

Patient trust in doctors in rural Tanzania: meanings, factors and benefits in the context of NCDs and hypertension care

Author:

Isangula, Kahabi

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Patient trust in doctors in rural Tanzania

**Meanings, factors and benefits in the context of NCDs and
hypertension care**

Kahabi Ganka Isangula

A thesis in fulfilment of the requirements for the degree of

Doctor of Philosophy



School of Public Health and Community Medicine

Faculty of Medicine

The University of New South Wales

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First name: **Kahabi**

Other name/s: **Ganka**

Abbreviation for degree as given in the University calendar: **PhD**

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Noncommunicable diseases (NCDs) are becoming a major public health challenge in low-income countries. Different strategies have been implemented to alleviate the burden of NCDs, but service uptake, compliance and continuing engagement with care remain suboptimal. This thesis investigated patient trust in doctors to establish whether it could form part of the NCD response in low-income African countries. To date, most studies on this issue have been conducted in high-income countries. This thesis provides much needed evidence around trust by exploring: the meaning of patient trust in doctors; what factors shape trust; and whether trust matters in hypertension care in rural Tanzania.

Semi-structured interviews were conducted in Swahili with 36 patients and eight providers. Participants were drawn from Western and traditional healing practices. Interviews were concurrently translated and transcribed, then systematically coded to facilitate the development of themes.

The findings show that participants' understanding of trust related to: patient expectations of a doctor before an encounter; patient satisfaction with the doctors' actions and behaviours during encounters and their post-encounter satisfaction with health outcomes associated with the doctor's treatment. Factors shaping trust in this rural Tanzanian context can be classified as patient, provider and health system factors. Novel factors identified were patients' faith in medications, patients' expectations of hypertension cure and the interplay between Western and traditional systems. Participants suggested that trust mattered in hypertension care in rural Tanzania because of its benefits in facilitating patient healthcare seeking, disclosure, adherence, return for subsequent hospital care, and reduced financial burden. Trust also matters because it benefited doctors by increasing their reputation and work morale, and benefited hospitals by improving their reputation and income. The interviews also revealed a range of potential disadvantages of trust, including increased patients' vulnerability to malpractice, inflated self-pride among doctors and increased workload.

This thesis establishes the value of improving patient trust in doctors as a means of increasing patient healthcare service uptake, adherence and continuity with hospital care for NCD response. The thesis offers context-specific considerations, and practice and policy recommendations for developing strategies to improve patient trust in doctors in low-income African countries.

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TABLE OF CONTENTS

ACKNOWLEDGMENTS	VIII
DEDICATION	X
ABSTRACT	XI
ABBREVIATIONS	XIII
GLOSSARY OF TERMS	XIV
LIST OF TABLES.....	XVII
LIST OF FIGURES.....	XVIII
CHAPTER 1: INTRODUCTION AND BACKGROUND	I
1.0 Introduction	I
1.1 Epidemiology of NCDs and hypertension.....	I
1.1.1 Persistent increase of risk factors for NCDs and hypertension	4
1.2 WHO response to NCDs and hypertension.....	6
1.2.1 WHO approach 1: Global strategies and policy actions.....	6
1.2.2 WHO approach 2: Cost-effective interventions	11
1.2.3 Progress on the WHO response to NCDs and hypertension	15
1.3 Importance of the biomedical response to NCDs	15
1.4 Biomedical NCD care in LIA and Tanzania	18
1.4.1 Organisation of healthcare services in LIA and Tanzania	19
1.4.2 Healthcare prioritisation in LIA: NCDs versus communicable diseases.....	20
1.4.3 Challenges of biomedical NCDs and hypertension care in LIA and Tanzania	20

1.5 Why this thesis matters	25
1.6 Thesis outline	26
CHAPTER 2: THE PATIENT-DOCTOR RELATIONSHIP	28
2.0 Introduction	28
2.1 Changes negatively affecting patient-doctor relationships	29
2.2 Tensions in patient-doctor relationships in LIA.....	31
2.3 Need to strengthen patient-doctor relationships	32
2.4 Approaches to strengthening patient-doctor relationships	34
2.4.1 Health system interventions.....	35
2.4.2 Competence-based interventions	40
2.4.3 Improving trust in patient-doctor relationships	44
2.5 Chapter summary and conclusion	47
CHAPTER 3: A REVIEW OF LITERATURE ON (PATIENT) TRUST ...	48
3.0 Introduction	48
3.1 Trust in patient-doctor relationships in HICs	48
3.1.1 Benefits of patient trust in doctors	49
3.1.2 Factors shaping patient trust in doctors.....	51
3.1.3 Interventions to improve patient trust in doctors.....	54
3.1.4 Measures of patient trust in doctors	58
3.2 Trust in LMICs	60
3.2.1 Factors shaping patient trust in LMICs.....	61
3.2.2 Patient trust in doctors in LIA and Tanzania	62
3.3 Gaps in the empirical literature on patient trust in doctors.....	65
3.4 Theorisation of trust in interpersonal relationships	68

3.4.1 What interpersonal trust means.....	69
3.4.2 Is interpersonal trust context-specific?	73
3.5 Chapter summary	74
3.6 Objective and research questions	75
CHAPTER 4: METHODS.....	77
4.0 Introduction	77
4.1 Study design	77
4.2 Study settings.....	80
4.2.1 Shinyanga as a region of inquiry	80
4.2.2 Shinyanga DC as a district of inquiry	82
4.2.3 Shinyanga MC as a district of inquiry	83
4.2.4 Selecting health facilities.....	84
4.2.5 Ethics approval and ethical conduct of this research	86
4.3 Research participant sampling, recruitment and interviews	86
4.3.1 Sampling of research participants.....	86
4.3.2 Recruitment of patients and doctors in Western practice	87
4.3.3 Recruitment of patients and providers in traditional practice	88
4.3.4 Scheduling interviews.....	90
4.3.5 Interview guide	91
4.3.6 Conducting interviews	92
4.4 Data management, coding and thematic analysis	94
4.4.1 Data translation and transcription.....	95
4.4.2 Thematic data analysis.....	96
4.5 Ensuring quality and rigor in this research.....	- 102 -

4.5.1 Credibility.....	- 103 -
4.5.2 Confirmability.....	- 104 -
4.5.3 Dependability.....	- 104 -
4.5.4 Transferability.....	- 105 -
4.6 Chapter summary	- 106 -
PREFACE TO RESULTS CHAPTERS.....	- 107 -
P.1 Participant characteristics.....	- 107 -
P.2 Individual participant characteristics.....	- 110 -
P.3 Results chapters	- 114 -
CHAPTER 5: WHAT TRUST MEANS TO PATIENTS AND DOCTORS IN RURAL TANZANIA	- 115 -
5.0 Introduction	- 115 -
5.1 The importance of understanding what trust means	- 115 -
5.2 What trust means to patients and doctors	- 118 -
5.2.1 Trust as meaning patients' positive expectations of a doctor	- 119 -
5.2.2 Trust as meaning patient satisfaction with encounter experiences	- 122 -
5.2.3 Trust as meaning patient satisfaction with doctors' treatment outcomes	- 126 -
5.3 Chapter summary and conclusion	- 128 -
CHAPTER 6: FACTORS SHAPING PATIENT TRUST IN DOCTORS IN RURAL TANZANIA.....	- 132 -
6.0 Introduction	- 132 -
6.1 Patient factors shaping trust in doctors.....	- 133 -
6.1.1 Patient factors related to expectation-based trust.....	- 134 -
6.1.2 Patient factors related to satisfaction-based trust.....	- 138 -
6.2 Provider factors shaping patient trust in doctors	- 140 -

6.2.1 Provider factors related to expectation-based trust	141 -
6.2.2 Provider factors related to satisfaction-based trust	142 -
6.3 Health system factors shaping patient trust in doctors	147 -
6.3.1 Healthcare facility accessibility	148 -
6.3.2 Healthcare facility level.....	149 -
6.3.3 Healthcare facility ownership	151 -
6.3.4 Healthcare resources	153 -
6.3.5 Quality of care	155 -
6.3.6 Limited Western healthcare options.....	156 -
6.4 Chapter summary and conclusion	158 -
 CHAPTER 7: NOVEL FACTORS SHAPING PATIENT TRUST IN DOCTORS IN RURAL TANZANIA.....	 162 -
7.0 Introduction	162 -
7.1 Patient trust in the interplay of Western and traditional practice	163 -
7.1.1 Affordability of traditional care and prohibitive cost of Western care.....	166 -
7.1.2 Patients' fears and generalised distrust in traditional healers	169 -
7.2 Patients' expectation of cure as a factor shaping trust in doctors	173 -
7.2.1 Social networks, expectations of cure and distrust in doctors	175 -
7.2.2 Traditional healers, expectations of cure and distrust in doctors	176 -
7.3 Patient faith in medications as a factor shaping trust in doctors	182 -
7.3.1 Patient faith in traditional medications	183 -
7.3.2 Patient faith in Western medications.....	185 -
7.4 Chapter summary and conclusion	188 -

CHAPTER 8: BENEFITS AND DISADVANTAGES OF TRUST IN RURAL TANZANIA.....	191 -
8.0 Chapter introduction	191 -
8.1 Abstract.....	192 -
8.2 Background	194 -
8.3 Results	195 -
8.3.1 Overview of findings	196 -
8.3.2 Benefits of trust for patients.....	197 -
8.3.3 Benefits of trust for health providers.....	200 -
8.3.4 Benefits of trust for the healthcare system	203 -
8.3.5 Disadvantages of trust for patients	206
8.3.6 Disadvantages of trust for doctors.....	207
8.4 Discussion and conclusion.....	208
8.5 Further reflections.....	212
8.5.1 Benefits of trust related to expectation-based trust	213
8.5.2 Benefits of trust related to satisfaction-based trust	213
CHAPTER 9: DISCUSSION AND CONCLUSIONS.....	217
9.0 Introduction	217
9.1 Major findings of this study in rural Tanzania	217
9.2 Can patient trust in doctors form part of the NCD response in LIA?	221 -
9.2.1 Trust in doctors amid poor health behaviours and NCD outcomes among patients in LIA	223 -
9.2.2 Trust in Western doctors in the interplay of Western and traditional practices in LIA	224 -
9.3 Implications of the research findings for designing effective trust improvement interventions for NCD response in LIA.....	226 -

9.4 Specific recommendations for designing trust improvement interventions	230 -
9.4.1 Interplay of Western and traditional practice	230 -
9.4.2 Barriers to NCD care	232 -
9.4.3 Patients' expectations of hypertension cure	233 -
9.4.4 Patients' faith in medications	234 -
9.4.5 Patients' religiosity and religious institutions as partners.....	235 -
9.4.6 Provider behaviours, perceived technical competence and reputation.....	236 -
9.5 Recommendations for further research	237 -
9.5.1 Generating measures of trust.....	238 -
9.5.2 Areas for further research	239 -
9.6 Strengths of this research	240 -
9.7 Limitations of this study.....	241 -
9.8 Reflections.....	242 -
9.9 Conclusion.....	244 -
REFERENCES.....	246 -
APPENDICES.....	312 -
Appendix 1: Key milestones in the global NCD response from 1999 to date.....	312 -
Appendix 2: Status of the 2013–2020 voluntary targets on NCD response by 2014 (a focus on CVDs in Africa)	314 -
Appendix 3: Demographic characteristics and map of Tanzania	316 -
Appendix 4: Gaps in DHIS hypertension data reporting from facilities in Shinyanga MC and DC (Oct 2014–Sept 2015).....	317 -
Appendix 5: Participants information and consent form (English version)	318 -
Appendix 6: Interview guide (English version)	323 -
Appendix 7: UNSW Ethical Clearance.....	326 -
Appendix 8: NIMR Ethical Clearance	327 -
Appendix 9: NIMR Data Transfer Authorization: Signature Page.....	328 -

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Kahabi Ganka Isangula

DEDICATION

Kwa wanangu wapendwa;

Evan Ganka Isangula

Eileen Ganka Isangula

Eileena Ganka Isangula

Kwa kuvumilia kutokuwepo kwangu karibu nanyi kama baba ili kunipa nafasi ya kukamilisha safari hii adhimu.

ABSTRACT

Noncommunicable diseases (NCDs) are a major public health challenge in low-income countries. Different strategies have been implemented to alleviate the burden of NCDs, but service uptake, compliance and continuing engagement with care remain suboptimal. This thesis investigated patient trust in doctors to establish whether it could form part of the NCD response in low-income African countries. To date, most studies on this issue have been conducted in high-income countries. This thesis provides much needed evidence around trust by exploring: the meaning of patient trust in doctors; what factors shape trust; and whether trust matters in hypertension care in rural Tanzania.

Semi-structured interviews were conducted in Swahili with 36 patients and eight providers. Participants were drawn from Western and traditional healing practices. Interviews were concurrently translated and transcribed, then systematically coded to facilitate the development of themes.

The findings showed participants' understanding of trust related to: patient expectations of a doctor before an encounter, patient satisfaction with the doctor's actions and behaviours during an encounter and their post-encounter satisfaction with health outcomes associated with the doctor's treatment. Factors shaping trust in this rural Tanzanian context were classified as patient, provider and health system factors. Novel factors identified were patients' faith in medications, patients' expectations of hypertension cure and the interplay between Western and traditional systems. Participants suggested that trust mattered in hypertension care in rural Tanzania because of its benefits in facilitating patient healthcare seeking, disclosure, adherence, return for subsequent hospital care, and reduced financial burden. Trust also mattered because it benefited doctors by increasing their reputation and work morale, and benefited hospitals by improving their reputation and income. The

interviews also revealed a range of potential disadvantages of trust, including increased patient vulnerability to malpractice, inflated self-pride among doctors and increased workload.

This thesis establishes the value of improving patient trust in doctors as a means of increasing patient healthcare service uptake, adherence and continuity with hospital care for NCD response. The thesis offers context-specific considerations, and practice and policy recommendations for developing strategies to improve patient trust in doctors in low-income African countries.

ABBREVIATIONS

CHWs	Community health workers
CMs	Complaints mechanisms
CSCs	Client service charters
CVDs	Cardiovascular diseases
DC	District Council
DHIS	District Health Information System
EANCD	East Africa NCDs Alliance
FBOs	Faith-based organisations
HIC	High-income country
HLHF	High level health facility
HMO	Health maintenance organisations
HTN	Hypertension
IoM	Institute of Medicine
ISH	International Society of Hypertension
LIA	Low-income Africa
LICs	Low income countries
LLHF	Low level health facility
LMICs	Low- and middle-income countries
MoHCDGEC	Ministry of Health, Community Development, Gender, Elderly and Children
MoHSW	Ministry of Health and Social Welfare
NBS	National Bureau of Statistics
NCDs	Non-communicable diseases
NHIF	National Health Insurance Fund
NIMR	National Institute for Medical Research
MC	Municipal Council
PCC	Patient-centred care
PEN	Package of essential NCDs interventions
PHC	Primary healthcare
RCTs	Randomised controlled trials
SGDs	Sustainable Development Goals
UN	United Nations
UNSW	University of New South Wales
URT	United Republic of Tanzania
WHO	World Health Organization

GLOSSARY OF TERMS

Biomedical care/response to NCDs

NCD care based on western scientific knowledge, skills and practices of disease prevention, diagnosis and treatment offered mostly in healthcare facilities (1, 2, 3).

Cardiovascular diseases (CVDs)

CVDs encompass a range of disorders of the heart and blood vessels. Hypertension is both a risk factor and a complication for cardiovascular diseases (1, 3).

High-income countries (HIC)

According to the World Bank (4), HICs have a gross national income per capita of \$12,736 or more as of the year 2016 e.g. USA, Canada, European Union and European free trade association countries, Australia and New Zealand. Countries such as Japan, South Korea, Singapore, Hong Kong, Macao, Qatar, and Israel are often left out when the term 'Western world' is used to denote developed countries.

Hypertension

Defined as a systolic blood pressure (SBP) equal to or above 140mmHg and/or diastolic blood pressure (DBP) of equal to or above 90mmHg. An average of two or more readings obtained in two or more separate occasions is often needed to make a diagnosis of hypertension (1,3).

Low income countries (LIC)

According to the World Bank (4), LICs are those with gross national income per capita of \$1045 or less as of the year 2016. In Africa, Low income African countries (LIA) includes: Tanzania, DRC Congo, Mozambique, Ethiopia, Uganda, Zimbabwe, Burundi, Rwanda and Malawi and, they constitute > 58% of 47 sub-Saharan African countries (4).

Medical pluralism

Medical pluralism refer to the employment of more than one medical system or the use of both western and traditional medicine for health and illness (5p829).

Non communicable diseases (NCDs)

A group of chronic disorders of long duration resulting from a combination of genetic, physiological, environmental and behavioral factors (e.g. hypertension, diabetes and cancer) (1, 3).

Patient-doctor relationship

A mutual participation of two individuals- patients and doctors - as they interact for therapeutic purposes in a safe and constructive environment that, in time, may allow the patient to convey highly personal and private matters (6 p58).

Patient trust in doctors

Where used in this thesis, patient trust in doctors refers to as patients' positive expectations of a doctor's actions and ability to offer good and correct treatment. This definition draws on the definitions of interpersonal trust in some social theories, and is detailed in Chapter 3.

Traditional care/practice/healing system

Health care services involving the knowledge, skills and practices based on the theories, beliefs, and experiences of indigenous culture that is used in the diagnosis and treatment of diseases by traditional healers or herbalists (7 p15).

Traditional healer (referred to as Mganga wa Jaji in Shinyanga):

A person who applies informal knowledge and skills mostly passed down from one healer to another to diagnose and treat diseases mostly using strategies such as foretelling, herbal remedies and/or spiritual cleansing (7).

Western care/practice:

Health care services involving knowledge, skills and practices of formally trained medical doctors and other healthcare professionals who recognise and treat diseases using biomedically tested western medications or scientifically researched strategies (1, 2 3)

SWAHILI WORDS/PHRASES USED IN THIS THESIS AND THEIR TRANSLATION

- Anatibu- Treats/can cure
- Daktari- Doctor
- Dawa- Medications
- Halmashauri –Council
- Imani- Trust
- Kata- Wards
- Kifua- Chest
- Kuaminika- Being trustworthy
- Kupata nafuu kabisa-Complete relief
- Kupona- Healing
- Kupona kabisa- Complete healing/cure
- Maumivu-Pain
- Mganga wa Jadi- Traditional healer
- Mgeni-Guest
- Moyo- Heart
- Mwaminifu-Trustworthy
- Mwenyeji- Host
- Mungu- God
- Presha- Blood pressure/hypertension
- Tarafa- Division
- Uaminifu- Trustworthiness
- Vijiji- Villages
- Waganga wa Jadi- Traditional healers

LIST OF TABLES

Table 1: WHO strategy/policy actions for NCD response	9
Table 2: PEN Protocol and requirement for successful implementation.....	12
Table 3: Features of common trust in physician scales	59
Table 4: Selected health facilities for qualitative inquiry	85
Table 5: Participants recruitment and interviews	91
Table 6: Moving from codes to themes	100
Table 7: Summary of participant characteristics	- 107 -
Table 8: Individual participant characteristics	- 110 -
Table 9: Participants' accounts of benefits of trust in health care settings.....	- 205 -
Table 10: The main findings of this research	- 219 -

LIST OF FIGURES

Figure 1: Health services organization in LIA	19
Figure 2: Positioning patient trust in doctors as a mediator of other interventions on patient-doctor relationships.....	46
Figure 3: The location of Shinyanga Region within Tanzania	81
Figure 4: Map of Shinyanga DC	83
Figure 5: Map of Shinyanga MC	84
Figure 6: Placards with promises of complete healing of hypertension “presha” and diabetes ‘kisukari” and other conditions	- 177 -
Figure 7: Drinking a ‘cup of cure’ for Chronic diseases from Babu wa Loliondo.....	- 179 -

Chapter I: INTRODUCTION AND BACKGROUND

'A patient who distrusts a doctor does not adhere to medications' (Limi, a farmer)

1.0 Introduction

Noncommunicable diseases (NCDs) have become a major public health challenge in low-income countries (LICs). Different strategies have been implemented to alleviate the burden of NCDs, but service uptake, compliance and continuing engagement with health care remain suboptimal. This thesis investigated patient trust in doctors to establish whether it could form part of the response to NCDs in low-income Africa (LIA). Although many previous studies have focused on this issue, most were conducted in high-income countries (HICs). This thesis provides much needed evidence around trust by exploring: what patient trust in doctors means; what factors shape trust; and whether trust matters in rural Tanzania in the context of hypertension care in both Western and traditional practices.

This chapter aims to position this thesis within a broader context of the growing burden of and response to NCDs. The chapter examines the global burden of NCDs, with a focus on hypertension in LIA, and specifically in Tanzania, as well as strategic responses initiated by the World Health Organization (WHO) and progress to date. It identifies current challenges associated with the biomedical response to NCDs in LIA and Tanzania, and clarifies the potential benefits of improving patient trust in doctors. In addition, the chapter outlines the relevance of this research to public health.

1.1 Epidemiology of NCDs and hypertension

The past decade has seen increasing concern over the rapidly growing burden of NCDs worldwide. The WHO indicates that NCDs accounted for 68% of all 56 million deaths

worldwide in 2012 (1, 8, 9), a rate that increased to 70% by 2017 (10). Current evidence suggests that 80% of the NCD burden occurs in low- and middle-income countries (LMICs) (1, 3, 11-16), which constitute over 50% of countries in Africa (4). A large body of literature indicates that LIA countries are not exempt from the growing burden of NCDs (11, 16-22). By 2012, NCD deaths accounted for 25%–49% of all deaths in LIA (22, 23). In Tanzania, NCD-related deaths accounted for 5.5% of deaths among adults aged ≥ 15 years in one urban and two rural areas between 1992 and 1995 (21); 16%–24% of deaths among adults aged 15–59 years in two rural southern districts between 2003 and 2007 (24); and 45.2% of deaths among adults in a tertiary hospital in the northern zone patients from rural and urban districts) between 2009 and 2011 (25). NCDs were rarely seen in LIA in the 1970s (26). However, the WHO projects Africa will account for 85% of the global NCDs burden by 2030 (1, 27), and NCDs will exceed communicable diseases as the more prevalent cause of death (8). Therefore, health systems in most LIA countries that were heavily directed toward management of acute and communicable conditions must now focus on NCD prevention and control.

Cardiovascular diseases (CVDs) are the most common contributor to the burden of NCDs globally, accounting for nearly half of all NCD deaths (10, 28). Research indicates that two-thirds of CVDs occur in LMICs, mostly LIA countries (1, 3, 11-16). In LIA, people who die from CVDs die on average 10 years earlier than those who die from CVDs in HICs (29). Current evidence suggests that among CVDs, hypertension is the largest contributor to NCD-related deaths worldwide (8, 9, 11, 12, 15, 30-36). Globally, the number of people with hypertension increased from 600 million in 1980 to 1 billion in 2008 (1, 3). In LIA, previous studies reported hypertension was an important contributor to NCD-related deaths (11, 16-21). In Tanzania, hypertension accounted for one-third of all NCD deaths between 2003 and 2007 in southern rural districts (24), and 34% of all NCD deaths between 2009 and 2011 (including 15% of all deaths that occurred in a tertiary hospital in

the northern zone that received patients from urban and rural districts) (25). This indicates that LIA countries, including Tanzania, are expected to increasingly suffer the negative consequences of NCDs.

Some reports suggest that Africa has the highest prevalence of hypertension among adults in the world (1, 3, 8). The WHO (3) indicated the prevalence of hypertension among adults aged 25 years and over was higher in Africa (46%) compared with the US (35%). Other reviews suggested that the hypertension prevalence among people aged 15 years or over across different LIA countries ranged from 6%–46% in 2011 (17), and from 15%–70% in 2015 (11). In Tanzania, a review conducted by Isangula and Meda (37) reported the hypertension prevalence in rural and urban populations ranged from 2%–10% in the 1960s and 13%–79% in 2016, indicating a rapid increase in the burden on the country. That review also suggested that LIA countries, such as Tanzania, will continue to host a large burden of NCDs compared with developed countries in the foreseeable future.

Hypertension is a major risk factor for other CVD mortalities and morbidities (26, 38-40). In addition, hypertension itself is one of the most common CVD disorders and poses a major public health challenge (11, 39, 41). The absence of early recognisable symptoms is an important feature of hypertension. Previously undiagnosed patients present to hospitals with complications including stroke, heart attacks or kidney failure, which are the most common causes of death among adults (3, 8, 42). For example, hypertension accounted for 57% of all stroke deaths and 24% of all CVD deaths among men and women aged 30 years and older in India (43). Opie and Seedat (19) noted that hypertension accounted for 62% of stroke, 49% of coronary artery disease and 14% of other non-fatal CVD events in the African region. In Tanzania, Mensah (44) reported an incidence of hypertensive stroke in adults aged 30–69 years as 120 per 100,000 person-years, one of the highest rates in the world and six to tenfold higher than rates in the US, UK and Canada. Patients with

hypertension in Tanzania are around 2.14 times more likely to suffer a stroke than patients without hypertension (20). Similarly, in a study conducted in northern Tanzania, Peck *et al.* (25) found hypertensive stroke and heart failure accounted for 53.2% and 27.1% of hypertension related NCD deaths, respectively. Based on this trend, the WHO (3) projected that by 2030, hypertension-related CVDs/NCDs will account for 23 million deaths worldwide, with LIA countries such as Tanzania carrying a large share of this burden.

1.1.1 Persistent increase of risk factors for NCDs and hypertension

The persistent increase of modifiable risk factors has contributed to the surge of NCDs and hypertension globally, and in LIA and Tanzania. A large number of reports have linked the global NCD and hypertension burden to rapid urbanisation and modern lifestyles (8, 16, 30, 41, 45-50). Modern lifestyles are thought to have resulted in increased nutritional and behavioural risk factors for hypertension and other NCDs, with risk factors including unhealthy diet, physical inactivity, excessive salt use, harmful use of alcohol, tobacco use (smoking) and persistent stress (8-10, 16, 30, 31, 48, 49, 51). In LIA, some literature suggests that modernity has contributed to socioeconomic, cultural and environmental transitions associated with increased modifiable risk factors for NCDs and hypertension (11, 16, 17, 19, 48, 52-55). According to Tibazarwa and Damasceno (55), rapidly growing economies in LICs have promoted urbanisation, made motorised transport more affordable and provided a reliable supply of processed food. This leads to physical inactivity, consumption of high-salt and high-fat foods sold in urban areas and a high incidence of overweight and obesity, and consequently increases the risk for hypertension. Local research suggests that because of rapid urbanisation in Tanzania, Westernised diets are increasingly replacing traditional dietary practices (47, 56-59). For example, Mazengo *et al.* (60) reported that a typical Tanzanian meal now contains more carbohydrates and limited proteins, with a generalised decrease in vegetable and fruit consumption. These nutritional transitions are thought to have contributed to the rise in obesity and overweight, which are

common modifiable risk factors for CVDs and hypertension. In support, Njelekela *et al.* (61) reported an obesity prevalence of 58% among urban women. Similarly, Shayo and Mugusi (62) and Muhihi *et al.* (63) reported obesity prevalence rates of 9% and 24.7% in 2008 and 13% and 36% in 2012 among urban adult men and women, respectively. This trend is expected to continue alongside persisting rural-urban migration and urbanisation of peri-urban and rural settlements in Tanzania.

Excessive alcohol consumption is another modifiable risk factor for NCDs and hypertension (22, 64). The prevalence of harmful alcohol consumption among adults aged 15 years and older in Tanzania ranged from 9%–46% in 1993 (38) and 20%–71% in 2015 (65). Harmful alcohol consumption is a widespread problem, including in other LIA countries (66, 67). Similarly, cessation of smoking reduces the risk for both NCDs and CVDs (68-71). However, smoking is on the rise in Tanzania, with the prevalence of smoking among adolescents ranging from 2%–6% among those aged 15–19yrs in 1993 (38) and 4%–13% among those aged 13–15yrs in 2003 (72). The prevalence of smoking among Tanzanian adults was reported to range from 16%–34% in 2002 (73) and 28%–43% in 2004 (74). Recent reports indicate tobacco smoking and alcoholism are common across rural and urban areas of Tanzania and other LIA countries (65, 75-79). This may partly explain the continued rise in the prevalence of hypertension in both rural and urban contexts (8, 18-21, 37, 80, 81).

Non-modifiable risk factors also contribute to the burden of NCDs and hypertension in LIA and Tanzania. Ethnic background and family history are documented as risk factors for hypertension (3, 8). Some studies in Africa have shown that NCDs, especially the prevalence of hypertension, increases with age (16, 82-84). In Tanzania, Edwards *et al.* (85) reported a high prevalence of hypertension among people aged ≥ 55 years: 69%–89% in urban residents and 54%–61% in rural residents. Consistent with this finding, Dewhurst *et*

al. (86) found that the prevalence of hypertension among participants aged ≥ 70 years was 70% in the north-eastern part of Tanzania, with women presenting the highest prevalence (79%) ever documented in sub-Saharan Africa. The aging population is also likely to increase the burden of NCDs. Van de Vijver *et al.* (16) projected a 14-fold increment in the older population in Africa. The older adult population will increase from the current estimate of 56 million to approximately 716 million by the end of the 21st century, exceeding other age groups in Africa and other world regions (16). The non-modifiable risk factors for hypertension may partly explain why NCDs in LIA countries are on the rise, despite the lower prevalence of modifiable risk factors compared with Western countries (12, 32, 87, 88). Overall, the persistent increase of modifiable and non-modifiable risk factors suggests that NCDs will continue to pose major challenges for the health sector in LIA countries including Tanzania, which is already crippled by other health priorities.

1.2 WHO response to NCDs and hypertension

In response to the growing burden of NCDs and hypertension, the WHO has adopted two complementary approaches: i) encouraging multinational political commitment targeting the policy level response and ii) developing and promoting 'cost-effective interventions' that target the primary healthcare (PHC) setting and prioritise low income countries. Some of these parallel WHO strategies are examined below.

1.2.1 WHO approach I: Global strategies and policy actions

In the past two decades, the WHO implemented several activities to encourage political commitment to NCD response among member states. These included drafting global strategies and policy actions, endorsement by the World Health Assembly and monitoring and reporting the progress of implementation (1, 8, 10, 27, 36, 71, 89-92). This has increased recognition of the economic and societal impact of NCDs, raised the profile of NCDs and LICs in the global health dialogue, and resulted in concrete political commitment

(10, 33, 36, 92-94). Appendix I summarises some of the key policy milestones achieved since 1999.

An iconic political commitment was the endorsement of the WHO consultative recommendations for the *Global Strategy for the Prevention and Control of NCDs* by the World Health Assembly in 2000 (90). The impact of NCDs on social and economic development was identified as requiring a response involving international cooperation and solidarity. The three aims of the endorsed global NCD strategy (90) were: i) mapping NCD epidemics; ii) reducing modifiable risk factors; and iii) strengthening biomedical care. Consequently, WHO member countries committed to generating local information bases through surveillance, establishing NCD response programmes, tackling contributing issues outside the health sector and ensuring health sector reforms were responsive to NCD challenges (90). To support member states' political commitment, the WHO developed implementation tools including the STEPwise framework for surveillance (95), the WHO/International Society of Hypertension (ISH) guideline for clinical management of hypertension and the WHO/ISH risk assessment charts (94, 96, 97). These tools are further discussed in Section 1.2.2.

In 2008, the *Action Plan for Global Strategy for the Prevention and Control of NCDs (2008–2013)* was proposed, and subsequently endorsed by the World Health Assembly (71, 91). Under this strategy, WHO member states committed to: i) fulfilling six policy objectives (Table 1) and ii) incorporating NCD response in poverty-reduction strategies. For example, WHO member states committed to developing and implementing national multi-sectoral frameworks to coordinate the NCD response (71, 91), and Tanzania developed its first NCD strategy in 2008 (98). To further support member states' commitment, the WHO developed 'Package of Essential NCD' (PEN) interventions for healthcare workers in low-resource settings in 2010, which is discussed in Section 1.2.2.3 below.

To fulfil the fourth research-centred objective of the 2008–2013 action plan, the WHO undertook consultative meetings between 2008 and 2010 to develop the *Prioritized Research Agenda for Prevention and Control of NCDs* (99). Mendis and Alwan (99) noted that one of the three NCD-oriented research agendas included a focus on ‘research that enables...effective interventions to become accessible and used appropriately in resource-constrained settings’ (p9). In the same document, a key aspect of CVDs that required further research in the context of NCD prevention and control was identified as, ‘investigating health system-related opportunities and barriers to care and develop feasible approaches to apply cost-effective interventions in primary health care’ (99 p26). This thesis contributes to the achievement of these NCD/CVD global research priorities.

Three years after the introduction of the 2008–2013 global NCD strategy, there were sustained concerns over persistent increases in the prevalence of NCDs, mortality and morbidity, particularly in LMICs (35, 68, 99). As a part of remedial strategies, the Moscow Ministerial Conference on Health, Lifestyle and NCD Control (92) and the United Nations (UN) high-level meeting on NCDs in 2011 (93) re-affirmed the need to include NCD response initiatives in national health strategic plans. To help strengthen national efforts, the WHO proposed a new *Global Action Plan for the Prevention and Control of NCDs 2013–2020*, which was subsequently endorsed by the 66th World Health Assembly in 2013 (1, 8, 9, 27). This global action plan further developed the objectives of the 2008–2013 strategy and set nine voluntary targets. Table I summarises the policy objectives of the 2000, 2008–2013 and 2013–2020 action plans.

Table 1. WHO strategy/policy actions for NCD response

GLOBAL NCDs STRATEGY 2000	GLOBAL NCDs ACTION PLAN 2008–2013	GLOBAL NCDs ACTION PLAN 2013–2020	PROPOSED OPTIONS FOR MEMBER STATES IN THE 2013–2020 ACTION PLAN
i. Mapping NCD epidemics ii. Reducing risk factors iii. Strengthening biomedical care	i. Priority raising and integration ii. National policies and plans iii. Reducing modifiable risk factors iv. Research for prevention and control of NCDs v. Partnerships vi. Monitoring and evaluation	i. International cooperation and advocacy ii. National capacity and partnerships iii. Prevention (reduction of modifiable risks) iv. Health system strengthening v. Research and development, monitoring and evaluation	i. Reduction of modifiable risk factors ii. Diagnosis, treatment and control -Early care seeking -Early diagnosis -Drug treatment and adherence -Solutions based on local insights and global perspectives iii. Health system strengthening -Universal Health Coverage -People-centred care -Availability and affordability -Infrastructure

Adapted from the WHO (1, 8, 9, 27, 71, 90, 91)

The third objective of the 2013–2020 strategy, enshrined in both the 2000 and 2008–2013 strategies, prioritised the reduction of modifiable risk factors as an ‘effective intervention’ for responding to NCDs/hypertension (1, 27, 71, 90). This complemented the broader calls for ‘nutritious food for all’ and ‘safe and sustainable cities for all’ (30, 31, 100–102). Clearly, interventions to reduce modifiable risk factors form an important entry point for NCD/hypertension response in LIA. However, given the significant contribution of non-modifiable risk factors (as detailed above), there is also a need for more overarching interventions that consider both modifiable and non-modifiable risk factors, alongside targeted interventions focusing specifically on modifiable risk factors to effectively address the growing NCD/hypertension burden in this context.

The fourth objective of the 2013–2020 strategy (Table 1, p10) moved beyond prevention to emphasise the biomedical response to CVDs and hypertension. Diagnosis, treatment and control were emphasised as one of the three proposed options for member states (Table 1, p10). The PEN strategy and WHO/ISH risk prediction charts (detailed below) were re-emphasised as ‘cost-effective interventions’ for detection, treatment and control of CVDs/hypertension (1, 8, 27). In 2014, 1 year after the introduction of the 2013–2020 strategy, the WHO released the *Global Status Report* on the nine voluntary global targets for NCD response (1). While 1 year may be an unrealistic timeframe within which to judge member states’ performance on the nine voluntary global targets set by the 2013–2020 strategy, the 2014 WHO global status report indicated some progress (1). However, this progress was uneven and overall unsatisfactory, and a key message of the report was that, ‘while some countries are making progress, the majority are off course to meet the global NCD targets’ (1 p4). Appendix 2 summarises the progress on NCDs and hypertension prevention and control as of 2014, with a focus on Africa.

Three events/activities resulted from the slow progress towards achievement of the voluntary targets for the reduction of NCDs and hypertension. First, the WHO placed increased emphasis on the ‘Best Buys’ (detailed below) as the most cost-effective interventions in 2014 (1). Second, the need to scale up NCD detection, diagnosis, treatment and care were re-affirmed by the *WHO Global Meeting of National NCD Program Directors and Managers* in 2016 (36). Lastly, the *2015 Agenda for Sustainable Development and Sustainable Development Goals* (SDGs) set out a number of NCD-related targets to be attained by 2030. These were placed within SDGs #3 that focused on ensuring healthy lives and promoting wellbeing for all at all ages (103). A key target included supporting research for NCDs, with a focus on developing countries (103). This thesis focuses on the potential value of trust in NCD response in LIA, and can be broadly seen as contributing to achieving this SGD target.

1.2.2 WHO approach 2: Cost-effective interventions

Alongside efforts to drive political commitment and policy actions, the WHO developed several cost-effective interventions to improve the biomedical NCD response, focusing on PHC in LICs. Of interest to this thesis are: i) STEPwise approach to Surveillance of NCDs (STEPS) (95); ii) WHO/ISH risk assessment charts for 14 WHO sub-regions (94, 96, 97, 104); iii) PEN (105, 106); and iv) 'Best Buys' interventions (104, 107). Sections 1.2.2.1–1.2.2.4 briefly examines each of these interventions.

1.2.2.1 STEPS

To support monitoring of the 2000 Global NCD Strategy, the WHO introduced STEPS as a surveillance framework in 2003. STEPS was expected to establish evidence for NCD prevention and control activities for WHO member states (95). Reports indicated that some WHO member countries have embraced STEPS and generated NCD incidence data (14, 15, 34, 59, 108, 109). A key observation was that the data generated through STEPS has provided useful input for NCD status reports by WHO; however, some LIA countries do not report data and some only report partial data (1, 9, 10). Therefore, the actual burden of NCDs and hypertension in LIA may be underestimated. Nonetheless, for NCD surveillance data to be gathered and reported, people's active engagement with NCD care is necessary.

1.2.2.2 WHO/ISH risk assessment charts

To support implementation of the 2000 Global NCD Strategy, the WHO and the ISH introduced CVD risk assessment charts for PHC providers to use in assessing their patients (94, 96, 97, 104). Research in some LMICs, including Jamaica (110), Cambodia, Malaysia, Mongolia (111) and South India (112) suggest that the WHO/ISH charts are cost-effective for CVD risk prediction and health service planning in PHC. For example, Fatema *et al.* (113) estimated that 20% of the adult population were at risk for developing CVDs in rural

Bangladesh using WHO/ISH charts. A problem with WHO/ISH charts is that their success in clinical settings largely depends on patient willingness to seek care and disclose personal information.

1.2.2.3 PEN interventions

To support implementation of the 2008–2013 global NCD strategy, the WHO introduced an evidence-based and action-oriented tool in 2010 to support the biomedical response; namely, PEN interventions for healthcare workers in low-resource settings (105).

According to the WHO, PEN was designed as a set of cost-effective interventions to facilitate early detection of NCDs, treatment and counselling to modify risk factors in resource-constrained settings (105, 106). PEN protocol comprises actions and activities that healthcare providers are expected to perform when encountering patients who seek biomedical care in PHC. These activities include asking questions related to NCD/CVD/hypertension risk factors, physically examining and estimating risks, making referral decisions, and providing treatment and counselling. Healthcare providers are expected to continuously repeat these actions/activities when patients return for care. Table 2 summarises the key actions/activities of the PEN protocol and proposed requirements for its success.

Table 2. PEN protocol and requirements for successful implementation

PEN actions	Recommended activities	Successful implementation of these actions may need:
ACTION 1 ASK ABOUT	Tobacco use, alcohol consumption, occupation (sedentary and active), physical exercise, family history of CVD risk	-Patient willingness to seek healthcare services in the first place -Patient trust in doctors for disclosure -Patient perception of providers' technical competence -Patient trust in doctors to willingly submit to bodily physical examinations -Patient's perception of confidentiality
ACTION 2 ASSESS	Physical examination, medical investigations	
ACTION 3 ESTIMATE RISK	Estimate cardiovascular risk for non-referrals	

ACTION 4 REFERRAL	Referral criteria for all visits	- Doctors' positive communication skills
ACTION 5 COUNSEL AND TREAT	Counselling on risk reduction Drug treatment	-Optimal engagement and participation by patients in decisions to increase 'ownership' of proposed interventions
SECOND VISIT REPEAT	Ask about adherence to advice on tobacco and alcohol use, physical activity, healthy diet, medications and so on	- Patient trust in doctors to visit the referral facility -A blame free environment, encouragement and support - Patient trust in doctors to accept and adhere to providers' instructions, medications and medical advice for risk reduction -Patient trust in doctors to willingly return for follow-up.

Adapted from WHO (105, 106): PEN interventions for PHC in low-resource settings

Table 2 suggests there are two key requirements for successful practical implementation of the PEN protocol in clinical settings. First, for healthcare providers to successfully administer the PEN protocol, patients need to seek biomedical care. Second, PEN success largely depends on strong patient-doctor relationships, in which a patient perceives shared goals, providers' technical competence, good communication and that the doctor will maintain confidentiality. When these conditions are met, a patient is more likely to: disclose personal information; submit to a physical examination; participate in treatment decisions; follow-up referral decisions; accept, own and adhere to the proposed interventions; and return to the healthcare facility for the PEN protocol to be re-administered. All of these issues suggest that a patient needs to trust a provider in the first place, which is at the heart of PEN implementation.

Current research suggests PEN is a promising health-facility based strategy to address the burden of NCDs in LICs (see 35, 104-106, 114-116). A good example is the study by Wangchuk *et al.* (116) that reported use of the PEN strategy increased the diagnosis of NCDs/hypertension, medication adherence and hypertension control after 3 months of implementation in PHC settings in parts of India. However, when considering that study,

two questions about the practical implementation of PEN remain unanswered. First, there is a question about how to draw people who may have no obvious symptoms (e.g. hypertension) towards the uptake of health-facility based PEN interventions. The second question concerns how to ensure continuing engagement with healthcare services of people diagnosed via PEN. For example, Wangchuk *et al.* (116) reported that of 896 patients diagnosed through PEN interventions in the first visit, 19.3% never attended their second visit and 50% missed their third consecutive visit. Similarly, of 43 patients diagnosed at their second visit and referred to a higher facility, 37% missed their follow-up visits. Those authors indicated a preference for traditional medicine was among the reasons for discontinuation of Western biomedical care. Therefore, patient willingness to use and continue using the Western healthcare system seems necessary for the success of PEN in low-income settings. Subsequent chapters discuss research that has examined patient trust in doctors as a means of increasing both patient healthcare seeking and continuing engagement with care.

1.2.2.4 Best Buys

Best Buys comprises 16 interventions for NCD response with an emphasis on resource-constrained settings (1, 32, 104-117). The Best Buys interventions were selected from a set of 88 interventions based on evidence of cost-effectiveness, high impact and feasibility for implementation (117). Drug therapy, risk management (using WHO/ISH charts/ PEN) and patient counselling were selected for biomedical control of CVDs/hypertension (117 p16). However, the success of these biomedical strategies as an effective response to CVDs/hypertension depends on patients adhering to drug treatment and adopting measures to reduce behavioural risk factors proposed by healthcare professionals (118-122). Non-adherence to medications and medical advice hinders successful implementation of CVD-focused Best Buys, contributing to poor NCD control. I will return to the challenges of adherence in section 1.4.3.3.

1.2.3 Progress on the WHO response to NCDs and hypertension

With only two years remaining, what is the current status of the implementation of the 2013–2020 Global NCD Strategy? This is an important question to consider. At the time of submitting this thesis, two reports were available that provided an indication of the implementation progress of the WHO NCD strategies: i) the *World Health Statistics 2017: Monitoring health for the SDGs* (28) and ii) the *2017 NCDs Progress Monitor Report* (10). While the former report discusses NCD progress as part of the SDGs, the latter tracks country level progress on 10 selected national commitments set during the UN high-level meeting on NCDs in 2011 and echoed in the 2008–2013 and 2012–2020 global NCD strategies (10, 28). These commitments range from developing time-bound national targets and multi-sectoral national strategy/plans, to adopting recommended cost-effective interventions/tools and implementing risk reduction measures and biomedical care by 2025.

