRED and country level partners <a href="http://gfbronline.com/partners.htm">http://gfbronline.com/partners.htm</a></td>
<td>To bring together key stakeholders from developing, developed countries to debate the ethics, social, legal and public policy issues related to health research in international settings</td>
</tr>
<tr>
<td>European and Developing Countries Clinical Trials Partnership (EDCTP)</td>
<td></td>
<td>EDCTP supports various projects in order to strengthen ethics, regulatory and clinical trials registration in sub-Saharan Africa.</td>
</tr>
<tr>
<td>Mapping African Research Ethics Capacity (MARC) project</td>
<td>COHRED</td>
<td>Three project components: 1) online mapping of research ethics committees, 2) building capacity in research ethics in Africa; 3) mapping of medicines regulatory authorities in Africa</td>
</tr>
<tr>
<td>Ethox Centre (2009-2013)</td>
<td>Wellcome Trust Ethox Centre Wellcome-KEMRI Unit, Kenya</td>
<td>“To establish an international research network on the ethics of collaborative global health research. The Network, will build ethics expertise and capacity both in the United Kingdom and in developing countries - with a particular emphasis on building capacity at the Wellcome Trust’s Major Overseas Programme sites.”</td>
</tr>
</tbody>
</table>