Both reports highlighted the slow pace of NCD response in LIA. NCD deaths are increasing; the World Health Statistics report (28) indicated NCDs accounted for 70% (about 40 million) of all 56 million deaths by 2017, and CVDs accounted for 45% of all NCD deaths. While CVD mortality is said to have ‘rapidly declined in recent years’, it remains far higher in LMICs (including LIA) compared with HICs (28 p31). Furthermore, LIA countries continue to report a higher proportion of premature NCD deaths (deaths among those younger than 70 years of age (18% in Tanzania, 22% in Uganda and 22% in Burundi) compared with HICs (~11% in the UK, 12% in Germany and 14% in the US) (10). This suggests that more needs to be done in LIA to curb the NCD burden.

1.3 Importance of the biomedical response to NCDs

As noted above, the WHO continues to emphasise the importance of the biomedical response to NCDs in low-income settings by promoting cost-effective PHC-based interventions (PEN, WHO/ISH charts and Best Buys) as a strategic action. The World

Health Statistics 2017 (28) and NCDs Progress Monitor 2017 reports (10) highlighted the persistent increase in NCD deaths, emphasising the need for biomedical responses to NCDs to facilitate early diagnosis, treatment and control.

The medical literature indicates there is extensive global consensus on biomedical drug treatment for NCD management and control. For example, antihypertensive drugs are seen as the most promising tools in controlling hypertension and reducing CVD events (118-122). Biomedical treatment and effective use of antihypertensive drugs can significantly reduce the hazards of stroke, chronic kidney disease, myocardial infarction and heart failure (41, 120, 123). This would result in a 7% reduction in CVDs and 10% reduction in stroke (124), and prevent up to 151,000 stroke and 153,000 CVD deaths in the global population (70). A reduction of 10 mmHg in blood pressure through use of antihypertensives decreases the lifetime risk for CVD and stroke death by 25%–40% (120). This provides the rationale for promotion of biomedical service uptake, adherence and return for hospital care as an important strategy to address the global burden of NCDs and hypertension.

Despite the undeniable value and need for effective biomedical NCD responses, recent WHO reports indicated that biomedical NCD care is still hindered globally by inadequate patient healthcare-seeking, under-diagnosis, poor treatment/control and non-adherence (9, 10, 28, 36). Most importantly, poor adherence to medications is a major and persistent problem for hypertension and other chronic conditions (16, 66, 93, 125-134). Brown and Bussell (127) identified the causes of non-adherence globally as related to three key groups: i) patient factors, such as knowledge, beliefs, attitudes, misconceptions, literacy, experiences, cost and time, poor engagement and lack of motivation and support; ii) physician factors, such as poor communication, short consulting times and the inability to recognise non-adherence, prescribe simple drug regimens, explain the benefits and side effects, consider the financial burden and elicit a history of alternative therapies; and iii)

health system factors, such as fragmented healthcare systems, poor coordination, limited access to healthcare services for patients, prohibitive drug costs or co-payments, poor health information technology and the substantial number of patients. To address these factors, Brown and Bussell (127) called for multiple interventions focusing on the patient, doctor and health system. However, public health interventions to increase adherence, which were mostly implemented in HICs, have primarily focused on: i) patients (e.g. instructions, counselling and telephone follow-up and reminders); ii) health service characteristics (e.g. improving convenience); and iii) medication features (e.g. formulation, dosing or packaging). These interventions have reported mixed results (129, 130, 135-138). This may suggest a mismatch between the proposed causes of non-adherence and what the interventions prioritise. For example, patient factors (e.g. attitudes, beliefs, misconceptions, literacy and engagement) and provider factors (e.g. communication) that can be addressed by improving patient-provider relationships appear to have received weaker attention in these interventions. Consequently, the problem of non-adherence to medications appears far from being solved. The next chapters explore the value of improving trust in patient-doctor relationships as a promising strategy to address some of the patient and doctor factors identified by Brown and Bussell (127) as contributing to non-adherence to medications.

As discussed above, the WHO has successfully mobilised political commitment and developed 'cost-effective interventions' for NCD response in PHC, prioritising LICs. However, the cost-effective interventions for PHC response (PEN, WHO/ISH charts and Best Buys) appear to place emphasis on: i) provider activities pertaining to risk assessment, diagnosis, biomedical drug treatment, counselling and continued monitoring and ii) patient activities pertaining to seeking care in the first place, disclosure, adherence and return for care. Recent reports indicate there has been substantial progress towards NCDs targets in HICs, but LIA countries continue to demonstrate unfavourable progress, with more NCD

deaths among younger populations. A lot needs to be done by different actors to address the challenges of NCDs and hypertension response in LIA. My work here focuses on the value of strengthening trust in patient-doctor relationships to maximise the success of the WHO cost-effective PHC-based interventions. As this study seeks to contribute knowledge to improve NCD care and treatment in LIA, the next section focuses on specific challenges for biomedical NCD care in LIA, and Tanzania in particular.

1.4 Biomedical NCD care in LIA and Tanzania

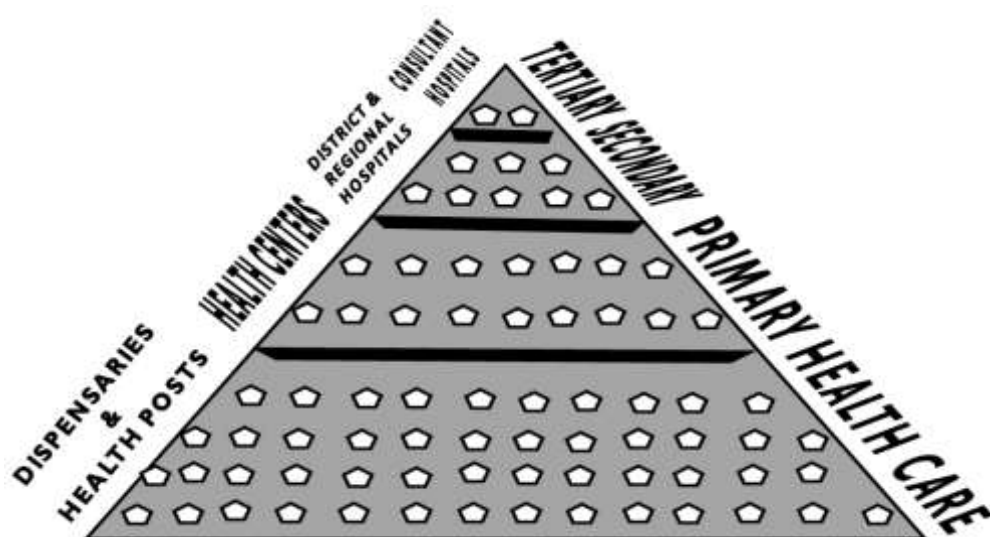
Before examining the challenges associated with implementing the biomedical NCD response in LIA and Tanzania, it is pertinent to the development of this thesis to briefly examine how LIA countries respond to NCDs. Broadly, LIA countries have embraced the WHO interventions for NCD and hypertension response. Governments in some LIA countries have politically committed to meeting their obligations under the 2013–2020 global action plan for NCD response (8, 9, 36, 139, 140). LIA countries have also increasingly adopted the cost-effective interventions recommended by WHO for biomedical NCD response in PHC settings (8, 9, 139–141). In addition, cross-sector political alliances and working groups, mainly advocating for national NCD response, are slowly being established across LIA (e.g. the East Africa NCDs Alliance), although their impact is far from being fully realised because of financial constraints (140, 142). In Tanzania, a NCD department has been established at the Ministry of Health to provide leadership, and a national 2016–2020 NCD strategic plan has been developed. This plan incorporates local experience and the WHO cost-effective interventions (PEN and Best Buys), and was officially launched in 2016 (37, 141). One year after launching the plan, the WHO NCD progress monitor report indicated Tanzania had successfully set NCD targets and developed an integrated NCD strategy/plan, but that it was struggling with other NCD targets (10). Although the current Tanzanian 2016–2020 strategy prioritises prevention activities such as promotion of physical exercise (37, 141), the response to NCDs and

hypertension in Tanzania (as in other LIA countries) relies heavily on biomedical care in healthcare facilities for diagnosis, management and control. More needs to be done by different sectors in Tanzania and other LIA countries to improve the biomedical NCD response. However, several features of healthcare services—*organisation* and *prioritisation*—seem to influence the biomedical NCD response in these countries.

1.4.1 Organisation of healthcare services in LIA and Tanzania

Health services in LIA are organised in a pyramid structure (Figure 1), ranging from PHC facilities (health posts, dispensaries and health centres) to secondary and tertiary hospitals (143-146). The pyramid base comprises many PHC facilities, which are sparsely distributed throughout rural areas and heavily resource-deprived (147-152). The pyramid apex comprises relatively fewer secondary and tertiary facilities, which are mostly concentrated in urban areas and better equipped with resources compared with rural facilities (147, 149-153). Over 68% of the LIA population reside in rural areas, and a continuing reliance on traditional healing practices delivered by trusted and familiar traditional healers is widespread (7, 154-159). Competition for clients between Western and traditional care for chronic disease management is inevitable. This calls for interventions that enhance patients' confidence in evidence-based biomedical treatments.

Figure 1: Health services organisation in low-income Africa



1.4.2 Healthcare prioritisation in LIA: NCDs versus communicable diseases

Regardless of resource constraints, PHC facilities in LIA are striving to offer biomedical NCD care. These facilities promote Western NCD care through health education, diagnosis, treatment and ongoing monitoring of patients (34, 152, 160). However, some researchers have expressed concern about their lack of capacity to address the challenges of the NCD/hypertension burden (19, 45, 150, 152, 161). This is partly because NCD/hypertension was previously considered rare in Africa (8, 16, 50, 52, 162, 163). Therefore, health sector resources and infrastructure have mainly prioritised communicable conditions such as malaria, diarrhoea, HIV, tuberculosis and maternal and child health conditions (16, 50, 147, 150, 161). However, LIA countries must continue to rely on under-resourced PHC services for NCD response until they improve their capacity for more sustainable and reliable formal alternatives.

1.4.3 Challenges of biomedical NCDs and hypertension care in LIA and Tanzania

Research in LIA indicates that there is poor service uptake for NCD/hypertension care, leading to under diagnosis, and inadequate treatment and control, despite political commitment and ongoing uptake of the WHO cost-effective interventions. As noted above, a key challenge for LIA is non-adherence to NCD/hypertension medications. Challenges for the NCD response in LIA are the focus of the following sections.

1.4.3.1 Low NCD services uptake and poor diagnosis, treatment and control

To date, studies of NCDs in LIA have reported poor healthcare seeking, under diagnosis, and poor treatment and control. A substantial number of individuals with NCDs/CVDs in LIA do not seek care (1, 8, 9, 16, 45, 122, 162, 164-169). For example, even after community screening for hypertension, 60%–80% of newly diagnosed patients in Tanzania

do not seek care from referral facilities (162, 166). Hypertension diagnosis is estimated to range from 11%–41% in LIA (88, 169) and 20%–38% in Tanzania (85, 86). Even for patients who are diagnosed and need medication, active engagement with treatment is estimated to range from 6%–10% in Tanzania (85, 86) and 3.5%–50% in Mozambique (3).

Correspondingly, hypertension control is estimated to range from 0.9%–1% in Tanzania (85, 86) and 1%–4.8% in Mozambique (3). These challenges appear to be universal in other LIA countries (19, 132, 163, 164, 167, 170, 171). Therefore, the question remains as to what interventions could be taken to address these challenges.

1.4.3.2 Approaches to increasing NCD service uptake and limitations

To increase biomedical NCD service uptake through diagnosis, community-based screening (162, 167, 172–174) and even screening at drug outlets (166) has been implemented in LIA.

As noted above, some previous studies indicated that not seeking care from referral facilities is common, even without limitations in access, convenience or diversity of Western sources (e.g. in parts of Tanzania) (162, 166). This leads to the examination of two key issues that continue to impact biomedical NCD care uptake and continuity in LIA: providers' technical and behavioural incompetence and medical pluralism.

1.4.3.2.1 Providers' technical and behavioural incompetence

Patient satisfaction studies in Tanzania (176–179), Uganda (180, 181) and Malawi (182, 183) suggested that negative provider attitudes, behaviours and technical incompetence impact uptake and continuing engagement with biomedical interventions. Patient complaints of negative provider behaviours and technical incompetence appear to have prompted politicisation of medicine in LIA, which further impacts the uptake of biomedical care services. Politicisation of medicine occurs when politicians consistently exercise their power directly towards accused health workers. This is evident in the following extracts from recent media stories in Uganda and Tanzania.

Kampala—President Museveni last week fired all health workers at the health facility, including the Director of Health Services, over [patients'] complaints of negligence and absenteeism by medical officers (184).

Dar Es Salaam—Doctors across the country were up in arms against what they described as growing mistreatment and harassment of health workers accused of malpractice in public hospitals. They said recent incidents have seen many of their colleagues suspended or fired by political appointees...sometimes on perceived malpractice (185).

While politicisation of medicine indicates the absence of effective complaint mechanisms and the powerlessness of professional bodies (e.g. in Tanzania) (177, 186, 187), it may also further fuel tensions between patients and providers and loss of confidence in public medical practice. When coupled with the clinical characteristics of hypertension, especially the lack of recognisable symptoms at earlier stages of the disease (8, 46, 188), a patient is likely to 'wait' for CVD symptoms to avoid encountering politically pronounced 'distrusted' or 'incompetent' healthcare workers. This may impact patients' willingness to seek care from public health facilities and potentially pull patients away from Western care and towards traditional healers. No intervention appears to have successfully addressed patient concerns about providers' technical and behavioural incompetence. This thesis shows that improving trust between patients and doctors may address some of these concerns, thereby promoting both patient healthcare seeking and continuing engagement with Western care.

1.4.3.2.2 Medical pluralism

Medical pluralism plays a significant role in patient uptake and continuity with Western biomedical interventions. Medical pluralism is widespread in hypertension care in both urban and rural areas in LIA, and there is a higher preference for traditional care for

diseases that are regarded ‘incurable’ in Western care (7, 157, 159). In Africa, medical pluralism is heavily influenced by several factors: i) a patient’s knowledge (i.e. supernatural causal ideation or perceiving hypertension as different from high blood pressure), which may weigh choices towards different treatment options (159, 163); ii) prolonged use of Western medications without disease control or ‘cure’, leading to loss of confidence in their ability and increased proclivity to supplement or replace biomedical with traditional medicine (133, 157, 163); iii) patient perception that herbal medications are natural and therefore safer than biomedical drugs (7, 155, 189-191); iv) patient perception of symptomatic relief from herbal medicine (163, 191-193); v) competition for clients between Western care and the traditional ‘curers’ of chronic diseases (170, 189-191, 194, 195); and vi) traditional healers’ ability to maintain good relationships with patients through promise and assurances of cure and expectation of patients referring their friends and relatives (7, 155, 189, 191-193, 196). The result chapters (5-8) show that most of these issues emerged in my analysis of participants’ accounts, which suggested that they can be addressed by improving trust in patient-doctor relationships in Western care.

1.4.3.3 Poor adherence to medications

As noted earlier, adherence to antihypertensive drugs is central to the realisation of their benefits in preventing CVD complications. However, research in LIA indicates unfavourable trends in patient adherence (84, 122, 133, 165, 197-199). Adherence to hypertensive medications was reported to range from 14% in Tanzania (162, 197) to 54.2% in the Democratic Republic of Congo (133), resulting in a low level of blood pressure control.

Consistent with the study by Brown and Bussell (127), research in LIA has identified patient, provider and health system factors contributing to non-adherence to NCD medications (84, 122, 125, 133, 198, 200). Patient factors (behaviours, perceptions, beliefs, choices and experiences) strongly contribute to poor adherence to hypertension

medications (84, 122, 133). Additionally, patient's poor knowledge about the complications of NCDs/hypertension, experience of side effects, perception of not needing medications on noticing symptom improvements, use of non-prescription medications, inadequate education at healthcare facilities, fears of addiction and forgetfulness are the major reasons for non-adherence (84, 133). Provider factors (doctors' ability to recognise non-adherence, explaining to and educating the patient about the benefits, complications and adverse effects of medications effectively) and considering the financial burden for the patient can promote adherence to prescribed medications (198, 201). Health system factors (unavailability of medications, cost of care and medical pluralism) are the most commonly reported contributors to non-adherence (84, 133). This brings me to examining what has been done to address these challenges.

1.4.3.4 Approaches to increase adherence and limitations

To increase adherence to medications, some interventions have been implemented in LIA that mirror those in Western countries. The main focus has been group education, phone-based reminders, pill combinations and home based self-blood pressure monitoring (202-205). While some of these interventions claim success, similar to reports in Western countries, the results indicate that solutions to the problem of non-adherence to medications in LIA have been beyond reach. In subsequent chapters, I examine research suggesting that improving trust in the patient-doctor relationship may improve patient adherence to biomedical interventions.

This section has focused on the challenges of biomedical responses to NCDs and hypertension in LIA. While some LIA countries have embraced the WHO cost-effective interventions, there remain persistent challenges in biomedical responses, including poor healthcare service use, underdiagnosis and undertreatment, non-adherence to medications, and inadequate continuing engagement with care leading to poor NCD/hypertension

management and control. Given that there has been some uptake of the WHO cost-effective interventions, it is of vital importance that biomedical NCD responses address the existing challenges in the best way possible. Strengthening trust in patient-doctor relationships appears to be an important entry point to address some of the challenges for NCD response in LIA. Chapter 3 details recent literature, mostly from HICs, that has established a positive relationship between patient trust in doctors and patient healthcare seeking/use, disclosure and participation, adherence to medications, continuing engagement with hospital care and NCD control (206-215). This brings me to the question of why this thesis matters.

1.5 Why this thesis matters

This thesis uses rural Tanzania as a LIA case study to explore the notion of patient trust in doctors in hypertension care. Appendix 3 summarises Tanzania's demographic characteristics and provides a map. Reasons for investigating patient trust in doctors in Tanzania include: i) the country lies in a LIA category with a gross domestic product (GDP) per capita of USD 955 (4); ii) Tanzania is my country of birth, my home and the country where I have spent most of my professional career; and iii) as evidenced throughout the discussion above, Tanzania faces a growing burden of NCDs and hypertension in both urban and rural settings. Conducting this research in rural Tanzania aims to address a gap in current research on patient trust in doctors, where evidence to date is predominantly from urbanised HICs (Chapter 3).

Investigating trust in rural Tanzania is of significant value to public health because of the major concern regarding the rising burden and the persistent challenges of NCDs globally, in LIA and Tanzania itself. These challenges call for research on different strategies to maximise the success of the WHO cost-effective interventions and take advantage of member states' political commitment (32, 95, 96, 104, 105, 107). More specifically, some

LIA countries, including Tanzania, have adopted the WHO policy actions and recommended PHC-based interventions for NCD/hypertension response (8, 9, 14, 217, 218). However, evidence suggests inadequate healthcare service uptake, non-adherence to medications and poor continuity with hospital care among patients with NCDs/hypertension (1, 9, 16, 45, 84, 133, 139, 162-164, 174) negatively impact the success of the WHO cost-effective interventions. Strengthening patient-doctor relationships may offer a promising entry point to address some of these challenges.

This research is of value to the public health response to NCD and hypertension in LIA because it establishes whether trust in patient-doctor relationships should form part of the NCD response. This is because, as noted above and detailed in Chapter 3, a large body of research has established associations between patient trust in doctors and positive patient health behaviours and outcomes. Such evidence positions patient trust in doctors as a promising entry point for addressing the challenges of the growing burden of NCDs and hypertension in LIA. However, what we know about patient trust in doctors to date mostly originates from HICs. Three research questions underpin this thesis: what patient trust in doctors means; what factors shape trust; and whether trust matters. These research questions will provide much needed evidence to support the institutionalisation of trust in patient-doctor relationships as a public health strategy in response to the burden of NCDs and hypertension in LIA.

1.6 Thesis outline

This thesis is structured as follows.

- Chapter 2 reviews the broad literature on patient-doctor relationships and provides a justification for investigating trust in patient-doctor relationships as a public health lens to address NCD and hypertension challenges in LIA.

- Chapter 3 focuses on the empirical literature on patient trust in doctors and identifies gaps in previous research. These include inadequate research on the topic of trust in LIA, failure to examine what trust means to research participants and limited involvement of providers. Additionally, many studies have emphasised the benefits of trust to patients alone and failed to examine the disadvantages of trust. Further, the chapter summarises the objectives and research questions investigated in this thesis as a way of addressing identified gaps.
- Chapter 4 provides details of the study design and settings, recruitment and interview procedures, thematic analysis and strategies used to ensure rigor in this research.
- Chapter 5 investigates the meaning of patient trust for patients and providers in rural Tanzania. The chapter discusses three meanings of patient trust in doctors (one expectation-based and two satisfaction-based meanings) emerging from participants' accounts and anchored in their experiences of hypertension care.
- Chapters 6 and 7 investigate the factors shaping patient trust in doctors in rural Tanzania. Chapter 6 discusses patient, provider and health system factors that shape trust that have been identified in other settings. Chapter 7 discusses three novel factors that emerged in this study.
- Chapter 8 investigates the question of whether trust matters in rural Tanzania by examining the benefits ascribed to trust by study participants. The chapter also discusses the disadvantages of patient trust in doctors that emerged in this study.
- Finally, Chapter 9 summarises the research questions and develops the main conclusions of this thesis. This chapter also discusses the implications and recommendations for medical practice, policy actions and future research, as well as highlighting the limitations of this study.

Chapter 2: THE PATIENT-DOCTOR RELATIONSHIP

A patient-doctor relationship is 'a consensual relationship in which the patient knowingly seeks the physician's assistance and in which the physician knowingly accepts the person as a patient' QT Inc v. Mayo Clinic Jacksonville (219 p6)

2.0 Introduction

This chapter examines research on strengthening the patient-doctor relationship. First, the chapter provides an outline of the current challenges facing patient-doctor relationships globally, and prevailing tensions between patients and doctors in LIA and Tanzania. It then considers the importance of different entry points for strengthening patient-doctor relationships. Finally, the rationale for investigating trust as a means of improving patient-doctor relationships to support the response to NCDs and hypertension in LIA is presented.

Before discussing the challenges facing patient-doctor relationships, it is essential to acknowledge that patient-doctor relationships have received extensive attention from sociology, public health and clinical practice perspectives (220-232). Some researchers have adopted a disease-specific approach to examine patient-doctor relationships, such as HIV (233) or diabetes care (234). Others have taken medical-cadre specific approaches, such as patient-dentist (235) or patient-nurse relationships (236, 237). Some researchers have also provided a detailed analysis of the evolution of patient-doctor relationships. For example, Meyer (238) conducted a sociological examination of changes in the drivers shaping patient-doctor relationships through monopoly, conflict and concentration phases, with an emphasis on change in obligations, responsibilities and power dynamics between patients and providers. Similarly, Kaba and Sooriakumaran (6) framed the history of patient-doctor relationships from ancient Egyptian to modern times, and indicated that accurate diagnosis

and effective treatment have always depended on the quality of relationships between patients and doctors.

Various authors define the patient-doctor relationship differently (220-232). The dominant constructs across these definitions appear to take a legal perspective in which a patient-doctor relationship is defined as a relationship in which a patient willingly seeks care from a doctor, and the doctor willingly agrees to offer medical care to a patient (219, 232, 239-241). This is echoed by Kaba and Sooriakumaran (6), who defined a patient-doctor relationship as 'a mutual participation of two individuals' (patients and doctors) as they interact for therapeutic purposes in a safe and constructive environment that, in time, 'allow[s] the patient to convey highly personal and private matters' (p58). The latter definition supports a view of strong patient-doctor relationships as more likely to facilitate patients' understanding, disclosure and participation in the treatment plan, and consequently their ownership of medical intervention, satisfaction with care and adherence to medications.

2.1 Changes negatively affecting patient-doctor relationships

One of the most significant discussions in Western countries involves the concern that developments and changes in health systems contribute to the deterioration of patient-doctor relationships. On one hand, the WHO (242) considered 'increasing specialization and over-dependence on technology' as negatively impacting patient-provider interactions (p31). This suggests that the benefits of technological advancements and medical specialisation in facilitating accurate and timely diagnosis may be accompanied by disadvantages such as reducing the time for patient-doctor interactions. On the other hand, changes in healthcare financing systems and organisation, such as changes in the UK National Health System following introduction of market-based reforms (e.g. devolution of central control and fixed price reimbursement and insurance systems) (243-246), are said

to have negatively impacted patient-doctor relationships. These changes have created barriers such as lack of continuity of patients with the same doctors, shortened consultation times and tasking doctors with multiple (potentially conflicting) responsibilities to patients and third-party entities (222, 247-251). A similar concern was noted in the US in terms of the impact of managed care on diminishing the time a doctor must spend with a patient (222). Grant (222) suggested:

Given that the average physician visit is between 15 to 20 minutes, many patients feel that their doctor is rushing and that they do not have time to ask questions and get answers or describe all symptoms and concerns. Together, these stressors can contribute to a lack of trust, understanding, and loyalty between a patient and a physician, and they can prompt doctors to become closed, defensive, and dissatisfied in their careers (p233).

Many health system changes have resulted in profit prioritisation in patient-doctor relationships, or what the WHO (242) referred to as 'commercialisation' of healthcare. Commercialisation of healthcare is considered to have influenced medical professionals to view healthcare as a trade for monetary reward rather than a profession, with some medical professionals divorcing themselves from ethical and professional duties to their patients, thereby leading to the 'deprofessionalisation' of medicine (242, 248, 249, 251-253). Furthermore, discussion has emerged in some sociological literature reflecting concerns about patients' reduced confidence in the power of scientific disciplines as a result of increased individual and societal reflexivity. This has led to a call for greater public accountability for professions such as doctors, who are normally considered trustworthy and concerned with a patient's situation (253-258). More specifically, increased patient access to information (which may be potentially conflicting) via various sources such as the media or Internet is said to have negatively impacted patient-doctor relationships (220, 242, 254, 259, 260, 446). For example, the media increasingly publicises medical errors and malpractice, which may undermine patient confidence in the medical profession (248, 254,

261). Dolce (262) reported that although Internet information empowered patients to influence and control healthcare decisions, it precipitated feelings of disappointment with healthcare workers when expectations were not met. For this reason, Fredericks *et al.* (220) suggested 'there is a crisis in the patient-physician relationship...the changing times introduce multiple stressors...managed care, mass media and malpractice affect doctors, who may become closed and defensive, and patients, who lose trust and loyalty' (p378). These changes have the potential to negatively affect patients' trust in doctors. An important question is whether these changes are evident in patient-doctor relationships in LIA. This issue is the focus of the next section.

2.2 Tensions in patient-doctor relationships in LIA

Although social researchers in Western countries have linked the deterioration of patient-doctor relationships to changes in healthcare systems, there appears to be limited accounts of such issues in LIA. Instead, a considerable body of literature has been published on the tensions patient-doctor relationships continue to endure in LIA (detailed below). As in Western countries, the media impact patient-doctor relationships in LIA. Current evidence suggests that medical errors are increasingly publicised, and patients in Africa are increasingly accessing health information through mass media and the Internet (263-266). The publication of medical errors appears to have made a major contribution to the politicisation of medicine and medical pluralism in LIA, and also affects the uptake of services in primary health facilities offering Westernised medical care (Chapter 1).

Of particular interest to this thesis is the dominance of patient complaints and dissatisfaction with providers' technical and professional incompetence (skills, reliability, assurance, confidentiality, patient engagement) and behavioural incompetency (demeanour, empathy, communication skills/language and respect) in LIA (176, 177, 181, 183, 267-272). Evidence suggests that providers' negative attitudes and behaviours have continued to sour

patient-doctor relationships in Tanzania (176-179), Kenya (271), Uganda (181) and Malawi (182, 183). Such tensions are increasingly evident even in middle-income African countries (e.g. South Africa) (273-275). Some researchers further documented concerns about providers violating patients' rights in healthcare settings. For example, Ojwang *et al.* (271) reported that patient-provider experiences in Kenyan hospitals were surrounded by providers' impoliteness and violation of patients' dignity, leading to erosion of patients' rights in healthcare settings. Patient dissatisfaction with doctors' care impacts patient trust and loyalty (220), and may also impact health service uptake, adherence to medication, continuing engagement with care and health outcomes (179, 232, 276, 277). Given the prevailing tensions between patients and doctors in LIA, there appears to be a need to strengthen their relationships as a means of facilitating patient healthcare service uptake, adherence and continuity with hospital care.

2.3 Need to strengthen patient-doctor relationships

The need for strong patient-doctor relationships in diagnosis, treatment and ongoing monitoring of chronic diseases is widely recognised in biomedical, public health and sociological literature (6, 215, 216, 221, , 232, 278-280). Some researchers have emphasised a strong patient-doctor relationship as an important and promising lens for achieving patient health outcomes and disease control (216, 221, 224, 228, 278, 279, 281). Furthermore, some scholars implicitly consider a strong patient-doctor relationship as an opportunity for doctors to fulfil their ethical, legal and professional obligations towards respecting and preserving patient's life, interests and dignity (as specified in the Hippocratic Oath) by demonstrating gratitude, compassion, justice, honesty, humbleness, sanctity, integrity, confidentiality and fidelity (6, 282-288). In addition, discussion in some social literature points to a suggestion that strengthening patient-doctor relationships may be a means of enduring the changes impacting these relationships due to societal reflexivity and modernity (248, 254, 255, 261, 289). Collectively, this literature indicates that strong therapeutic

relationships may facilitate: i) patient engagement with care and positive achievement of health outcomes; and ii) doctors effectively fulfilling their therapeutic obligations for disease management and control.

There is limited published literature to date that specifically calls for strengthening patient-doctor relationships for NCD/hypertension response in LIA. Some researchers have indicated strong patient-doctor relationships are needed to improve patient-doctor communication and inter-personal exchanges in acute diseases. A recent study in Uganda noted poor service provider performance on communication practices and limitations in inter-personal exchanges between patients and providers related to malaria testing processes impacted patients' perceptions of proposed treatments (290). Some researchers specifically recommend strengthening the patient-doctor relationship as a means of enhancing healthcare use, adherence and patient health outcomes in communicable diseases. In Tanzania, Mkopi *et al.* (291) indicated that poor involvement of patients in therapeutic decisions negatively impacted uptake and continuity of tuberculosis interventions. Another study focused on maternal care indicated that decision-making power asymmetry in favour of providers and unclear communication resulted in missed services and adversely influenced patient uptake of all components of prevention of mother-to-child transmission of HIV services (179). This suggests that improving patient-provider relationships in LIA may bring dual positive impacts: i) enhancing satisfaction with care (292) contributing to reducing interpersonal tensions in healthcare (see above); and ii) contributing to improving patients' healthcare use behaviours and health outcomes (207, 213). Improving patient-doctor relationships may also have benefits for health outcomes pertaining to both communicable and non-communicable. Given the need for strong relationships between patients and doctors in LIA, as outlined above, it is important for the development of this thesis to examine different strategies for improving patient-doctor

relationships. In reviewing the relevant literature, the vital importance of patients' trust in doctors—the focus of this thesis—emerges.

2.4 Approaches to strengthening patient-doctor relationships

PHC as a central aspect for NCD and hypertension management and control is evident in the WHO 2013–2020 strategic plan for NCD/hypertension response (Chapter I) and the African Union's 2016–2030 health strategy for reducing disease burden (293). Effective PHC service delivery depends on: i) patients' healthcare seeking tendencies; ii) what happens during patient-doctor interactions; and iii) patients' actions after the encounter (230, 231). As such, the value of strengthening patient-doctor relationships to maximise the impact of health services on patient health in chronic diseases (where ongoing interactions and long-term relationships are necessary) cannot be understated.

Adopting a classification commonly used in health research, the WHO (242) and Fredericks *et al.* (220) characterised factors impacting patient-doctor relationships in three categories:

- i. *Patient factors*, such as sociodemographic characteristics (income, age, education and race) impacting healthcare access and power in patient-doctor relationships, knowledge, beliefs, customs, habits and use of complementary and alternative medicines.
- ii. *Provider factors*, such as attitudes and behaviours related to interpersonal communications (e.g. insensitivity towards the poor or failure to maintain standardised care), malpractice, work overloads and dissatisfaction (from discontent with compensation and reimbursement, insurance and reforms).
- iii. *Health system factors*, such as funding (e.g. in managed care), healthcare costs, provider diversity, malpractice and medical errors, malpractice litigation, mass media and the Internet, direct to consumer advertising, online access to medications, unequal distribution of health facilities between rural and urban

contexts, problems with medical education and absence of continuing medical education programmes, dysfunctional medical councils and poor enforcement of codes of ethics.

The WHO (242) proposed a ‘framework of action’ prioritising health system interventions and competence-based interventions as ways of addressing the patient, provider and health system factors that impact patient-doctor relationships.

2.4.1 Health system interventions

Health system interventions through changes in institutional mechanisms are part of addressing factors impacting patient-doctor relationships. The WHO (242) recommended strategies such as improving governance, service organisation, promoting clients’ rights, establishing reconciliation bodies, enhancing the work of professional bodies, developing client service charters, advocating for quality assurance, patient feedback mechanisms and social support systems. According to the WHO (242), implementation of such strategies is expected to improve patient access to doctors, good communication, information exchange, empathy and compassion, supportive environments and more time spent in patient-doctor encounters. These elements are anticipated to lead to increased patient satisfaction, increased patient trust in doctors, adherence, literacy and patient-centredness of care. A brief examination of some system-based interventions for strengthening patient-doctor relationships is presented below.

2.4.1.1 Health governance reforms and policies

A considerable amount of published literature indicates that health governance reforms and policies with the potential to impact patient-doctor relationships positively occurred or were introduced before the WHO introduced a framework of action for improving patient-doctor relationships in 2013. Globally, some countries had introduced healthcare service

organisation and governance reforms to motivate competitive healthcare markets, provider diversity and patient choice before the 2013 WHO framework was proposed (243-245, 294-296). Many countries had also already established medical regulatory boards¹ or committees, professional codes, guidelines and health policies (287, 297-302). Even some countries in LIA (e.g. Tanzania and Rwanda) had developed and implemented health policies several years before the 2013 WHO framework was proposed (143, 287, 303). An important question is whether system-based interventions alone can strengthen patient-doctor relationships.

As this investigation focuses on Tanzania, I will briefly examine the challenges of implementing some system-based interventions in this country. The Tanzania health policy (303) places emphasis on patient-centred care (defined in section 2.4.2.2) by envisioning a health system that is 'more responsive to the needs of the people' (p4). In this policy, ensuring access to health services and resources, the availability of competent and adequate health workers, community sensitisation and multi-sectoral collaboration are considered key policy objectives for the provision of equitable, quality and affordable health services (303). However, persistent tensions between patients and doctors in Tanzania (177-179), interpersonal complaints attracting political interventions (185, 304, 305) and poor health seeking, diagnosis, adherence and disease control (Chapter 1) indicate that policy-level interventions have not successfully improved patient-doctor relationships. To offer more insights on what did not work, I examine three strategies that have the potential to positively impact patient-doctor relationships below. Two strategies sit within the Tanzanian Health Policy (303): client service charters (CSCs) (p6-7) and health facility governance committees (HFGCs) (p8). The third essential tool is complaints mechanisms (CMs), which have received some attention from advocacy entities in Tanzania.

¹ For example, the American Medical Association (<https://www.ama-assn.org/>)/Medical Board of Australia (<http://www.medicalboard.gov.au/>).

2.4.1.2 CSCs

Local reports in Tanzania characterise CSCs as ‘social pacts’ between service providers and receivers (e.g. companies, health facilities and customers/patients) that specify standards for service delivery that a customer has the right to expect, complaint handling and feedback mechanisms (306-312). The Tanzania Health Policy (303) considers CSCs as a way of helping [patients] understand the service delivery commitments, means of communication, achieving the service standards, means of correction of mistakes done and how to claim their rights’ (p6). This suggests that when used effectively, CSCs can empower patients to communicate the broader service quality issues that impact patient-doctor relationships in PHC settings to facility managers/Ministry of Health. Where medical practice is highly politicised (Chapter 1), medical errors are widely discussed in the media (as previously noted) and complaints mechanisms are dysfunctional (see below), the existence and effective use of CSCs by patients may serve as a bridge between patients and providers to ensure smooth service delivery. The problem with CSCs is twofold. First, while the Ministry of Health committed to ‘generate CSC guidelines and review the charters on annual basis’ (303 p6), available charter documents mostly focus on clients of the Ministry itself (311) and some of its agencies, such as the Medical Stores Department (309), National Institute for Medical Research (312) and the Food and Drug Authority (310). To date, there is limited evidence of the availability of CSCs at low-level healthcare facilities in Tanzania. Second, there have been limited empirical analyses of the effectiveness of CSCs or their potential contribution in strengthening patient-doctor relationships in medical practice in Tanzania and other LIA countries. Clearly, if CSCs are made available and effectively used by patients, they may have the potential to positively impact patient-doctor relationships by clarifying what patients should expect from providers and how to communicate any dissatisfaction. However, there remains a question as to whether CSCs can effectively address the significant challenges of NCD/hypertension response in Tanzania and other LIA countries.

2.4.1.3 HFGCs

HFGCs constitute democratically-elected representatives of the communities surrounding a healthcare facility (303). According to the Tanzanian Health Policy (303), HFGCs are expected to 'own health resources and, to ensure that health facilities and services provided are of acceptable quality, managed by qualified personnel according to staffing level in line with the Ministry of Health policy guidelines and standards' (p8). Research in LIA indicates that HFGCs are mainly charged with financial planning, management and resource mobilisation, promoting health worker performance and promoting smooth relationships between community members (service users/patients) and the health facility (providers) (see 313-316). My personal experience with HFGCs in Tanzania is that they promote health worker performance and smooth relationships between community members and healthcare workers, mainly by seeking to address any disputes between patients and providers (e.g. through complaints mechanisms as detailed below). Research in Tanzania indicates problems with HFGCs are poor community awareness of their existence, underrepresentation of the community and low motivation among committee members (314). Similar challenges have been highlighted in the neighbouring country of Kenya (313, 315, 316). The failure of health systems to address these persisting challenges continues to limit the effectiveness of HFGCs as an entry point for strengthening patient-doctor relationships in Tanzania and other LIA countries. However, similar to CSCs (above), a question remains as to whether the activities of HFGCs alone could address the current challenges of the growing burden of NCDs/hypertension in Tanzania and other LIA countries.

2.4.1.4 CMs

The Danish Refugee Council (317) defined CMs as, 'simple procedures and mechanisms that give [service] users access to safe means of voicing complaints on areas relevant and within the control of the agency' (p12). A considerable amount of literature has positioned

effective CMs as part of good healthcare institutions, and noted that they give patients opportunity to monitor and report the quality of care, doctors' incompetence, patient dissatisfaction and maltreatment (317-327). According to Mahindi *et al.* (187) and the Australian Ombudsman (321), CMs may empower patients to reactively report negative experiences (e.g. providers' technical or behavioural incompetence and poor participation in decision making) that may impact the quality of service delivery and patient-doctor relationships in PHC settings. Mahindi *et al.* (187) viewed effective CMs as impacting both provider-user relationships and the quality of health service delivery because they increase the 'chance of service users to raise their concerns for the betterment of health services' (p1).

The problem with CMs is that there appears to be limited empirical analyses of their effectiveness in medical practice in LIA. In Tanzania, CMs have only been examined from advocacy standpoints. A survey by Sikika, a health advocacy entity in Tanzania, reported that 68%–78% of participants in urban districts of Dar es Salaam and 22%–40% of participants in rural districts of Dodoma and Pwani affirmed the availability of CMs (187). Over 80% of participants in that survey reported suggestion boxes were the most common CMs, with their perceptions of the effectiveness of this form of CM ranging from 29%–64% (187). These data are reported in Mahindi *et al.* (187) amid concerns by those authors that the methods they used to establish the effectiveness of CMs 'may not represent the true effectiveness of the mechanism' (p8). Concerns regarding the unavailability of CMs in some facilities, non-responsiveness, patient dissatisfaction with the way their complaints were managed, patient fears and uncertainties related to the absence of confidentiality, patient unawareness of their existence and illiteracy emerged as common reasons for non-use of CMs leading to perceived ineffectiveness (187). Similar concerns were noted in other countries, including Nepal (328). Clearly, CMs offer a promising entry point for addressing tensions between patients and providers to positively affect patient-doctor relationships in

LIA. However, the challenges related to their implementation appear to limit the effectiveness of this tool in medical practice. Nevertheless, as with CSCs and HFGCs (above), the challenges of NCD response in Tanzania and other LIA countries (detailed in Chapter 1) indicate that there is room to examine other interventions that may achieve more results than what can be achieved through CMs.

Collectively, health system-based interventions, if implemented well, offer useful entry points for strengthening patient-doctor relationships in Tanzania and LIA. However, these interventions (e.g. CSC, HFGCs and CMs) continue to face challenges that limit their effectiveness in strengthening patient-doctor relationships. Nevertheless, it is unclear whether strengthening patient-doctor relationships through CSCs, HFGCs and CMs could address challenges relating to NCDs in Tanzania and LIA. This creates a room for considering another entry point proposed in the WHO (242) framework of action; that is, competence-based interventions.

2.4.2 Competence-based interventions

Improving patient and providers' competence and skills related to facilitating smooth therapeutic interactions has long been considered a stepping stone for strengthening patient-doctor relationships in medical practice. The WHO (242) recommended training providers in communications, medical ethics, social and cultural competence and patient education to improve patient-doctor relationships. Similarly, a large body of literature indicates that patient-doctor communication and provider behavioural interventions have been prioritised in improving patient-doctor relationships (216, 278, 280, 329, 330).

Although improving patient-doctor communication skills and provider behaviours is often considered part of patient-centred care (detailed below), extensive research has been conducted on communication and behaviours beyond the rubric of patient-centred care.

2.4.2.1 Improving communication skills and provider behaviours

Patient-doctor communication and behavioural interventions have mainly focused on providers and to a lesser extent, on patients. Research focused on patients' communication skills and behaviours has examined how improving health literacy, health information seeking, participation in care and questioning skills in patient-doctor relationships can impact patients' self-efficacy, satisfaction with care (331), disease control and improved quality of life (329). Research focused on providers' communication suggests that improving patient-doctor communication skills during therapeutic encounters impacts patient behaviours and health outcomes (216, 278, 280, 329, 330). The impact of improving doctors' communication skills are widely documented, including improving patients' disclosure, engagement, adherence, reducing anxiety and distress, symptom resolution and disease control (216, 280, 330, 332, 333). Reviews from Western countries indicated that doctors' positive verbal and non-verbal communication skills improved patient-doctor relationships and contributed to patient health outcomes in chronic diseases (332-337). Here, improving communication between patients and doctors appears to be an important strategy for strengthening patient-doctor relationships.

A related body of research has focused on how providers' behaviours impact patient-doctor relationships and patient health outcomes. Hojat *et al.* (338), Derksen *et al.* (339) and Kim *et al.* (340) reported the impact of physician empathy on chronic disease control. In Hojat *et al.* (338), patients of doctors with high empathy scores were more likely to have good glycaemic and cholesterol control than those of doctors with low empathy scores. Here, promoting good provider behaviours toward patients appears to be another important strategy for strengthening patient-doctor relationships.

Most importantly, the growing emphasis on patient-centred care to advance chronic disease control (detailed below) appears to have extended the research focus beyond provider

communication and behaviour competencies. Many interventions to improve communication and providers' behaviour in patient-doctor relationships (see below) are framed as part of patient-centred care packages.

2.4.2.2 Promoting patient-centred care

Over the past 30 years, extensive literature from Western countries has advocated for a patient-centred approach as the most important aspect of the patient-doctor relationship in medical practice. Patient-centred care entails (providers) providing care that is respectful of and responsive to patient preferences, needs and values, and ensuring that patient values guide all clinical decisions, particularly in chronic diseases (341-343). Interventions to improve patient-centred care may encompass some of the health system interventions detailed above, such as patient health education and training providers on communication and patient-centred care. Consequently, the quality of interaction, patient participation, health behaviour, satisfaction with care and health outcomes can be positively impacted (344, 345, 346). Here, promoting patient-centred care appears to be an important strategy for strengthening the patient-doctor relationship.

Patient-centred care is a critical component of healthcare delivery in many HICs. In the UK, financial incentives (e.g. pay for performance) were introduced as part of health system reforms to reward providers for achieving a range of patient-centred care objectives (347, 348). In addition, advocacy organisations and resource centres to advance patient-centred care are growing. In the US, the Institute for Patient and Family Centred Care was established in 1992 to advance understanding and practice regarding patient- and family-centred care². In contrast, patient-centred care is not currently a central aspect of service delivery in many parts of Africa. A recent review entitled, *Patient-Centered Care and People-*

² Institute for Patient and Family Centered Care website: www.ipfcc.org

Centered Health Systems in Sub-Saharan Africa: Why So Little of Something So Badly Needed? by Man *et al.* (349) found limited evidence of implementation of patient-centred care interventions in sub-Saharan Africa. Man *et al.* (349) identified factors contributing to lack of implementation of patients-centred care in sub-Saharan Africa as:

- i. Issues influencing and shaping the performance of providers, including training models dominated by the biomedical perspective with little attention to psychosocial aspects of patients' illness experiences;
- ii. Structural and organisational features of healthcare systems, with many African countries placing emphasis on programmatic outputs that creates pressure on health workers to forgo patient-centred care activities; and
- iii. The socioeconomic environments of healthcare delivery where a gap exists between the norms that govern the public health sector and the actual behaviours portrayed by healthcare workers.

In support of the second factor influencing the poor implementation of patient-centred care in sub-Saharan Africa (above), McGee (350) reported that patient-centeredness was not a focus of many interventions in South Africa, and that health system reforms (that were not prioritised) were necessary to fully implement patient-centred care strategies. The need for patient-centred care is strongly echoed in a recent discrete choice research in Tanzania entitled, *Moving Toward Patient-Centred Care in Africa* by Larson *et al.* (351). That report showed providers' interpersonal skills, such as kindness and medical knowledge, were valued by patients in patient-doctor relationships compared with health facility resources and infrastructure. However, the current basic infrastructure in Tanzania 'is not sufficient for the provision of high quality, patient-centred care...[and that]...there is an urgent need to build an adequate, competent and kind health workforce to...promote patient-centred care' (351 p1). Taken together, these studies suggested that changes in health systems along

with adequate, competent and kind health workers are required to promote patient-centred care in Africa, especially LIA and Tanzania.

Collectively, patient-centred care matters and offers promise in improving patient-doctor relationships, particularly in chronic diseases (242, 349-351). However, current evidence suggests that African countries, particularly LIA, are far from fully adopting patient-centred care interventions in healthcare delivery, and that massive health system reforms are required for successful adoption and implementation of such initiatives (349-351). There is also a question as to whether patient-centred care by itself can remedy the current challenges of the growing burden of NCDs/hypertension in LIA; that is, patient uptake of Western care, adherence and continuing engagement with Western care among patients. Most patient-centred care interventions seek to benefit patients who have already sought Western care by promoting better provider behaviour and communication competences during therapeutic encounters (336, 337, 351, 352). While these are needed in LIA, there are also issues related to patients' low level of seeking NCD care from Western practice amid medical pluralism (Chapter 1) and a need for deep commitment from both patients and providers in an ongoing and long-term relationship to support optimal health outcomes for patients and NCD control. The unanswered question is what interventions could improve patients seeking NCD care, promote patient-centred care and guarantee deep commitment from patients and providers in long-term therapeutic relationships within the current limitations of the health system structure, organisation and environment in LIA? This is where improving patient trust in doctors comes into play.

2.4.3 Improving trust in patient-doctor relationships

Recent developments in research on patient-doctor relationships have led to a renewed interest in patient trust in doctors. Some research on the depth of patient-doctor interactions has situated patient trust in doctors as a critical driver of ongoing patient-

doctor relationships (279). Other authors have identified the provider's ability to gain the trust of the patient as the most important requisite when a patient is seeking to develop a good relationship with a doctor in PHC (353). While the next chapter specifically looks at research on trust, it is important to answer the question of why this thesis prioritises patient trust in doctors over the other possible strategies for strengthening patient-doctor relationships discussed above.

This thesis prioritises the investigation of trust as a means for strengthening patient-doctor relationships among other interventions for two reasons. First, as discussed in Chapter 1, the WHO introduced cost-effective PHC-based interventions for response to NCDs and hypertension. However, unless patient-doctor relationships are strengthened to improve patient uptake of these WHO cost-effective interventions in Western care (e.g. WHO/ISH charts, PEN or Best Buys), adhere to doctor's advice and medications and continue with hospital care in LIA, implementation of these cost-effective interventions is likely to be negatively impacted (8, 10, 105, 107, 242, 354). A large body of research (predominantly from HICs and urbanised settings) has documented how trust in doctors contributes to patients' health service use behaviours and health outcomes. Detailed in Chapter 3, high patient trust in doctors is positively associated with increased healthcare seeking; adherence to medical advice, medications and healthy lifestyles; continuing engagement and satisfaction with care; and disease control (206, 207, 211, 213, 225, 353, 355-358). Many studies have indicated the growing burden of NCDs and hypertension in LIA is characterised by massive concerns relating to poor healthcare service uptake, non-adherence and poor continuity with care, which result in poor disease control (Chapter 1). This suggests that building patient trust in doctors may be a promising part of the efforts to address the burden of NCDs and hypertension in LIA. However, important questions remain as to whether such findings in Western and urbanised settings are transferable to rural LIA contexts. This thesis is positioned to answer this question.

The second reason this thesis prioritises patient trust is based on how it sits in relation to other interventions to improve patient-doctor relationships. When considering interventions to improve patient-doctor communication, behaviours and patient-centred care (above), patient trust in doctors is an important mediator or intermediary of the impact of these interventions on patient health outcomes, particularly in chronic diseases. A large body of research indicates that interventions specifically focused on improving patient trust in doctors largely embrace activities that enhance communication, behaviours and patient-centred care (213, 215, 247, 359-367). Given the centrality of trust in other interventions to improve patient-doctor relationships, this warrants specific consideration. This is because sufficient knowledge about how to build and sustain patient trust in doctors in LIA may facilitate developing patient-centred care and strengthening patient-doctor relationships in this context more broadly. The figure below illustrates how patient trust in doctors sits in relation to other interventions to strengthen patient doctor-relationships.

Figure 2: Positioning patient trust in doctors as a mediator of other interventions for improving patient-doctor relationships.



2.5 Chapter summary and conclusion

This chapter examined the literature on patient-doctor relationships. The chapter highlighted the challenges that patient-doctor relationships continue to face globally, the tensions between patients and doctors and the need to improve patient-doctor relationships for NCD response in LIA. The chapter also examined healthcare system and competence-based interventions to improve patient-doctor relationships, highlighting some challenges in their implementation in LIA. Finally, the chapter demonstrated why this thesis considers patient trust in doctors as a means of improving patient-doctor relationships. Patient trust in doctors forms the focus of this thesis because of: i) its promise in increasing uptake of the WHO cost-effective interventions in PHC based on widely-documented benefits in Western countries; and ii) its position as an intermediary of other interventions (patient-centred care, communication and behavioural interventions). The unanswered questions in this chapter are: i) What do we know about patient trust in doctors from previous research? and (ii) How such an understanding can facilitate framing of this investigation in rural Tanzania? Chapter 3 examines these two questions.

Chapter 3: A REVIEW OF LITERATURE ON (PATIENT) TRUST

'The notion of trust is often regarded as ambiguous, difficult to define and to investigate. Trust has only recently begun to be measured and analysed in the health sector and almost no empirical investigation has been conducted in developing countries' Rădoi and Lupu (248 p11)

3.0 Introduction

This chapter reviews the literature on trust in interpersonal relationships, with a particular focus on the patient-doctor relationship. The chapter is divided into five sections. The first section presents a critical analysis of research on the *benefits, factors, interventions* and *measures* of trust in patient-doctor relationships in HICs. The second section offers an overview of literature on trust in patient-doctor relationships in LMICs, with an emphasis on LIA countries. The third section provides a summary of critical gaps in the empirical literature to date. The fourth section examines social theories of trust in interpersonal relationships to shed more light on some of the empirical gaps and identify concepts that may be useful in analysing my own data. Finally, I conclude with an explanation of the objectives and research questions guiding this qualitative inquiry in rural Tanzania.

3.1 Trust in patient-doctor relationships in HICs

The past 30 years have seen increased research in the field of trust in patient-doctor relationships. A search of the empirical literature across databases including MEDLINE, Embase, PubMed, Psych Info, CINAHL, Scopus, Google Scholar and the Web of Science, as well as the grey literature, revealed that trust in the patient-doctor relationship has mostly been researched in HICs. Available studies reflect a range of concerns, objectives and approaches, which I broadly categorise into four groups. First, a large body of literature focused on the *benefits of patient trust in doctors*. Such studies aimed to establish the role of trust in addressing the challenges of healthcare use, disease management and control (206,

207, 253, 359-362, 369-372). There is broad consensus that greater trust in doctors is associated with better patient behaviours and health outcomes. A second body of literature examined *factors shaping patient trust in doctors*, and attempted to understand how trust in patient-doctor relationships may be improved (209, 210, 214, 373-381). Factors related to the patient, the provider/doctor and the health system were identified as shaping trust in different contexts. A third body of literature reported on *interventions to improve patient trust in doctors* (365-367, 382-392). These interventions were primarily implemented in North America and sought to address some patient and provider factors that shape trust. Finally, a growing body of literature generated *measures of patient trust in doctors* in PHC settings (292, 393-400). Several 'trust in physicians' scales that aimed to generate evidence on factors that shape trust and trust improvement interventions have been developed and validated in different contexts. Below, each of these themes is examined in detail.

3.1.1 Benefits of patient trust in doctors

Over recent years, an increased amount of literature has examined the role of patient trust in healthcare seeking, disease management and control. A considerable amount of research suggests that patient trust in doctors influences patients' willingness to seek and use healthcare, uptake of preventive services and initiation of treatment (207, 211, 215, 371, 372, 401, 402, 404, 431). A study on the use of preventive services among low income African-Americans in the US identified trust as a powerful predictor of patients' willingness to initiate treatment and use preventive services (211). In another study examining race and trust in physicians in the same country, Boulware *et al.* (207) suggested that lower levels of trust could account for lower rates of care seeking and use of preventive services among African-Americans compared with white people. These two studies highlighted the vital role of trust in doctors as a factor influencing patients' healthcare seeking behaviours.

A considerable body of literature suggested trust plays a significant role in shaping the quality of patient-doctor interactions. Patient trust is often associated with: increased willingness to submit to medical examinations; increased engagement, participation and disclosure; greater patient autonomy in decision-making; and more positive interactions (213, 253, 371, 391, 401, 403-411, 447). In a study involving three clinics in a Canadian teaching hospital (breast cancer, prostate cancer and fractures), Kraetschmer *et al.* (411) found trust had a significant influence on patient participation in care, even after controlling for patients' education, age and sex. Recently, a review of patient participation studies in HICs by Vahdat *et al.* (412) reported that many factors facilitating patient involvement in treatment decisions were related to patient trust in doctors (discussed in the next section). Because most rural LIA healthcare facilities have limited diagnostic infrastructure (Chapter 1), the most feasible strategy for improving diagnosis may be facilitating patient involvement and disclosure.

A large body of literature has associated patient trust in doctors with increased acceptance of doctors' recommendations and adherence to prescribed medications (212, 213, 215, 359-363, 369, 370, 413-418). In the US, Nguyen *et al.* (370), Piette *et al.* (362) and Altice *et al.* (360) found patient trust was associated with increased adherence to therapy for irritable bowel syndrome, diabetes and antiretroviral therapy, respectively. Other studies reported lower trust was associated with decreased adherence to medication for hypertension (206) and diabetes (369). Patient trust has also been associated with increased acceptance of medical advice and greater amenability to behavioural change (212, 213, 406, 407). Patient trust in doctors was associated with a greater tendency to pursue recommended changes in health behaviours, such as exercising more and smoking cessation (212, 213). Some literature indicated that patient trust was associated with overall service satisfaction and the likelihood of returning for follow-up appointments (212, 213, 215, 247, 355, 363, 409, 414, 419, 420). Other research suggested patient trust may reduce

unnecessary medication and testing, mainly through promoting patient disclosure of sensitive information, thereby improving early and accurate diagnosis (213, 215, 363, 372, 406, 407). Collectively, these studies showed the important impact of trust on patients' compliance with doctors' treatment recommendations, which is essential for disease management and control.

Finally, a considerable body of literature suggested that trust plays a role in improving patients' clinical symptoms and achieving positive health outcomes (213, 215, 280, 361, 409, 415, 420-424, 431). Patient trust has been linked to improved outcomes for diabetes treatment (420, 424, 431), hypertension control (361) and rheumatologic care (425). Although there remain questions as to the mechanisms through which trust impacts patients' health outcomes, Safran *et al.* (213) suggested that trust in doctors impacts health outcomes by influencing patients' choice to minimise health risks (e.g. smoking cessation and engaging in exercise). Lee and Lin (409) proposed a model suggesting that patients' compliance with medication and disclosure tendencies mediated health outcomes related to trust. Together, these studies highlighted trust as a valuable tool in healthcare provision. This has been the subject of a proliferating body of research on factors shaping the establishment and maintenance of trust in PHC settings, as detailed in Section 3.1.2 below.

3.1.2 Factors shaping patient trust in doctors

Empirical studies investigating the establishment and sustainment of trust in patient-doctor relationships have been undertaken in the US (214, 374, 375, 379, 381, 404, 427-436), Australia (209, 210, 254, 437), the UK (373, 380, 438, 439), Northern Italy (440), Canada (441), Poland (400, 426) and China (442-444). Factors shaping patient trust can be categorised as patient-, provider- and health system-related factors. This classification system is commonly used across health research.

3.1.2.1 Patient factors

Previous research established a range of patient-related factors that shape trust in doctors, including: race and ethnicity (214, 373, 374, 376, 381, 402, 404, 431, 433, 434, 436); age (210, 215, 376, 400, 430, 437, 439, 440, 442); education and knowledge (210, 431, 437, 440, 442); gender (210); marital status, religion and religiosity (214, 431); upbringing and morals (437); financial capacity (income, occupation) and residence (373, 374, 442); and health insurance ownership (442). Some literature noted that in the context of serious and chronic diseases, the nature or stage of the patients' disease impacted their trust in doctors (209, 210, 215, 238, 430, 437, 439, 445). In addition, factors such as patient familiarity with the provider and the health facility, as well as patients' perceptions, beliefs, interpretation and attitudes were identified as shaping trusting decisions in some studies.

3.1.2.2 Provider factors

Much of the current literature on trust has directed attention to provider characteristics that shape patient trust, with a particular focus on technical and behavioural competencies. All of the empirical literature reviewed identified providers' technical competence (as perceived by patients) as the most important factor shaping patient trust. Two exceptions were Tarn *et al.* (214) and Meyer *et al.* (210), whose study objectives did not include examination of this factor. Providers' technical competencies largely correlated with perceived knowledge, expertise and ability to diagnose and treat, technical quality of care, understanding of/interest in patients' problems, thoroughness, willingness to share correct information and treatment success (209, 254, 379, 381, 403, 414, 427, 428, 432, 437, 440, 441, 443). A recent study based on interviews with 21 patients new to an HIV clinic in the US suggested that factors that shaped trust during initial visits were the providers' ability and tendency to offer assurance, invite the patient to ask questions, share laboratory results, explain what they mean and inquire about patients' goals and preferences (428).

Similarly, the reviewed studies indicated that trust can be influenced by various aspects of providers' communication skills, including:

- i. Listening and clarity (209, 376, 403, 422, 428, 429, 432, 435, 437, 441, 443);
- ii. Demeanour, such as caring, sincerity, compassion, benevolence, respect, honesty, kindness, empathy, understanding and (positive) attitude towards patients (209, 401, 413, 422, 427, 428, 435, 437, 440, 443);
- iii. Ethical conduct and fairness (209, 427); and
- iv. Social skills (427).

In analysing the interaction between patients and general practitioners (GPs) in Northern Italy, Riva *et al.* (440) explained how providers' honesty signals influenced patient trust through: i) influence (reassuring and use of more informal and friendly style); ii) mimicry (showing shared understanding); iii) activity (expressing words of encouragement); iv) comprehension (of the patient's point of view, consistence, empathy in recognising emotions of fear, caring, clarity, calmness and friendliness, ability to display non-verbal/verbal signals of understanding); and v) reciprocity and accessibility (timeliness of care, better management of appointments and punctuality). The evidence presented in this section suggests the need to consider provider competencies (both technical and behavioural) when investigating trust in patient-doctor relationships.

Some factors shaping patient trust involve both parties (patients and providers) as they interact in healthcare settings. These include past encounters (positive outcomes, positive relationships), quality of previous visits and the circumstances of the interaction. It matters whether the interaction occurs during an emergency versus a routine matter or follow-up visit (210, 374, 380, 435, 437, 438). Other influential factors include frequency and duration of the patient-doctor relationship and provider continuity (209, 214, 215, 373, 374, 380, 427, 434, 438). Additional factors are patient involvement in decision-making, interdependence and cooperation in treatment, absence of competing interests between

patients and providers, shared values and goals, nature of the conversation (rich, deep and personal) and intentional efforts to build trust (209, 373, 427, 435, 437). Similarly, the environment of comfort, confidence and shared language are documented as factors shaping trust in some of the literature above.

3.1.2.3 Health system factors

Finally, compared with factors pertaining to patients and providers, few studies in HICs have examined how health system factors shape trust. To date, research has identified four main factors as shaping trust: i) institutional resources (e.g. availability of alternative providers, functioning medical system and low provider turnover) (380, 432, 437, 438); ii) infrastructure (e.g. healthcare infrastructure, transport services and networks with other hospitals) (440); iii) mechanisms of fostering provider continuity and ensuring an effective communication process (209, 432, 435, 444); and iv) the cost of care (374, 427).

Collectively, this literature identifies a range of factors shaping trust in patient-doctor relationships in HICs. Some of these factors were identified using scales that quantify trust (e.g. 379, 400, 427, 430, 436). I return to this topic in Section 3.1.4).

3.1.3 Interventions to improve patient trust in doctors

Because of an awareness of the significance of trust as a variable in health outcomes, various interventions have been implemented in HICs to improve patient trust. Some interventions have focused on improving patient-doctor relationships (e.g. patient-doctor communication, patient health literacy, provider behaviours and patient-centred care; see Chapter 2). These studies often reported improved patient trust in doctors as an outcome. However, a number of randomised controlled trials (RCTs) have tested strategies for improving patient trust in doctors, especially in North America. As indicated in previous reviews, RCTs on the efficacy of improving trust, which tend to focus largely on providers and patients, have shown mixed results (247, 364).

3.1.3.1 Interventions focusing on patients

A number of RCTs that tested interventions to improve patient trust in doctors by focusing on patients have reported positive results. For example, Weymiller *et al.* (390) and Nannenga *et al.* (386) showed that providing patients with tailored decisional aids on statin-based diabetes treatment (e.g. materials on cardiovascular risk estimation, absolute risk reduction and the disadvantages of using statin drugs) before or during consultations improved patient trust in doctors. Another study in northern California sought to improve trust by helping new patients in managed care to navigate the healthcare system by conducting induction sessions led by a physician and a health educator (389); attendees showed significantly greater trust in their doctors. Similarly, two separate interventions in South Carolina both targeting uninsured and inadequately insured patients with type 2 diabetes compared a group-based care management strategy with typical individualised care (382, 383). These interventions showed an improved sense of trust in physicians among patients who received care in groups compared with patients who received individualised care. In addition, a study in San Francisco by Thom *et al.* (378) sought to improve trust through health coaching for 224 patients with diabetes and hypertension, which was provided during hospital visits and through phone follow-up over 12-months. Coaching focused on: active listening, self-management, lifestyle modification, setting consultation agendas, finding their way around the clinic, details about medications, supporting them socially and emotionally and providing information about how to access resources within their communities. Even when the results were adjusted for the number of visits to a primary care facility, coaching appeared to improve patient trust in providers. An intervention in northern California by Hsu *et al.* (365) that involved providing patients with information about provider characteristics (which was intended to facilitate the selection of a new doctor) showed increased patient-provider continuity and patient satisfaction. However, the effect on trust disappeared when adjusted for patient age, gender, education,

ethnicity and health status. This suggests that although some interventions may improve patient trust in doctors, individual patient demographics remain an important influence.

3.1.3.2 Interventions focusing on providers

RCTs that sought to improve patient trust in doctors by focusing on providers reported mixed results. Two RCTs in California assessed the training of physicians in communication and cultural competence using workshop models; a short 7-hour workshop (448) and half-day workshop or three sessions of 1–1.5 hour each (366). Both RCTs showed no significant effect on patient trust. Those researchers suggested that more intensive training interventions could improve patient trust in doctors. A study by Tulskey *et al.* (367) involved training oncologists in North Carolina on communication during medical consultations using an interactive CD-ROM. Patient trust in their oncologists was greater in the intervention group, suggesting that different provider training models may yield different results on improving patient trust.

An intervention in South Carolina by Hall *et al.* (384) investigated disclosure of physician financial incentives in health maintenance organisations. That study found that disclosure did not reduce patient trust in the short-term but had a mild positive impact on trust in the long-term. A similar study in Boston and Los Angeles by Pearson *et al.* (387) involved mailing patients disclosure letters written by the chief medical officer of their physician group. The findings showed a positive impact on patient knowledge of physicians' compensation models, but did not indicate increased trust in physicians. However, a more recent trial involving a disclosure website by Hwong (385) reported high patient trust scores for physicians who disclosed receiving no payments from pharmaceutical and medical device industry compared with those who received payment. Generally, the higher the amount physicians received from industry, the less trust patients had in their regular

physician. This suggests that providers' financial disclosure may or may not improve patient trust in doctors.

Overall, the reviewed RCTs focused on providers' skills, disclosure of financial incentives and a few other issues pertaining to patients' knowledge or perception of their physicians. What was significant in the context of this thesis, which is focused on Tanzania and LIA, is that most of these RCTs were implemented in North America. This raises questions as to: whether trust matters in LIA in the first place, and if so, whether similar interventions may show different results in LIA where healthcare finance, organisation, prioritisation and provider characteristics differ from North America (see Chapter 1). Nevertheless, while current reviews suggest that results are mixed and that evidence is insufficient to conclude whether any particular intervention increases or decreases patient trust in doctors (247, 364), some interventions seem worthy of further investigation.

Results are mixed for two primary reasons. First, there has been criticism of the ability of RCTs to determine what really works, especially concerning matters investigated through a social science lens (449-454). In such cases, RCTs may not be the best approach to establish evidence on trust improvement interventions. Second, and as detailed in Section 3.1.4 and Chapter 2, the concept of trust is often multifaceted and characterised by ambiguity, complexity, contextual specificity and difficulty of measurement (248, 455-460, 495). Indeed, trust in RCTs is often measured according to different metrics. While the study by Hall *et al.* (384) on disclosure of physicians' financial incentives applied a 10-item researcher-developed scale (396), the study of models of care by Clancy *et al.* (382) applied an 11-item scale developed by Anderson and Dedrick (393). Thom *et al.* (366) applied an 8-item scale developed by Safran *et al.* (212) to measure trust associated with provider training on cultural competence. The variation in the number of items in these scales suggests that some of the variables constituting 'patient trust' in one RCT might not have been included

in another. This brings me to the fourth body of research, which concerns the measurement of patient trust in doctors.

3.1.4 Measures of patient trust in doctors

Development and validation of measures of patient trust were initiated in different populations from the 1990s, with over 80% of measures designed, tested and validated in the US (248, 439, 461-463). Anderson and Dedrick (393) developed a short, self-administered 11-item 'trust in physician scale,' which was later modified by Thom *et al.* (464). Safran *et al.* (212) developed an 8-item trust measurement scale within the 51-item self-administered 'primary care assessment survey'. Kao *et al.* (465) developed a 10-item 'patient-trust scale' administered through telephone surveys to assess the relationship between payment methods and patient trust. Additionally, Hall *et al.* (396) developed a 10-item 'Wake Forest Physician Trust Scale,' that focuses on patient trust in their individual physicians (and non-physicians). Most recently, Marcinowicz *et al.* (400) validated an 11-item scale in Poland. Other researchers have modified or refined these scales in different settings. These include Leisen and Hyman (398), who drew on Anderson and Dedrick (393) and Thom and Campbell (363) to generate an improved 'patient trust-in-physicians scale' that was validated with university students. Ozawa and Walker (445) modified the Wake Forest scale (396) for use in Cambodia. In addition, Bova *et al.* (394) developed a 13-item 'healthcare relationships trust scale' building on their previous work. Most recently, Aloba *et al.* (466) refined the scale used by Anderson and Dedrick (393) for use at a psychiatric clinic in Nigeria. The following table summarises key features of some of these measures.

Table 3: Features of common trust in physician scales

Authors	Country	Validation settings	No. of items	Validity and reliability
Anderson and Dedrick (393)	US	Older diabetic men at a southern Virginia clinic	11-items	Cronbach's alpha: 0.85 Test-retest: 0.77
Safran <i>et al.</i> (212)	US	Massachusetts state employees	8-items	Cronbach's alpha: 0.86
Kao <i>et al.</i> (465)	US	Health management organisation members in three large cities	10-items	Cronbach's alpha: 0.94
Thom <i>et al.</i> (464)	US	Family medicine patients at a Californian clinic	11-items	Cronbach's alpha: 0.87 Test-retest: 0.77
Hall <i>et al.</i> (396)	US	National general population and health management organisation members	10-items	Cronbach's alpha: 0.93 Test-retest: 0.75
Bova <i>et al.</i> (394)	US	Adult primary health care patients	13-items	Cronbach's alpha: 0.96 Inter-item correlation: 0.4–0.84
Marcinowicz <i>et al.</i> (400)	Poland	Adult primary health care patients	11-items	Cronbach's alpha: 0.90

The advantage of these measures is that they are quick, short and can be self-administered in either a single sitting or online. Instruments have fewer items, ranging from eight (212) to 13 (394). Statistically, some of these scales had test-retest scores that fell within an acceptable spectrum, from 0.75 (396) to 0.77 (393, 464), and with Cronbach's alphas ranging from 0.85 (393) to 0.96 (394). Some scales have been widely applied in PHC settings to establish evidence on trust in the US, particularly concerning domains such as providers' communication, honesty, confidence, fairness, competence, confidentiality and fidelity (461). Despite the advantages, these measures also faced some challenges, which I discuss when examining gaps in the literature below.

These studies, which aimed to quantitatively measure the impact of trust, differ significantly from my own approach, which is to offer a culturally sensitive, qualitative account of the meanings, factors and benefits of trust that could aid in generating a context-specific measure in the future. This strategy was used by Gopichandran *et al.* (467) who first attempted to outline a culturally sensitive description of trust (468, 469), which later culminated in a contextualised tool that was used in southern India. In support of this strategy, Goudge and Gilson (487) suggested that:

Where little is known about how trust functions, qualitative research to explore how respondents view trust and trusted behaviour is important in advance of quantitative investigation. The results of qualitative inquiry facilitate the development and refinement of hypotheses about how trust functions and can be used to generate questions for use in structured [quantitative] questionnaires (p1439).

3.2 Trust in LMICs

Before moving on to identify the gaps in current empirical literature, it is pertinent to review the literature on trust in doctors in LMICs. The four classifications used to organise research in HICs above (benefits, factors, interventions and measures of patient trust) are used here in a review of relevant literature from LMICs.

Compared with HICs, previous studies in LMICs have not addressed the benefits of trust in much detail. Most research in LMICs cited the benefits of trust reported in Western contexts as justification for its practical investigation (401, 445, 461, 468, 469, 471) or to highlight the research needs in LMICs (472). Elder *et al.* (361) represents a notable exception by specifically establishing a link between trust and hypertension control among men in Southern Africa. However, a considerable amount of literature has been published on factors shaping patient trust in doctors in LMICs; for example, in Sri Lanka (401), rural

Cambodia (445) and India (468, 469, 471). Some studies examined trust as a function of workplace performance, such as in South Africa (473). To date, there appears to have been little research conducted on interventions for improving patient trust in LMICs. However, a few studies generated and validated measures of patient trust in doctors in LMICs; for example, in India (467) and Nigeria (466). Some have gone on to generate measures of patient trust in the public health institutions (474).

3.2.1 Factors shaping patient trust in LMICs

Overall, evidence on factors shaping trust in LMICs versus HICs generally agrees. The patient, provider and health system factors shaping patient trust in doctors in urban and rural areas of Tamil Nadu in India (468, 469), are similar to those discussed in Australia (254, 437). Similarly, provider competence prevails as a crucial factor affecting trust in LMICs. In Sri Lanka, Russell (401) documented high trust based on the perceived technical quality of public hospital providers' care for more serious illness. That study reported the perception that doctors in public hospitals were the best and most experienced for testing and managing serious diseases compared with doctors in private hospitals, which was a factor influencing patient trust.

Furthermore, some findings in LMIC-based studies extended factors documented in HICs. In Cambodia, Ozawa and Walker (445) suggested that a combination of patients' prior experiences and their interactions with non-medical staff impacted how they built trust with medical providers. Research in India (468, 469) suggested that patients' ability to tolerate drawbacks in healthcare settings was a critical determinant of how trust was built. These associations were not identified in literature from HICs. Second, health system barriers and patients' socio-cultural values appeared to carry more weight as factors shaping trust in LMICs compared with HICs. For example, while some studies in HICs (209, 210, 214, 373, 376, 380, 437) weakly documented health system factors as predicting

patient trust, almost all reviewed literature from LMICs offered a detailed profile of health system factors as shaping patient trust. Factors such as healthcare resources (medications and doctors), infrastructure, service organisation, institutional practices, codes and procedures, mechanisms for discipline and accountability, facility ownership and level and referral systems dominated participant responses as shaping trust in doctors in LMICs (401, 445, 468, 469, 473). Better health systems (infrastructure, medications, staff, access and quality of care) in HICs may partly explain why the health system factors are more pronounced in shaping trust in LMICs.

3.2.2 Patient trust in doctors in LIA and Tanzania

Given the focus on LIA in this thesis, it is important to examine the literature on trust in this context. Goudge and Gilson (487) suggested that research on this issue requires prior understanding of the personal, social and political issues surrounding the experience of trust in particular settings. Chapter I highlighted key socio-political issues impacting patient experiences of the patient-doctor relationship in LIA. Before investigating patient trust in doctors in LIA, it is important to consider how trust has been discussed in this context.

There has been little specific empirical investigation of the benefits, factors, interventions and measures of trust in LIA. However, a recent thesis by Earles (475) examined health beliefs and trust in providers among 139 adults in rural Kenya. That thesis reported a negative correlation between trust and patient characteristics, such as younger age and higher education level, but a positive relationship with speaking similar language with providers. Furthermore, Ostergaard (476) reviewed nine studies from sub-Saharan Africa, seven of which were conducted in LIA. The benefits of trust reported in research from HICs were cited to explain why trust mattered in LIA. The problem with this literature is that: i) half of the studies reviewed were not specific to patient trust; ii) most were from urban and semi-urban rather than rural settings; and iii) most involved participants other

than patients. This suggests that a trust-focused study involving both patients and providers may offer context-specific insights as to whether trust matters in LIA. Nevertheless, a study by Tibandebage and Mackintosh (477) that examined market forces influencing healthcare transactions in Tanzania caught my attention. In that study, the term trust was designated as 'imani' in Swahili, with 'mwaminifu' meaning 'trustworthy person' and 'uaminifu' meaning trustworthiness. These terms provided useful insights for generating a culturally attuned translation of an interview tool for the present research (Chapter 4). That study identified patient factors shaping trust (e.g. income and familiarity) as well as provider and health system factors in the context of healthcare institution ownership. For example, healthcare workers in religious institutions were described as trustworthy, with patients referring to their politeness and the warmth with which they were welcomed. Most participants associated religious healthcare facilities with ethical commitment, resistance to profit motives and moral institutional control mechanisms. Public facilities were trusted for their technical competency but distrusted because of expectations of bribery, patient abandonment and inadequate resources; similarly, private facilities were distrusted because they were perceived to be motivated by profit (477). Some of these findings reflect those of Russell (401) in Sri Lanka.

Two other studies also contribute to understanding the role of trust in healthcare in LIA. One study by Dynes *et al.* (478) generated a measure of inter-provider trust among frontline health workers in rural Ethiopia. Another study by Sripad *et al.* (479) investigated the meanings and types of trust in maternal care near urban areas of Kenya. The latter study attempted to understand what trust meant to participants, an issue that has received limited empirical attention. However, most of the meanings of trust identified by Sripad *et al.* (479) (communication, integrity, mutual respect, competence, fairness and confidentiality) were based on provider-oriented factors that shape trust (see above) rather

than what trust meant per se. Limited literature on this topic in LIA indicates that more needs to be done in this context.

Some non-trust specific studies conducted in LIA have shown the importance of trust in patient-doctor relationships. Satisfaction studies in Zimbabwe (267), Zambia (268), Tanzania (176, 177, 270), Kenya (272) and Uganda (181), and patient-doctor interaction studies in Uganda (290), Malawi (480), rural Ethiopia (481) and Kenya (482) have investigated patient experiences with HIV care, maternal and general care in LIA. The results in some of these studies indicated that improving trust may be useful in addressing some of the challenges identified. For example, a survey of mothers of children aged under 5 years in rural Ethiopia by Shaw *et al.* (481) found that trust and familiarity were the primary influences on care seeking among caregivers of sick children. In Malawi, a survey of pregnant mothers and providers by Roberts *et al.* (480) found that poor patient-provider relationships impacted both antenatal care attendance and antenatal clinical participation. In Tanzania, Van Rijsbergen and D'Exelle (178) surveyed women of child-bearing age in Lake zone regions and found that providers' negative attitudes and poor engagement in decision making influenced patients' choices about where to attend for childbirth. Similarly, a survey involving patients with TB, treatment supporters and providers in rural and urban districts by Mkopi *et al.* (291) found that providers' attitudes impacted patient uptake and continuity of TB interventions. A survey of community members, women who recently gave birth and providers in rural public facilities by Gourlay *et al.* (179) found that weakly shared decision-making and unclear communication resulted in missed services and poor adherence to subsequent interventions for the prevention of mother-to-child transmission of HIV. These concerns, as previously suggested, imply that improving patient trust in providers may be useful beyond the NCD response in LIA, and more broadly across both communicable disease and NCD conditions.

3.3 Gaps in the empirical literature on patient trust in doctors

There are a number of gaps in available research on the benefits, factors, interventions and measures of trust; these gaps inform how trust is investigated in this thesis. First, there is lack of empirical research investigating patient trust in doctors in rural LIA. A review by Brennan *et al.* (391) reported that of 596 studies on trust in patient-doctor relationships published between 2004–2010, 44% came from the US, 12% from the UK and 20% from other European countries. Of the 45 measures of trust developed since the 1990s, 84% were generated and validated in the US, 7% in the Netherlands and the rest in Thailand, Singapore and Ireland (461). This thesis seeks to bridge this gap by investigating patient trust in rural Tanzania as a case study of rural LIA.

Second, the findings of most of the reviewed research do not always include doctors' perspectives (e.g. 207, 210, 214, 361, 373, 376, 437, 440, 445). Brennan *et al.* (391) noted that of 596 studies of trust in patient-doctor relationships, only 18% somewhat engaged patients and providers (doctors, nurses, dentists, allied professionals and other cadres). The nature of trust in therapeutic relationships requires attention to providers rather than patients alone, because both parties shape the interactions and exchanges in the clinical setting (210, 248, 254). This thesis seeks to investigate the perspectives and experiences of both patients and providers to generate a comprehensive understanding of trust in therapeutic relationships in LIA.

Third, there remains a gap in the literature regarding the ways that trust benefits doctors. Most studies have limited the discussion of the benefits of trust to patients (207, 211, 215, 371). Little attention has been paid to the benefits of trust for providers, healthcare institutions or healthcare systems. We need to understand the various perceptions of benefits of patient trust to doctors and the health system more broadly, because patient trust in doctors in interpersonal relationships is 'negotiated' between patients and doctors

when they encounter one another in a healthcare system (209, 254, 483, 484). In the same vein, no previous study has investigated the negative consequences of high patient trust. Two sociological studies briefly alluded to the potential dangers of trust (292, 472). Gilson (472) suggested that, 'trusting too much without caution may enable abuse of power in the form of [patient] exploitation [by providers]' (p364). For example, healthcare providers may seek to benefit from patient trust in terms of over prescription or misdiagnoses. Similarly, Thom *et al.* (292) suggested that excessive patient trust in doctors may heighten patient vulnerability and lead to poorer care because patients were 'less likely to seek a second opinion or question inappropriate medical advice' (p127). This indicates a need to understand whether trust is perceived to have negative impacts in LIA, and whether remedial strategies need to be incorporated in the design of trust improvement interventions.

Fourth, there is ambiguity about the factors shaping patient trust in doctors. Some studies reported potentially conflicting findings in different settings. For example, the frequency of interaction and provider continuity (duration of the relationship and familiarity) are widely recognised as factors shaping trust in Australia, the US and Japan (209, 214, 427). However, Tarrant *et al.* (376) did not find that these factors independently influenced trust in the UK. This raises a question as to whether trust in patient-doctor relationship is context-specific. A South Australian cardiac rehabilitation programme (209), a community-based sample of Japanese-Americans in Japan (214) and GP patient surveys (national and specific practice sample) in the UK (376) represent diverse settings for investigating trust in patient-doctor relationships. These studies suggest that trust in patient-doctor relationships may be context-specific (see below), and that some factors shaping trust in HICs may not manifest in LIA/rural Tanzania, thereby supporting this investigation.

Fifth, despite many uncertainties, RCTs for improving trust continue to show mixed results. Given that these interventions were predominantly implemented in North America (247, 364), they may not reflect the situation in LIA contexts. Nevertheless, it is of vital importance to understand whether trust matters to patients and providers in rural LIA, which may offer insights about potential trust-focused interventions that could be implemented in this context.

Sixth, there remains uncertainty about the aspects of trust that are measured in physicians' scales. Although it is not the purpose of this study to generate a quantitative measure of trust, it is pertinent to its development to highlight some of the problems in existing measures that influence how trust is investigated. The continued proliferation of measures and variations in settings/populations for validation and number of items and key constructs/variables of trust suggest the absence of a universal measure. Despite overlaps, each scale measures one or more unique items related to trust that another does not. For example, the Wake Forest scale (396) measures variables related to provider's fidelity, competence and honesty but not confidentiality. Safran's trust in physicians scale (212) measures providers' confidentiality, fidelity and honesty but not competence. Similarly, Kao's trust in physicians scale (465) measures providers' competence, fidelity and confidentiality but not honesty. This may explain why questions about instrument quality have been raised, with further psychometric testing often recommended (462). This also highlighted the need to understand what is being measured and whether measures tap into the same or different things. In addition, ambiguities remain in terms of variations in the settings and populations used for validation (even within the same country). For example, the Wake Forest scale (396) was validated using a national-wide population sample, but scales used by Bova *et al.* (394) and Safran *et al.* (212) were validated using adult patients in PHC and state employees, respectively. The variation in settings and participants might have contributed to variations in the number of items and key variables observed in these

measures (486). These variations (in settings and participants) add to the question of whether trust is context-specific. The context-specific nature of these measures was further evidenced by the need for modifications of the Wake Forest scale when investigating trust in Cambodia (445), and most recently to the Anderson and Dedrick (393) scale for use in Nigeria (466). If a single tool was to be adopted for measuring trust in LIA, the selected scale risks not assessing the dimensions of trust specifically measured by other scales; see also Nelms *et al.* (375). This calls for a contextualised understanding of trust in LIA to aid future attempts to generate a contextualised measure.

Finally, existing empirical accounts fail to resolve the question of what trust means for participants. Research on benefits of trust (e.g. 207, 211, 401), factors shaping trust (e.g. 209, 214, 373, 376, 381), interventions to improve trust (e.g. 367, 382, 386-388) or measures of trust (e.g. 393, 396, 400) has tended to draw on theoretical definitions of trust without investigating participants' perspectives of what trust means. This concern has been expressed in some literature (487, 488). To date, there has been some debate about what trust means and its context-specific nature (noted above) in social theories. Therefore, the next section briefly reviews some social theories of interpersonal trust to: i) shed more light on what trust could mean and whether it may be context-specific; and ii) identify concepts that may be useful in framing the investigation and explaining the results from rural Tanzania.

3.4 Theorisation of trust in interpersonal relationships

Before summarising the objectives and research questions, it is pertinent to the development of this thesis to briefly examine theoretical concepts that may shed more light on critical questions arising from a review of empirical literature; namely what trust means and if trust is context-specific. I will also examine some of the key concepts of trust discussed in theoretical literature that may be useful in explaining the results of this

investigation in rural Tanzania, including: i) institutional trust; ii) generalised trust; and iii) dependence.

The topic of trust has attracted theoretical attention across a range of disciplines and sectors (e.g. sociology, public health, political science, psychology, economics, management and business). Trust has also been discussed in the context of different concerns, which leads to it being described in different ways (289, 406, 456-458, 488-495, 516, 518). Some theories discuss trust as a tool for social cooperation, order, exchanges, communication and dialogue, positioning it as a social lubricant, essential glue or building block of interpersonal relationships within society (289, 405-407, 458, 491, 494-498). Others discuss trust as a tool for social/economic development, with low level of trust considered to inhibit social/economic growth (499-501, 503). Still other theories specifically frame trust within the context of discourse between patients and doctors (230, 231). Alongside the abundance of theoretical discussions of interpersonal trust are differing views of what it could mean.

3.4.1 What interpersonal trust means

A major theoretical issue that has dominated the field for many years concerns what trust means. To date, there has been little agreement on what trust means, with some authors suggesting it may be perceived differently by different social groups (455-460, 495, 516). Simpson (458) suggested, ‘...trust is a complex, multidimensional construct, making it difficult to operationalize, measure, and interpret...can be constructed in different ways’ (p264). This may partly explain the existence of different definitions and typologies.

3.4.1.1 Definitions of interpersonal trust

Along with the abundance of social theories, there are many definitions of trust. Some definitions place the trustors’ beliefs and the trustees’ reliability as central concepts. For

example, Simpson (459) defined trust as the ‘...generalized beliefs and attitudes around the degree to which other people are likely to be reliable, cooperative, or helpful, independent of the specific context or situation in which an interaction...might take place’ (p588). In support, Giddens (494) considered trusting someone as ‘recognizing that [the person] can be relied upon to produce the behaviour in question, given appropriate circumstances’ (p30). Other definitions prioritised the trustors’ expectations and vulnerability and the trustees’ intentions as central concepts. For example, Mollering (456) defined trust as ‘...state of favourable expectation regarding other people’s actions and intentions’ (p403). Similarly, Robinson (502) defined trust as ‘expectations, assumptions, beliefs about the likelihood that another’s future actions will be beneficial, favourable or at least not detrimental’ (p576). The four psychological definitions of trust described by Lewicki *et al.* (460) consider the trustors’ acceptance of vulnerability with expectations, assumption or beliefs in the trustee’s intentions that they are in their best interest and not detrimental as the central themes. The centrality of acceptance of vulnerability in trust definitions was cemented by Mayer *et al.* (504), who defined trust as ‘the willingness of a [trustor] to be vulnerable to the actions of [a trustee] based on the expectation that the [trustee] will perform a particular action important to the trustor, irrespective of the ability of [the trustor] to monitor or control the [trustee]’ (p712). In support, Rousseau *et al.* (505) defined trust from a psychological angle as a ‘...psychological state comprising the intention [of a trustor] to accept vulnerability upon positive expectations of the intentions or behaviour of another [trustee]’ (p395). It is clear that despite some differences in the central concepts of interpersonal trust in these studies (see also 489), there are significant alignments in these definitions. Focusing on these alignments, the working definition of trust in this thesis is:

An individual’s [patient’s] beliefs and willingness to accept vulnerability with positive expectations of and reliance on another individual’s [doctor’s] future actions, intentions and behaviours.

3.4.1.2 *Typologies of interpersonal trust*

This thesis is situated around interpersonal trust. Some literature designates interpersonal or personal trust as the type of trust that manifests when one person places trust in another (253, 289, 401, 426, 483, 484-485, 494, 506-509, 512, 516). Russell (401) suggested that interpersonal trust in medical practice is 'built, sustained or damaged through face-to-face encounters with health providers and is more likely to increase with long-term doctor-patient relationships' (p1397). However, this typology often contrasts with institutional or system trust, which entails trust directed to social establishments and institutions such as schools, hospitals or clinics (253, 289, 426, 494, 506, 507, 509, 512). There appears to be consensus in some theoretical (and some empirical) literature that trust in institutions (institutional trust) is based on the trustor's knowledge and perception of functional institutional or system arrangements that ensure a trustee upholds the trustor's interest (248, 289, 368, 405, 426, 489, 494, 508-512). In the context of a health system, these might include training mechanisms, resources, guidelines, professional codes of ethics and disciplinary procedures, all of which contribute to good standards of care. The discussion of institutional trust brings me to the question of its relationship with interpersonal trust.

Social theorists have attempted to establish a relationship between institutional and interpersonal trust. There is some debate in social literature concerning trustor, trustee and institutional/system factors that shape how trust is built, sustained and damaged (253, 289, 455-460, 494, 508, 509, 513-515). For example, Luhmann (509) viewed trust in the system (institutional trust) as a requirement for trust in the systems' representatives (interpersonal trust). In contrast, Giddens (494) suggested that trust between 'the flesh-and-blood people' (interpersonal trust) is a requirement for 'trust in the abstract system' (institutional trust) (p85). These views are echoed in Meyer *et al.* (506), Meyer (238) and Schilke and Cook (514). Similarly, Campos-Castillo *et al.* (515) suggested patient familiarity with a healthcare institution facilitated the translation of interpersonal to institutional trust.

What this debate suggests is that to some patients, interpersonal trust may contribute to institutional trust and vice versa. However, Radoi and Lupu (248) recently called for 'qualitative inquiry that explores the way in which both patients and doctors perceive the concept of trust...and how such a relationship is created and developed' (p15) to shed more light on the relationship between interpersonal and institutional trust.

Some literature has discussed the specific typologies of interpersonal trust more broadly. Generalised trust is regarded as a type of interpersonal trust that trustors (e.g. patients) place on all trustees (e.g. all doctors), based on the beliefs that they will always act in their best interest regardless of the risk of trusting (238, 253, 489, 509, 517). Similar to interpersonal and institutional trust, generalised trust can be placed on the institutions/system, but often is always reaffirmed through interpersonal relationships within healthcare institutions (209, 494, 517). Generalised trust has received some empirical examination. A study of trust in patients with coronary heart disease in Australia by Meyer (238) found older and low-income patients were more likely to have generalised trust in all doctors, and patients that were female and those with chronic diseases were more likely to have generalised trust in the healthcare system. Furthermore, 'blind trust' is a type of interpersonal trust placed on the trustee without caution or where the trustor does not question the trustee's decision (209, 250, 253, 254, 411). Moreover, 'dependence' is a type of interpersonal trust that manifests in the absence of options, heightened risk and urgent need for care due to the seriousness of a condition; as such, a patient has no choice but to follow 'expert' treatment recommendations (209, 519-521). Dependence has also received some empirical examination. Meyer and Ward (437) and Meyer and Ward (209) used empirical data from a study involving patients with coronary heart disease in Australia to generate a semantic distinction between dependence and trust. They suggested that dependence was a weaker form of patient trust in doctors. 'Marginal trust' is another type of interpersonal trust that can be built or lost as an individual acquires new information

(456). Finally, 'distrust' is often considered the opposite of trust and is said to be more likely to occur concurrently with trust (489), or a form of negative interpersonal trust that manifests when a trustor does not consider trusting an option (209). It is known that rural settings in LIA are characterised by health system challenges (Chapters 1 & 2) that may impact how some of these typologies of interpersonal trust manifest.

Some literature has discussed typologies of interpersonal trust in relation to power symmetry in decision making within a trusting relationship. On one hand, symmetrical interpersonal trusting relationships manifest when both trustor and trustee have almost equal or equal decisional power in a trusting situation; for example, some sexual or business relationships (455). On the other hand, asymmetrical interpersonal trusting relationships manifest in situations of decisional power imbalances (e.g. when one person holds more power in relation to decision making). Patient-doctor or citizen-politician relationships exemplify asymmetrical relationships (261, 455, 522).

3.4.2 Is interpersonal trust context-specific?

The idea that trust is context-specific has received weaker emphasis in both empirical literature and social theories. However, my discussion above revealed a number of variations in factors shaping trust across settings, as well as variations in the number of items used to measure trust. In social theories, the idea that trust can be perceived differently by different social groups (455-460) suggests trust may be context-specific. Furthermore, Simpson's (459) discussion of the foundations of interpersonal trust adds credibility to the claim that trust is context-specific. Simpson (459) suggested that, 'the greatest hindrances (to understanding) trust have been...the tendency of investigators to define and operationalise trust differently in different settings' (p588). This may explain the existence of different definitions of interpersonal trust (above). Moreover, the different typologies (detailed above) also suggest that trust may be context-specific, as one or more

typologies may manifest in one context but not in another context. The context-specific nature of trust may explain the absence of an 'all-embracing' theory that provides a holistic conceptualisation of trust relevant to patient-doctor relationships (209, 524). The evidence presented thus far suggests that trust may be context-specific, meaning trust may be conceptualised and constructed differently in LIA than in HICs.

This section has examined social theories to shed more light on what trust may mean and whether it is context-specific. Various definitions and typologies of trust were examined, as well as evidence suggesting trust may be context-specific. In considering social theories of trust, this section did not attempt to resolve theoretical debates over trust. Rather, it identified some concepts related to what trust means and typologies of trust that informed my thinking about the study design and analytical approach. First, the complex, multifaceted and context-specific nature of trust, rooted in its tendency to be perceived and constructed differently by different social groups, highlights the need for a qualitative inquiry to generate an understanding of trust in the LIA context. Second, the discussion of what trust may mean unmasked some alignments in central concepts in interpersonal trust definitions, suggesting that [patient] trust in doctors involves positive expectations and reliance on [doctors'] future actions, intentions and behaviours. These concepts (patients' positive expectations and doctors' future actions, intentions and behaviours) require thematic examination of participants' accounts of what trust means to them to determine whether they emerge in LIA. Finally, the typologies of trust (interpersonal, institutional, generalised, dependence and distrust) may be useful in explaining some of the results of my investigation of trust in the LIA context.

3.5 Chapter summary

This chapter examined empirical literature on the benefits, factors, interventions and measures of trust in PHC. Despite the prevailing focus on HICs in the literature, there is a

growing recognition of trust as a public health tool in LMICs. A number of gaps in previous studies were identified including: i) limited research on patient trust in LIA; ii) lack of attention to doctors' perspectives; iii) lack of attention to the benefits of trust for both doctors and health systems; iv) lack of attention to the disadvantages of trust; and v) a failure to tackle the complex question of what trust means to research participants. By examining theories of trust, I have demonstrated the importance of approaching trust as context-specific, rather than as a static and universal variable. Therefore, factors shaping trust in HICs, the theoretical concepts applied to define trust (patient expectations, doctors' actions, intentions and behaviours) and the typologies used to distinguish between different aspects of trust (interpersonal, institutional, generalised trust, dependence, marginal trust, blind trust and distrust) will be of varying relevance in rural LIA. The gaps in previous literature and existing social theories informed the manner in which this study seeks to investigate patient trust in doctors in rural Tanzania.

3.6 Objective and research questions

The broad objective of this thesis is to investigate patient trust in doctors to establish whether trust should be a component in the response to the growing burden of NCDs in LIA. Hypertension in rural Tanzania is used as a case study of NCDs in LIA. The specific research questions are:

Question #1: What does patient trust in doctors mean to patients and providers involved in hypertension care in both Western and traditional practices in rural Tanzania?

Question #2: What are the factors shaping patient trust in doctors based on hypertension care experiences in rural Tanzania? Here, factors pertaining to patients, provider and the health system, with specific attention to Western care, will be explored.

Question #3: Does trust matter in rural Tanzania? This includes consideration of the perceived benefits and disadvantages of patient trust in doctors.

In the next chapter, I detail the study design and methods used to gather information on patients and providers' perceptions and experiences of trust in rural Tanzania.

Chapter 4: METHODS

'Where little is known about how trust functions, qualitative research to explore how respondents view trust and trusted behaviour is important in advance of [any] quantitative investigation' Goudge and Gilson (487 p1439)

4.0 Introduction

This chapter discusses the practical approaches used in data gathering and analysis to answer the three research questions: what trust means, what factors shape trust and whether trust matters in medical practice in rural Tanzania. Paying attention to methodological domains of the standards for reporting qualitative research (523), the Chapter is divided into five sections. The first section outlines the study design in relation to the three research questions. The second section provides an overview of the procedures used in selecting the study sites from which participants were accessed, and presents a brief description of these sites. Section three outlines the strategies used in participant sampling, recruitment and conducting interviews. The fourth section describes the data management and thematic analysis process and resulting subthemes and themes. Finally, the fifth section presents the strategies used to ensure qualitative research rigor.

4.1 Study design

In developing the design of this research, I needed to first resolve the question of how patient trust can be investigated in rural Tanzania. As discussed in Chapter 3, there is no over-arching theory of interpersonal trust in the patient-doctor relationship, nor is there a universal framework that attends to all the specificities of patient trust in doctors (209, 524). Rather, trust must be investigated in its complexity, multifacetedness and specific contexts, as suggested by some social theories (455-460). Consequently, I allowed a contextualised account of patient trust in doctors in rural Tanzania to emerge throughout data collection and analysis without viewing trust through an existing theoretical

framework. Investigating trust this way positioned my research within the constructivist research paradigm, relying on participants' descriptions to examine how patient trust in doctors is constructed in this specific context, as a construct with different meanings, different factors shaping it and different perceptions of its importance in rural Tanzania, (rather than assuming a positivist concept with a universal definition). Previous studies on trust in therapeutic relationships appears to have employed this strategy in Kenya (447) and India (469).

A qualitative descriptive approach was deemed appropriate to answer the questions of *what* trust means to research participants, *what* factors shape patient trust in doctors, and whether/*why* trust matters in rural Tanzania (525). The qualitative descriptive approach is appropriate to this inquiry as it seeks to develop an understanding and describe phenomena (e.g. patient trust in doctors) without necessarily testing an existing theory (525). The approach offers an effective way of gathering a deeper and richer understanding of research participants' perceptions and perspectives (525-530). This takes into consideration that patients and providers in rural Tanzania may understand and experience trust differently from people in other contexts according to their perceptions, expectations, values, culture, and relationships (528,585,595). The qualitative descriptive design allowed me to acknowledge the subjective of experiences of both the participants and myself as a researcher, to actively engage in the research process, and to collect data in a natural setting (Section 4.2) (525). Furthermore, by listening to patients and providers' descriptions in rural Tanzania, the design allowed me to learn from their experiences and perceptions of trust and "...using this knowledge to influence interventions" and/or generate research findings of "specific relevance to practitioners and policy makers" in response to NCD burden (525 p3). This is in keeping with the broader aim of this research, which is to establish whether trust could be incorporated within the broader responses to the growing burden of NCDs in LIA.

The qualitative descriptive approach involved purposeful sampling of the study sites (country, region and health facilities) and study participants. Palys (534) defined purposeful sampling as selection of ‘the person or place or situation that has the largest potential for advancing your understanding’ of the topic under investigation (p698). In this research, purposeful sampling aimed to recruit patients currently seeking and doctors/providers currently offering hypertension care in both Western and traditional practice (detailed in Section 4.3.1). Purposeful sampling is a common approach in qualitative research where statistical representation is not a primary goal (532, 535-538). Some authors have insisted that sampling of research participants in qualitative research should also be governed by considerations such as depth, duration and feasibility of the interviews (535, 536). I will elaborate how these considerations apply to this research in subsequent sections.

Qualitative methods in this study involved semi-structured in-depth interviews to obtain rich insights into patients’ and providers’ experiences, perspectives, values, attitudes, feelings and desires related to trust in hypertension care. Because this is the first study of its kind in this setting, semi-structured interviews were chosen to collect data as they would allow patients and providers to answer questions in their own terms and with more detail than structured interviews. A structured interview has categories into which participants’ responses must fit, allowing less room for research participants to share their own opinions (529,531-533). In contrast, semi-structured in-depth interviews include open-ended questions and raise relevant topics that may go beyond the interview guide (detailed in Section 4.3), offering flexibility for identifying new ways of understanding the topic (530). To synthesize the qualitative data provided by interviewed patients and providers in rural LIA, the research draws on analytical strategies that have been developed as part of grounded theory (526), in particular, the inductive strategy of thematic analysis (detailed in Section 4.4). While grounded theory is often aimed at generating novel theories or explanations of social phenomena (526, 578), the primary aim of my data analysis was to develop a rich account of how trust operates in the context of this particular study, to

inform efforts to improve trust. The following sections describe the study settings and the procedures employed in data collection and analysis in detail.

4.2 Study settings

Within LIA, Tanzania was purposefully selected because it is a LIC and the country of my residence³ (see Chapter 1). Tanzania (Appendix 3) is a relevant site for this investigation because of the growing burden of NCDs and associated challenges in biomedical care and widespread medical pluralism. As noted in previous chapters, current Tanzanian data indicate there is a rising burden of NCDs in both rural and urban contexts, inadequate NCDs service uptake, poor adherence to medications, politicisation of medicine and medical pluralism (37, 59, 196). Local studies have reported widespread patient dissatisfaction with care, largely rooted in poor interpersonal relationships with providers, with some studies indicating the need for strengthening patient-doctor relationships (178, 179, 291, 539, 540); however, there is limited understanding of the topic of trust in Tanzania. Shinyanga region was purposefully selected because it is a low-income rural region (541-543), and the region of my residence in which I have spent most of my professional career³. More specifically, the Shinyanga District Council (DC) and Shinyanga Municipal Council (MC) were purposefully selected because they have high rural occupancy, patients interact with providers through both Western and traditional channels and transport networks meant I could access these areas³ (544-546). This site selection aimed to address some of the criticisms of previous studies, which were mostly conducted in high-income and urban settings (Chapter 3).

4.2.1 Shinyanga as a region of inquiry

The Shinyanga region (Figure 3) extends about 160 kilometres from the southern part of Lake Victoria's shoreline, forming part of what used to be known as the *Sukuma land*.

³ The importance of this is the self-funded nature of the data collection phase of my research.

During this study, the region was administratively divided into five districts: Shinyanga MC, Shinyanga DC, Kishapu DC, Kahama MC and Kahama DC. The 2012 national census documented the region's population at 1,534,808 (or 81 people per square kilometre), with 83.4% rural occupancy (547, 548). The region falls within the low-income category (543). Ethnically, the region is predominantly inhabited by Bantus, with the Sukuma as the dominant tribe and presence of smaller percentages of other Bantu cultural groups. Itandala (549), Butt (550) and Brandström (551) suggested that Bantus share some words in their languages, along with a range of socio-cultural beliefs and practices with minimal diversity. Swahili is the formal language of interaction for all tribes across the region and countrywide.

Figure 3: Location of Shinyanga region in Tanzania⁴



Shinyanga region has generally received weak health research interest to date. Available data indicate there is a growing burden of NCDs marked by prevalent modifiable risk factors in both rural and urban contexts (552-554). However, reliable data on patient-doctor relationships are limited. Anecdotal information suggests that patients in the region

⁴ Generated from maps found at www.google.com and <https://en.wikipedia.org/>

have access to both Western (mostly public and few private and faith-based facilities) and traditional care. Western healthcare services have been reported as inadequate (541, 542, 555). Traditional healers (known as ‘*Waganga wa Jadi*’) are considered active in Shinyanga compared with other regions, and are said to implicitly compete for patients with chronic diseases with Western practice. Patients’ access to both formal and informal channels (medical pluralism) in Shinyanga formed an important selection criterion, as examining patients’ and providers’ experiences in both channels is central to this inquiry (Chapter 3). This brings me to Shinyanga DC and Shinyanga MC as the districts for this inquiry.

4.2.2 Shinyanga DC as a district of inquiry

Shinyanga DC (Figure 4) is characteristically a rural district (over 99% rural occupancy). It covers an area of 4,212 square kilometres, of which, 40.6%, 49.7% and 5% are used for agriculture, cattle herding and people’s settlement, respectively (544)⁵. Like other districts in Tanzania, Shinyanga DC administratively extends from highest to lowest levels: one council (*Halmashauri*), three divisions (*Tarafa*), 26 wards (*Kata*), 117 villages (*Vijiji*) and 685 sub-villages. The population in 2012 was estimated at 334,417 people (548). Sukuma is the dominant tribe in the district with a small number of other Bantu tribes.

The District Health Information System (DHIS) data indicated that patients mainly access Western care mainly from primary health facilities: four health centres (*Vituo vya Afya*) and 42 dispensaries (*Zahanati*), of which more than 98% are publicly owned (544, 556). At the time of this study, the district had neither public nor private hospital-level facilities. Plans were underway for construction of a district public hospital at Nindo division, approximately 60 kilometres from Shinyanga regional headquarters. Anecdotal information suggested that traditional practice is most active and commonest in this district compared

with other districts. In addition, anecdotal information indicated that modifiable risk factors for NCDs and hypertension (e.g. alcohol intake, salt usage and smoking) are prevalent.

Figure 4: Map of Shinyanga District Council⁶



4.2.3 Shinyanga MC as a district of inquiry

Shinyanga MC (Figure 5) is the headquarters of Shinyanga region. The 2012 census data indicated a population of 161,391 people, with an average household size of 4.8 persons (548). It comprises 548 square kilometres, and the rural area covers 94.5%, making it predominantly a rural district (545). Shinyanga MC comprises three divisions, 17 wards, 19 villages, 25 streets and 95 hamlets. Sukuma constitutes the major tribe, with a range of Bantu tribes from other regions, particularly the Nyamwezi, and some Arabs and Indians.

Patients access Western care from a mix of government owned, private and faith-based facilities. There are two hospitals: a regional hospital (often referred to as ‘government’) located at the Shinyanga town centre and a faith-based hospital located approximately 15 kilometres from the town (556). During this study, Shinyanga MC had three health centres (two government owned, and one faith-based) and 26 dispensaries (mostly government owned). Traditional healers are active in this district, with many vendors of traditional medicine within the urban area. DHIS data indicated that Shinyanga MC contributed over 50% of reported hypertension cases in the region, because patients from other districts are often channelled to the regional (government) hospital. A special cardiac/hypertension clinic is held every Tuesday in the regional (government) hospital; however, it is said to be

crippled by a high number of patients and inadequate human, medical and physical resources. Modifiable risk factors for NCDs and hypertension (e.g. alcoholism, physical inactivity and modernised lifestyles) are characteristically higher in the urban part of the district because of prevailing social and business activities.

Figure 5: Map of Shinyanga Municipal Council⁷



4.2.4 Selecting health facilities

Purposeful selection was used to obtain a diverse range of health facilities, reflecting some of the health system factors shaping trust described in Chapter 3. Specific criteria for selecting health facilities were: any facility offering care to patients with hypertension, geographical accessibility from Shinyanga centre (where I resided⁸) and location (urban vs. rural), level (mix of primary and secondary) and ownership (public, private and faith-based). The mix of rural and urban facilities considered patients' barriers to healthcare services in rural settings, which are said to differ from their urban counterparts (86, 150, 157, 555, 557).

The initial commitment to use the number of patients receiving hypertension care as a means of differentiating potential health facilities was not possible because of poor reporting in the DHIS. DHIS data included facility-level reporting of different conditions and

⁷ Source: Wikipedia: <https://goo.gl/images/9GN646>

⁸ The importance of this is the self-funded nature of the data collection phase of my research.

services within the district (556). The regional data aggregates indicated that Shinyanga MC and Shinyanga DC accounted for 40.1% and 11.1% of the 6205 patients reported to receive hypertension care across the Shinyanga region between October 2014 and September 2015, respectively. However, the quality of these data was impacted by irregular facility-level reporting, with most reporting no data for several months, making it hard to gauge the annual case load at each facility. Appendix 4 summarises the gaps in DHIS hypertension data reporting from facilities in Shinyanga MC and DC between October 2014 and September 2015.

Twelve health facilities were purposefully selected in early October 2015, including a mix of dispensaries, health centres and hospitals; private, faith-based and government owned; urban and road-accessible facilities in remote areas. Dispensaries and health centres accounted for 83.3% of the selected facilities, government owned facilities accounted for 75% and rural facilities accounted for 66.7%. Facilities in Shinyanga MC accounted for 58.3% based on their easy geographical accessibility from Shinyanga town. Table 4 summarises these statistics.

Table 4: Selected health facilities for qualitative inquiry

District	Level				Ownership		Geographical location	
	Hosp. (%)	Health centre (%)	Dispensary (%)	Total (%)	Public (%)	FBOs/ Private (%)	Rural (%)	Urban (%)
Shinyanga MC	2	3	2	7 (58.3)	4	3	3	4
Shinyanga DC	0*	4	1	5 (41.7)	5	0	5	0
Total	2 (16.7)	7 (58.3)	3 (25.0)	12 (100)	9 (75.0)	3 (25.0)	8 (66.7)	4 (33.3)

*At the time of the survey, there was no hospital-level facility in Shinyanga DC.

Note: DC, District Council; FBO, faith-based organisation; MC Municipal Council.

4.2.5 Ethics approval and ethical conduct of this research

This research received ethical approval from the UNSW (HC15535, Sydney, Australia). In Tanzania, approval was granted by the National Health Research Committee of the National Institute for Medical Research (NIMR) (NIMR/HQ/R.8a/Vol.IX/2024, Dar es Salaam). There was a short delay in Tanzania due to centralisation of the ethical approval process resulting in a temporary authorisation (NIMR/HQ/R.8a/Vol.I/2015) before full approval was granted. In Shinyanga, written authorisations were granted by the Regional Medical Officer and medical officers of Shinyanga DC and Shinyanga MC. At the health facility level, verbal approval from managers of the selected facilities was granted after providing letters from the district medical officers and copies of clearances. Verbal consent was obtained from all research participants before participation. Specific strategies used to ensure the ethical conduct of the research during interviews are described as part of a description of the research process below. After data gathering, data transfer approval was secured from NIMR to transfer the interview materials to Australia.

4.3 Research participant sampling, recruitment and interviews

This section outlines the strategies used in sampling patients and providers, their recruitment to participate in this study and the interview process.

4.3.1 Sampling of research participants

As noted above, patients and providers in either Western care or traditional healing systems were purposefully selected to participate in this study. Purposeful sampling of research participants aimed to access: i) patients currently seeking hypertension care either from Western or traditional healing practices; and ii) doctors currently offering hypertension care in Western practice and traditional healers currently offering hypertension care. Involving providers aimed to address the limitations of previous research on trust that mainly restricted the focus to patients (Chapter 3). Similarly, involving patients

currently seeking hypertension care aimed to address the limitations of previous trust studies, most of which were conducted with patients with non-ongoing therapeutic relationships (Chapter 3). In addition, the involvement of both patients and providers in either Western or traditional practices aimed to acknowledge the widespread practice of medical pluralism in chronic disease management in LIA (Chapter 1). Procedures used to recruit participants principally involved in either Western and traditional practices are outlined below.

4.3.2 Recruitment of patients and doctors in Western practice

A formal visit to selected health facilities involved describing the research to facility managers and seeking approval to conduct the study. Facility managers facilitated identification of enrolment assistants on the same visit. A second visit to the selected facilities involved orientation of enrolment assistants to the study objectives, how to uphold ethical principles during participant enrolment and enrolment procedures. Orientation on ethical principles placed emphasis on informed consent, respect for potential participants, non-coercive enrolment and providing information about the risks and benefits of participation. The Swahili version of the Participants' Information Statement and Consent (PISC) form (Appendix 5) was used as an orientation tool. Enrolment assistants were instructed to consider: i) patients currently seeking hypertension care and not hospitalised; and ii) doctors who offered hypertension care to patients.

Recruitment commenced immediately after the orientation visit (mid-October 2015).

Patients were verbally invited to participate during health education sessions or via peer referrals. Doctors were verbally invited to participate during institutional meetings, via peer referrals or by approaching them directly following patients' suggestions. Following enrolment, details of willing participants were communicated by enrolment assistants through phone calls which facilitated scheduling interviews. A total of 36 patients and six clinicians from Western practice were enrolled in this study (Table 5). Following discussion

with my supervisors, it was decided to cease recruitment in March 2016, as I had reached a point at which no additional information was being generated and participants kept offering the same information. Some researchers have referred to this as data saturation (558, 559).

4.3.3 Recruitment of patients and providers in traditional practice

Patient and provider enrolment in traditional practice involved different procedures. For patients, it was impractical to enrol them through their providers (*Waganga*). Traditional healers claimed that their patients had returned to different districts or regions beyond the authorised study settings after being completely cured (*kupona kabisa*) of hypertension (*presha*). Tracing these 'cured' patients (*waliopona kabisa*) required re-application of ethical clearance and extra time and resources beyond that available for the present study. A patient who had defaulted Western hypertension care and was currently using traditional medicine was conveniently recruited by an enrolment assistant after he had sought care for a different medical problem at the health facility. This participant facilitated recruitment of a fellow patient by providing the enrolment assistant with contact information. Relying on participants to recruit others with similar desired characteristics is referred to as a snowball approach (529, 535). Therefore, two patients currently relying on traditional medicine for hypertension management were enrolled in this study.

It is important to mention that during interviews with patients in Western care (described below), more than half described either combining Western medications with traditional and/or home-made herbal remedies (medical pluralism), or had used traditional medicine at some point before or after seeking Western care. Some described the content, preparation and dosage of traditional medicine for hypertension management. This facilitated tapping into their trust experiences related to both Western and traditional care during interviews.

Information that facilitated enrolment of traditional healers came from two sources. First, healthcare workers associated with the selected facilities named healers in surrounding communities. These healers had either recommended their patients to healthcare facilities for management of acute conditions such as malaria, fever and cough, or they themselves had used the facility for these conditions. Second, community health workers in selected facilities (covering for human resource deficits) have close relationships with healers in their communities. Enrolment assistants obtained the names of reputable healers and conducted initial visits, later providing me with contact information for those that were willing to participate. Then, to build trust, I conducted a second visit accompanied by the enrolment assistant or a community health worker to village leaders for a brief introduction, and then to the healers to schedule an interview. Four traditional healers were approached, and one declined to participate (Table 5).

The challenges of enrolment were twofold. First, women participants (77.3%) exceeded male participants (22.7%). Equal representation of male and female participants was not the goal of recruitment in this study; however, possible explanations for this were: i) nine out of 12 enrolment assistants were female; ii) the study was conducted during a farming season, meaning most men may have prioritised farming activities over study participation; iii) hypertension is more prevalent among females than males in Tanzania (e.g. 54, 86) possibly making women more likely to frequently seek hypertension care compared with men; and iv) it has been shown that women are more likely to participate in research (542, 560-564) and talk about their health (565-567) than men. Second, in Western practice, while 98% of all enrolled patients and providers completed an interview, the proportion of doctors and clinicians (12.8%) enrolled and interviewed was less than that of hypertensive patients (87.2%). Similarly, equal representation of patients and providers was not the goal of recruitment in this study. However, there were four possible contributors to fewer providers participating in this study. The first contributor may be the subtle 'wall' of

superiority between doctors and nurses in healthcare systems (568). Enrolment assistants, mostly nurses, may have felt too inferior to approach doctors. The second contributor could be the prevailing low doctor to patient ratio, which ranges from one doctor per 25–35,000 people in urban areas to one per 50,000 in rural areas (153, 569, 570). Therefore, the number of doctors participating in this study cannot equate patients. The third contributor could be the sensitivity of the topic (patient trust in doctors) amid the tensions in healthcare arising from heightened media attention to doctors' malpractice and politicisation of medicine during the study period (Chapter 2). Doctors might have been uncomfortable with the topic. For example, in one peri-urban facility, a clinical officer withdrew after I observed a verbal confrontation with a patient using harsh language and shouting a few minutes before the scheduled interview. Related to this, doctors who participated in this study either considered themselves or were identified by patients as trustworthy. This may explain why my attempts to recruit more providers in Western care (including personal follow-up) were not fruitful. The impact of this is, the experiences and perspectives of doctors who were considered untrustworthy could not be gathered. The fourth and final contributor may be that many patients might have been attracted to participate in seeking an avenue to relieve stresses accumulated through inadequacies in hypertension care (short engagement, long queues and absence of medications) that they frequently mentioned. Some patients claimed to feel better after the interview because 'talking heals'. Murray (571) suggested that undertaking a qualitative interview session has some therapeutic benefits for participants in the context of trust and connectedness with the researcher.

4.3.4 Scheduling interviews

Scheduling interviews with participants occurred in three ways. First, I contacted participants with mobile phones for their preferred date, time and place after receiving contact information from enrolment assistants. Second, those without mobile phones were asked to choose from various date and time slots during enrolment. All participants in

Western care preferred to be interviewed at the health facilities where they had enrolled in this study. All participants (36 patients and six doctors) voluntarily agreed to participate (Table 5). The high willingness to participate may be attributed to the non-coerciveness of the enrolment process and comprehensiveness of the information (about the study objectives, procedures and process, risks and benefits, and the information about possibilities of discontinuing the interview at any time) offered to participants using the Swahili version of PISC form. Interviews with two traditional care patients were scheduled after obtaining their contact information from an enrolment assistant. While one preferred to attend an interview at a nearby health facility, the other preferred her residence. Third, the date, time and place preferences of interviews for traditional healers were set during a physical visit. Two preferred their residence and one opted to come to the nearby health facility for an interview. Table 5 summarises this information.

Table 5. Participant recruitment and interviews

Channel of care	Category	Invited for interview			Interviewed			Used for analysis
		Shinyanga MC	Shinyanga DC	Total	Shinyanga MC	Shinyanga DC	Total	
Western	Patients	29	7	36	29	7	36	34
	Providers	5	1	6	4	1	5	5
Traditional	Patients	2	0	2	2	0	2	2
	Providers	2	2	4	1	2	3	3
Total		38	10	48	36	10	46	44⁹

4.3.5 Interview guide

Before recruitment, a semi-structured in-depth interview guide was generated and translated. A five-step process was used to develop the interview guide¹⁰ comprising open ended questions (Appendix 6). First, a literature review (Chapter 3) informed the initial set of questions. Topics covered included: trust experiences in hypertension care, perceived benefits and disadvantages of trust, perceived factors shaping trust and perceived meaning

⁹ Two of the patient interviews were unusable (one because of recording difficulties, the other because the interview was terminated early because of language problems).

¹⁰ The general interview guide for patients and doctors/providers was generated before data gathering in Tanzania as one of the documents required for ethical clearance application.

of trust. Second, peer review by experts in both Australia and Tanzania resulted in the addition and removal of questions. Third, applying a unicentred (asymmetrical) forward translation strategy described by Vreeman *et al.* (572), I (a bilingual and native Swahili speaker) translated the guide from English into Swahili. Some of the translated words were matched with those used in previous studies; for example: *imani* (trust), *kuaminika* (being trustworthy) and *uaminifu* (trustworthiness) in (477) and *presha* (blood pressure) in (573). Then, the translated version was reviewed by four bilingual and native Swahili speakers with extensive experience both in Tanzania and Australia. The involvement of bilingual and native Swahili translators aimed to ensure against the loss of meaning that can occur during translation (see 574, 579). The guide in Swahili that reflected reviewers' comments related to wording was used for interviews with participants. Finally, the guide was further developed after the first three and subsequent interviews to reflect emerging issues raised by participants (detailed in Section 4.3.6 below).

4.3.6 Conducting interviews

All interviews began with rapport building. I welcomed and exchanged greetings with participants, often in the Sukuma language, a dominant vernacular. Then, participants' information and consent phase continued in Swahili, using the translated PISC form (Appendix 5). Although all participants had been informed about the study by enrolment assistants, I re-emphasised the study objectives, risks and benefits, how confidentiality of the data would be ensured, how the data would be used and the capacity to withdraw at any time, to ensure this research was conducted ethically. As I went through the PISC form, I frequently checked participants' understanding and addressed their questions and concerns. In one remote facility, the enrolment assistant had portrayed me as an 'expert in hypertension'. Therefore, two participants had come expecting a medical consultation in addition to the interview. This points to how my profession as a medical doctor may have impacted patients' participation in this study. To minimise my impact on participants' participation, I successfully negotiated my position as a 'researcher' and avoided being a

'doctor' in this research. Negotiations involved informing the participants that this is a research not a medical consultation session. I re-explained the research questions, addressed their concerns and inquired whether they were still willing to take part in the research. Orb *et al.* (575) suggested that:

Negotiation of the researcher's role...is important. If the role of the researcher is clearly identified by the group and the purposes of the study are discussed, the researcher will be regarded as such...It will also reduce the [research participants'] false expectations (p96).

At the end of the information and consent phase, I asked participants whether they were willing to continue with the interview and obtained their permission to audiotape their consent. All participants agreed to continue with the interview, their consent was audio taped and the interview continued using the interview guide¹¹.

Three events manifested during interviews. First, one interview necessitated moving to the participants' home (located a few hundred metres away) following noise interference with the recording device at the health facility. Second, I became aware of the relationship between two participants who were a couple. The interview with the wife took place at her house on the same day. Last, two of the traditional healers requested a bilingual community health worker be present during the interview in expectation of language barriers. This was because they had no formal education and inadequate Swahili proficiency, requiring frequent translation to/from the Sukuma language. Then, I verified the translated words with a bilingual HCW in the nearby healthcare facility immediately after the interview. The purpose of verification of the translations with a bilingual individual not directly involved with data collection was to enhance the trustworthiness of the data generated through a cross-language research (579).

¹¹ Each participant was reimbursed with a transport and refreshment package of up to 4500 Tanzanian Shillings (equivalent of AUD3) for taking part in the study.

Excluding the consent phase, the average duration of each interview was 45 minutes, with a range of 35–65 minutes. Two pragmatic factors shaped the interview duration. First, the information and consent phase became unexpectedly prolonged to uphold ethical principles. The information and consent section lasted 15–20 minutes. This time was not audio recorded, and therefore not factored into total interview duration. Participants' comprehension (which was dictated by their level of education), the slow speed of talking common among Sukuma, language barriers and addressing their questions all took time. Second, some interviews ended sooner than expected. This occurred when participants became less involved and offered short answers (four patients) or where a participant was needed to attend to unexpected call of duty (two clinicians).

The first three interviews served the purpose of pre-testing the interview guide. As noted above, the guide was developed in Australia, where access to populations with similar characteristics to the target population in rural Tanzania was limited. Hurst *et al.* (576) suggested that pre-testing of research tool is an 'effective technique for improving validity in qualitative data collection procedures and the interpretation of findings' (p3). Coding of these interviews (detailed below) enabled engagement of supervisors in guide refinement, reflection on early emerging topics and improving the interview process, which enhanced the credibility and trustworthiness of research, (see 530, 532). The interview guide was then used as a topic guide rather than a rigid interview structure in subsequent interviews, as suggested by Ritchie (530). This facilitated detailed exploration of the emerging topics, such as the role of insurance and benefits enjoyed by patients who were health workers; issues that were not initially considered.

4.4 Data management, coding and thematic analysis

This section describes the strategies used in transcription and translation of the data from Swahili to English, and the thematic data analysis.

4.4.1 Data translation and transcription

Interviews in Swahili required transcription of audio recordings into English. Transcription and translation aimed to capture the verbal content of participants' accounts, and attempted to understand the meanings behind the fluctuation of their intonation. Markle *et al.* (577) suggested that when a researcher transcribes their own data, it is a way for them to be immersed in the data. Embracing this suggestion, simultaneous transcription and translation started soon after data gathering in the first three interviews. Given my proficiency in Swahili and English, I listened and re-listened to the audio recordings in Swahili, generated written transcripts in English, read and re-read the transcribed data and made necessary corrections. The transcripts were then shared with a local bilingual supervisor (native Swahili speaker and English fluent) for verification and then with English proficient Australia-based supervisors for review. Some authors referred to this strategy as peer engagement, an important strategy for enhancing research rigor and trustworthiness (530, 532, 579) (detailed in the Section 4.5). Upon the supervisors' satisfaction with the quality of the initial transcripts, transcription of subsequent interviews continued throughout the data collection period.

Because of electricity power rationing in the study settings that affected the use of computers in the field, transcribing the last 50% of the data was completed in Australia after obtaining a data transfer authorisation (detailed above). After transcription, interview transcripts were de-identified, pseudonyms generated for each participant and the data uploaded into NVivo 11 software (QSR International, Australia) for coding.

Translation required two important challenges to be addressed. First, there was a possibility of distorting the message and loss of meanings behind the Swahili transcripts. Markle *et al.* (577) and van Nes *et al.* (574) suggested this was common when a simple word in one language can be said in several different ways in another language. For example, although the word 'trust' translates to '*imani*' in Swahili (477), it may also be used for both

faith in God and faith in a person or things. Related to this is the concept of 'cure'. The word '*kupona*' in Swahili translates to 'complete healing', and is more relevant to a curable disease such as malaria. However, it was used by most participants to indicate 'complete healing' from chronic diseases (e.g. hypertension) and being 'emotionally settled' following relief of disease-related stress. It was also used by some participants to indicate the disappearance of comorbidities or symptoms related to high blood pressure, such as leg/body swelling, dizziness, chest tightness and palpitations. Re-listening, re-reading and making necessary changes to the transcripts, and sharing audio and written transcripts with a local supervisor for review ensured retention of participants' meanings.

The second challenge related to the blurred boundary between the doctor (*daktari*) and the medication prescribed (*dawa*). For some patients who were less educated and those in remote areas, a trustworthy doctor (*mwaminifu*) was described as one that offered medications that facilitated 'complete relief' (*kupata nafuu*) or 'cure' (*kupona kabisa*). This raised a number of questions: i) whether their trust (*imani*) was directed towards the medications (*dawa*), a doctor (*daktari*) or both; ii) whether patients in rural areas linked medications to doctors because of learning from traditional healers who usually offer both medical care and medications to patients (not pharmacies); and iii) whether this was rooted in lack of a direct Swahili translation of a 'prescription', and therefore, participants considered it synonymous with medications. Recurrence of the accounts linking doctors to the therapeutic effectiveness of medications in many transcripts necessitated considering 'patient faith in medication' and the 'doctors' treatment (medication) outcomes (relief or cure)' as potential factors that shaped patient trust in doctors. These issues are explored in more detail in Chapters 6 and 7.

4.4.2 Thematic data analysis

Thematic analysis was used to address the questions of *what* trust means, *what* factors shaped trust and whether trust matters in the study context. This analytical strategy has

been described in detail by Braun & Clarke (578). Thematic analysis allows the researcher to actively engage in identifying patterns within data and organising them into categories or themes and making interpretations (526, 578). Thematic analysis involved coding of transcripts, defining and naming subthemes and themes and then generating an analysis. The next sections describes these steps in detail.

4.4.2.1. Data coding

Data coding involves organising chunks or segments of data in meaningful groups. In coding, a researcher looks at what the participant is saying, creates appropriate labels or codes and links the word, phrase or paragraphs to each label (578). Coding may take an inductive path (or data-driven process) in which the data are coded without trying to fit them into pre-existing coding frame using a 'bottom up approach' (578 p83). Coding may also take a deductive path or a 'top-down approach', where a researcher attempts to accommodate the data into a pre-existing coding framework or research question (578 p83). The data coding in this study used a largely inductive approach at earlier stages, with a deductive approach used to check for pre-existing codes (from the literature review) and ensure that coded extracts and subthemes were tailored towards answering research questions.

4.4.2.2 Inductive and deductive coding

Inductive coding aimed to generate a rich description of patients and providers' lived trust experiences in the study setting. The use of inductive coding of data drawn from interviews exploring participants' descriptions of their experiences and the meanings they ascribed to them points to grounded theory (see 526, 529, 530, 537, 578, 580, 581). However, while a grounded theory approach involves generating a new way of theorising social phenomena (526, 529, 530, 580, 581), this study used inductive coding to generate a rich descriptive account of the data. This was used to identify codes and subthemes that might otherwise have been lost if a deductive approach alone was taken at this early stage. To develop the

coding schedule, I closely examined the contents of first three transcripts using NVivo software to identify words, concepts, phrases or terms related to trust, and generated an initial list of codes without paying attention to the research questions. This facilitated identification of new topics such as patients' faith in medications, patients' distrust in traditional system/medications, providers' assurance of cure, providers' self-pride, providers' morale, traditional healers' self-promotion and the ability of doctors' treatment to facilitate relief and cure, that had received little attention in previous studies (Table 6).

Further, deductive coding aimed to ensure the known codes/topics in keeping with previous studies and research questions were not lost. This was because the primary goal of this research was not to use patients and providers' accounts of their trust experiences for theoretical development (above). Rather, the aim was to generate an understanding of what trust meant for participants, factors shaping trust and whether trust mattered to patients and providers in this context. Therefore, I identified additional words, concepts, phrases or terms to deductively generate codes related to research questions informed by the analysis of previous research. Such codes included: patient healthcare seeking, adherence, disclosure, participation, return for care, expectations, satisfaction, familiarity; provider behaviours, competence and income; and cost of care, medications and income (Table 6).

Codes generated through both inductive and deductive approaches were then refined to generate a combined list of initial codes. This initial list of codes underwent review by the supervisory team who had independently read the selected transcripts and the field notes. This generated a consensual list of codes. I then continued coding the rest of transcripts, refining and generating more codes upon coming across new segments of data that could not fit into initial codes (Table 6). This, as per Braun and Clarke (578) allowed moving back

and forward by revisiting previously coded transcripts to verify whether the codes still applied and re-coding where necessary.

4.4.2.3. Generating subthemes and themes

The emerging codes were organised into subthemes paying attention to the research questions. For example, codes related to patient healthcare seeking, adherence, disclosure, participation and return for care formed a subtheme of 'benefits to patients'. Then, both semantic and latent approaches were used to review the subthemes for the entire dataset, and generate themes. A semantic approach involves identifying 'the surface meaning of the data' in relation to the research questions without going beyond participants' words or written texts (578 p13). It differs from latent theme generation, which examines the 'underlying ideas, assumptions, concepts and ideologies' theorised to inform the semantic contents of the data (578 p13). The use of a semantic approach was rooted in the exploratory nature of the study; however, a latent approach was particularly necessary in examining the question of what trust meant to research participants. Some subthemes persisted as themes; for example, those related to meanings of trust. As detailed in Table 6 below, final themes included: trust as meaning expectations of a doctor before the encounter, satisfaction with doctors' actions during the encounter and satisfaction with doctors' treatment outcomes after the medical encounter; factors that participants considered as shaping trust (patients factors, provider factors and health system/facility/institutional factors); and whether trust mattered in hypertension care (benefits and disadvantages of trust). This was followed by collating the related coded data extracts and subthemes within each theme for analysis.

Table 6. Moving from codes to themes

Codes	Subthemes	Themes
Patient expectations before the encounter -Expectations of doctors' (good) behaviours, actions and treatment that will be offered	Patients' positive expectations of a doctor before the encounter	Trust as positive expectations of a doctor before the encounter
Patient satisfaction during n encounter -Satisfaction with doctors' behaviours, demeanour, expertise and skills observed	Patient satisfaction with experiences during the encounter	Trust as satisfaction with doctors' actions during the encounter
Patient satisfaction after an encounter -Satisfaction with the ability of doctors' medications to facilitate relief (nafuu) or cure (kupona)	Patient satisfaction with treatment outcomes after the encounter	Trust as satisfaction with outcomes of treatment after an encounter
Demographic characteristics (religiosity, residence and occupation) Familiarity (doctors and facility) Faith (in all doctors, facility and health sector) A patient is satisfied with doctors' care Social networks A patient returns to the hospital Expectations of cure (kupona) Faith in medications Distrust in traditional healers/medications	Factors related to the patient	Patient factors shaping trust
Reputation (community and patient social networks: offers care, good behaviours, his/her medicine brings relief or cure) Behaviours and demeanour (warm welcome, exchange greetings, positive facial expressions, respectful posture, gentleness and care) and communication (polite, kind words, sympathy, good language and hospitality) Technical skills (ask many questions, bodily examination, touching the patient and engaging the patient in treatment decisions) Doctors' treatment outcomes or ability of doctors' treatment/medications to bring relief (nafuu) or cure (kupona)	Factors related to doctors/providers	Provider factors shaping trust
Facility accessibility (within the patient's village or far away) Facility level (low level/dispensary and health centres or higher level/hospitals) Facility ownership (public, private or faith-based) Availability of resources (enough medications, health workers)		Health system factors shaping trust

Quality of care (prolonged waiting time, congestion) Limited Western care options (in rural areas) Cost-medicated issues (affordability, payment options) Interplay between Western and traditional healers (social networks, medical pluralism, self-promotion of healers, healers foretelling patient disease and promise of cure)	Factors related to health systems (health sector and healthcare institutions)	
Patient behaviours (healthcare seeking, acceptance and adherence, disclosure, engagement and participation, learning and freeness and return for care) Patient health outcomes (correct diagnosis, relief, healing and cure, pain and stress reduction) Improved patient-doctor relationship (positivity, satisfaction, referral, promoting doctors' reputation, gifts to doctors) Finance (reduce time and cost)	Benefits of trust to patients	Benefits of trust
Reputation (respect, recognition and a sense of belonging) Job satisfaction (praise, feeling loved, comfort, solace, happiness, joy, self-pride and actualisation, confidence and competence, effort, readiness, competence, actualisation) Client load (referrals, closeness, income)	Benefits of trust to doctors/providers	
Reputation (praise, positivity, referrals, client load, income, reduced legal claims) Reduced mortality (early and correct diagnosis, reduced medical errors, drive quality, increased adherence) Pull factor (rural to urban, traditional to Western, private to public) Reduced patient-doctor tensions Resource increment (advocacy, reduce medical tourism)	Benefits of trust to institution/sector	
Increased vulnerability (inability to question, malpractice) Poor health outcomes (loyalty, distrust, discontinuity) Financial exploitation (competition, monetary bribes) Sexual exploitation (closeness, immorality, sexual bribes)	Disadvantages of trust to patients	Disadvantages of trust
Behaviour changes (self-pride, patient avoidance, sluggishness) Increased workload (many patients)	Disadvantages of trust to doctors	

4.4.2.4. Developing the analysis

The generated themes, related subthemes and coded data extracts were then moved from NVivo to a Microsoft Word document. In the Microsoft Word document, participant descriptions were reorganised into relevant patterns for interpretation. A focus was to identify the significance of each theme in understanding what trust meant for participants, factors shaping trust and whether trust mattered in the study settings. The next three chapters (results chapters) discuss the findings addressing each of the research questions in line with findings and discussions from previous research.

4.5 Ensuring quality and rigor in this research

There is much debate about how to ensure quality and rigor in qualitative research because the terms ‘validity’ and ‘reliability’ that are used in quantitative research are less common in qualitative research (527-529, 532, 559, 582-590). The criteria for ensuring rigor appear to vary across qualitative research traditions and methodologies (531, 532, 535, 582, 585-587, 590-593). A common criterion to ensure rigor in qualitative research introduced by Lincoln and Guba (585) involved establishing the trustworthiness of the research. According to Lincoln and Guba (585), trustworthiness of research involves establishing its: i) credibility; ii) confirmability; iii) dependability; and iv) transferability. Hadi and José Closs (594 p642) suggested that these four criteria for establishing trustworthiness (rigor) in qualitative research are equivalent to the dimensions of quantitative research (internal validity, objectivity, reliability and generalisability). A number of techniques have been proposed to meet the dimensions of credibility, confirmability dependability and transferability (see 582, 585, 594). Below, I discuss some of the strategies I used to ensure rigor of this research in keeping with these criteria.

4.5.1 Credibility

Credibility entails establishing the truthfulness of the research findings (582). Strategies to establish credibility include prolonged engagement, reflexivity, triangulation, direct quotes, member checking and peer engagement (528, 529, 532, 582, 585, 586, 588-590). Ensuring credibility matters because it is a way of increasing readers' confidence in the truth of the research findings. To ensure credibility of the results, first, triangulation was used.

Triangulation involves using multiple and various sources of data within a study to facilitate understanding of the phenomenon under investigation (583, 590, 595). Barbour (583), Denzin (595) and Patton (590) discussed four types of triangulation: i) triangulation of research methods; ii) triangulation of data sources; iii) triangulation of theories or perspectives; and iv) triangulation of research analysts. In this study, data source triangulation involved gathering data from multiple participants (patients, clinicians and traditional healers) from both Western and traditional channels. Data drawn from these participants were used to answer the three research questions that guided the inquiry. In addition, analyst triangulation was used by involving multiple analysts (myself and supervisors) at various stages to guide the research process and review developed content. This brought multiple insights, reflections and conclusions to this research. Analyst triangulation is considered a way of bringing different perspectives to the research and affirming the research findings (528, 530, 584, 590, 595).

Direct quotes from participants were also used to ensure the credibility of this research. Multiple participants' direct quotes are used in reporting and discussing the findings of this research to ensure accurate presentation of their world views. Direct quotes form the basis of my interpretation, and also enhance the reflexivity on the data and the findings

(530, 533). Using direct participant quotes in this research aimed to enable the reader to 'hear' the voice of participants from rural Tanzania with respect to the research questions.

4.5.2 Confirmability

Confirmability establishes whether the research findings are supported by the data gathered. Strategies to establish confirmability include an audit trail, triangulation (above) and reflexivity (528, 529, 532, 582, 585, 586, 588-590). An audit trail is kept by documenting the research process in a traceable manner that provides a chronological sequence of the steps involved and the justifications for undertaking these steps (see 530). A clear audit trail provides transparency of the research process and confirmability of data, and establishes the credibility and dependability of the qualitative research findings (584, 585, 589). Every step of the research was documented in a journal, including entry into the study settings, enrolment and conducting interviews and personal reflections on these steps. The details of how I gained access to the research sites and recruited participants, collected and recorded the data and the procedures used for translation, transcription and analysis are outlined above. Similarly, minutes of communications with supervisors were kept, particularly when seeking to address the challenges and key decisions. On returning to Australia, this documentation was organised into field notes, which facilitated writing this chapter.

4.5.3 Dependability

Dependability focuses on ensuring the consistency and repeatability of the research findings. It may be addressed by being systematic in the research process, analysis and presentation (588). The details of the research design, site selection and participant selection and recruitment are provided. The process of simultaneous translation and transcription of

audio data into written data and thematic analysis is clearly elaborated. This information will enable another researcher to understand the methods used in this inquiry and their effectiveness, and also to gauge the similarity of results when the inquiry is repeated in similar settings.

4.5.4 Transferability

In establishing whether research findings and conclusions from one setting or population are applicable to others (external validity), quantitative researchers use the term 'generalisability' (530, 532, 587, 594). Malterud (587) suggested that qualitative research findings may not be generalisable because of the context-specific nature of the knowledge. Instead, qualitative researchers commonly strive for transferability. Transferability refers to the likelihood of the research findings being transferable to other contexts, as judged by the readers of the research (532, 583, 587, 594). The specific details of the study settings, participants and the research process offer opportunity for interested readers to ascertain which situation or findings may be transferable beyond the context in which the study was performed (583, 587). In this research, the specifics of the research settings, methods, participants' demographics, analysis and the reasons for key decisions made are described. The process of thematic data analysis with the goal of exploring patients and provider's perceptions and experiences of trust is clearly described. Explanations of how the analytical themes were developed are provided, with consideration of the research questions. In the results chapters, 'thick descriptions' of the data are provided to allow readers' reflections, judgments and interpretations (583, 584), which may facilitate their judgment of transferability.

Being a medical doctor, a public health expert and having worked for a health advocacy organisation in Tanzania might have impacted the choice of themes, related sub-themes and codes that I considered most appropriate to answer the research questions. It also might have impacted the interpretations and the conclusions drawn from participants' descriptions. Readers are therefore welcome to judge which aspects of the findings presented may be used to guide their future studies on the topic within similar or other settings with similar characteristics.

4.6 Chapter summary

This chapter discussed the approaches adopted in this research. The chapter detailed practical matters related to research design, selection of study sites, recruitment of study participants, conducting interviews and data management and analysis. The chapter concluded by outlining how rigor was ensured throughout the research. In the next chapters, the research findings are presented and discussed, illuminating patients' and providers' descriptions of their meanings of trust, and the factors shaping trust and whether trust matters in rural Tanzania.

PREFACE TO RESULTS CHAPTERS

P.1 Participant characteristics

In this study, 46 participant interviews were undertaken with 36 women and 10 men, whose ages ranged from 28–75 years. Participants in Western care were 36 patients with hypertension currently receiving care in selected facilities and five doctors who offered hypertension care. Two of the patient interviews were unusable (one because of recording difficulties and the other because language problems meant the interview was terminated early). Participants in traditional care were two patients who had defaulted to Western care and three traditional healers. Finally, 44 interviews were included in the final analysis, as summarised in Table 7.

Table 7. Summary of participant characteristics

ALL PARTICIPANTS (N=44)	
CHARACTERISTICS	n (%)
Channel of care	
Patients in w/care	34 (77.2)
Providers in w/care	5 (11.4)
Patients in t/care	2 (4.6)
Providers in t/care	3 (6.8)
Sex	
Male	10 (22.7)
Female	34 (77.3)
Marital status	
Married	30 (68.2)
Widowed	11 (25.0)
Single	2 (4.5)
Divorced	1 (2.3)
Tribe	
Sukuma	30 (68.2)
Undisclosed	14 (31.8)
Level of health facility for interviews	
Dispensary	3 (6.8)

Health Centre	20 (45.5)
Hospital	15 (34.1)
None/Traditional	6 (13.6)
Ownership of health facility for interviews	
Government	28 (63.6)
Faith-based/ Private	10 (22.8)
None/Traditional	6 (13.6)
PATIENTS' DEMOGRAPHICS (n=36)	
Age, years	
30–40	4 (11.1)
41–50	13 (36.1)
51–60	10 (27.8)
61–70	6 (16.7)
>70	3 (8.3)
Religion	
Christian	28 (77.8)
Muslim	7 (19.4)
None	1 (2.8)
Level of education	
None	3 (8.3)
Primary incomplete	2 (5.6)
Primary complete	13 (36.1)
Secondary incomplete	5 (13.9)
Secondary complete	13 (36.1)
Occupation	
Farmer	10 (27.8)
Nurses	6 (16.7)
Teacher	5 (13.9)
Housewife	3 (8.3)
Small Business	3 (8.3)
Medical Assistant	2 (5.6)
Others*	7 (19.4)
Insurance ownership	
National Health Insurance Fund	20 (55.6)
National Social Security Fund	1 (2.8)
Community Health Fund	1 (2.8)
None	14 (38.8)
Average daily expenditure (Tshs)	
≤4000	7 (19.4)
4000–7999	8 (22.2)
8000–11,999	20 (55.6)
≥12,000	1 (2.8)
Years since hypertension diagnosis	
<5	14 (38.9)
5–10	6 (16.7)
11–20	7 (19.4)

>20	1 (2.8)
Undisclosed	8 (22.2)
Average distance to primary health facility (kms)	
<1	12 (33.3)
1–2	13 (36.1)
3–5	9 (25.0)
>5	2 (5.6)
Average distance to referral facility (kms)	
<5	11 (30.6)
5–10	17 (47.2)
11–50	4 (11.1)
51–100	4 (11.1)
PROVIDERS' DEMOGRAPHICS (n=8)	
Age, years	
20–30	2 (25.0)
31–40	2 (25.0)
>50	4 (50.0)
Religion	
Christian	5 (62.5)
None	3 (37.5)
Cadre	
Clinical officer	1 (12.5)
A/medical officer	3 (37.5)
Medical officer	1 (12.5)
Traditional healer	3 (37.5)
Average number of patients per day	
Government facilities	54 (75.0)
Faith-based facilities	14 (19.4)
Traditional healers	4 (5.6)

**Other occupations included: laboratory assistant, records assistant, radio technician, retired officer (n=2), office attendants and a clinical officer interviewed as a patient.*

P.2 Individual participant characteristics

Table 8 describes individual participant pseudonyms and characteristics.

Table 8. Individual participant characteristics

Patients in Western care		
ID	Pseudonym	Demographics
01	Rose	Female, 50 yrs, married, Chaga tribe, nurse, Christian, incomplete secondary school education with a nursing diploma, average daily expenditure of Tshs 15,000–20,000, NHIF insurance, 2 kms to PHC and 3 kms to HTN clinic (referral), time since HTN diagnosis not indicated.
02	Nkwabi	Female, 50 yrs, married, undisclosed tribe, nurse, Christian, primary education with a nursing certificate, average daily expenditure of Tshs ≥10,000, NHIF insurance, 3 kms to PHC and 4 kms to HTN clinic (referral), 6 yrs since HTN diagnosis.
03	Katarina	Female, 41 yrs, married, undisclosed tribe, laboratory assistant, Christian, secondary school education with a certificate in laboratory science, average daily expenditure of Tshs ≥5000, NHIF insurance, 6 kms to PHC and 7 kms to HTN clinic (referral), time since HTN diagnosis not indicated.
04	Budodi	Female, 53 yrs, married, Sukuma tribe, housewife, Christian, primary school education, average daily expenditure of Tshs ≥10,000, no insurance, <1 km to PHC and 2 kms to HTN clinic (referral), 13 yrs since HTN diagnosis.
05	Magdalena	Female, 45 yrs old, married, undisclosed tribe, clinical officer, Christian, secondary school education with a medical diploma, average daily expenditure of Tshs 10,000–15,000, average patients per day of 50, NHIF insurance, 2 kms to PHC and 3 kms to HTN clinic (referral), time since HTN diagnosis not indicated. Interviewed both as a clinician and a patient.
06	Regina	Female, 49 yrs old, married, Sukuma tribe, farmer, Christian, incomplete secondary education, average daily expenditure of Tshs 6000–15,000, NHIF insurance, <2 kms to PHC and 8 kms to HTN clinic (referral), time since HTN diagnosis not indicated. Husband a civil servant.
07	Limi	Female, 46 yrs, widow, Sukuma tribe, farmer, Christian, incomplete primary education, average daily expenditure of Tshs ≥5000, no insurance, 3 kms to PHC and 8 kms to HTN clinic (referral), time since HTN diagnosis not indicated. Co-infected with HIV/AIDS.
08	Misoji	Female, 54 yrs old, divorced, Sukuma tribe, farmer, Muslim, no formal education, average daily expenditure of Tshs ≥1000, CHF insurance, <2 kms to PHC and 8 kms to HTN clinic (referral), <1 yr since HTN diagnosis.
09	Mary	Female, 67 yrs, married, Sukuma tribe, housewife, Christian, no formal education, average daily expenditure of Tshs 1000–2000, NHIF insurance

		through her son, <2 kms to PHC and 8 kms to HTN clinic (referral), 2 yrs since HTN diagnosis.
10	Kabula	Female, 63 yrs, married, Sukuma tribe, retired nurse, Christian, primary school with nursing certificate, average daily expenditure of Tshs ≥5000, NHIF insurance through her son, <1 km to PHC and <1 kms to HTN clinic (referral), time since HTN diagnosis not indicated.
11	Masanja	Male, 75 yrs old, married, Sukuma tribe, farmer, no religion, no formal education, average daily expenditure of Tshs 2000–3000, no insurance, 4 kms to PHC and 6 kms to HTN clinic (referral), 2 yrs since HTN diagnosis.
12	Neema	Female, 45Yrs old, married, undisclosed tribe, small business owner, Christian, primary education, average daily expenditure of Tshs ≥10,000, NHIF insurance, <1 km to PHC and <2 kms to HTN clinic (referral), 6yrs since HTN diagnosis.
13	Asha	Female, 44 yrs, married, Sukuma tribe, farmer, Christian, primary education, average daily expenditure of Tshs ≥3000, no insurance, 4 kms to PHC and 6 kms to HTN clinic (referral), 1 yr since HTN diagnosis.
14	Mabula	Male, 71 yrs, married, undisclosed tribe, retired officer, Muslim, secondary school education with certificate in measurements, average daily expenditure of Tshs 4000–5000, NHIF insurance, <1 km to PHC and <2 kms to HTN clinic (referral), 7yrs since HTN diagnosis. Wife a public servant.
15	Pius	Male, 75 yrs old, married, undisclosed tribe, radio technician, Christian, secondary school education with certificate in broadcasting, average daily expenditure of Tshs 5000–10,000, NSSF insurance, <2 kms to PHC and 3 kms to HTN clinic (referral), 8yrs since HTN diagnosis.
16	Bujiku	Male, 70 yrs, married, Sukuma tribe, farmer, Christian, incomplete secondary school, average daily expenditure of Tshs 5000–10,000, no insurance, 2 kms to PHC and 3 kms to HTN clinic (referral), 1yr since HTN diagnosis.
17	Urio	Male, 43 yrs, married, Chagga tribe, teacher, Christian, secondary education with a teaching certificate, average daily expenditure of Tshs 5000–6000, NHIF insurance, <1 km to PHC and >80 kms to HTN clinic (referral), 2 yrs since HTN diagnosis.
18	Shija	Female, 53 yrs, widow, Sukuma tribe, farmer, Christian, primary education, average daily expenditure of Tshs ≥2500, no insurance, <1 km to PHC and >80 kms to HTN clinic (referral), 1 yr since HTN diagnosis.
19	Nyamizi	Female, 53Yrs old, married, Sukuma tribe, medical attendant, Christian, primary education, average daily expenditure of Tshs 10,000/=-, NHIF insurance, 2 kms to PHC and >80 kms to HTN clinic (referral), 9yrs since HTN diagnosis.
20	Hollo	Female, 34 yrs, single, Sukuma tribe, nurse, Muslim, secondary education with a nursing diploma, average daily expenditure of Tshs 6000–7500,

		NHIF insurance, 2 kms to PHC and >90 kms to HTN clinic (referral), 1 yr since HTN diagnosis.
21	Minza	Female, 52 yrs, married, Sukuma tribe, nurse, Christian, secondary education with nursing diploma, average daily expenditure of Tshs 10,000–15,000, NHIF insurance, <1 km to PHC and 15 kms to HTN clinic (referral), 23 yrs since HTN diagnosis.
22	Maduhu	Male, 62 yrs, married, Sukuma tribe, retired officer, Muslim, secondary education, average daily expenditure of Tshs ≥10,000, NHIF insurance, <1 km to PHC and 5 kms to HTN clinic (referral), 3 yrs since HTN diagnosis.
23	Zainabu	Female, 64 yrs, widow, Sukuma tribe, farmer, Christian, primary education, average daily expenditure of Tshs ≥10,000, no insurance, <1 km to PHC and 5 kms to HTN clinic (referral), 11 yrs since HTN diagnosis.
24	Mlasi	Female, 40 yrs, married, Muha tribe, housewife, Muslim, primary education, average daily expenditure of Tshs ≥10,000, no insurance, 3 kms to PHC and 5 kms to HTN clinic (referral), >10 yrs since HTN diagnosis.
25	Kalunde	Female, 59 yrs, widow, Sukuma tribe, teacher, Christian, primary education with teaching certificate, average daily expenditure of Tshs ≥5000, NHIF insurance, <2 kms to PHC and 5 kms to HTN clinic (referral), 7 yrs since HTN diagnosis.
26	Mwasi	Female, 49 yrs, widow, Sukuma tribe, small business owner, Christian, incomplete secondary education, average daily expenditure of Tshs 5000–10,000, no insurance, 3 kms to PHC and 5 kms to HTN clinic (referral), 12 yrs since HTN diagnosis.
27	Rebeka	Female, 63 yrs old, widow, Sukuma tribe, small business owner, Muslim, incomplete primary education, average daily expenditure of Tshs 5000–6,000, no insurance, 3 kms to PHC and 5 kms to HTN clinic (referral), 1 yr since HTN diagnosis.
28	Pendo	Female, 48 yrs, married, undisclosed tribe, records assistant, Christian, secondary education with a certificate in records management, average daily expenditure of Tshs ≥10,000, NHIF insurance, 2 kms to PHC and 3 kms to HTN clinic (referral), time since HTN diagnosis not indicated.
29	Mwila	Female, 53 yrs, married, Sukuma tribe, teacher, Christian, secondary education with teaching certificate, average daily expenditure of Tshs ≥10,000, NHIF insurance, 10 kms to PHC and 25 kms to HTN clinic (referral), 1 yr since HTN diagnosis.
30	Misuka	Female, 52 yrs old, widow, undisclosed tribe, nurse, Christian, incomplete secondary education with nursing certificate, average daily expenditure of Tshs 6000–10,000, NHIF insurance, 3 kms to PHC and 4 kms to HTN clinic (referral), >10 yrs since HTN diagnosis.

31	Masaza	Female, 57 yrs, widow, Sukuma tribe, teacher, Christian, secondary education with teaching certificate, average daily expenditure of Tshs ≥5000, NHIF insurance, 6 kms to PHC and 7 kms to HTN clinic (referral), 15 yrs since HTN diagnosis.
32	Nyazula	Female, 51 yrs, widow, Sukuma tribe, medical assistant, Christian, primary education, average daily expenditure of Tshs 5000–7000, NHIF insurance, <1 km to PHC and <1 km to HTN clinic (referral), 12 yrs since HTN diagnosis.
33	Christina	Female, 40 yrs, married, Sukuma tribe, office attendant, Christian, primary education, average daily expenditure of Tshs 5000–10,000, no insurance, 5 kms to PHC and 10 kms to HTN clinic (referral), 2 yrs since HTN diagnosis.
34	Milembe	Female, 42 yrs, widow, Sukuma tribe, farmer, Christian, secondary education, average daily expenditure of Tshs 8000–10,000, no insurance, <1 km to PHC and 32 kms to HTN clinic (referral), time since HTN diagnosis not indicated.
Patients in traditional care		
01	Josephina	Female, 35 yrs, married, Sukuma tribe, teacher, Christian, secondary education with teaching certificate, average daily expenditure of Tshs ≥10,000, NHIF insurance, <1 km to PHC and 12 kms to HTN clinic (referral), 1 yr since HTN diagnosis.
02	Joseph	Female, 45 yrs, married, Sukuma tribe, farmer, Muslim, primary education and average daily expenditure of ≥Tshs 3500, no insurance, <1 km to PHC and 12 kms to HTN clinic (referral), time since HTN diagnosis not indicated.
Doctors in Western care		
01	Habiba	Female, 51 yrs, married, Sukuma, clinical officer, Christian, secondary education with medical certificate, average 15–20 patients per day.
02	Vanessa	Female, 40 yrs, married, tribe undisclosed, clinical officer, Christian, secondary education with medical diploma, average 30–40 patients per day.
03	Charles	Male, 63 yrs, married, Sukuma tribe, clinical officer, Christian, secondary education with medical certificate, average 10–12 patients per day.
04	James	Male, 32 yrs, married, undisclosed tribe, medical officer, Christian, university education with a medical degree, average >95 patients per day.
05	Joyce	Female, 23 yrs, single, Chaga tribe, assistant medical officer, Christian, high school education with diploma in medicine, average 30–40 patients per day.
Traditional healers		

01	Jilala	Female, 70 yrs, widow, Sukuma tribe, traditional healer, no religion, no formal education, average 6–8 patients per day.
02	Jisena	Male, 28 yrs, married, Sukuma tribe, traditional healer, no religion, no formal education, average 3 patients per day.
03	Bulekele	Male, 65 yrs, married, Sukuma tribe, traditional healer, no religion, no formal education, average 2–3 patients per day.

P.3 Results chapters

The results of this study are spread across four chapters (Chapters 5–8). Chapter 5 examines the question of what trust means to research participants. Chapters 6 and 7 examine the question of what factors shape trust. Finally, Chapter 8 (a published journal article) examines the benefits of trust and highlights its disadvantages.

Chapter 5: WHAT TRUST MEANS TO PATIENTS AND DOCTORS IN RURAL TANZANIA

‘When you say a patient trusts a doctor it means the doctor cured a patient. For example, the doctor treated me, prescribed the medications and I am cured’ [Misuka, a Nurse]

5.0 Introduction

This chapter presents and discusses findings related to the first research question: *‘What patient trust in doctors means to patients and providers in the context of hypertension care in rural Tanzania?’* It begins with an overview of why answering this question is important to achieving the aim of this study, which is to investigate patient trust in doctors to explore whether it could form part of NCD response in LIA. The chapter also provides an overview of the meaning of patient trust in doctors that emerged from patients’ and providers’ accounts in terms of three main patterns. As each pattern is examined, its alignment with and differences from existing theoretical definitions of trust are considered. The chapter concludes by discussing the implications of what trust means to patients and providers in rural Tanzania in relation to further examination of this as a promising entry point for NCD response in the LIA context.

5.1 The importance of understanding what trust means

The burgeoning interest on the topic of patient trust in doctors has heightened the need to understand what trust means for research participants. The likely benefits of understanding what trust means to research participants are twofold. First, it may increase our confidence in the practicability of research findings in addressing healthcare challenges (487, 488).

Second, as established in Chapter 3, trust is a multidimensional and multifaceted concept that is largely context-specific (207, 456, 457, 487). Therefore, understanding what trust means to research participants in a rural LIA context may allow us to determine whether research about or interventions designed to target trust take into account its specificities in this LIA context, and identify aspects that need further consideration (for transferability) or development (487, 489). McKnight and Chervany (489) suggested that ‘a good conceptualisation of trust is a necessary condition for producing good research...both theory-testing studies and psychometric measures of trust’ (p29). As this is the first trust study in rural Tanzania, developing understanding of what trust means to patients and doctors in this context adds to the comprehensiveness and transferability of the findings.

Previous research on trust in patient-doctor relationships has provided useful input for our understanding of its benefits, factors shaping trust, interventions for improving trust and measures of trust in medical practice (Chapter 3). However, as noted in Chapter 3, previous studies did not inquire what trust meant to research participants in much detail. Most researchers tended to draw on definitions of interpersonal trust from different social theories when setting the scene for its practical investigation (207, 209, 215, 254, 359, 360, 397), leaving the question of what trust meant to their research participants largely unanswered.

Some scholars have highlighted that there have been few practical attempts to understand what trust means to research participants. In an editorial entitled, ‘*patients’ trust in physicians: many theories, few measures and little data*’, Pearson and Raeke (488) noted some developments on the topic, but argued that few attempts have been made to ‘ground the

conceptualization of patient-physician trust in actual patient perspectives and (lived) experiences' (p511). Pearson cited an exploratory work by Thom and Campbell (363) involving 29 patients in general care as an example. However, the patients' lived experiences in that study were mainly linked to provider factors shaping trust, such as doctors' technical and interpersonal competences; thoroughness, demeanour, rapport, compassion, understanding and honesty, rather than what trust actually meant. Furthermore, in a discussion entitled, '*How can trust be investigated? drawing lessons from past experience*', Goudge and Gilson (487) suggested that 'only a small number of papers primarily aimed to explore the meaning of trust in a particular setting or a particular group of respondents' (p1443). They cited Lyon (596) as the only study they found that generated meanings of trust from participants and the local language. That paper examined how trust was constructed as a function of economic activity processes among tomato farmers, agricultural input suppliers and traders in Ghana. However, those participants represented different social relationships that may not provide an understanding of trust applicable to the patient-doctor relationships in medical practice.

There were limited attempts to understand the meaning of trust for research participants until 2013, when Sripad *et al.* (479) explored the meaning of trust for pregnant women and those who recently gave birth, their male partners, frontline providers and managers in a peri-urban hospital in Kenya. In that study, research participants linked trust to dimensions such as confidence, communication, integrity, mutual respect, competence, fairness, confidentiality and system trust, which were articulated in relation to either the providers or the facility. Similar to Thom and Campbell (363) (discussed above), although the content areas of trust described in Sripad *et al.* (479) added to our understanding of trust, they

largely pointed to what many other researchers have reported as factors shaping patient trust in doctors (207, 373, 376, 379, 427, 469). Furthermore, looking beyond the literature on trust in patient-doctor relationships, Sheikh and Hoeyer (597) recently examined what trust meant for blood donors in genetic research in Denmark and Pakistan. Although that study focused on participants' trust in the researchers, the emerging meanings largely resonated with the definitions of interpersonal trust in social theories (Chapter 3). Blood donors in that study used different idioms to position trust as meaning their expectations and beliefs in either the good intentions of researchers or the system in circumstances of uncertainties and risks.

5.2 What trust means to patients and doctors

I asked patients and doctors in rural Tanzania to describe what patient trust in (Western) doctors meant to them. I placed emphasis on 'trust in a doctor' (*imani kwa daktari* or *kumuamini daktari*) because the Swahili word for trust (*imani*) can also be used to refer to faith in God (*Mungu*), other people or things (Chapter 3). My analysis of participants' accounts resulted in three distinct patterns: i) the positive expectations a patient holds of a doctor before a physical encounter for hypertension care; ii) patient satisfaction with the doctors' actions and behaviours demonstrated during a physical encounter and; iii) patient satisfaction with the health outcomes associated with the doctor's treatment after a therapeutic encounter.

Before proceeding, it is important to highlight three critical considerations in examining these accounts. First, while the accounts of some participants pointed to one meaning, the accounts of others suggested additional meanings. Second, while the accounts relating trust

to patient satisfaction with the outcomes of doctors' treatment were dominant, most participants tended to talk about what trust means (and factors and benefits of trust) in relation to what happens in a patient-doctor relationship along the spectrum of healthcare (before, during and after a therapeutic encounter). These two considerations suggested that some research participants may hold one or more meanings of trust depending on the point along the spectrum of care to which they are referring. I discuss the implication of this in Section 5.3. The third consideration was that there were clear alignments between the first meaning of trust (patients' positive expectations of a doctor before an encounter) and theoretical definitions that largely centre on patient expectations (Chapter 3). Below, I examine each of these three meanings, and consider their conceptual alignments with and differences from existing theoretical definitions of interpersonal trust.

5.2.1 Trust as meaning patients' positive expectations of a doctor

When describing what patient trust in doctors meant to them, some patients' and providers' accounts pointed to patient trust as meaning patients' positive expectations of a doctor before a therapeutic encounter for hypertension care. Participants' descriptions of patient expectations of a doctor before the encounter that constituted trust ranged from expectations about doctors' future behaviours and technical actions to expectations about treatment that would be offered by doctors. For example, Masaza (a teacher) suggested, 'trusting a doctor means that when I go to him, he will use good language and give me an opportunity to explain what I am suffering from'. Rose (a nurse talking about her experience as a patient) suggested that, 'patient trust in a doctor means that when I go to him, the doctor will offer me the best care'. On the same note, Regina (a farmer) said:

Trusting a doctor starts when you leave your house to [go to] the hospital. When you leave your house, you believe that you are going to get the right treatment from a doctor.

Collectively, these accounts suggested that some patients and providers characterised patient trust in doctors as meaning patients' positive expectations that a doctor will behave appropriately, offer the best care and provide the right treatment that will resolve their medical problems. These accounts resonate with the findings of a study by Skirbekk *et al.* (484) in Norway that reported every patient held positive expectations that their physicians would 'listen to their problems and help find a solution to these problems' (p1184). However, while Skirbekk *et al.* (484) did not frame these expectations as meaning trust, some participants in rural Tanzania extended these expectations to what trust meant to them.

This pattern of participants' accounts appeared to align with some of the concepts in existing theoretical definitions described in the discussion of interpersonal trust in social theories. In Chapter 3, I generated a working definition of trust based on key concepts such as patients' beliefs and willingness to accept vulnerability, positive expectations of and reliance on doctors' future actions, intentions and behaviours. This was because some social literature, for example, Mollering (457), Luhmann (509), Giddens (494), Simpson (459) Mayer *et al.* (504), Robinson (502) and Rousseau *et al.* (505), placed a trustor's expectations (a patient, in this case) of a trustee (a doctor, in this case) as a cornerstone of the definition of interpersonal trust. Even from an economic perspective, Zucker (490) viewed trust as a 'set of expectations' within interpersonal exchanges (p2). However, some

content areas (e.g. patient willingness to accept vulnerability and doctors' intentions) that appeared in my working definition of interpersonal trust did not specifically emerge in my data, although they may be implicit in some participants' accounts.

A plausible reason for participants characterising trust as meaning positive expectations of a doctor may be because they often established doctors' trustworthiness before therapeutic encounters. As detailed in Chapter 6, some patients in the study settings described actively seeking recommendations for a good doctor (based on their reputation of good behaviour, actions and treatment outcomes) from their social networks before visiting the hospital. For example, Urio (a teacher) described that he 'often ask [his] friends who is a good doctor and whether he is available on the day [he] want to visit'. Urio suggested this as a 'way [a patient] find herself having initial trust towards the doctor before even talking to him'. Therefore, it seems possible that characterising trust as meaning patients' positive expectations of a doctor before an encounter may be rooted in the established trustworthiness of the doctor in question.

A key learning from this section is that some patients and providers' thoughts largely placed positive expectations about a doctor's future actions, behaviours and treatment at the centre of what trust meant to them. These accounts largely affirmed the content areas in some existing theoretical definitions of interpersonal trust. Positive expectations of a doctor before an encounter were derived from patient access to information about a doctor's trustworthiness (good behaviour, actions and treatment outcomes) within their social networks. Positioning trust as meaning positive expectations may have significant implications for factors that shape trust before an encounter, how trust can be measured

and the focus of interventions for improving trust in this context. This will be explored in Section 5.3.

5.2.2 Trust as meaning patient satisfaction with encounter experiences

Another pattern of data related to the question of what patient trust in doctors means reflected how some participants described trust as meaning patient satisfaction with what a doctor actually did (technical actions/skills) and how a doctor actually behaves (behaviours and demeanour) during a physical encounter. A good example was shared by Kabula (a housewife) who described trust in the context of doctors' actions (listening, welcoming, sympathy, care, compassion and comfort) demonstrated during an encounter:

When we say a patient trusts a doctor, it means that a doctor receives [welcomes] you nicely, listens to your problems and gives you a prescription and you see that the doctor took a good care of you...and the doctor is very compassionate about your problem...You can look at him and see that this doctor has sympathy for your problem...the blood pressure is very high, but the doctor sympathises with you...he does not tell you things that may cause your blood pressure to increase again...The doctor says good words to you. The words that can make you feel comforted...Sometimes the doctor may tell me that 'mother you are worrying a lot...please try to stop worrying too much...' he advises you well and yes, you trust him.

Consistent with Kabula's account, Habiba (a clinical officer) characterised patient trust in doctors as:

...means that the relationship with my patient is good...for example, the way a doctor interviews a patient, the way the doctor examines the patient, the way the

doctor offers health education...when the patient leaves the doctor's office, she becomes very comfortable. Consequently, these [encounter] experiences build a good relationship between a patient and a doctor.

The idea of trust as meaning patient *satisfaction* with doctors' actions was more evident in other participants' accounts. An example of this was shared by Nkwabi (a nurse), who characterised patient trust in a doctor as meaning 'when a doctor offers [the patient] good medical care, she becomes satisfied with care and develops faith in the treatment itself'. Joyce (an assistant medical officer) also characterised patient trust as meaning 'the patient accepts and is satisfied with the service [a doctor] offers her'. Similarly, Urio, a teacher said:

The way I know it, when a patient says he trusts a doctor, it has all to do with how the doctor provides medical care to the patient. The way a doctor welcomes a patient, the way he talks to the patient, the way he advises the patient etcetera. So, the patient is satisfied with the medical care offered because the doctor advises you well, explains things to you and instruct you what to do. In short, it is about how the doctor talks, advices and instructs you.

Looking at this pattern of data, the central content areas in participants' description of what trust meant to them was patient *satisfaction* with a doctor's observable *technical actions* and *behaviours* during a physical encounter. Two key issues emerged when these accounts were viewed in relation to the existing literature. First, the content areas in these accounts appeared to differ slightly from the dimensions of interpersonal trust in existing theoretical definitions. Referring to the working definition of trust for this thesis in Chapter 3, most social theories viewed interpersonal trust as something that involved *patient expectations* and *confidence* in doctors' *future actions* (289, 437, 458, 459, 494, 502, 504, 505, 508, 509).

For example, the 65 articles and monographs from management and communication, psychology, economics, sociology and political science that were reviewed by McKnight and Chervany (489) indicated that 92% of the definitions of trust mainly related to a trustor's positive expectations of the trustee's future actions related to benevolence (caring, goodwill and responsiveness), integrity (honesty and morality), competence (expertise) and predictability, most of which can be observed during a personal encounter. The difference here is that in contrast to social theories defining interpersonal trust as a function of patient expectations on prospective (future) actions of a trustee, some participants in rural Tanzania described trust as meaning patient *satisfaction* with a doctor's technical and behavioural skills that were personally observed during therapeutic encounter.

Second, these accounts suggested that when describing what trust in doctors meant to them, some participants from rural Tanzania envisioned provider factors shaping trust (Chapter 6). These factors were characterised by some literature (discussed in Chapter 3) as *predictors*, *dimensions* or *determinants* of interpersonal trust (375, 427, 440, 445, 468). The tendency of some participants' accounts to discuss provider factors shaping trust (as established in previous research) in terms of the meaning of trust is not unexpected. The few scholarly attempts to ground the concept of trust in participants' perspectives and experiences often moved from meanings of trust to factors shaping trust (363, 479). This move may be because the concept of trust in medical practice is frequently discussed based on patient experiences of provider behaviours and actions (483, 484, 487). However, a key difference between previous empirical attempts to determine what trust meant to research participants and the findings of the present study is that patients and doctors in rural Tanzania capitalised on the notion of *patient satisfaction* with providers' technical

skills/actions and behaviours as a central content area. Here, trust was not only seen by some participants as a function of doctors' behaviours and technical actions, but as extending to how the *patient felt* (e.g. satisfied) about the behaviours and actions that were personally observed and judged during a medical encounter. Conceivably, this may be why Lewis and Weigert (598) regarded trust as an individual's orientation between *self* and *others* that encompasses cognitive, emotional and behavioural dimensions of their experiences.

There are two possible explanations for why patients and doctors in rural Tanzania spoke of trust as meaning patient satisfaction with doctors' observed actions and behaviours. The first explanation is the complexity and possibly context-specific nature of trust. As previously noted, trust is complex and can have different meanings in different settings (207, 456-459, 489,495, 516). Therefore, the understanding of participants in rural Tanzania might have reflected these features of trust. Second, this particular meaning of trust may be rooted in research participants' implicit recognition of the doctors' cultural obligations in therapeutic relationships. From a cultural perspective, the *Sukuma*, a prevalent tribe in the study setting, often assigns a host (*Mwenyeji*) an obligation to be nice to a guest (*Mgeni*), and also to attend to his/her needs. A good host is someone who fulfils these cultural obligations in a physical encounter (549, 551). As a medical doctor in a similar setting, I personally observed an extension of this guest-host relationship to therapeutic relationships during my medical practice. This suggests that other underlying contextual factors might have influenced some participants' characterisation of trust as meaning satisfaction with doctors' actions during therapeutic encounters.

A key learning in this section is that most patients and providers in the study setting viewed trust as meaning patient satisfaction with doctors' technical actions and behaviours that transpired in therapeutic encounters for hypertension care. Similar to the accounts discussed above, positioning trust as meaning patient satisfaction with doctors' observed technical skills and behaviours may have significant implications for the discussion of factors that shape trust during the encounter, and the measures of and interventions for improving trust in this context.

5.2.3 Trust as meaning patient satisfaction with doctors' treatment outcomes

The final pattern of data related to participants' characterisation of patient trust in doctors as meaning patient satisfaction with doctors' hypertension treatment outcomes. This emerged as the dominant theme in participants' accounts (those with and without medical qualifications) when asked to describe what trust meant to them. Participants without medical qualifications, such as Christina (an office attendant) were of the view that 'trust in a doctor means that your problem has been managed and healed after the doctor treated you'. Budodi (a house wife) also characterised patient trust as meaning 'that a patient gets healed when the doctor treats her'. Similarly, Rebeka (a small business owner) said:

Patient trust in a doctor means that when the doctor treats me, I get a relief from what I am suffering from. For example, if I wake up with nausea, when I meet that doctor and explain that I wake up with nausea today, the doctor prescribes medications and after taking the medications offered I get a relief.

Many participants with medical qualifications also characterised patient trust as meaning patient satisfaction with doctors' treatment outcomes. For example, Nyazula (a medical

assistant) described patient trust in a doctor as meaning the 'the treatment a doctor is offering solves patients' problems...the patient becomes satisfied and happy because she is cured'. Similarly, Misuka (a nurse) said:

When you say a patient trusts a doctor it means the doctor cured a patient. For example, the doctor treated me, prescribed the medications and I am cured; that is only when I can say I trust him.

Characterising trust as meaning patient satisfaction with doctors' treatment outcomes was further emphasised by some participants with medical qualifications who described that trust cannot exist in the absence of achieving these outcomes. For example, Misuka, a nurse, said, 'I may have faith that if this doctor treats me, I will be cured, but if I don't get cured that trust disappears'. Similarly, Magdalena (a clinical officer) said, 'I think if you don't get healed...you won't completely trust [the doctor]'. This suggested that patient dissatisfaction with treatment outcomes may translate to less trust or disappearance of trust (distrust).

Collectively, these accounts suggested one meaning of trust is achieving positive outcomes from the doctors' treatment interventions to patient satisfaction. On one hand, achievement of positive treatment outcomes may signal that the doctor (trustee) has acted in the patient's best interest and has met the patient's (trustor's) expectations in the interpersonal relationship, as envisioned in some theoretical definitions of interpersonal trust (458-460, 502, 504, 505, 509). On the other hand, characterising trust as meaning patient satisfaction with doctors' treatment outcomes appears to take a different path from existing theoretical definitions. As discussed above, most existing social theories view interpersonal trust as something that involves [patient] expectations and confidence in

[doctors'] future (prospective) actions (289, 437, 458, 459, 494, 502, 504, 505, 508, 509). In contrast, many patients and providers in this study viewed trust as something that involved patients' satisfaction with the outcomes of the (retrospectively evaluated) doctors' actions of offering hypertension treatment. This misalignment may also be rooted in the complexity, multifaceted and context-specific nature of trust.

In summary, patient trust in doctors in rural Tanzania was characterised by research participants as meaning: i) patient's *positive expectations on a doctor's actions, behaviours and treatment* that develop before the therapeutic encounter; ii) patient *satisfaction with the doctor's behaviours and technical actions* that transpire during a therapeutic encounter; or iii) patient *satisfaction with doctors' treatment outcomes* after a therapeutic encounter. These three meanings of trust suggest trust has different meanings along the spectrum of care: before, during and after the encounter. Below, I conclude this chapter by examining the possible implications of these meanings.

5.3 Chapter summary and conclusion

This chapter presented findings relating to the first research question concerning the meaning of patient trust in doctors for patients and providers in the context of hypertension care in rural Tanzania. Participants' responses to the question of what trust meant suggested that patient trust meant patients' positive expectations of a doctor before the encounter, patient satisfaction with what a doctor did and how they behaved during an encounter and patient satisfaction with doctors' treatment outcomes after an encounter. It became clear that characterisation of trust as meaning patient satisfaction with what

transpires during therapeutic encounters and doctors' treatment outcomes differs slightly from existing theoretical definitions of interpersonal trust.

The findings in this chapter mark one of the few attempts to ground what trust means in terms of research participants' thoughts and experiences in a specific low-income rural setting. Therefore, we now know what trust means in rural Tanzania. As noted above, the three meanings of trust discussed in this chapter suggested that trust in rural Tanzania has different meanings before, during and after a therapeutic encounter. This contrasts with approaches to trust that focus on patient expectations and confidence in doctors' future actions (Chapter 3). An implication of different meanings of trust at various stages along the spectrum of care is that pursuing one universal meaning of trust within medical practice is misguided if trust has different meanings before, during and after care. As Goudge and Gilson (487) noted, what trust means should be 'adapted to the behaviors [and participants' perspectives] relevant in a specific context' (p1440). Therefore, researchers who seek to further investigate trust (e.g. designing interventions for improving trust or validating measures of trust) in the study setting need to be careful because the meaning of trust may differ between research participants, or some research participants may hold two or all three meanings of trust, depending on the point along the spectrum of care to which one is referring (before, during or after the encounter). For example, if we were to measure trust in the study setting as a form of expectations only, the dimensions related to how a patient felt about the doctor's actions and behaviours during the encounter as well as treatment outcomes after the encounter may be missed. Therefore, considered together, these accounts suggest that when seeking to apply trust in NCD response (e.g. by designing interventions or measures of trust) in this context, researchers may need to: i) tap into

patients' expectations before the encounter, what patients' think about doctors' actions and behaviours observed during the encounter and patients' thoughts in relation to the outcomes of the doctors' treatment after the encounter; or ii) specify the meaning of trust in which they are interested and justify why they are not looking at the other meanings.

Considering trust as having different meanings along the spectrum of care further appeared to influence how patients and providers spoke about other two research questions (what factors shape trust and the perceived benefits of trust in rural Tanzania). For example, viewing trust as meaning patient expectations of a doctor following establishment of their trustworthiness before the encounter appeared to explain why doctors' reputations in patients' community/social networks emerged as both a factor shaping patient trust before the encounter (Chapter 6) and a potential benefit of improving trust in rural Tanzania (Chapter 8). Similarly, viewing trust as meaning patient satisfaction with doctors' treatment outcomes appeared to explain why the ability of doctors' treatment to facilitate positive outcomes emerged as a factor shaping patient trust (Chapters 6 and 7), and facilitation of patient achievement of positive treatment outcomes emerged as a perceived benefit of patient trust in doctors (Chapter 8). This explains why the discussion of factors shaping trust (Chapters 6 and 7) and the benefits of trust (Chapter 8) largely mirrors the events along the spectrum of care (before, during and after the therapeutic encounter).

In conclusion, participants' accounts suggest that when improving patient trust in doctors is considered as an entry point for NCD and hypertension management in rural Tanzania, we need to see it as potentially having different meanings along the spectrum of care. These meanings are based on patient expectations of a doctor before the encounter (now

referred to as *expectation-based trust*) and patient satisfaction with either doctors' behaviours and actions during the encounter or doctors treatment outcomes after the encounter (now referred to as *satisfaction-based trust*). These meanings provide useful content areas in generating contextualised interventions for improvement of and measures for trust along the spectrum of care (before, during and after encounters). They also provide useful input for analysing the factors shaping trust and the benefits of trust in subsequent chapters. Different meanings signal that factors shaping patient trust and perceived benefits of trust may differ before, during and after therapeutic encounters. In view of this, the next chapter discusses factors perceived by participants as shaping patient trust in doctors in the study setting.

Chapter 6: FACTORS SHAPING PATIENT TRUST IN DOCTORS IN RURAL TANZANIA

'A person trusts a doctor depending on how the doctor treats the disease, depending on how the doctor is listening carefully to patients' accounts of the disease' [Mwasi, a small business owner]

6.0 Introduction

In examining the findings from participant interviews related to the second research question (*'What factors are shaping patient trust in doctors in western care in rural Tanzania?'*), the discussion is divided into two chapters. This first chapter provides a general discussion of three groups of factors that emerged from participants' accounts as shaping patient trust in doctors in rural Tanzania. The first section examines patient factors, the second section considers provider (doctor) factors and the third section focuses on health system factors that emerged as shaping trust in the study setting. In examining each of these groups of factors, emphasis is placed on how they appeared to relate to what trust meant to participants in this setting (Chapter 5) and how they differ from, reaffirm or extend previous research on trust in other settings. Finally, the chapter concludes by briefly unpacking the implications of the findings in relation to how trust could be improved to play a role in NCD response in LIA context. The following chapter (Chapter 7) examines three novel factors that dominated patients and providers' accounts as shaping patient trust in doctors in rural Tanzania that have not previously been reported in the literature.

6.1 Patient factors shaping trust in doctors

The first group of factors that emerged from the thematic analysis of patients' and providers' accounts were those related to patients. Using both semantic and latent analysis strategies, nine subthemes emerged under the 'patient factors' theme:

- i. Patients' social networks
- ii. Patient trust in healthcare institutions (institutional trust)
- iii. Patient familiarity with doctors
- iv. Patient faith in all doctors in general (generalised trust)
- v. Patient satisfaction with doctors' care
- vi. Patient religiosity (strong religious beliefs)
- vii. Patient faith in medications
- viii. Patient expectations of hypertension cure
- ix. Patients' generalised distrust in traditional healers.

In analysing these factors in relation to the accounts of what trust meant to participants (Chapter 5), each meaning appeared to be related to particular patient factors. The expectation-based meaning of trust largely related to the factors that constructed patients' positive expectations of doctors before physical encounters. Patients' social networks, trust in healthcare institutions (institutional trust), generalised trust in doctors, expectations of hypertension cure and distrust in traditional healers appeared to largely construct patients' positive expectations of Western doctors before an encounter. However, the satisfaction-based meanings of trust largely related to factors that impacted how patients interacted with doctors, how they felt towards doctors' behaviours and actions observed during the encounter and how they felt about doctors' treatment post encounter. While patient

familiarity with doctors largely related to how they interacted with doctors during medical encounters, patient satisfaction with doctors' care largely related to how they felt about the doctors' behaviours and actions observed during the encounter. Some accounts of patients' faith in medications related to both expectation- and satisfaction-based trust. This section briefly considers some of these factors; however, a detailed discussion of two patient factors (patient faith in medications and patients' expectations of cure) as well as issues related to patient distrust in traditional healers is reserved for the next chapter as part of the novel findings of this study.

6.1.1 Patient factors related to expectation-based trust.

A range of patient factors shaping trust related to participants' accounts of expectation-based trust. Social networks were frequently cited by participants as a way to construct their expectations of doctors by facilitating their access to information about doctors' trustworthiness (behaviours, actions and treatment outcomes) before the encounter. For example, a quote from Urio (Chapter 5, Section 5.2.1) indicated that information about a doctor's trustworthiness drawn from social networks facilitated initial expectation-based trust before an encounter and contributed to actively seeking to encounter the doctor in question. This suggested that patient access to information about the doctors' untrustworthiness may fuel initial distrust and avoidance of encountering a particular doctor. Furthermore, social networks were also linked to two other patient factors: patients' faith in medications and patients' expectations of hypertension cure. I return to these in Chapter 7.

Some participants indicated that patients' trust in a healthcare institution (institutional trust) contributed to expectations and beliefs about receiving appropriate care from doctors

within that institution, thereby fuelling patient trust of them before the encounter. A good example is Vanessa (a clinical officer) who said:

...If the patient trusts the facility and believes that if s/he goes to the facility will receive appropriate care and his/her problem will be solved, even if s/he find that the doctor s/he trusts the most is not around, s/he will trust other doctors and go to them to receive medical care.

Vanessa's account suggested that patients' institutional trust may construct generalised trust in all doctors within an institution (see below), fuelling initial trust before a physical encounter and contributing to seeking/willingness to encounter any doctor within that institution.

There was also a sense among some participants that patients' faith in all doctors (generalised trust) contributed to positive expectations of good medical care and initial trust in all doctors within an institution before a physical encounter. The drivers of patients' generalised trust in all doctors before an encounter appeared to be six-fold. The first two drivers of patients' generalised trust in doctors before encounters were: i) patients' trust in institutions (see above); and ii) the influence of social networks on their trusting choices (see above, also detailed in Chapter 7). The third driver of patients' generalised trust in doctors before encounters was patients' own beliefs that doctors are worth trusting because they are all experts in disease management and are certified by medical institutions. Regina (a farmer) shared that:

Personally, I trust them all because they are both experts. The doctor is an expert, he has been certified by the medical institution...I trust him. He cannot be there if he does not have the expertise required to offer medical care.

In support, Pendo (a records assistant) suggested:

I trust any doctor who studied medicine, whether a specialist or general doctor.

Every doctor studied different specialization—others are general doctors, others studied paediatric diseases, and others studied about women's diseases or abdominal diseases or surgery...

The fourth driver for patients' generalised trust in doctors before encounters was uncertainty about encountering the same doctor in subsequent visits. For example, Pendo (above) further rooted her generalised trust in doctors in the frequent change of doctors at the hypertension clinic:

The doctors who offer care at the (hypertension) clinic keep changing every day.

The doctor I met last month is different from the one available today. Every time I come here, I meet a different doctor. Every day we are attended by different doctors. So, I trust any doctor who I meet when I come to the hospital.

The fifth driver of patients' generalised trust in doctors before encounters was patients' perception of the risk of not trusting doctors, because doctors are the only hope when one suffers from a serious medical condition. Zainabu (a farmer who had suffered stroke) said:

To me, the most important thing is just getting treatment. I do not choose doctors. We have a say that a person who chooses a hoe is no farmer. Every doctor I find there, if he offers me medical care I trust him. This is because I am sick and if I am too choosy, will I get well? Patients who are stupid do not trust doctors but those of us who suffered from stroke; we believe that the doctors are the people who keep us alive.

The sixth and final driver of patients' generalised trust in doctors before encounters (and which also formed another patient factor shaping trust) was patient religiosity. Patient

religiosity emerged as a reason for generalised trust in doctors because they are expected to fulfil their duties as agents of God. Budodi (a housewife and devoted Christian) said:

I trust all doctors because...when a doctor does his work by offering care to a patient, God is there with him. I can confidently say that when a doctor is offering you care, God is blessing him...I never felt like distrusting any doctor. You cannot say that you do not trust a certain doctor because God put him there with a specific purpose of serving people.

These patient factors appeared to relate to expectation-based trust by facilitating patient expectations of good and appropriate care from doctors before a therapeutic encounter. The initial expectation-based trust toward doctors appeared to consequently contribute to some patients actively seeking to encounter them in Western care. This may raise a question as to what happens to this initial expectation-based trust when a patient enters a therapeutic encounter but are either dissatisfied with the doctors' actions and behaviours physically observed during the encounter or treatment fails to achieve good outcomes. I address this in Section 6.2.2.

Comparison of these accounts with previous literature showed some of these patient factors have been discussed as determinants, predictors or dimensions of trust in other settings. Detailed in Chapter 3, patient trust in healthcare institutions (institutional trust) has been debated as contributing to interpersonal trust in some social theories (289, 484, 494, 508, 509), as well as being reported as a factor shaping patient trust in doctors (210, 253, 483, 494, 506-509, 512). Furthermore, some theoretical and empirical literature designated generalised trust as the typology of trust (209, 494, 509). Generalised trust in doctors is considered to be based on patients' expectations that all doctors will (always) act

in their best interest (253, 489, 509). The accounts of participants in rural Tanzania extended these views by indicating that generalised trust in doctors is not only rooted in patient faith in all doctors as experts but also in patients' institutional trust, the influence of social networks, uncertainties about encountering the same doctor in subsequent visits, the perception of the risk of not trusting and religiosity. This suggests that some of the facets/typology of trust identified in HICs may be transferable to LIA settings and vice versa, but contextual issues may influence how they manifest. Moreover, patients' religiosity and social networks have been reported as shaping patient trust in doctors in Northern Italy (214) and South India (469). This suggests there is some homogeneity between the findings in rural Tanzania and those reported in other settings. However, the accounts of participants in rural Tanzania extended these patient factors by suggesting that they may shape expectation-based trust that manifests before therapeutic encounters.

6.1.2 Patient factors related to satisfaction-based trust.

Although some of the patient factors discussed above may somewhat relate to satisfaction-based trust, two patient factors emerged in participants' accounts as largely related to satisfaction-based trust. Patient familiarity with doctors was the first patient factor that related to satisfaction-based trust to emerge from participants' accounts. Familiarity fuelled trust by enabling smooth interactions between patients and doctors and influencing patient engagement in treatment decisions during therapeutic encounters. Familiarity-mediated trust was indicated in the accounts of some patients who described encountering doctors they personally knew (mostly from previous encounter experiences). For example, Milembe (a farmer) spoke about trusting the doctor she encountered on the day of the interview and said, 'I know this doctor, we are very close, and I have faith in him that he always offers good medical care'. Similarly, familiarity-mediated trust emerged in the

accounts of other patients who described encountering their usual (familiar) doctor after being dissatisfied with experiences of encountering unfamiliar doctor. For example, Rose (a nurse talking about her experiences as a patient) said:

[I] met a new doctor who is not that understanding. I know what I am suffering from and when I told a doctor, the diagnosis he offered was totally different. So, I had to go to my usual doctor. This means I did not trust [the new doctor] and this happened at [facility name].

Patient satisfaction with doctors' care was the second patient factor related to satisfaction-based trust to emerge from participants' accounts. While Urio, Nkwabi and Joyce (Chapter 5, Section 5.2.1) cited patient satisfaction with doctors' care in describing what trust meant to them, their accounts re-emerged in my analysis of patient factors shaping trust. These accounts indicated that patients' satisfaction with doctors' care (as a function of observed behaviours and technical actions during the encounter) shaped satisfaction-based trust in a positive direction before achievement of the desired treatment outcomes.

In previous literature, patient familiarity with doctors has been debated as contributing to interpersonal trust in some social theories (427, 445, 509), and also reported as a factor shaping patient trust in doctors; for example, in the US and rural Cambodia (427, 445). Some literature documented patient satisfaction with care as a factor shaping trust (e.g. in the US) (213). This further suggests homogeneity between the present findings from rural Tanzania and those reported in other settings. However, the accounts of participants in rural Tanzania extended these patient factors, suggesting that they may also shape satisfaction-based trust.

This section has examined some of the patient factors shaping patient trust in rural Tanzania in relation to what trust meant to research participants. There appears to be a great deal of homogeneity between the findings in rural Tanzania and those reported in other settings. Such homogeneity generally has important implications for developing interventions to improve trust in rural Tanzania and other settings. I will return to this in Section 6.4. Some patient factors documented as shaping patient trust in other settings, such as age, occupation, ethnicity and gender (209, 214, 440, 468), did not specifically emerge in the present data, possibly because of the research questions and design. However, I show in subsequent sections and chapters that some patient factors (e.g. education, income and residence) emerged in this study as potentially influencing patients' perceptions of trust experiences in the study setting.

6.2 Provider factors shaping patient trust in doctors

The second group of factors shaping patient trust in doctors that represented a recurrent theme in this analysis were provider (doctor) factors. Participants' accounts related to provider/doctor factors were coded into four subthemes:

- i. Doctors' reputation in the community
- ii. Doctors' behaviours and demeanour
- iii. Perceived doctors' technical skills
- iv. Doctors' treatment outcomes.

These factors were mostly cited by participants when differentiating a good '*trustworthy*' doctor from a bad '*untrustworthy*' doctor. In analysing these factors in relation to the accounts of what trust meant to participants (Chapter 5), each meaning appeared to be

related to particular provider factors. On one hand, expectation-based trust appeared to be related to a doctor's reputation in the community. On the other hand, satisfaction-based trust appeared to be related to doctors' behaviours, demeanour and technical skills (trust as meaning patient satisfaction with doctors' actions and technical skills), as well as doctors' treatment outcomes (trust as meaning patient satisfaction with doctors' treatment outcomes). In this section I mainly focus on doctors' reputation in the community and their behaviours, demeanour and technical competence. A discussion of the accounts related to doctors' treatment outcomes is reserved for Chapter 7, when examining novel findings of this study.

6.2.1 Provider factors related to expectation-based trust

As previously noted, a doctor's good reputation (in the community and among patients' peers and social networks) was cited as fuelling patient trust in doctors. The opposite (a bad reputation) was cited as fuelling patient distrust in doctors. Doctors' good reputation in the community and patients' social networks were cited by some patients as especially important in constructing their initial (expectation-based) trust before a personal encounter. For example, Urio (a teacher in a remote school), quoted in Chapter 5, indicated that a patient 'may trust a doctor because [s/he] already has (positive) information about him'. Urio further indicated that, 'information about the reputation of providers spreads in the community' and that he 'often asks [his] friends who is a good doctor and whether he is available on the day [he] wants to visit'. Most importantly, Urio saw this as a reason for 'having initial trust towards the provider before even talking to him'. Urio's account suggested that patient access to (positive) information about doctors' trustworthiness fuelled initial trust that was rooted in patients' expectations that doctors will replicate their reputation upon encounter.

Comparing Urio's account with existing literature, the idea of patient trust in doctors commencing with initial trust constructed with access to (positive) information about doctors' reputations before a personal encounter reflected what some literature referred to as 'established providers' trustworthiness'. Conviser (455) and Lewicki *et al.* (460) suggested that established trustworthiness is based on a trustor's judgment of a trustee's abilities and rank compared with others before an encounter. The intention here is not to debate theorised levels of trust as performed in Lewicki *et al.* (460). However, providers' reputations in the patients' community and social networks appeared to be especially important in a patient's establishment of providers' trustworthiness, which fuelled initial expectation-based trust before a personal encounter. This may explain why some patients in rural Tanzania described trust as meaning positive expectations of a doctor before the encounter (Chapter 5), which may be embedded in their perceptions of the established trustworthiness of a provider.

6.2.2 Provider factors related to satisfaction-based trust

Compared with patient factors, provider factors dominated participants' accounts of the interpersonal factors shaping patient trust. Doctors' behaviours and demeanour that portrayed good care during the rapport building phase of patient-doctor encounters emerged as important in building patient trust. Doctors' behaviours and demeanour that fuelled patient trust included: sitting in a respectful posture when a patient entered the room, identifying the patient by his/her name, offering a warm welcome, exchanging greetings (*salamu*) and showing positive facial expressions by smiling (*tabasamu*). Other behaviours included: expressing gentleness, care and sympathy (*huruma*) and good verbal communication (kind words and good language). For example, Magdalena (a clinical officer) valued doctors' 'hospitality and language' as important in building patient trust during the

initial phase of the encounter. Magdalena held a view that 'other doctors in the study setting have bad language that makes patients afraid of coming to see them'. Few patients identified doctors' appearance (*mwonekano*) in terms of attire as shaping their trust.

Furthermore, doctors' technical skills (as perceived by patients) during the disease diagnosis and management phase of the patient-doctor encounter were cited as shaping patient trust. A doctor's tendency to take a detailed medical history by asking many relevant questions and engaging a patient in treatment decisions was highly valued by many participants as shaping their trust. For example, Mlasi (a housewife), suggested:

There are two kinds of doctors: the bad one, who, when you meet, he does not ask questions, and the good one, who asks a lot of questions ranging from your progress to how do you feel that day.

Most patients considered a doctor who performs bodily examination activities, such as checking a patient's blood pressure, listening to the chest (*kifua*) or heart (*moyo*) using a stethoscope and touching where there was pain (*maumivu*) as trustworthy. For example, Mabula (a retired government officer) suggested that a bodily examination 'comforts [the patient] psychologically', leading to more patient satisfaction and trust in doctors. The perception of psychological impact of bodily examination was also evident in the account of Shija (a farmer from a remote village), who requested a doctor check his blood pressure, but 'the doctor said go and check your blood pressure anywhere'. This contributed to Shija becoming 'emotionally disturbed' and dissatisfied because he had 'endured so many troubles to come to [urban facility]'. Shija further said 'I can trust a doctor who examines me, who does or orders investigations that I went to the hospital for as well as giving me medical advice'.

In general, participants' accounts suggested that doctors' behaviours and perceived technical competence were important (when demonstrated to patients' satisfaction) in shaping patient trust in doctors in rural Tanzania. These accounts offered useful insights into the question of what happens to initial expectation-based trust with which a patient may enter a therapeutic encounter (see above). They suggested that entering a therapeutic encounter with expectation-based trust may not guarantee satisfaction-based trust. For most patients in rural Tanzania, satisfaction-based trust could be constructed only when a doctor demonstrated good behaviours and actions during the encounter to the patient's satisfaction. The opposite, patient dissatisfaction with doctors' behaviours and actions, may construct distrust, even when a patient had entered an encounter with initial expectation-based trust. In support of this, Joyce (an assistant medical officer) said, 'you may have an initial [generalised trust in all doctors] in a healthcare facility, but once you meet a specific doctor, based on experiences, you lose that trust'. Furthermore, some participants described the consequences of satisfaction-based trust and distrust. Patient satisfaction with doctors' behaviours and actions during the encounter was said to promote patient faith in the treatment offered and continuity with the same doctor. For example, Katarina (a laboratory assistant) said:

...it is all about [doctors'] care; the way [a doctor] welcomes a patient and offer medical care it gives her hope, even if the patient does not get well, she is more likely to come back to the hospital looking for the same doctor.

In contrast, patient distrust rooted in dissatisfaction with doctors' behaviours and technical actions was said to contribute to non-adherence to medications. For example, Rose (a nurse), who was dissatisfied with the care and diagnosis made by a (new) non-

understanding doctor (above), said, 'such doctor can prescribe medications, but when I reach home I don't use them'. On the same note, Nyazula (a medical assistant), described dissatisfaction with doctors' actions during the encounter that contributed to non-adherence:

I went to see a doctor, upon arrival, I told him that I am a known hypertensive patient and I am sick. He started asking furiously 'why are taking all these medications? They want to kill you entirely...all four antihypertensives?' He crossed all the medications that I was using that time. It made me feel weird. I lost faith completely in that doctor. I did not even use the medications he prescribed.

Compared with previous literature, most of the doctors' behaviours and technical competence cited as shaping patient trust in this study affirmed factors reported in both HICs and LMICs (214, 373, 375, 376, 379, 445, 484, 599). Doctors' behaviours portraying good customer care and reflecting good technical competence (e.g. detailed medical history and bodily examinations) have received extensive scholarly attention as shaping patient trust in doctors (221, 401, 427, 468, 470-471, 473, 484, 599, 600). Other issues emerging from the data that may be considered as being of less importance (e.g. doctors' attire) have also been documented in some literature as shaping patient trust (601, 602). Notably, in this study, concerns related to doctors' behaviours dominated in participants' accounts as shaping trust compared with those related to doctors' perceived technical skills. This suggested that doctors' interpersonal behaviours may be more important in shaping patient (satisfaction-based) trust in rural Tanzania compared with their perceived technical skills.

Issues related to doctors' education and ability to speak the Sukuma language were cited by a few participants as important for developing patient trust. However, other provider demographic factors identified in previous research as shaping patient trust, such as gender, religion, culture and tribe (214, 215, 380, 468, 475), did not shape trust in the present analysis. This suggests that, other than education and language, doctors' demographic details may not be of importance for trust development to most patients in this study setting.

Most features of good (trustworthy) and bad (untrustworthy) doctors cited by patients and providers in rural Tanzania as shaping patient trust in doctors can also be found in other literature beyond the topic of trust. Literature on patient satisfaction with care and patient-provider interactions that did not have the main objective of examining patient trust in doctors reported doctors' good technical and interpersonal competence as impacting patient satisfaction with providers' general care, maternal and child health and HIV care in LIA (e.g. 179-181, 268). Most medical professional codes of ethics and conduct cite pro-patient, respect and caring as characteristics of a good doctor, including the American Medical Association (302) and the Medical Council of Tanganyika (287). Similarly, some reviews (603), health service research (604), patient-centred care literature (605, 606) and medical authors (607-609) have also highlighted what makes a good doctor, with an emphasis on both technical and behavioural competence. These bodies of literature agree that technical competence and interpersonal behaviours are central in characterising a good doctor, and are also qualities that may influence patient trust towards them.

A key learning in this section was that doctors' good interpersonal behaviour and perceived technical competence were highly valued as shaping patient trust in rural Tanzania.

Participants' accounts suggested that when a doctor demonstrated good behaviours and technical skills during an encounter (to patient satisfaction), satisfaction-based trust was more likely to be built. Conversely, doctors' failure to demonstrate behaviours and demeanours that portray good care during a patient-doctor encounter may fuel distrust, which may in turn impact adherence and continuity with doctors' care. This may explain why some patients in rural Tanzania described trust as meaning patient satisfaction with doctors' behaviours and technical actions during the encounter (Chapter 5). I discuss the implications of these findings in Section 6.4.

6.3 Health system factors shaping patient trust in doctors

The third and final group of factors emerged as shaping patient trust in doctors in the accounts of study participants were concerns related to healthcare system characteristics in the study setting. Participants' accounts of health system concerns were coded into six subthemes:

- i. Healthcare facility accessibility
- ii. Healthcare facility level
- iii. Healthcare facility ownership
- iv. Healthcare resources
- v. Quality of care
- vi. Limited Western healthcare options in rural areas
- vii. The interplay between Western and traditional care.

In this study, health system factors were highly valued by participants as contributing to either trust or distrust in doctors. In analysing health system factors in relation to

participant's accounts of the meaning of trust, they appeared to be 'overarching factors', meaning they may be related to expectation-based trust satisfaction-based trust or both. This section briefly examines some of these factors in relation to previous literature. The Western-traditional care interplay, a new factor, is reserved for Chapter 7 as a novel finding of this study.

6.3.1 Healthcare facility accessibility

The accounts of some participants indicated a healthcare institution's proximity (e.g. to patients' homes) contributed to trust in doctors. These issues were prevalent in the accounts of patients from remote areas who indicated the need to travel to secondary and tertiary facilities in urban areas for better care (detailed in Section 6.3.2). A good example was shared by Milembe (a farmer from a remote village) who described having higher trust in doctors in 'a facility which is very close to [her] home'. Two reasons emerged from my analysis to explain why healthcare facility accessibility fuelled patient trust in doctors in the study settings. First, healthcare facility accessibility shaped patient trust in doctors by facilitating patient *familiarity* with the doctors in the healthcare facility near their home. For example, Milembe (above) indicated having faith in a doctor who she personally 'knew' and noted they were 'very close'. Similarly, Masanja (a farmer), when asked whether he trusted a doctor he met at the nearest facility, said, 'I trust the doctor I met very much'. Masanja further said, 'I have been coming here for a long time...for about 2 years. I know them all [doctors] and they all know me'. Here, physical accessibility of the healthcare facility appeared to fuel patient trust in doctors by facilitating a patient encounter with a familiar doctor in a familiar healthcare facility. As noted above, familiarity has been theorised to shape interpersonal trust within society (494, 509) and identified as fuelling patient trust in doctors (427, 437). Second, healthcare accessibility shaped patient trust in doctors by

ensuring patients' quick access to doctors' help in the event of a medical emergency. For example, when asked whether he trusted a doctor he met at the nearest facility, Urio (a teacher) explained, 'Yes, I trust him' not only because of the 'closeness [of the clinic] to [my] home' but also 'if [I] get any serious problems, it is easier to go to [there] than any other facility'. A key learning here was that the proximity of a healthcare facility to a patient's home positively shaped trust in doctors in the facility.

6.3.2 Healthcare facility level

The accounts of some participants pointed to the healthcare institution level as contributing to trust in doctors. It is important to note that hypertension care in rural Tanzania is organised in such a way that some patients need to move from local facilities or lower level health facilities (LLHFs) to urban-based (district or regional) hospitals or higher-level health facilities (HLHFs). A pattern of data in some participants' accounts suggested that LLHFs fuelled more patient trust in doctors than HLHFs. Two reasons for this emerged from my analysis. First, the characteristics of healthcare services at LLHFs, such as the ease of encountering a doctor and speedy services, compared with the complex process and prolonged waiting time in HLHFs. For example, Rebeka (a small business owner) who affirmed trusting a doctor in a local LLHF said, 'a doctor (in a LLHF) does not have other (administrative) responsibilities and we get medical care on time'. Second, some patients perceived that LLHFs possessed fair technical competence and resources to manage acute conditions such as malaria and fever. For example, Rebeka further said that she goes to 'a LLHF for 'conditions such as fever or malaria' because a patient can easily go 'to the lab to do a malaria test and if you have malaria you take the results back to the doctor and he timely prescribes antimalarial for you'. An opposing pattern of data suggested that HLHFs fuelled more patient trust in doctors than LLHFs in the study setting. This was because they

were perceived to have doctors who were more educated and possessed more expertise, and had fair resources to manage chronic diseases/hypertension better than LLHFs. For example, Pendo (a records assistant), was of the view that HLHFs have 'all necessary services' fuelling patient trust in doctors. To elaborate, Pendo asserted that when equipment such as 'BP machine at one section is not working [at a HLHF], I may be directed to [a different section] within the hospital where there is a BP machine'. This was different in LLHFs, where Pendo suggested that 'in most cases when you go there [LLHFs], they say the BP machine is not working or it has no batteries' leading to returning home without checking blood pressure.

Previous research on the topic of trust, most of which is from HICs, indicated that healthcare facility level as a factor shaping patient trust in doctors has received little attention. However, the finding that patients trust doctors in HLHFs more than LLHFs appeared to align with that of Russell (401) in urban Sri Lanka. In examining healthcare seeking patterns in Colombo, Russell (401) reported a tendency of some patients with chronic diseases, such as hypertension and diabetes, to trust in doctors at a large public hospital (HLHF) than those in municipal dispensaries (LLHFs). Those participants perceived HLHFs (tertiary) to have the 'the best staff and equipment to deal with serious conditions' (p1403). Similarly, Russell (401) reported concerns of patient dissatisfaction with interpersonal relationships as fuelling distrust in providers in LLHFs. Dissatisfaction with interpersonal relationships did not emerge in the present data with reference to health facility levels as shaping trust. This suggested that some factors shaping patient trust in rural Tanzania may differ from those shaping trust in high-income and urban settings.

6.3.3 Healthcare facility ownership

The accounts of some participants highlighted healthcare institution ownership (faith-based facilities or government owned) as contributing to shaping trust in doctors. Similar to facility level (above), the present analysis of participants' accounts of facility ownership as a factor shaping trust revealed two opposing patterns. One pattern suggested that faith-based ownership shaped more patient trust in doctors than government (public) ownership. Two reasons emerged to explain this. First, similar to LLHFs (above), faith-based facilities were thought to have speedy services because of fewer patients and shorter waiting time compared with government facilities. For example, Bujiku (a farmer) affirmed trusting doctors in a faith-based facility where he 'always receives care' because 'they have few patients...when you come here you receive appropriate care timely...' Second, faith-based facilities were said to facilitate good interpersonal behaviours among doctors and other workers because of the perceived closeness of and fear in God. For example, Rose (a nurse) described bypassing a government facility where she works for a faith-based facility, and characterised 'doctors and other staff in faith-based hospitals' as 'more caring than the government hospitals' and as having 'good language and comforting words'. Similarly, Charles (a clinical officer in a faith-based facility) characterised doctors in faith-based facilities as those who 'adhere to both work ethics and religious principles' and 'always around when the patient arrives'.

An opposing pattern of data suggested government ownership of healthcare facilities shaped more patient trust in doctors than faith-based (or private) ownership. Two reasons emerged to explain this. First, government-owned facilities were said to have doctors who possess better technical competence than those in faith-based facilities and are trained in government institutions and 'trusted' by the government to work in public facilities. For

example, Mwila (a teacher) believed that the ‘doctors [in government facilities] are more educated than those in [faith-based facilities]’. Second, government facilities in this setting were said to have necessary equipment for management of chronic diseases. For example, Maduhu (a retired government officer), supported Mwila’s views (above) and said:

...personally, I cannot trust doctors in faith-based and private hospitals because government hospitals have doctors who have been trained by the government. Also...the government facility has the necessary equipment and sometimes other patients come to this hospital from [faith-based and private] hospitals. So, I think, in my case, my trust in the doctors in the government hospital is very high than my trust in doctors in [faith-based and private] hospitals.

The opposing patterns of data in the present study support the findings in some previous studies. The findings that some patients trust doctors in faith-based facilities more than those in government facilities because of their good interpersonal behaviours and speedy services were consistent with those of Tibandebage and Mackintosh (477), who analysed healthcare market transactions in Dar es Salaam and Mbeya in Tanzania. In that study, religious ownership of a healthcare facility was perceived to guarantee good (providers’) ethical commitment, (providers’) resistance to profit motives and good institutional control mechanisms. Consequently, healthcare workers in religious-owned institutions in that study were described as trustworthy because of politeness and the warm welcome given to patients. Similarly, the findings from the present data that some patients trusted doctors in government facilities more than faith-based facilities because of their perceived technical expertise were consistent with those of Tibandebage and Mackintosh (477), who reported health workers in public facilities in were trusted for good technical competence. Furthermore, while private–government ownership comparisons emerged in the accounts

of fewer participants compared with faith-based–government ownership comparisons, the opposing patterns in participant accounts in the present study somewhat support a healthcare seeking study by Russell (401) in two poor urban communities in Colombo, Sri Lanka. Using household survey and qualitative data, Russell reported two opposing patterns of participants' accounts related to trust in doctors in private and government sectors. Russell reported that participants perceived overall higher patient trust in private providers because of speedy services, better interpersonal skills and their capacity to treat acute diseases. That study also reported that public providers were trusted for management of more serious diseases because of their technical expertise. Similar to the present findings, participants in Russell (401) demonstrated 'confidence in the qualifications and technical competence of...doctors in [government-owned facilities]', with quality of training as a main driver of trust (p1403). This suggested that the ownership of the facility where doctors work may be a key factor that shapes patient trust in doctors.

6.3.4 Healthcare resources

The accounts of nearly all participants valued healthcare resources at the healthcare institution as somewhat contributing to patient trust in doctors (and the institution). The resources mentioned included medical equipment and service scope, and enough doctors with sufficient technical expertise and medications. Concerns about limited resources were prevalent in both LLHFs and HLHFs; however, patients in remote villages appeared to be severely impacted compared with those in urban areas, where alternative mechanisms exist (e.g. private pharmacies). It may take the whole chapter to discuss the limitations of healthcare resources (medications, equipment and human resources) in rural Tanzania that have been broadly documented in local literature (150, 152, 153, 186, 200, 610, 611). Some patients attempted to establish a link between healthcare resources and trust in doctors.

For example, Misuka (a nurse) referred to medications to establish how they may shape patient trust in doctors:

Missing medications may...affect [trust in doctors] when a patient blames a doctor for prescribing the medications which are not available. That is why a patient may go back to the same doctor for him to change the medications. But, once the doctor changes the medication and you use the new medications without healing you may be thinking that you could have healed if you were able to take the medications the doctor prescribed in the first place. So, missing medications may impact how trust is developed because the doctor's work becomes incomplete. But when the doctor changes the medications, you lose faith in the new medications thinking that you could have healed if only you were able to get the medicines he prescribed earlier.

Misuka's account suggested that missing prescribed medications because of unavailability at the healthcare facility's pharmacy may fuel 'blame' on the prescribing doctor, pointing to distrust. However, it may fuel further distrust when a doctor responds to unavailability by changing a prescription to medications that may delay or fail to facilitate healing.

Availability of healthcare resources as a factor shaping patient trust in doctors has been identified in some research in LMICs (401, 445, 468, 471, 612). Some literature in LMICs has suggested the availability of healthcare resources (enough doctors, medicines and medical equipment) as essential in creating smooth environment where satisfaction-based trust can be established and sustained (401, 468, 473). For example, patients expecting a bodily examination and medical investigations as detailed above (Section 6.2.2), may be disappointed with the absence of functional medical equipment. This may impact their trust

in doctors by not fulfilling patient desires (refer to the discussion of doctor-related factors above).

6.3.5 Quality of care

Quality of care was not explicitly articulated by participants, but my analysis of some participants' accounts suggested issues related to quality of care impacted patient trust in doctors. During the thematic analysis of participants' accounts, several codes fell within the quality of care subtheme. These codes related to: i) health service structure issues, such as personnel (number, behaviours and technical competence), medical equipment and medications (discussed above); and ii) health service process issues, such as opening hours, waiting times and provider continuity. This grouping was based on the classification described by Lanska and Hartz (613) of the three traditional aspects of measuring quality of healthcare (health service structure, health service process and health service outcomes (satisfaction and patient health status)).

Some participants expressed concerns about quality of care that related to satisfaction-based trust in both doctors and healthcare institutions. For example, Mabula (a retired officer) affirmed trusting doctors in one primary facility because it was 'open during the weekends' when there 'are no hypertension clinic services' at a large secondary facility. Concerns about prolonged waiting times at hypertension clinics (because of many patients) in a large public hospital as impacting the quality of care offered by doctors were particularly significant. Prolonged waiting times (because of many patients) was cited by Misuka (a nurse) as a reason patients 'do not have enough time to express what [they] desire' when encountering a doctor. Prolonged waiting times (because of many patients) was also cited as something that 'discouraged' Nkwabi (a nurse in a primary facility) from

returning to a large secondary facility for the next scheduled visit. Prolonged waiting times in government facilities was cited by Josephina (a teacher) as the reason ‘why people who are well off go to private facilities’, and a reason given by Joseph (a farmer) to seek care from a traditional healer ‘because there is no patient congestion’. This suggested that prolonged waiting times in some government facilities may fuel patient distrust in doctors (and lead to them not seeking care or seeking care from non-government facilities or traditional healers). Identifying quality of care as a factor shaping trust is consistent with the findings in some previous research (374, 440, 445, 473). A key learning here was that patients’ perceptions of quality of care may be a crucial factor shaping their satisfaction-based trust or distrust in doctors in rural Tanzania.

6.3.6 Limited Western healthcare options

The accounts of some participants suggested limited western healthcare options in rural areas shaped trust in doctors. Most patients in remote villages indicated that neither faith-based/private nor government-run facility existed in their home village. For example, Misoji (a farmer in a remote village) spoke about her hypertension care experiences:

For most part of my life, I lived in a very remote village. I spent my earlier years of marriage in a very remote village...very far. It was very difficult to see a doctor there. There was not any healthcare facility.

In support of Misoji’s account, some local reports and DHIS data point to the absence of Western care facilities in some villages (614, 615). A media report by Nkwame (615) highlighted the Tanzanian government initiative of ‘One-Village-One-Dispensary’ by 2017. However, DHIS data suggest a mismatch between what has been planned and what has been achieved. A good example is the DHIS data for Shinyanga DC, (one of the study sites) that indicates the district comprises 117 villages but only had 45 government-run facilities

and one private facility at the time of this study (544, 556). What this means is that 62% of the villages in Shinyanga DC had no primary health facility as at March 2017. A recent visit to the district towards the beginning of 2018 suggested nothing has changed since then. What we can learn here is that the absence of health facilities in many villages means some patients in villages without any health facility may have limited Western hypertension care options in their locality.

Some participants' accounts indicated that limited Western options may fuel patient dependence on doctors in any facility in their reach, irrespective of technical or interpersonal quality of care. For example, Masanja (a farmer) indicated dependence on doctors at the nearest facility because 'no other hospital around...[and, he] cannot go to another hospital, which is very far'. In support, Nyazula (a medical assistant) indicated there was dependence on doctors in the hospital where she worked, because '[patients] don't have an alternative...there is no any other hospital...offering hypertension care'. Similarly, other patients indicated dependence on doctors in the nearest facilities because there were no other options should they need urgent care, such as for hypertension-related emergencies (recall Urio's quote above, Section 6.3.1). Also, some patients indicated dependence on doctors in the nearest facilities as a way of avoiding the costs related to encountering doctors in distant urbanised facilities. For example, Mlasi (a housewife) said, 'I cannot go to other places [very far]...I do not have money to go to other facilities. I always come to the [facility nearby home] and I do not incur extra travelling costs'. Additionally, the accounts of some patients indicated patient dependence on any available doctor in a facility as most rural facilities only have a single clinician.

Comparisons between these accounts and previous literature showed patient dependence on doctors was characterised as a weak form of patient trust placed in doctors when faced with limited options. This concept has been discussed in detail in Meyer and Ward (437), Ward (380) and Meyer and Ward (209), who differentiated dependence from trust. I concur that dependence is a weak form of trust because a patient is forced to trust doctors, even in the circumstance of poor interpersonal or perceived technical quality of care. Meyer and Ward (437) discussed dependence from the perspective of patient decision-making during healthcare emergency situations; however, patient dependence in rural Tanzania appeared to be shaped differently by: i) limited options characterised by absence of other better doctors or health facilities in their locality; ii) patient desire to avoid cost of encountering doctors in distant facilities; iii) patient fear of where to go in case of an emergency; and iv) lack of choice when a facility only has a single clinician. It can therefore be suggested that limited Western healthcare institutions, particularly in rural areas, may force some patients to have a weaker form of trust in doctors.

6.4 Chapter summary and conclusion

The analysis presented in this chapter suggested a range of patient, provider and health system factors shape patient trust in doctors in the study setting. Patient factors shaping trust included institutional trust, familiarity with doctors, generalised trust in doctors, satisfaction with care, religiosity, social networks, faith in medications, expectations of hypertension cure and generalised distrust in traditional healers. Provider factors identified were doctors' reputations in the community, behaviours and demeanour, perceived technical skills and doctors' treatment outcomes. Finally, healthcare facility features, such as accessibility, level and ownership, availability of resources, quality of care, limited Western

care options and the interplay between Western and traditional care emerged as health system factors shaping patient trust in doctors in this study setting. It is important to note that a detailed discussion of some of these factors is provided in Chapter 7.

A great deal of homogeneity can be seen between patient, provider and health system factors that shaped patient trust in this study and what has been reported in other settings. Some patient factors (e.g. institutional trust, social networks, generalised trust and familiarity), doctors' factors (e.g. behaviours and technical skills) and health system factors (e.g. healthcare resources and quality of care) have been reported to shape trust in other settings (Chapter 3). As interventions for trust improvements are always constructed around factors shaping trust (Chapter 3), such homogeneity suggests that some of the interventions to improve trust in HICs may be transferable to rural Tanzania and vice versa. Amid the possibility of transferability of trust improvement interventions, the findings of this study offer some evidence to suggest that context matters when talking about factors shaping trust. Some factors identified in this study as shaping trust (e.g. patients' faith in medications, patients' expectations of cure, patient distrust in traditional healers, doctors' reputation in the community, doctors' treatment outcomes and the interplay between Western and traditional care) have not been reported in other settings. Conducting a study in a rural setting of a LIC with widespread medical pluralism (157, 163, 190, 191, 194, 193, 546, 555, 652), concerns of healthcare resource constraints (150, 152, 153, 185, 200, 610) and a context in which patient trust is perceived to have different meanings may explain these differences.

The different meanings of trust (Chapter 5) provided a useful entry point to analyse the factors shaping trust in this context. When patient, provider and health system factors shaping trust in rural Tanzania were viewed from the perspective of what trust means, they largely related to expectation-based trust, satisfaction-based trust or both. On one hand, factors that largely related to expectation-based (initial) trust before therapeutic encounters ranged from patients' social networks, institutional trust, generalised trust in doctors, expectations of hypertension cure, religiosity and distrust in traditional healers to doctors' reputation in the community/social networks. On the other hand, factors that largely related to satisfaction-based trust ranged from patients' familiarity with doctors and satisfaction with care to doctors' behaviours and demeanour, doctors' technical competence and doctors' treatment outcomes. Most importantly, health system factors appeared to represent overarching issues that related to expectation-based trust, satisfaction-based trust or both. This suggests that while most patient, provider and health system factors discussed in this chapter shape either expectation- or satisfaction-based trust, some may shape both.

An approach to the question of factors shaping trust from the perspective of expectation- and satisfaction-based trust contrasts with current approaches (Chapter 3). Previous research on patient trust in doctors has not attempted to examine factors shaping trust in relation to what trust meant to research participants (207, 209, 215, 254, 359, 360, 397). As noted in Chapter 3, trust is multidimensional, multifaceted and may have different meanings in different settings (207, 456, 457, 487). It is therefore not surprising that trust in rural Tanzania has different factors related to different meanings. An implication of examining factors shaping trust as relating to either expectation- or satisfaction-based trust

is that seeking to improve or measure trust in LIA using the using current approaches predominantly used in HICs may be misguided. This is because any intervention to improve or measure trust in rural Tanzania and LIA needs to be adapted to how trust is understood and perceived by research participants in this context (487). Furthermore, researchers seeking to improve trust for NCD response in LIA by designing interventions in the study setting need to be careful because there may be a need for combined interventions focusing on both expectation and satisfaction-based trust. For example, combining interventions targeting patients' social networks and improving doctors' behaviours and technical skills and those focusing on increasing Western healthcare facilities may have more impact. Similarly, researchers seeking to generate and validate measures of trust in the study settings need to be careful because the measures of expectation-based trust may not be relevant to, or may miss some key aspects of, satisfaction-based trust. Similar to what I proposed in Chapter 5, the accounts of participants in this chapter suggest that when seeking to apply trust in NCD response (e.g. by designing interventions or its measures) in the LIA context, researchers may need to consider patient, provider and health system factors shaping both expectation and satisfaction-based trust. These implications will become clearer as I examine the novel factors shaping trust in the next chapter.

Chapter 7: NOVEL FACTORS SHAPING PATIENT TRUST IN DOCTORS IN RURAL TANZANIA

'I believe that hypertension cannot be cured by doctors in hospitals but can be cured with traditional medicine' [Josephina, a teacher]

7.0 Introduction

This chapter begins by examining the *interplay between Western and traditional practice* (health system-related factor), as the first novel factor. I start with this factor because the discussion in this chapter is framed around what is happening in a context in which both Western and traditional healing systems prevail. I draw on participants' experiences and perceptions related to Western and traditional care to explain how this factor can positively or negatively shape patient trust in doctors in Western care. As noted in Chapter 6, this factor represents an overarching factor in which participants' accounts relate to either expectation- or satisfaction-based trust. The chapter also examines *patients' expectation of a cure for hypertension* (a patient-related factor) as the second novel factor. I draw on the roles of social networks, traditional healers and local events to explain how this factor negatively shapes patient trust in doctors in Western care. As noted in Chapter 6, this factor largely relates to expectation-based trust. The third novel factor examined in this chapter is *patient faith in medications* (a patient-related factor). I explore participants' accounts of faith in traditional and Western medications to explain how this factor negatively or positively shapes patient trust in doctors in Western care. As noted in Chapter 6, this factor also relates to both expectation- and satisfaction-based trust. The

chapter concludes by considering the implications of these findings in relation to how trust could be improved to play a role in NCD response in the LIA context.

It is important to note that some of the issues discussed in this Chapter are not things participants explicitly described as factors shaping trust. Rather, these aspects were suggested as shaping how patient trust is built through my analysis of their accounts using both semantic and latent approaches (Chapter 4) in comparison with local literature, events and my personal experience as a medical doctor in the study setting.

7.1 Patient trust in the interplay of Western and traditional practice

One of the key findings of this research pointing to a novel factor was that patient trust in doctors was shaped by the interplay of two healing systems in the study setting: Western and traditional practices. The traditional healing system (*Tiba za asilikienyeji/jadi*) existed in Tanzania and other African countries before Western care was available, and has continued to be highly valued by people (159, 189-191, 194-196, 546, 616-620). Having lived in Tanzania from childhood, I can attest that nearly all people within the country, including myself (621), have had personal experience with traditional healers (*Waganga wa jadi/kienyeji*) at some point in their life, or have been exposed to messages or information regarding healers' promises of complete cure (*kupona kabisa*) for certain chronic diseases that are said to be incurable by Western medications. Prevalent traditional healing in Tanzania and Shinyanga continues to contribute to medical pluralism in chronic disease management (Chapter 1), forming an important rationale for conducting this research in rural Tanzania. What appears as a consensus among local reports is that traditional practice

competes with Western practice for chronic disease management, as detailed in Sections 7.1.1 and 7.2.

The accounts of most participants in this study were dominated by issues related to patient experiences of hypertension care in both Western and traditional healing systems (medical pluralism). As noted in Chapter 4, almost all patients interviewed in Western care described having 'tried' traditional options or were currently practicing medical pluralism for hypertension treatment. Some patients (e.g. Rose, a nurse) went further to describe the content, preparation steps and dosage of traditional medicine for hypertension management. Other participants described attending Western practices for hypertension diagnosis and proceeding with traditional practices for hypertension care. For example, Josephina (a teacher) currently receiving traditional medicine said:

...I went [to Western care] at the beginning for checking my blood pressure. After I was told that I have hypertension...I did not go on with hospital services...I started using traditional medicines.

Some patients were said to go to traditional healers because of the failure of doctors in Western care to correctly diagnose their disease. For example, Jisena (a traditional healer) said:

The patient may say, 'I went to the hospital, but they did not see the problem and I went to a different one, also they did not see it. That is why I decided to come here for you [a healer] to help me'. You take some herbal mix with warm water and a patient uses it to wash his/her body. This is a cleansing remedy to wash away the bad omen that a patient might have stepped onto. After that, you start giving oral medications and the patient starts having a relief.

These accounts helped me to generate a subtheme concerning the interplay between Western and traditional care as factor that shaped trust. However, as this study is focused on patient trust in doctors in Western medical practice, this discussion is limited to examination of participants' experiences of hypertension care in traditional practice in relation to how these experiences shaped patient trust in doctors in Western care. A detailed examination of patient trust in traditional healers is beyond the focus of this thesis.

The interplay between Western and traditional care appeared to shape patient trust in doctors in Western care in either a positive or negative direction. Some participants' accounts indicated that the interplay shaped trust in a negative direction by constructing patient distrust towards doctors in Western care. I identified five distinct patterns in the data related to this issue:

- i. Patient faith in traditional medicines
- ii. Patients' social networks
- iii. Patient expectations of hypertension cure
- iv. Traditional healers
- v. Affordability of traditional care and prohibitive cost of Western care.

In contrast, other participants' accounts indicated that the interplay between Western and traditional care shaped trust in a positive direction by constructing patient trust towards doctors in Western care. To understand how the interplay between Western and traditional care constructed patient trust in doctors in Western care, I identified two distinct patterns in the data related to:

- i. Patient faith in Western medications

- ii. Patient fears and generalised distrust in traditional healers.

Given that most of the identified patterns in the data also formed a large part of the discussion relating to the other two novel factors (expectations of hypertension cure and patient faith in medications), I focus on data related to affordability of traditional care and patients' fears and generalised distrust in traditional healers. I reserve the discussion of other patterns of data for subsequent sections.

7.1.1 Affordability of traditional care and prohibitive cost of Western care

One pattern of data that suggested the interplay of the two types of care negatively shaped patient trust in doctors in Western care was related to the affordability of traditional care and prohibitive cost of Western care. While participants did not specifically link cost of care and trust in doctors, the accounts of many participants suggested that lower cost and multiple payment forms in traditional care compared with the higher cost and inflexible payment form in existing Western facilities may contribute to patient distrust in doctors in Western care and Western institutions. Negotiable payment and a simple and flexible payment schedule (e.g. paying when you have the money), multiple payment options (animals, cereals, cash or manual labour) and higher patient control over pricing and time to pay (paying after obtaining relief or cure) emerged in the analysis of the accounts of both patients and traditional healers as features of the cost of care in traditional practice that may result in more patient trust in healers and less trust in doctors in Western care (where the cost is higher and payment options less flexible). Josephina (a teacher) receiving

traditional medicine suggested that ‘traditional healing [of hypertension] costs Tshs 25,000¹² for the medications...until you get tired’. The affordability of traditional care coupled with the promise of complete hypertension cure (detailed in Section 7.2) may undermine patient trust in Western care.

While traditional care was perceived as affordable, the cost of Western care was perceived as ‘unbearable to patients’ (Rose, a nurse). This is because most patients in Tanzania pay out of pocket for healthcare services, with health insurance coverage projected to range between 15%–16% of the total population (622). The most impacted group appears to be farmers, who account for 90% of the working population in Shinyanga Region (623). Farmers also accounted for 28% of interviewed patients in this study (Table 7, Section p.1). Being resident and a doctor in the study setting, I have noted that farmers are mostly uninsured, have seasonal income, reside in rural areas and incur travel costs to attend urban facilities for quality care. A common phenomenon noted during this study was for hypertensive farmers in rural areas to incur extra travel cost to urban areas when their disease could not be managed by doctors in the PHC facilities in their locality. If uninsured, patients also incur costs related to user fees, medical investigations, medications and sometimes accommodation. Similar concerns were noted by Berruti *et al.* (624), who found that patients with HIV in Tanzania spend around Tshs 50,600¹³ per year on average for HIV care, even when antiretroviral drugs are obtained for free. In the same study, travel and accommodation costs were found to account for 70% and 13% of expenditure, respectively.

¹² Average monthly expenditure for hypertension care in Western care (Tshs): Maduhu 27,000–30,000, Shija 32,500, Rebeka 40,000 and Mwasi >60,000.

¹³ Berruti *et al.* (624) cited USD 35 per year. The exchange rate as at 31 December 2012 was USD 1 for 1581 Tshs (www.exchangerates.or.uk).

A patient travelling from a rural to an urban area incurred 90% more cost per year on average compared with those residing in urban areas.

The prohibitive cost of accessing Western care means rural hypertensive patients with low income must depend on doctors in a nearby facility to avoid the cost of travelling to better urban facilities (refer to dependence, a weaker form of trust in Chapter 6), or stay home without returning to hospital for care leading to poor continuity of care. For example, Nyamizi a (medical attendant) said she had ‘not gone’ back to the urban-based hypertension clinic for 3 months, citing excessive costs of travel and medical care as among the reasons. Other patients described travelling to urban facilities but missing services they could not pay for, failing to buy the medications prescribed by doctors or only managing to buy half a dosage of recommended medications. For example, Maduhu (a retired government officer) reported having seen a patient ‘who went back home because he didn’t have Tshs 5000 (~AUD 3) to pay for X-ray cost’. Similarly, Habiba (a clinical officer) said that because of the higher cost of hypertension medications, ‘many patients buy medications for some time but stops using them when they run out of money’, which contributes to non-adherence to medications. Some accounts of the cost of Western care specifically pointed to cost-mediated clinical and prescription choices doctors make by prescribing cheaper and less potent medications that may fail or delay yielding positive treatment outcomes. For example, James (a medical doctor) said:

A doctor has not much options because, although you know that a certain medication is effective for a patient’s disease, but you decide to prescribe a cheap and less potent medication because most of [patients] complain that they have no money to buy medications. So, sometimes, as a doctor you know that a certain

medicine is not effective to the patient's disease, but you have to prescribe it anyway.

Taken together, these accounts indicated that the high cost of Western care may contribute to: i) patient avoidance of Western healthcare resulting in poor continuity; ii) patients seeking Western care but failing to undergo the necessary investigations that may result in incorrect diagnosis; iii) patient only buying partial or incomplete dosage resulting in poor adherence to medications; and iv) doctors prescribing cheap but less effective medications. This suggests that patients may fail to achieve positive treatment outcomes. Achievement of positive outcomes following doctors' treatment emerged as a content area in one of the three meanings of trust described by participants (Chapter 5) and as a factor shaping patient trust in doctors (identified in Chapter 6). Therefore, a possible hypothesis is that cost-mediated challenges impacting patient achievement of positive outcomes from doctors' treatment may impact their perceptions of trust in the interplay of Western and traditional practice. This may explain why some patients defaulted from Western to traditional practice. In addition, the high cost of Western care and medications has been identified in some reports as among the determinants of traditional medicine use in Tanzania (625, 626) and Africa more widely (7,189, 616, 627). This further suggests that cost-mediated preference for traditional care in the interplay of Western and traditional practice may fuel patient distrust in doctors in Western care. The high cost of Western care was also reported by Cunningham (374) and Liu *et al.* (628) as among factors reducing patient trust in doctors in the US.

7.1.2 Patients' fears and generalised distrust in traditional healers

One pattern of data explaining how the interplay between the two types of practice positively shaped patient trust in doctors in Western care related to patient fears and

generalised distrust in traditional healers. Some participants concurrently expressed generalised fear and distrust in traditional healers and generalised trust in doctors in Western care. A good example was shared by Misoji (a farmer). Comparing her trust between the two healing systems, Misoji described having 'fear of traditional healers' because they 'cannot treat [hypertension]...they will just lie to [her]' and she would 'rather wait for death' than visit them'. Misoji's belief that traditional healers were liars and cannot treat hypertension points to generalised distrust in them. Misoji's account of fearing traditional healers differed from the accounts of many other farmers residing in remote areas who mostly favoured the traditional healing system. Misoji also expressed generalised trust in doctors in Western care by saying, 'Yes...I trust them because I am alive today because of [them]'. Misoji's divergent views of trust towards both traditional healers and doctors in Western care suggests that for some people, generalised fear/distrust in traditional healers may construct generalised trust in doctors in Western care in a positive direction.

In seeking to explore this further through analysis of other patients' accounts, it emerged that patients' generalised distrust in traditional healers was mainly framed around patients' religion and religiosity. Although Misoji (a Muslim) did not specifically describe herself as very religious, the accounts of other patients describing themselves as very religious pointed to a relationship between religiosity, generalised distrust in traditional healers and generalised trust in doctors in Western care. Good examples were shared by Pius (a technician and devoted Christian) and Budodi (a housewife and church assistant). Pius affirmed that he 'trusts the [Western] doctors very much', and went on to link his non-use

of traditional medicine to the fear that it involves 'dark magic', pointing to generalised distrust of traditional healers. Pius said:

I personally do not use traditional healers and their medicines. I never even thought about using it. The problem is, these traditional medicines are sometimes practiced in conjunction with dark magic or sorcery. I was born in a Christian family—my father was a Reverend. My grandfather was a Reverend too, so, when I came here, the person who hired me [a Christian priest] placed me in church-based work. So, things which involve dark magic or sorcery do not interest me.

While Pius' account may suggest that generalised distrust in traditional healers may occur together with generalised trust in doctors in Western care, it also raises a question as to whether the former could translate into the latter. Similarly, Budodi said:

Personally, I never used traditional herbs...I always use these modern medications. Those herbs are available, but when I get sick, I go to the hospital and they prescribe these modern Western drugs and I use them.

Budodi further affirmed generally trusting doctors in Western care because they are the 'agents of God' and 'God is working through them' (see Chapter 6). Here, Budodi's account suggested that non-use of traditional medicine rooted in religiosity may be associated with generalised distrust in the traditional healing system and generalised trust in doctors/medications in Western practice.

The relationship between patient religiosity and trust in doctors in Western practice has not been thoroughly researched. One study that considered this issue was Tarn *et al.* (214), who reported patient religiosity and religious affiliation as a factor shaping patient trust in doctors among Japanese and Japanese Americans in the US. The context-specific nature of

trust (Chapter 3) may explain why some participants in rural Tanzania used religious idioms to associate their fears and distrust towards traditional healers and more trust towards doctors in Western care. Constructing trust in doctors around religion may also be explained by the fact that Tanzania is among the countries where religion is highly valued in people's lives (629). Therefore, it is logical to suggest that patient religiosity may be a reason why some people turned away from traditional care, and also may construct patient trust in doctors in Western care in the interplay of Western and traditional practice.

Collectively, participants' accounts offered some evidence to suggest that we cannot talk about trust in doctors in Western care in the study setting without considering how the interplay of these two complementary healing systems impacted on patients' trusting experiences. These findings suggest that that in the interplay of Western and traditional care, patient trust in doctors in Western care can be shaped in two directions. On one hand, trust in doctors in Western care may be shaped in a negative direction when more patient trust towards traditional healers and distrust/less trust towards doctors in Western care is constructed. This may occur through the affordability of traditional care, and patient faith in traditional medicines, patients' social networks and patient expectations of hypertension cure and traditional healers (Sections 7.2 and 7.3). This may further explain why some patients distrusted doctors in the Western healing system and defaulted to traditional care. Defaulting in this context means leaving the Western healing system altogether to seek care in the traditional healing system. For example, the two patients interviewed in traditional practice, Josephina and Joseph, had defaulted from Western to traditional care. Their accounts indicated distrust towards doctors in Western care because of the challenges of hypertension care in the Western healing system, along with

traditional healers' promise of hypertension cure. Joseph's and Josephina's accounts affirmed the findings of Ross (630) that patients' negative experiences with Western care were a main reason for consulting traditional healers in South Africa. On the other hand, trust in doctors in Western care may be shaped in a positive direction when less trust towards traditional healers and more trust towards doctors in Western care is constructed. This occurred through patient fear and generalised distrust in traditional healers framed around religiosity, and patient faith in Western medications (Section 7.3). A tendency of some patients to generally fear traditional healers and religiosity may explain why some patients avoided traditional care and remained with Western care. Most importantly, the interplay between Western and traditional practice as a factor shaping trust has not received much attention in previous research. Limited trust research in LIA, where both Western and traditional healing systems are prevalent, may be a possible explanation for this.

7.2 Patients' expectation of cure as a factor shaping trust in doctors

An important finding of this research related to a novel factor was an indication in many participants' accounts that patients' expectations of hypertension cure (*kupona presha kabisa*) negatively shaped trust in doctors in Western care. The accounts of all patients receiving traditional medicine and most of those practicing medical pluralism pointed to hypertension as a completely curable disease (*ugonjwa unaopona kabisa*). A good example was shared by Josephina (a teacher), who had defaulted from Western to traditional care in search for hypertension cure. Josephina said, 'I am using traditional medicine so that I can be cured (*nipone kabisa*) of hypertension'. The accounts of many participants in both traditional and Western care indicated that not only did they perceive hypertension as

curable, they also linked 'cure' (*kupona*) to patient trust in providers. For example, Joseph (a farmer receiving traditional medicine) said, 'a patient trusts his provider when she has been cured (*amepona kabisa*) and that she no longer suffers from the same problem'. On the same note, when asked whether she could trust a doctor without achieving hypertension cure, Masaza (a teacher receiving Western medicine) said, 'No. I may have trust in him that if this doctor treats me, I will be cured but if I don't get cured that trust disappears'. Patient expectations of hypertension cure may explain why some patients portrayed distrust in the capacity of doctors in Western care to offer hypertension cure. For example, Josephina also said:

You know there are some diseases which cannot be cured in hospitals but can be completely cured by traditional medicines...like hypertension. I believe that hypertension cannot be cured by doctors in hospitals but can be cured with traditional medicine.

Taken together, these accounts suggested that a patient who enters a patient-doctor relationship with expectations of complete cure may develop distrust when a doctor's treatment fails to facilitate cure. It is therefore possible that perceiving hypertension as curable constructs patient expectations of complete cure, which may shape trust in a negative direction when the expectation is unmet.

Possible explanations for why participants spoke about hypertension in the context of cure may include inadequate knowledge of the nature of hypertension among patients, which has been reported in some local research (14, 157, 163, 175). Few of the interviewed patients in this study demonstrated awareness of the nature of hypertension as an incurable disease consistent with WHO information (Chapter 1). For example, Mwila (a teacher) said, 'there

are other diseases which cannot be cured; for example, this hypertension I do not think it can be completely cured—a patient just gets a relief'. In support, Mary (a housewife) said, 'if this hypertension is a curable disease, I have been taking antihypertensives for 2 years—I would have been cured'. Mary further suggested that, 'once you get [hypertension] you stay with it as a patient, your task becomes taking the medications every day'. Second, I noted in Chapter 4 the issue of Swahili translation¹⁴ where the word '*kupona*' that translates to complete cure/healing and is more relevant to curable disease such as malaria, was used by most participants to indicate: i) complete healing from chronic diseases such as hypertension; ii) being emotionally settled from disease-related stress; or iii) disappearance of comorbidities or symptoms related to high blood pressure. Therefore, while the accounts of participants I report here are those largely pointing to hypertension as a (completely) curable disease, the accounts of some participants may not have meant the complete disappearance of the disease as we know it. Finally, the finding that many participants talked about hypertension as curable appeared to be rooted in the idea that expectations of cure are socially constructed and widely shared in rural Tanzania. To examine how patients' expectations of cure are socially constructed in rural Tanzania I turn to the roles of *patients' social networks* and *traditional healers*.

7.2.1 Social networks, expectations of cure and distrust in doctors

As noted in Chapter 6, patient social networks were highly valued in the study setting as influencing patient's expectations of cure and their trust in providers who were promoted as capable of facilitating cure. Most patients mentioned friends, family, neighbours and fellow patients as offering affirmations of cure or knowing someone who had been

completely cured of hypertension by a certain provider. Unfortunately, most of these affirmations of cure were cited as favouring traditional healers as the source of complete cure over doctors in Western care. In the process of friends, family, neighbours and fellows convincing the patient to 'try' traditional options for achieving complete cure, they were also described as discrediting doctors in Western care for their inability to completely cure hypertension. Consequently, some patients developed distrust of doctors in Western care in favour of trust in traditional healers. For example, Josephina (a teacher) described using traditional medicine because of the influence of her hypertensive partner who was currently using medications from a similar healer with a reputation of curing hypertension, and other people she talked to who spoke about the healer's reputation. We saw that Josephina held high expectations of hypertension cure of the traditional healer. We also saw (above) that she now distrusted Western providers for their inability to cure hypertension. Here, patients' social networks appeared to construct their expectations of hypertension cure by promoting traditional healers' reputations and discrediting doctors in Western care. Consequently, patient trust in doctors in Western care was shaped in a negative direction.

7.2.2 Traditional healers, expectations of cure and distrust in doctors

Traditional healers may also cultivate patients' expectations of complete cure. It should be noted that this study did not set out to validate or invalidate claims of complete hypertension cure in traditional practice. Therefore, the present analysis of these accounts is limited to how traditional healers constructed patients' expectations of cure in the study setting, and how these expectations impacted patient trust in doctors in Western care in a negative direction. To examine this, I explored three distinct patterns of data: traditional healers' *promise of cure*, *diagnostic approaches* and *assurance of cure*.

7.2.2.1 Traditional healers' promise of cure of chronic diseases

Traditional healers use the media to offer promises of chronic disease cure before therapeutic encounters. For example, Joseph (a farmer), who had defaulted from Western to traditional care, described listening to 'traditional healers on the radio who says they can cure hypertension...that is how [he] developed faith in [them]'. During data gathering, I witnessed many TV and radio sessions and newspaper adverts by self-proclaimed curers of chronic diseases. Most often, they discredited doctors in Western care for their inability to cure such diseases in their message of promise of cure (see also 632). I also observed many placards posted by traditional healers claiming to cure hypertension, diabetes and other diseases. Figure 6 presents some examples of placards promising cure of hypertension and other conditions.

Figure 6: Placards with promises of complete healing of hypertension 'presha', diabetes 'kisukari' and other conditions

 <p>A placard for Dr. Ngulumo with text in red and black ink. The text reads: 'DR NGULUMO ANATIBU: PRESHA, KESI NGUVU ZA KIUME PETE YABAHATI, UKIMWI, KUSAFI SHANYOTA, KUTOA JINI 0769 738800'.</p>	 <p>A placard for Dr. Chipoteka with text in red and black ink. The text reads: 'DR. CHIPOTEKA ANATIBU: KISUKARI, CHANGO LA UZAZI, NGUVU ZA KIUME, KUJIUNGA NA FREE MASON, DAWA ZA MAPENZI NK. 0717-425429'.</p>
<p>Text translation: Dr. Ngulumo: Can cure¹⁵ hypertension, impotence, HIV/AIDS and removing bad spirits</p>	<p>Text translation: Dr. Chipoteka: can cure diabetes, infertility, impotence, joining freemason and sexual attraction</p>

¹⁵ The relevant Swahili word referring to providers' activities or process of facilitating cure is 'anatibu'.

	
<p>Text translation: Dr. Mkombozi: can cure impotence, hypertension, increasing hip size, sexual attraction, recovering stolen goods, getting work promotions and success in business.</p>	<p>Text translation: Dr. Dullah: Expert in traditional healing for chronic diseases and HIV/AIDS. Can solve (kutatua) the following problems: Problems related to body, farms, preventing disloyalty in intimate relationships, dissolving court cases, cleansing, treats stroke, cures hypertension, impotence and work promotions.</p>

A good example of how traditional healers who promise cure may facilitate patients' expectations of cure and distrust in doctors in Western care was an event involving Reverend Ambilikile Mwasapila (Babu wa Loliondo) in 2010 (633). Previous reports indicated there was a huge influx of patients with chronic diseases from different African countries to Babu wa Loliondo, who was self-proclaimed to cure chronic diseases (190, 191, 194, 195). I was working in the country as a medical doctor and observed many patients with HIV, hypertension and diabetes defaulting from Western care to this healer. Thielman *et al.* (191) reported that 56% of HIV-infected research cohort participants sought HIV cure from the healer. Consequently, most of these patients stopped using Western medications (191, 194, 195). Figure 7 shows some patients drinking a cup of chronic disease cure from Babu wa Loliondo.

Figure 7: Drinking a ‘cup of cure’ for chronic diseases from Babu wa Loliondo¹⁶



It is also important to note that self-promotion of traditional healers occurs in a setting where there are legal loopholes meaning healers can self-advertise, although doctors in Western care cannot (287, 632, 634, 635). This may raise a question as to whether strengthening regulations related to traditional healers' self-promotion may facilitate more trust towards doctors in Western care. These findings and events suggest that traditional healers' promise of hypertension cure appeared to construct expectations of hypertension cure in many patients in the study setting, which may undermine patient trust in doctors in Western care who are unable to meet these expectations.

¹⁶ Source: JamiiForums: <https://goo.gl/images/YRIQxa>.

7.2.2.2 Traditional healers' diagnostic approaches to chronic diseases

The second pattern of data suggested how traditional healers constructed patients' expectations of cure related to their diagnostic approaches. Some patients suggested expectations of cure were generated when healers foretold their medical problems without a patient verbally explaining them. Josephina indicated that 'there are two types of traditional healers: those who uses spirits thus when the spirits enter them, they will tell you your problems...and there are those who use things like chicken'. In describing how diseases are diagnosed in traditional practice using a chicken, Joseph (a farmer receiving traditional medicine) said:

Once you go there, first, the traditional healer starts foretelling what you are suffering from. When you are sick, you just look for a chicken and you start saying your problems. If you are suffering from the legs or hands or anything else, you speak your problems while spitting in a chicken's mouth. You go with that chicken...after having said your needs at home. Once you arrive, the traditional healer starts foretelling your problems. S/he kills the chicken and starts reading the intestines and telling you everything you spoke at home...You do not explain the problem to him upon arrival, s/he just diagnoses your problem using the chicken. So, you ask yourself how can s/he know exactly what I said to the chicken at home when I am just meeting him/her now? I spoke my problems to the chicken at home...maybe I spit into the chicken's mouth or I spoke to the seeds and fed the chicken and took it to the healer. The healer [without talking to me] prepared his/her things...slaughtered the chicken and started inspecting the chicken and do foretelling...and says you are suffering from this and that...So, you start having faith

that may be his medicine can cure you. This is what makes me trust him completely because he was able to predict what I said to the chicken in his absence.

7.2.2.3 Traditional healers' assurances of cure of chronic diseases

The third and final pattern of data suggested how traditional healers constructed patients' expectations of cure related to their assurance of cure during therapeutic encounters. The interviewed traditional healers affirmed their capacity to completely cure hypertension. For example, Jilala (a traditional healer) said:

...When the relatives brought the [hypertensive] patient...they explained the problem and asked if I can treat and cure him. So, I told them I can cure him...[Hypertension] can be completely cured. To me, I can cure hypertension. I have cured patients...They get cured completely, the hypertension will not return...

When comparing patient trust in doctors and in traditional healers, Jilala, further said:

I think they trust me [a healer] more. These are people who come to me after hospitals fails to cure them. People come from Bugando [zonal tertiary hospital] and get cured here. Some come from Muhimbili [national hospital] and get cured here. So, they become happy after being cured and when they go home, they often come back to bring me gifts.

When I asked the healers to connect me with patients who had been completely cured of hypertension, they pointed to people living beyond the approved study settings. However, given the healers' assurance of cure, some of the interviewed patients affirmed building excessive hope for cure. For example, Joseph (a farmer), who said he had been 'suffering a lot' and was assured of cure by a healer, portrayed higher 'expectations [of being completely] cured', leading to defaulting from Western care. These findings suggested that

traditional healers' assurance of cure during initial phases of therapeutic encounters constructed patients' expectations of cure, which may undermine patient trust in doctors in Western care.

Collectively, participants' accounts suggested that patients' expectations of complete cure of hypertension may shape their trust in doctors in Western care in a negative direction. Patients' social networks and traditional healers' promises, diagnostic approaches and assurance of cure were highly valued as constructing patients' expectations of cure and trust in traditional healers. Consequently, some patients defaulted from Western care to traditional healers when their expectations of hypertension cure were not met. This may explain why some patients considered trust as meaning patients' satisfaction with doctors' treatment outcomes (i.e. relief or cure, Chapter 5) as a factor shaping trust (Chapter 6, also discussed below) and some considered the benefits of trust as facilitating relief and cure (Chapter 8).

7.3 Patient faith in medications as a factor shaping trust in doctors

Patient faith in medication was another novel factor that emerged in participants' accounts as shaping patient trust or distrust in doctors in Western care in the study setting. The accounts of some patients suggested that faith in medications reflected their confidence (trust) in prescribing doctors. For example, Budodi (a housewife) said:

What makes a person develops hopes in medications is because the person who prescribed the medications is someone who is experienced in offering care to many patients and has studied extensively on disease management.

Furthermore, the accounts of many participants indicated that patients' faith in medications was also based on their perceived ability to facilitate positive treatment outcomes (relief or cure). Misuka (a nurse) described changing doctors after encountering one 'who prescribed medications that [she] used for a long time without any relief'. Such accounts suggested that patient faith in medications not only reflected patient confidence in the provider who offered (prescribed) them, but also that failure to achieve positive treatment outcomes after using medications may fuel distrust towards the prescribing doctor. To shed more light on the relationship between faith in medications and trust in doctors, I briefly examine two distinct patterns of data: i) patient faith in traditional medications; and ii) patient faith in Western medications.

7.3.1 Patient faith in traditional medications

My analysis of participants' accounts indicated that patient faith in traditional medicine (reflecting trust in healers) may fuel patient distrust in Western medications (reflecting distrust in Western doctors). Some of the patients practicing medical pluralism suggested faith in traditional medications fuelled less trust towards doctors in Western care and Western medicines, contributing to poor adherence. Neema (a small business owner) commented that:

When I tried [traditional medicine], I noted that my blood pressure is going down...becoming normal, so I started believing in the traditional medicine. The [Western] doctor gave me the medications and instructed me how to take them...I took them on the first and second day...I stopped taking them. Honestly, I did not finish the dose and they are in a drawer from that time to date.

Neema's account suggested that her faith in traditional medications from a traditional healer might have fuelled her distrust in medicine prescribed by doctors in Western

practice. It can therefore be assumed that patient trust in traditional healers or their medications (satisfaction with traditional healers' treatment outcomes) may undermine trust in doctors in Western care and Western medications (dissatisfaction with Western doctors' treatment outcomes).

Patient faith in traditional medications appeared to be constructed in three ways. The first way involved achieving positive treatment outcomes after 'trying' traditional medicines (as described above). The second way related to patient loss of faith in Western medications after having used them for a prolonged period without achieving positive treatment outcomes. The third way was the influence of patients' social networks. Mwila (a teacher) said:

After having suffered and used [Western] medications for a very long time without relief, my neighbour who was also hypertensive and has used [traditional] medications and cured, she told me to look for a certain healer who know the medication. This is the reason I went to see a healer and the healer agreed to prepare the medicine for me...using herbs, mixing with honey which I was asked to buy. Then, I started using it.

Mwila's account appeared to suggest that patients' social networks were important in constructing patients' faith in traditional medications when a patient had lost faith in Western medications. Similar to what I noted above, most patients described friends, family, neighbours and fellow patients who had confidence in the therapeutic effectiveness of medications offered by a certain healer to bring positive outcomes as influencing their faith in traditional medications before personally encountering that healer. This indicated that patient faith in traditional medications did not have to be direct personal experience of

using them, but could be the experience of other people close to the patient. It can therefore be assumed that patient faith in traditional medications (constructed by loss of faith in Western medications, social networks and achieving positive outcomes after trying them) may undermine trust in Western doctors and medications.

7.3.2 Patient faith in Western medications

There was a tendency among participants to strongly link the therapeutic effectiveness of Western medications to trust in doctors who prescribed them. For example, Limi (a farmer) said:

There are the kinds of doctors who give you a very effective medication which heals the problem that you were suffering from and makes it disappear. That is when you can affirm that the doctor has helped you and you trust him.

Some patients went further to suggest that when a patient achieved positive treatment outcomes after using medications, patient trust in the prescribing doctor moved to *complete trust*. A good example was Rebeka (a small business owner) who described ‘completely’ trusting a doctor who ‘...prescribes medications and after taking them [she] get a relief’. Here, patient trust in doctors appeared to be associated with the perceived effectiveness of the medications they prescribed to facilitate achievement of positive treatment outcomes. Complete trust may indicate the highest level of trust to be reached in a therapeutic relationship. Some management and patient-centred care literature refers to this higher level of trust as ‘patient loyalty’ (636-641). Patient loyalty to doctors has been considered to increase patients’ closeness and emotional connectivity to providers and the likelihood of a patient returning to the same doctor (636, 642-644). A key learning here is that the perceived effectiveness of medications to facilitate achievement of positive treatment

outcomes strongly shaped some patients' trust in the prescribing doctor in a positive direction.

Some participants suggested that when a patient used doctors' medications without achieving positive treatment outcomes, it contributed to distrust in the prescribing doctors. For example, I asked Magdalena (a hypertensive clinical officer) if she thought a patient may trust a doctor before being cured. Her response was:

No. I think that is difficult...before being cured? I think if you do not get cured you will have to go back to the doctor. If you go back twice or thrice and use medications prescribed without getting well...you will not completely trust him. Personally, I will completely trust a doctor after using the medications and getting well. If I go back twice and use medications without getting cured, I would lose hope and I will definitely change a doctor.

Magdalena's account suggested that the inability of medications to facilitate positive treatment outcomes may contribute to patient distrust in the prescribing doctor leading to change of a doctor. Changing a doctor because of failure of the prescribed medications to bring positive outcomes points to 'complete patient distrust' or disloyalty. This claim was supported by Misuka (a nurse) when asked if she could trust a doctor without relief or cure after using medications. Misuka affirmed that she 'may have some faith' that if a certain doctor gives her medications she 'will be cured, but if [she] don't get cured that trust disappears'.

Collectively, these findings suggested that the therapeutic effectiveness of medications was a crucial factor shaping patient trust in a prescribing doctor. However, this finding raises a

question as to whether patient trust is directed towards medications (based on their therapeutic effectiveness) or doctors? This thesis may not provide definitive answers to this question, and more research may be required in this area. However, the accounts of many participants in this study directly linked the therapeutic effectiveness of medications to trust in prescribing doctors. Notably, many issues in this context may impact the therapeutic effectiveness of Western medications, including: (i) whether the most effective drug was prescribed or a less effective one was chosen for cost reasons (above) or drug class (645); ii) patient adherence (646); and iii) interaction with food (647), drinks (648) and any traditional medicine (given the prevalent medical pluralism) (649-652). While patient faith in medications may partly reflect faith in the competence of a prescribing doctor in offering the correct treatment, it may also signal ‘patient trust in medications’ as a facet of trust in the patient-doctor relationship that has not received sufficient attention, or as a new factor shaping patient trust in doctors in this context.

Similar to the interplay of Western and traditional practice, patient faith in medications has not received adequate attention as a factor shaping patient trust in doctors in previous research. As detailed in Chapter 3, there appears to be an interest in medications as an outcome, such as adherence to medications in HIV (360), hypertension (206, 359, 361) and diabetes (362, 369), but less interest in medications as a factor. In contrast, participants’ accounts in this study suggested that patient faith in the therapeutic effectiveness of medications may shape patient trust in doctors—both negatively and positively. Faith in medications shaped patient trust in a positive direction when a patient achieved positive treatment outcomes leading to a higher level of trust (complete trust or patient loyalty) towards a doctor who prescribed them. Similarly, faith in medications shaped trust in a

negative direction when a patient failed to achieve positive treatment outcomes, leading to patient distrust or disloyalty towards a prescribing doctor. It is possible that the documented impact of patient trust in doctors on adherence to medications (Chapters 3 and 8) may be mediated by patient faith in the therapeutic effectiveness of medication, which in turn strengthens patient trust in doctors when positive health outcomes are achieved.

7.4 Chapter summary and conclusion

This chapter, together with Chapter 6, discussed the findings related to the second research question that examined factors shaping trust in the study setting. This chapter examined participants' accounts related to three novel factors shaping patient trust in doctors in rural Tanzania: i) Western–traditional practice interplay; ii) patient expectations of hypertension cure; and iii) patient faith in medications. In discussing each of these novel factors, it became evident that we cannot discuss trust in doctors in Western care in rural Tanzania without considering how the interplay of Western and traditional healing systems impacts on patients' trusting experiences and choices.

The interplay of Western and traditional practices emerged as an overarching factor that positively or negatively shaped patient trust in doctors in Western care. On one hand, patient faith in Western medications and generalised distrust towards traditional healers emerged as explanations of how the interplay of Western and traditional practice shaped trust in doctors in Western care in a positive direction. On the other hand, patients' faith in traditional medicine, social networks, patients' expectations of hypertension cure and traditional healers and affordability of traditional medicine emerged as explanations for how

the interplay of Western and traditional practices shaped trust in doctors in Western care in a negative direction. Furthermore, most participants spoke about hypertension as a curable disease, leading to patient expectations of cure when they encountered providers. The expectations of hypertension cure appeared to be socially constructed and shared across the study settings. Social networks were particularly important because most patients reported their family, friends, neighbours and fellow patients constructed their expectations of hypertension cure from traditional healers, potentially fuelling patient distrust in doctors in Western care. Similarly, traditional healers, who are prevalent and highly valued in the study settings, appeared to construct patients' expectations of hypertension cure by offering promise, foretelling and assurance of hypertension cure as well as discrediting doctors in Western care for their inability to cure the disease. This shaped some patient trust in doctors in Western care in a negative direction. Finally, patient faith medications emerged as shaping trust in doctors either positively or negatively. On one hand, faith in medications rooted in their ability to facilitate achieving positive treatment outcomes may fuel complete trust or loyalty towards a prescribing doctor. On the other hand, the failure of medications to facilitate positive treatment outcomes may fuel distrust or disloyalty towards a prescribing doctor.

Participants' accounts suggest that there may be no a single best intervention for improving patient trust in doctors to support NCD response in the context of patient access to both Western and traditional healing systems. It is therefore possible that a combination of interventions focusing on patients, providers and health systems may be needed when seeking to improve patient trust in doctors in the study settings. To address the interplay of Western and traditional care, interventions may need to include those seeking to improve

patient access to diverse and affordable Western care. Patient access to affordable Western care may be achieved by first, diversification of PHC facilities. Diversification may be better achieved by encouraging a greater public-private mix as a way of increasing the number of healthcare facilities in rural areas. A related issue is universalisation of health insurance. However, insurance may not cushion patients against the cost of travel from rural to urban areas. Third, ensuring availability of resources (e.g. medications and number of doctors) in facilities where there is inadequacy. Furthermore, to address patients' expectations of hypertension cure and issues related to patient faith in medications, strategies focusing on individual players in the health system are recommended. These may include educational interventions targeting patients and their social networks on the nature of and what to expect in biomedical NCD management, and communication interventions focusing on the content of NCD information providers share with their patients during therapeutic encounters. Similarly, strategies that extend beyond the healthcare system, such as strong regulation of self-advertisement of traditional healers may be considered as a way of promoting trust towards doctors in Western care.

Having evidenced what trust means and identified factors shaping patient trust in the study setting in Chapters 6 and 7, respectively, the focus of the next chapter is on this third research question: *Does trust matter in rural Tanzania?*

Chapter 8: BENEFITS AND DISADVANTAGES OF TRUST IN RURAL TANZANIA

'When you trust a doctor, you will accept and adhere to any kind of advice he gives you' [Neema, small business owner]

'Trust in doctors reduces a tendency of patients to go to traditional healers' [Katarina, laboratory assistant]

8.0 Chapter introduction

This chapter addresses the third and final research question that aimed to examine whether patient trust in doctors matters in rural Tanzania. The chapter provides evidence that patient trust in doctors does matter in rural Tanzania because of its perceived benefits for patients, doctors/providers and the health system. Most of the content of this chapter has been published as:

Isangula KG, Seale H, Nyamhanga T, Jayasuriya R, Stephenson N. Trust matters: Patients' and providers' accounts of the role of trust in hypertension care in rural Tanzania. Tanzania Journal of Health Research. 2018; 20 (1): 1-15. Doi: <http://dx.doi.org/10.4314/thrb.v20i1.3>

The chapter begins with the abstract of the original publication. It then provides background information and justifications for investigating why trust matters in rural Tanzania, which formed the introduction section of the original publication. Next, the results section of the original publication is presented, including the perceived benefits of trust for patients, doctors and the health system, and the perceived disadvantages of trust for both patients and doctors. This is followed by the merged discussion and conclusion

sections of the original publication. The chapter concludes with further reflections of the findings in relation to what trust meant to the research participants (Chapter 5) and factors shaping trust (Chapters 6 and 7). The chapter does not include the methods section of the original publication because that information has already been presented in Chapter 4 of this thesis. Formatting/editing changes were made to parts of the original publication to align with the thesis submission requirements.

Authors' contribution

I confirm that I, Isangula KG, was involved in study design, data gathering, analysis and interpretation, conceptualisation of the paper, generating initial draft and re-drafting of final manuscript in view of the supervisors and reviewers' comments. Stephenson N and Seale H provided guidance during data analysis, interpretation, commenting on the drafts and response to reviewers' comments. Jayasuriya R and Nyamhanga T provided guidance during study design and data gathering, and commented on the initial draft of the manuscript.

8.1 Abstract

Background: Recent research indicates that the biomedical response to the growing burden of noncommunicable diseases in low-income African countries is impacted by poor healthcare seeking, non-adherence to medication and poor continuation with hospital care. One of the potential entry points to addressing these challenges is improving patient trust in doctors. The objective of this paper was to investigate whether trust matters to patients and doctors/providers in the context of hypertension care in rural Tanzania as a case study.

Materials and Methods: This research employed a qualitative approach. In-depth interviews with patients and providers engaged in either Western care or traditional healing systems were conducted in two predominantly rural districts of Shinyanga. The interview transcripts were coded and analysed thematically.

Results: A total of 36 patients and eight providers were interviewed. There was consensus among patients and providers in both Western and traditional healing systems that patient trust in doctors matters for NCD response in rural Tanzania. Benefits of trust in doctors were cited by participants as extending beyond patients to doctors, hospitals and the health sector. Trust in doctors was described as facilitating patient's healthcare seeking behaviours, participation in care and disclosure, adherence to medication, return for follow-up, reduced financial burden and relief, healing or cure. Trust in doctors was also described as increasing doctor/provider's societal reputation, work morale and income. Further, trust in doctors was described as increasing hospitals' and health sectors' societal reputation, income and driving healthcare resource increment. Despite these benefits, disadvantages of patient trust in doctors were also raised. Some participants indicated that trust in doctors may increase patient's vulnerability to malpractice when doctors misuse the trust vested in them. Also, trust was considered as potentially contributing to behaviour changes among doctors, such as excessive self-pride, faking being busy and sluggishness in care provision as well as increasing their work load.

Conclusion: The findings suggest that trust in the patient-doctor relationships matters for hypertension care in rural Tanzania. Improving trust in the patient-doctor relationship may be one of the important lenses in addressing some of the challenges of NCD response in low-income African countries.

8.2 Background

In recent years, the rapidly growing burden of noncommunicable diseases (NCDs) has received much scholarly attention. Research indicates that NCD deaths in low-income Africa (LIA) are rapidly soaring, with cardiovascular diseases (CVDs) and hypertension being the largest contributors (11, 17, 66, 93, 139). Previous reviews in LIA have documented the prevalence of hypertension as ranging between 6% and 48% in community surveys of NCDs and their risk factors in 2011 (17), and between 15% and 70% in 33 surveys involving 110,414 participants with an average age of 40 years in 2015 (11). The growing burden of NCDs/hypertension in LIA is characterised by poor health service uptake, non-adherence to medications and poor continuity with hospital care (11, 17, 66, 128, 139, 157, 163, 167, 175, 653). Various entry points to addressing some of these challenges have been proposed in different contexts, for example, prioritising patient preferences, improving service features and tackling institutional barriers (138, 166, 205, 654). However, their success has been largely unsatisfactory.

At the heart of the current discussion on NCD response, the concept of improving patient trust in doctors has been acknowledged in other contexts as a promising strategy. The literature on the topic of trust in patient-doctor relationships, predominantly originating in high-income countries, suggests the benefits of improving patient trust in doctors include increasing primary health care (PHC) service uptake, adherence to medications and continuity with hospital care. Patients who trust doctors are more likely to: i) have increased willingness to seek and utilise healthcare (206, 207, 211, 401); ii) accept doctors' recommendations/medical advice; iii) adhere to prescribed medications; and iv) behavioural changes for secondary prevention (213, 359-363). Some authors have reported high patient

trust to be associated with increased medication adherence in irritable bowel syndrome therapy, diabetes and antiretroviral therapy (360, 362, 370). In contrast, a low level of patient trust in doctors is associated with declines in medication adherence among diabetics (361) and patients undergoing care for hypertension (206).

Improving trust in patient-doctor relationships seems to offer an opportunity to address some of the challenges in NCD response in LIA. However, what we know about patient trust in doctors mostly originates from high income and urban contexts. Little is known on the topic of patient trust in doctors in rural LIA. To date, there have been no previous studies undertaken to examine how trust is experienced and perceived in this setting. The objective of this paper was to investigate whether trust matters to patients and doctors/providers within the context of hypertension care in rural Tanzania as a case study of LIA.

8.3 Results¹⁷

A total of 44 participants were interviewed, including 36 patients being treated for hypertension (34 receiving care in hospitals and two patients receiving traditional care). The remaining participants were five clinicians in Western care and three traditional healers. There were 34 adult females and 10 adult males, aged from 28–75 years (refer to preface to the results chapters, Table 7¹⁸).

¹⁷ The methods section of the original publication is part of methods chapter of the thesis (Chapter 4).

¹⁸ The table in the original publication is part of table of participants' characteristics for this thesis (Table 7, preface to result chapters, Section p. I).

8.3.1 Overview of findings

Broadly, many themes emerged in this study following thematic coding. Themes related to the question of what patient trust means to research participants were: i) *trust as meaning expectations of a doctor before the encounter*; ii) *trust as meaning patient satisfaction with doctors' actions during encounter*; and iii) *trust as meaning satisfaction with doctors' treatment outcomes after a medical encounter*. Similarly, themes related to factors shaping trust were: (i) *patients' factors*; ii) *providers' factors*; and iii) *health system (facility/institutional) factors*. Themes related to what trust means and factors shaping trust are described elsewhere. The focus of this paper is the two main themes that emerged in relation to the question of whether trust matters in rural Tanzania: i) *the benefits of trust*; and ii) *the disadvantages of trust*.

On one hand, there was a consensus among patients and providers in both Western care and the traditional healing system that trust matters for hypertension care. What varied were participants' feelings regarding the impact of trust and the point along the spectrum of care where trust matters. The benefits of trust were coded into three subthemes: benefits of trust to patients, benefits of trust to doctors/providers and benefits of trust to the health system (facility/health sector). The benefits of trust to patients were coded into six categories: facilitating healthcare seeking behaviours, enhancing engagement in care and disclosure, improving adherence to medications, facilitating relief, healing and cure, enhancing satisfaction with care and contributing to reduced financial burden. The benefits of trust to doctors/providers were coded into three categories: improved reputation in the community, elevated work morale and increased income. Finally, the benefits of patient trust to the health system (healthcare institutions and health sector) were coded into two categories: improved reputation and income. On the other hand, a common theme resonating among participants was that trust in doctors has disadvantages, with an emphasis

placed on Western care. What varied were the descriptions of a person and the circumstances facing such disadvantages. Participants limited their descriptions of disadvantages of trust to patients and doctors, and not to the healthcare institutions/health sector. Disadvantages of trust to patients were coded into two categories: increasing patients' vulnerability and contributing to poorer health outcomes. Disadvantages of trust to doctors were also coded into two categories: trusted doctors' behavioural changes and increased workload. Each of these is explored below and illustrated with quotes from the interview transcripts.

8.3.2 Benefits of trust for patients

Trust in doctors was described by some patients in Western care as especially important in facilitating service uptake for disease diagnosis. A good example was a small business owner who suggested that 'a patient who distrusts doctors and just stays at home' risks her medical problems not being diagnosed. Facilitating patients' active participation in care and disclosure was highly valued as an important benefit of trust in doctors. Patients in Western care suggested that trust enhances learning about the disease from doctors, participation and cooperation leading to disclosure of sensitive information that may facilitate correct diagnosis and shared decisions. For example, a retired government officer described trust in doctors to enable patients to propose additional investigations for correct diagnosis or recommend modifications in the medicines. Similarly, doctors in Western care regarded trust to benefit patients in terms of facilitating correct diagnosis through disclosure. One medical doctor said:

The first benefit [of trust] is that, the patient will get the right medical treatment because the doctor was able to get the right diagnosis. How did a doctor arrive to

the right diagnosis? It is because the patient gave you a thorough medical history—the patient did not hide anything. The good thing is, for a patient who trusts you, since you will have an engaging conversation, when making the management plan, you will work cooperatively. The patient can tell you the medications that cause side effects to her and you reach a consensus on the treatment options.

In contrast, participants in the traditional healing system did not acknowledge the value of trust in patients' participation in care. This has been described as rooted in the limited patient participation in care in this channel. For example, during disease diagnosis, patient participation was described as 'not needed' as the healer 'foretells' patients problems without undertaking a medical history. Similarly, during treatment, patient participation was reported as 'not being needed', as patients are expected to accept treatment without questions because of the seclusion of traditional healing systems where healing powers are said to be inherited from elders' spirits.

Facilitating adherence to medications and acceptance of doctors' advice emerged as another important benefit of trust in doctors in the accounts of participants in both Western and traditional care. An HIV-positive hypertensive farmer approached this question differently by describing the disadvantages of patient 'distrust' in a doctor and suggesting:

A patient who distrusts a doctor does not adhere to medications. Those who do not trust doctors, some of them don't care about the medications given, they may discontinue using the hospital medications and go to traditional medicine.

Another important benefit described by participants in both Western and traditional care was linking trust in doctors to being healed or cured of hypertension. Even patients and doctors in Western care that were expected to have a fair knowledge on the non-curability

of NCDs described trust to facilitate hypertension healing or cure. For example, Rose, a nurse interviewed as a patient, suggested that a patient who trusts a doctor 'becomes healed' linking this to adherence to medications. In support, Vanessa (a clinical officer) suggested that a patient without trust in a doctor 'will not get healed even after taking (hypertension) medications'.

Compared with those strictly on Western medications, the concept of NCDs/hypertension cure as a benefit of trust in doctors was more prevalent among participants strictly receiving traditional medicine and those in Western care who had previously used traditional care or were currently practicing medical pluralism. This was because NCD 'cure' was described by participants as both a focus of use of traditional medicine and a reason for seeking traditional care. In addition, NCD 'cure' was described by patients as always a central message in traditional practitioners' self-promotion adverts through the media. Traditional healers proposed a bidirectional relationship between trust and cure; that is, patient trust facilitates cure and cure leads to more trust in a healer:

[Because of trust], the patient becomes cured. The patient trusts you because you restored her health to normal after you helped solve the problem which was disturbing her and now she is fine.

Issues of satisfaction and continuity with care as the benefit of trust were also prevalent. Some patients in Western practice who reported satisfaction with care also described other related benefits of trust such as increased patient's positivity towards doctors leading to reduced tensions between the two. Interestingly, a clinician interviewed as a patient, extended the benefits of trust beyond facilitating satisfaction with care to the likelihood of a patient returning for care and returning to the same doctor in subsequent visits.

A few patients described the benefits of trusting doctors as reducing their financial burden. This was described to result from the reduced time and unnecessary costs resulting from a tendency of unsatisfied patients to shop for different doctors. These views were also offered by a clinical officer who further considered trust as a factor which pulls patients from 'the private sector where the cost of medical care is very expensive' to 'government hospitals' where the cost of care is more affordable.

Collectively, participants' accounts suggested that trust in doctors/providers mattered to patients and impacted their healthcare seeking choices, participation in care, adherence to medications, continuity with care decisions and health outcomes. The need for partnership in the patient-doctor relationship to realise these benefits raises the question of how doctors benefit from patient trust. This question is addressed next.

8.3.3 Benefits of trust for health providers

Improving doctors' reputations within a community was especially important because of the tendency among patients to refer their peers to a trustworthy doctor. Patients in both Western and traditional healing systems described relying on information from friends, family and peers when choosing where to seek care. For example, the reason given by a traditional healer for not putting up 'a signboard for [his] services' was that a patient who has been cured 'meets another person with a similar problem, she will refer them to [him]'. In support, a medical assistant referring to Western practice said:

The doctor benefits because his services become recognised. This is because if I received good services it won't end with me, I will tell others and refer them to [a

doctor]...‘Go and see a certain doctor, he is a real doctor’. So, his services become reputable.

Participants also described trust as impacting doctors/providers’ work morale. Trust in doctors was said to increase their confidence, pride and love for work. Some patients in Western care suggested that trust fuelled doctor’s realisation of the benefits of their education, motivating the doctor to invest more effort in their work or work harder, becoming more positive toward patients and more likely to offer care without hesitation. Supporting this, a small business owner and a teacher suggested that patient trust in doctor made them feel comfort, happiness and solace:

When the patient comes back and tells a doctor that, ‘the medications you gave me have healed me or I am experiencing a relief’. The doctor benefits by realising the medications he prescribed to his patients or a patient has healed her. The doctor gets comfort and solace in his mind because he has healed patients.

Patients’ views were substantiated by doctors in Western care who felt that as well as enhancing their reputation and respect within society, trust also brought joy, comfort and peace of mind, pride in their work, confidence, competency and realisation of the benefits of their education. One doctor asserted:

The biggest benefit to a doctor when is trusted by patients, the doctor’s builds confidence that ‘I can do something’. That, this patient was healed because I treated him/her, therefore, I can heal other patients as well. The second benefit is that the doctor’s reputation and respect increases. A patient respects the doctor that has healed her.

Issues of trust in doctors enhancing the closeness and friendship between patients and doctors also emerged in some participants' accounts. The consequence of this was described to reduce tension between the two, and also increase the likelihood of the doctor/provider receiving material gifts from patients as a way of expressing appreciation. While gifts to doctors/providers may be questioned as crossing the ethics of care, it appeared to be a customary practice in both Western and traditional care in the study settings. For example, a housewife asserted:

Another benefit is, the doctor may establish close relationship with patients; they become like his friends or relatives. A doctor may visit the patient's home and they would offer him food, maize or other things...the doctor becomes like one of the family members.

Finally, trust in doctors was described by participants in both Western and traditional healing systems as impacting providers' income. This benefit was more prevalent in the transcripts of patients and providers referring to providers in Western private and traditional care where an 'influx of patients' due to the perceived trustworthiness of providers translated to more income. For example, a traditional healer suggested that trust increased a healer's reputation and number of clients, consequently, increasing that healer's income. Some providers in traditional care considered trust as a guarantee of patient payment for the cost of care. Two traditional healers described the cost of medicines (such as cash, cereals or livestock) as often paid after a patient had perceived healing or complete cure.

One patient in Western practice held a different perspective on the benefits of patient trust to a doctor, and said, 'treating a patient is a doctor's obligation...and patients are his

customers'. This raised a question as to whether some patients may see doctors as robotic vehicles of healthcare service delivery. All things considered, these participants' accounts indicated that trust mattered to providers in both Western and traditional care and impacted their reputation, morale and income. The need for a healthcare institution where both patients and providers interact to realise these benefits raises the question of how trust in doctors' benefits health system (institution/sector).

8.3.4 Benefits of trust for the healthcare system

Both patients and providers in Western and traditional healing systems acknowledged the impact trust could have on a healthcare institution's reputation. A positive hospital reputation was described as increasing the number of clients seeking care. A nurse insisted:

In the hospital, when there are many doctors who are trusted by patients, many patients will come for treatment. Its reputation will increase; and hence many patients will come. Even if it is a government hospital, the reputation will increase.

Related to this was a view among doctors in Western care that trust in doctors may reduce patient negativity, complaints and legal claims, and promote their positivity towards hospitals and the health sector. For example, a medical doctor suggested that as trust facilitated correct diagnosis through patient disclosure tendencies, it contributed to 'avoidance of medical complications, medical errors and deaths at the facility' leading to reduced legal claims. In addition, a clinical officer suggested that trust reduced tensions between patients and doctors, negativity and complaints towards providers in public facilities, consequently increasing 'acknowledgment and positivity towards health workers'.

Compared with comments referring to public institutions, the description of benefits of trust for healthcare institutions' income was prevalent in participants' accounts concerning

to private institutions. Related to this, a few participants considered trust in doctors as driving healthcare resource increment. According to a retired government officer, this happens in two ways. First, the influx of patients into a hospital with many trustworthy doctors may drive resource increment to meet the growing demand. Second, when the health sector becomes saturated with patients who trust doctors, it will earn a 'good image and will be acknowledged for protecting people's health'. He further suggested that because of this, people would be more likely to 'advocate for the national parliament to increase the health sector budget so that the services could be improved'.

Trust in doctors was also characterised as 'pull factor' in the health sector in three ways. Firstly, trust in doctors was described to draw patients from untrustworthy doctors/hospitals towards trustworthy doctors/hospitals, and from rural areas towards urban facilities. Second, trust in doctors was described to draw patients from traditional care towards Western care, facilitating early diagnosis. A laboratory staff member asserted:

...if the patient doesn't trust doctors, she will end up going to traditional healers and consequently the disease may become chronic or she may even die because a patient may think that she has been bewitched. So, trust in doctors reduces a tendency of patients to go to traditional healers.

Lastly, trust in doctors was described as deterring patients from seeking care outside the country (specifically in India), a common trend in the country. In general, trust in doctors was considered to benefit patients, doctors and the healthcare system (Table 9).

Table 9: Participants' accounts of benefits of trust in healthcare settings

Perceived benefits of trust to patients	Perceived benefits of trust to providers	Benefits to the health sector	Benefits to a hospital
<ul style="list-style-type: none"> -Increases healthcare seeking behaviours -Increases interest in learning about diseases -Increases the likelihood of receiving detailed instructions from doctors -Increases the likelihood of the correct diagnosis -Increases disclosure tendency -Increases engagement/participation in care by providing medical history and freely expressing desires and needs -Increases cooperation in developing a treatment plan -Increases acceptance and adherence to the doctor's advice, instructions and medications -Increases faith in medication -Facilitates and speeds relief, healing and cure -Contributes to reducing pain and stress and consequently blood pressure -Increases positivity towards doctors -Increases satisfaction with care -Increases the likelihood of looking for the same doctor in subsequent visits -Reduces possibility of side effects through disclosure -Reduces time and cost of shopping for doctors -Increases the likelihood of offering gifts to providers and promoting the provider's reputation -Increases referral tendency within social networks -Reduces the likelihood of a defaulting from Western to traditional care 	<ul style="list-style-type: none"> -Increases praise and love from patients -Makes a doctor feel good -Increases comfort, solace, happiness and joy -A doctor becomes proud of his work -Increases doctor's positivity towards patients -Motivates doctors to work harder without hesitation and invest more efforts in patient care -Increases doctor's confidence and competency -Offers an opportunity for effective use of one's skills -Increases doctors' reputation, respect and recognition in a society -Increases the number of patients looking for the doctor/provider through patient referrals -Strengthens the doctor's relationship with patients -Enhances doctor's closeness with patients -Increases the likelihood of receiving gifts from patients -Increases the likelihood of being considered as part of the patient's family -Increases actualisation and realisation of the benefits of one's education -Increases provider's income (private, traditional care) 	<ul style="list-style-type: none"> -Increases early healthcare seeking and early disease diagnosis, therefore contributing to reducing mortality related to late care seeking -Pulls patients from private to public practice -Increases acceptance of medical advice and health education, consequently contributing to reducing disease prevalence and mortality -Increases adherence to medications and doctor's advice -Reduces tension between doctors and patients, especially in public practice -Reduces negativity and complaints towards health workers -Increases acknowledgment and positivity towards health workers in public practice -Increases people's advocacy tendency towards health sector budget increment 	<ul style="list-style-type: none"> -Increases reputation within the community -Increases praises from patients -Increases positivity towards a facility -Pulls patients from private to public facilities -Pulls patients from traditional to public facilities -Increases referral tendency within patients' social networks -Increases the number of patients seeking care -Contributes to an increase in hospital income -Contributes to reducing mortality at the hospital by facilitating correct diagnosis -Contributes to reduction in medical errors -Reduces legal claims towards a facility -Drives quality of care

Looking at the benefits of trust cited by participants, a reader may suppose that trust in doctors is only perceived as a 'good thing' for patients, doctors and the healthcare system. However, participants in this study cited several disadvantages of patient trust in doctors.

8.3.5 Disadvantages of trust for patients

Concerns that trust in doctors may increase patients' vulnerability in patient-doctor relationships were more prevalent among patients compared with doctors. Some patients felt that trust in doctors increased their vulnerability to malpractice when doctors misused the trust invested in them. For example, a small business owner suggested that in excessive trust situations, a patient is more likely to accept anything a doctor does/gives. A trusting patient may therefore suffer in the long run because of 'trust-induced blindness' towards doctor's medical errors or when a doctor offers interventions or medications that may affect their health. A small business owner asserted:

Negative consequences may happen. This is because you already trust him, so, even if he does something outside his expertise, you will just accept it. He may one day make a mistake or give you something different, which may affect your health, so, you just suffer without knowing.

Trust was also described as increasing patients' vulnerability to both monetary and sexual bribes in therapeutic relationships. According to a nurse, inter-patient competition for fewer trustworthy doctors in a hospital may compel some patients to 'offer money' to maximise chances of encountering the highly-demanded doctor. Similarly, while some patients considered an increase in closeness between patients and doctors as a benefit, one records assistant thought that immoral doctors may 'take advantage of [an emotionally vulnerable] patient' and want to establish a 'sexual relationship'. She further suggested that

a patient may 'decide to offer herself sexually as a means of acknowledging the doctor for his goodness and niceness'.

Concerns that trust in doctors may negatively impact patients' health outcomes were widely shared among participants. Some patients considered trust in doctors to contribute to overreliance on a trustworthy doctor. This was because trusting a doctor was described to create loyalty to one doctor that 'can affect trust in other doctors'. Loyalty to one doctor was described by a medical doctor to occur when a patient had 'built that kind of trust in mind that if a certain doctor treats [her, she] get a relief and that if [she, is] treated by other doctors [she] doesn't get a relief'. A nurse was of the opinion that distrust in other doctors creates uncertainties about care provided and medications prescribed when the continuity with a doctor to whom a patient is loyal becomes unexpectedly interrupted. In support, another nurse suggested that the inability to encounter one's trusted doctor because of an unexpected absence on a scheduled visit forces a patient to 'go home without treatment' to avoid encountering untrustworthy doctors. In her view, this may lead to interrupting therapy continuity if the patient is 'out of medications', leading to 'distrust induced non-adherence' that may pose 'some health risks'.

8.3.6 Disadvantages of trust for doctors

Concerns about a doctor's behavioural change due to patient trust were also more prevalent among patients compared with doctors. Behavioural changes were described to occur when a highly-trusted doctor developed too much self-pride, faked being busy to avoid treating patients and became sluggish in care provision. A nurse stated:

If a patient trusts a doctor too much it has negative consequences...when many patients want to see a certain doctor, the doctor may develop too much pride in himself. This is because a doctor may see his patients but acts as if he is not interested in treating them. He becomes slow in offering care and just walking around the hospital.

In contrast, the concerns of increased doctors' workload due to patient trust were more prevalent among doctors compared with patients. A medical doctor suggested that healthcare providers in public facilities already have high workloads, often seeing inpatients and outpatients totalling 150–200 patients or more per day. Therefore, being trustworthy may mean higher workload.

8.4 Discussion and conclusion

Patients and providers in this study described a diverse set of considerations about why trust mattered in healthcare delivery in rural Tanzania. Most participants in this study associated trust in doctors with facilitating patients' healthcare seeking, participation in care, adherence to medications and continuing engagement with hospital care. Similar benefits have been noted in previous studies of trust in patient-doctor relationships in high-income countries (207, 211, 359-362). Although other benefits of trust to patients valued by participants in this study (e.g. enhancing patient satisfaction with care and contributing to reduced financial burden to patients) have received some attention in existing literature, this has been insufficient. Less literature has focused on the two benefits of trust in doctors. For example, participants' perceptions of the role of trust in patient satisfaction with care in this study were consistent with Safran et al. (213), who found patient trust was the single strongest correlate associated with patient satisfaction with care. This suggests that

improving patient trust in doctors may be a good entry point to reducing the persistent and widespread patient dissatisfaction with care in the study settings (177-179, 181, 271, 539, 540). Similarly, trust benefits related to reducing the cost of care described by participants in this study were consistent with those discussed in a review of trust research by Rolfe *et al.* (247), who reported trust to have some impact on medical cost by reducing costs associated with unnecessary medicalisation and medical tests in Western care. However, in traditional care, while patient trust may result in satisfaction with care, limited evidence is available of its effect on costs. More research may be needed on satisfaction with care and reducing cost of care as benefits of trust.

There was a tendency among participants in this study to strongly associate patient trust in doctors with facilitating hypertension healing or cure. Some previous studies, mostly in urban settings, linked high trust to clinical symptom improvement and positive health outcomes, such as disease control (206, 213, 361-363, 370), but not to complete healing or cure. Participants in this study described trust as facilitating healing and cure, despite broad acceptance in the scholarly world that hypertension (a chronic disease used to elicit these descriptions) can be controlled but not biomedically healed or cured (8, 11, 118). A possible explanation for this may be language issues, as the Kiswahili word 'kupona' used by participants to indicate healing or cure, translates into both disappearance of chronic disease symptoms or comorbidities and complete cure or healing of acute diseases. Other possible explanations for this may be: i) the poor knowledge about chronic diseases among patients in the country (157, 175, 655); ii) rurality, where traditional and Western care for chronic disease care appear in competition and patient expectation of complete 'healing' or 'cure' was described as a reason for seeking hypertension care from healers; and iii)

persistent exposure to contradictory messages of 'complete cure' for chronic diseases from self-promoting traditional healers in Tanzania (157, 190, 191, 655).

Although most existing literature has restricted examination of the benefits of trust to those for patients (207, 211, 359-362), rural participants in this study perceived patient trust as also benefiting doctors. These benefits should be viewed in light of the persistent patient dissatisfaction with doctors' interpersonal care in Tanzania and other low-income countries (177-179, 181, 271, 539, 540). We know that dissatisfied patients are more likely to share their negative interpersonal experiences with a doctor/provider through their social networks. This may worsen the doctors' reputation in the community. In turn, this may impact on doctors' work morale and interpersonal quality of care when they feel their efforts are under-acknowledged by community members. Sharing dissatisfaction through social networks may also impact on fellow patients' service uptake. We know that a multitude of complex interpersonal and institutional factors impact patient service uptake and quality of care (178, 179, 181, 271). Basically, a belief that patient trust elevates doctors' reputations and work morale suggests that improving patient trust in doctors may positively impact doctors' interpersonal aspects of quality of care, contributing to a decrease in the persistent patient dissatisfaction in LIA.

There was a feeling among some participants that trust in doctors may contribute to increasing healthcare institutions' income among private rather than public institutions. It is important to note that the primary goal of public healthcare institutions in Tanzania is considered to be offering social services to the needy and mostly poor citizens, not profit making (147, 656). However, participants in this study emphasised that they incurred out of

pocket payments for medical care under the cost-sharing scheme. As this is a common phenomenon in low income countries (147, 178, 656), the current scheme positions public healthcare institutions to similarly benefit from the financial impacts of trust.

The disadvantages of trust have received less attention in the existing literature related to trust in doctors. This has continued to raise a question as to whether trust in doctors is only a 'good thing' without negative consequences. Participants in this study were concerned that trust in doctors may have negative consequences for both patients and doctors. Participants suggested that trust may heighten patients' vulnerability to malpractice when doctors misuse the trust vested in them. Participants' concerns were consistent with the theoretical views of Thom *et al.* (292), who hypothesised high patient trust as leading to acceptance of medical interventions without question. The result of such vulnerability may be poorer care, because patients will be less likely to question inappropriate medical advice and treatment or seek a second opinion. There was also a concern among participants that trust may incentivise both monetary and sexual bribes when inter-patient competition for a trustworthy doctor and provider's immorality cloud the therapeutic relationship. These statements were offered in a context where hypertension care was described to be centralised and characterised by overcrowding, prolonged waiting times, fewer doctors and it being almost impossible to encounter the same doctor in subsequent visits.

This study did not explore all of the perceived benefits of trust valued by patients and providers. However, conducting a study in a rural setting where most participants were of the same ethnic group implied that the findings cannot be applied without criticism to patients and providers from diverse social, cultural and linguistic backgrounds. In addition,

conducting the study in a rural setting during the farming season where most males may have prioritised farming over study participation and the sensitivity of the topic (patient trust in doctors) might have limited the number of male and provider participants, respectively. Further, drawing from both Western care and the traditional healing system in a rural setting was a major strength of this study, but may also be a disadvantage. The two practices differ in their focus of NCD management (control versus cure) and diagnostic methods (modern technology versus foretelling) (157, 190, 191). This might have contributed to different patient expectations, experiences and challenges, and may have impacted participants' descriptions.

In conclusion, our findings appeared to bridge the gap in the scholarly literature between what is known on the topic of trust in patient-doctor relationships in high-income context and the unknown in rural low-income Africa. While we do not seek to undermine other potential strategies, our findings suggest that strengthening trust in the patient-doctor relationship may be a key entry point for addressing some of the challenges of NCD response in rural African settings. This calls for interventionists to consider trust as a possible lens in NCD response. Nevertheless, should interventions for patient trust be considered, it is recommended to embrace activities that cushion against its negative consequences for both patients and doctors.

8.5 Further reflections

This paper provides evidence that trust matters in rural Tanzania and that its improvement could be useful in NCD response in the LIA context. Participants' accounts of the benefits of trust for patients, providers and the health system appear to largely point to specific

meanings of trust in rural Tanzania. Below, I briefly examine how the perceived benefits of trust points to expectation- and satisfaction-based meanings of trust.

8.5.1 Benefits of trust related to expectation-based trust

Participants' accounts of benefits pointing to the expectation-based meaning of trust appeared to be those suggestive of patient construction of positive expectations towards doctors (Chapter 5). Examples are the perceived benefits of trust for: i) patients, such as increasing referral tendency within their social networks towards trustworthy doctors; ii) doctors, such as increasing the reputation, respect and recognition within the society; and iii) the health system, such as increased reputation within the community. Patient access to positive information about doctors' (and institutions') trustworthiness through their social networks/community emerged as one way by which they constructed positive expectations towards doctors' replication of their established trustworthiness or reputation contributing to seeking care from them (Chapters 5–7). This may explain why trust was further perceived to increase patients' healthcare seeking, increase the number of patients seeking to encounter doctors through peer referrals and pulling patients from traditional to Western care. It may further explain why patient social networks, institutional trust, generalised trust in all doctors and doctors' reputation in the community emerged as factors shaping patient trust in doctors (Chapters 6–7).

8.5.2 Benefits of trust related to satisfaction-based trust

Compared with the benefits pointing to the expectation-based meaning of trust, most of the benefits cited by participants appeared to point towards satisfaction-based meanings of trust. The benefits pointing to one meaning of satisfaction-based trust related to what happens when a patient is satisfied with what transpires the therapeutic encounter

(Chapter 5). The benefits of trust to patients, such as increased patient engagement in care and disclosure and cooperation in treatment decisions, related to what happens when a patient is satisfied with doctors' behaviours and actions during therapeutic encounters. This may explain why trust was further perceived to facilitate correct diagnosis and increase patient faith in prescribed medications, patient adherence to medications/medical advice and patient satisfaction with care. Similarly, the benefits of trust for doctors such as increased confidence, work effort and increased pride in their work, related to what happens when a doctor is satisfied or receives acknowledgement from (satisfied) patients for the care they had received. This may explain why trust was further perceived to increase doctors' comfort, happiness and solace. The findings may further explain why doctors' behaviours and technical skills, and patients' faith in medications and satisfaction with care emerged as factors shaping patient trust in doctors (Chapters 6 and 7). These accounts suggest that satisfaction-based trust is important to both patients and doctors. This may be why some researchers have attempted to examine physician trust in patients in a way that is cognisant of the bidirectional nature of trust benefits in the patient-doctor relationship (657, 658).

The benefits of trust pointing to another meaning of satisfaction-based trust related to what happens when a patient is satisfied with doctors' treatment outcomes (Chapter 5). Benefits for patients (e.g. facilitating relief, healing or cure, increasing likelihood of looking for the same doctor and increased likelihood of promoting providers' reputation) and benefits for doctors (e.g. increased clients load through patient peer referrals, increased income and increased likelihood of receiving gifts) were suggestive of what happens when a patient is satisfied with the doctors' treatment outcomes. These benefits resonated with what some

patient-centred care literature has explained as happening when the highest level of trust (complete trust or patient loyalty) is reached (636, 642-644). This may partly explain why doctors' treatment outcomes emerged as shaping patient trust in doctors (Chapter 6). However, benefits for the health system, such as increased acknowledgement and positivity towards health workers, may be equally pointing to expectation- and satisfaction-based trust.

The trust disadvantages cited mainly pointed to the negative consequences of satisfaction-based trust. Concerns that trust may increase patients' vulnerability and exploitation and impact patients' health outcomes by promoting patient reliance and loyalty to one doctor and distrust in others, as well as contributing to doctors' behavioural change and workload were suggestive of what may happen when a patient harbours high satisfaction-based trust (complete trust) towards a doctor.

Participants' accounts of the benefits of trust pointed to both expectation- and satisfaction-based meanings of trust. However, the accounts of the disadvantages of trust appeared to mainly point to the negative consequences of high satisfaction-based trust. Benefits related to expectation- and satisfaction-based meanings of trust also explained why some of these factors prevailed as factors shaping trust in participants' accounts. This suggests that what trust means to research participants in any context forms an important entry point for examining their perceptions of factors shaping and benefits of trust. Although these accounts suggest that patient trust in doctors may be useful in NCD response in the LIA context, they also suggest that interventions for improving trust and measurements of trust

may need to consider the dominating themes in participants' accounts of what trust means to them, factors shaping trust and the perceived benefits of trust.

Chapter 9: DISCUSSION AND CONCLUSIONS

9.0 Introduction

This thesis investigated patient trust in doctors to establish whether this trust can form part of the NCD response in a rural LIA context. The thesis considered the current literature (predominantly from HICs), which provided some evidence that improving trust in patient-doctor relationships is associated with improved patients' health behaviours and outcomes. To achieve the proposed aims, I examined what trust means, the factors shaping trust and whether trust matters in hypertension care in both Western and traditional practices, using rural Tanzania as a case study. This chapter summarises the major findings and considers relationships between the findings. It then discusses the implications of this research, and provides recommendations on how trust can be improved. These recommendations place emphasis on medical practice, policy actions and areas for future research. The strengths and limitations of the research are also explored, along with a discussion of how this research has potential to impact my own practice as a medical doctor and future research career.

9.1 Major findings of this study in rural Tanzania

To establish whether patient trust in doctors could form part of the response to NCDs in rural LIA, this thesis examined three important questions:

- i. What does patient trust in doctors mean to patients and providers?
- ii. What are the factors shaping patient trust in doctors (in Western care)?

- iii. Whether trust matters, by exploring the perceived benefits of patient trust in doctors in rural Tanzania.

Table 10 summarises the major findings of this study.

Table 10: Main findings of this research

Chapter 5: What patient trust in doctors means to research participants in rural Tanzania			
Expectation-based meaning	Patients' positive expectations of a doctor's actions, behaviours and treatment that develops before therapeutic encounter.		
Satisfaction-based meanings	i. Patients' satisfaction with the doctor's behaviours and technical actions that transpire during the therapeutic encounter; and/or ii. Patients' satisfaction with doctors' treatment outcomes after the therapeutic encounter. *		
Chapters 6 and 7: Factors that shape patient trust in doctors in rural Tanzania			
Related meaning of trust	Patient factors	Provider factors	Health system factors
Expectation-based trust	-Social networks -Trust in healthcare institutions (institutional trust) -Faith in all doctors (generalised trust) -Expectations of hypertension cure* -Religiosity (strong religious beliefs) -Distrust in traditional healers	-Reputation within the community	-Ease of access to a healthcare facility -Healthcare facility level and ownership -Healthcare resources -Quality of care -Limited Western healthcare options in rural areas -Interplay between Western and traditional care*
Satisfaction-based trust	-Familiarity with doctors -Faith in medications* -Satisfaction with care	-Behaviours and demeanour -Perceived technical skills -Doctors' treatment outcomes*	
Chapter 8: Trust matters: benefits and disadvantages of patient trust in doctors in rural Tanzania			
Related meanings of trust	Benefits for patients	Benefits for doctors (providers)*	Benefits for the health system*
Expectation-based trust	- Increasing referral tendency within social networks -Facilitating healthcare seeking behaviours	-Improving reputation, respect and recognition within the community	-Improved reputation in the community -Reduced patient negativity and complaints towards health workers -Reduced legal claims towards healthcare institutions -Pulling patients from traditional to Western care -Pulling patients from private practice to public institutions -Increased income
Satisfaction-based trust	-Enhancing engagement in care and disclosure -Enhancing satisfaction with care -Facilitating continuity with doctors and hospital care -Improving adherence to medications -Facilitating relief, healing and cure -Contributing to reduced financial burden	-Elevated confidence, work morale and commitment -Increased income	
Disadvantages of trust*	Disadvantages for patients	Disadvantages for doctors (providers)	
Satisfaction-based trust	-Increased patient vulnerability to malpractice -Contributing to poorer health outcomes	-Trusted doctors' behavioural changes, such as inflated self-pride -Increased workload	
* Novel findings of this study			

The findings of this study indicated that patient trust in doctors means different things along the spectrum of care: before, during and after the patient-doctor encounter (Chapter 5). Before a therapeutic encounter, trust in doctors entails positive expectations that a patient holds of doctors' future actions, behaviours and treatment outcomes. I refer to this as *expectation-based trust*, which aligns with the content areas in some theoretical definitions of interpersonal trust that largely centre on patient expectations (Chapter 3). During a therapeutic encounter, trust in doctors entails patient satisfaction with the doctors' behaviours and technical actions. This meaning of trust appears to align with some of the scholarly attempts (albeit limited) to investigate what trust means that often move from meanings of trust to factors shaping trust (Chapter 5). After therapeutic encounters, trust in doctors entails patient satisfaction with doctors' treatment outcomes. I refer to these two meanings to as *satisfaction-based trust*, and they appear to differ slightly from the content areas in existing theoretical definitions of interpersonal trust.

Expectation- and satisfaction-based meanings of trust provided useful entry points for my analysis of the remaining two research questions (what factors shape patient trust in doctors and the perceived benefits of trust). The tendency of participants to characterise patient trust in doctors as having different meanings along the spectrum of care (Chapter 5) influenced how they spoke about the factors shaping trust in relation to expectation- and satisfaction-based trust (Chapters 6 and 7). Similarly, the characterisation of patient trust in doctors as having different meanings along the spectrum of care (Chapter 5) influenced how participants perceived benefits and disadvantages in relation to expectation- and satisfaction-based trust (Chapter 8).

We now know what patient trust in doctors means to patients and doctors in rural Tanzania, the factors shaping patient trust in doctors and its perceived benefits and disadvantages (Table 10). Therefore, it is important to examine these findings in relation to the overall aim of this thesis, which was to establish whether patient trust in doctors could form part of the NCD response in LIA. Below, I draw on the findings to answer a critical question: *Can patient trust in doctors form part of the NCD response in LIA?*

9.2 Can patient trust in doctors form part of the NCD response in LIA?

Before answering this question, it is important to reflect on the growing burden of NCDs in low-, middle- and high-income countries. Coupled with this growing burden are challenges associated with low levels of patient engagement with healthcare, non-adherence with treatment regimens and poor continuity with care (1, 3, 11-16). As noted in Chapter 1, these challenges contribute to the burden of NCDs in LIA amid a persistent increase of modifiable NCD risk factors (1, 3, 16, 17, 19, 48, 52-55). LIA and other African countries are expected to carry a greater burden of NCDs by 2030 compared with other countries (1, 27).

The provision of biomedical services through PHC continues to be an important entry point for addressing the NCD burden in LIA. Although there remains a lot to be done in terms of improving healthcare access, resources and quality of care, the WHO has developed cost-effective interventions/tools for biomedical NCD response in PHC focusing on resource-constrained settings. There are three main interventions/tools. The WHO/ISH risk assessment charts for healthcare providers in PHC to facilitate NCD risk prediction, management and health service planning (94, 96, 97, 104). The second intervention is the

PEN protocol with step-by-step actions and activities for healthcare providers, such as questions to ask in relation to NCD/CVD/hypertension risk factors, physically examining and estimating risks, making referral decisions and treatment and counselling when encountering NCD patients in PHC (105, 106). The third tool is the 16 cost-effective and feasible interventions for NCD response in low-income settings ('Best Buys'), including drug therapy, risk management and patient counselling (106, 117). Together, these interventions place emphasis on early diagnosis, risk management, drug treatment/counselling and people-centred care (94-107). Current evidence suggests that these WHO cost-effective interventions offer promising results for the NCD response in some countries (35, 59, 104-106, 110-116). However, their implementation continues to be hindered by persistent poor healthcare seeking, non-adherence to medications and medical advice, and poor continuity with care among patients.

Chapter 1 showed that the success of the WHO cost-effective interventions in LICs depended on strong patient-doctor relationships (e.g. Chapter 1, Table 2). Chapter 2 indicated that strengthening trust in patient-doctor relationships was an important strategy with potential to maximise the success of the WHO cost-effective interventions as part of the biomedical NCD response in PHCs. This is because successful implementation of the WHO cost-effective interventions requires patient trust in doctors to seek care from them in the first place, disclose sensitive and personal information that may facilitate risk identification and correct diagnosis, adhere to medications and medical advice and return to hospital for follow-up visits (207, 211, 213, 225, 353, 355-358). Chapter 3 indicated that current literature (predominantly from HICs) continues to place emphasis on the potential role trust could have in improving uptake of biomedical interventions, adherence and

continuity with care. The chapter also indicated there was limited evidence on the topic of trust in LIA.

In gathering evidence about whether patient trust in doctors can support the NCD response in LIA, this thesis began by examining the question of what patient trust in doctors meant to research participants (Chapter 5). This was because trust is complex, multifaceted and largely context-specific (Chapter 3). The emerging expectation- and satisfaction-based meanings of patient trust in doctors provided a useful gateway for my analysis of factors shaping trust (Chapters 5–7) and the perceived benefits of trust (Chapter 8). Participants' accounts related to the benefits of trust suggested that patient trust in doctors matters for NCD response in rural Tanzania to doctors and healthcare systems as well as to patients. In explaining why trust matters and could form part of the NCD response in LIA, two important contributions of this thesis will be discussed:

- i. Patient trust in doctors amid poor health behaviours and NCD outcomes in LIA.
- ii. Patient trust in doctors amid the interplay of Western and traditional practice in LIA.

9.2.1 Trust in doctors amid poor health behaviours and NCD outcomes among patients in LIA

The findings of this study indicated that patient trust in doctors could play a role in patient healthcare behaviours and outcomes related to NCD management and control. Participants cited several benefits of trust for patients that confirmed and extended beyond those commonly reported in previous studies (Chapter 3, Section 3.1.1). Benefits included those related to facilitating patients' health behaviours (such as care seeking, adherence, disclosure and return to care) as well as facilitating health outcomes (relief or cure). These

benefits were cited by participants in LIA amid concerns about poor service uptake contributing to underdiagnosis, non-adherence and poor continuity with hospital care, and consequently poor NCD management and control (84, 122, 133, 197-199). These findings confirmed reports from previous studies, most of which were conducted in HICs and some in LMICs (Chapter 3), and offered some evidence to suggest that improving patient trust in doctors could make an important contribution to NCD management and control in LIA.

Research participants extended the benefits of trust to reducing patients' healthcare associated costs. This was linked to the idea that patients in trusting relationships will stop 'shopping' for different doctors in circumstances of distrust or uncertainty. These findings support Thom *et al.* (292), who linked trust to reduction of costs associated with unnecessary referrals and diagnostic tests arising from patients' tendencies to seek to verify doctors' treatment recommendations and opinions. Moreover, participants in this study linked patient disclosure to facilitating correct diagnosis, which may translate to less costs for unnecessary medical investigations and unnecessary medicalisation (Chapter 8). This finding also supports the ideas described in Thom *et al.* (292) and Rolfe *et al.* (247). This finding also has important implications for NCD management in the LIA context where the financial burden of seeking care, medical investigations and hypertension medications emerged as contributors to non-adherence and poor continuity with hypertension care when analysing the cost-related factors shaping trust (Chapters 6 and 7).

9.2.2 Trust in Western doctors in the interplay of Western and traditional practices in LIA

Participants in this study described the potential role trust can have in improving the reputation of Western medicine (Chapter 8). This benefit was cited in the context of

chronic disease care in LIA being heavily impacted by medical pluralism, with many patients seeking care through both Western and traditional channels (133, 157, 159, 163, 189-191). Over half of the patients interviewed that were receiving Western care described having used or currently using both Western and traditional healing for hypertension management (Chapter 4). Some of those practicing medical pluralism expressed more faith in traditional than Western care, and some had defaulted from Western to traditional care (Chapter 7). More trust in traditional healers was rooted in their tendency to offer promises of hypertension cure, diagnosis of medical problems by foretelling and offering assurance of hypertension cure, along with the influence of participants' social networks (Chapter 7). These descriptions suggested that traditional practice heavily competes with Western practice, and negatively impacts uptake, adherence and continuity with scientifically-proven biomedical interventions for NCD management. Therefore, the finding that patient trust in doctors can contribute to the increased reputation of Western institutions (Chapter 8) offers some evidence to suggest that its improvement may contribute to more acceptance of Western practice for NCD management in LIA in the context of medical pluralism.

Collectively, the findings that patient trust in doctors mattered in hypertension care in rural Tanzania informs the aim of this thesis, which was to establish whether it could form part of the NCD response in rural LIA settings. These findings offer evidence to suggest that patient trust in doctors is worth considering as a promising lens for NCD response in LIA. This is because improved trust has the potential to address some of the challenges of NCD response in LIA (in particular uptake of Western healthcare, adherence to Western medications and continuity with Western care) that continue to negatively impact the

success of the WHO cost-effective PHC-based interventions. The specific implications of the research findings in relation to NCD response in LIA are discussed next.

9.3 Implications of the research findings for designing effective trust improvement interventions for NCD response in LIA

Given the overall aim of this thesis to establish whether patient trust in doctors could form part of the NCD response in LIA, the findings of this study indicate that this aim has been met. We now know that patient trust in doctors matters in LIA context and may offer a promising entry point for NCD response (above). The following section considers the implications of these research findings in terms of designing effective trust improvement interventions for NCD response in LIA. It should be noted that the intention of this thesis is not to position patient trust in doctors as a 'magic pill' for all of the challenges of NCD response in LIA. I focused on patient trust in doctors because it is central to other NCD interventions seeking to improve patient-doctor relationships, such as provider behaviours and communication and patient-centred care interventions (Chapter 2). In other words, interventions seeking to improve patient trust in doctors as part of NCD response are likely to also promote positive provider behaviours, communication and patient-centred care (see below).

A review of previous trust improvement interventions, predominantly conducted in North America (Chapter 3), indicated that they largely sought to address patient and provider factors shaping trust. While reviews tended to conclude that there is insufficient evidence on the impact of these interventions on trust (247, 364), research on specific interventions reported some promising results (367, 378, 382-386, 389, 390), although other studies

reported unfavourable results (365, 366, 387, 448, 671). Given the mixed results of these interventions, a question worth exploring is: *What is needed to design effective trust improvement interventions in the LIA context?*

The analysis of both patients' and providers' accounts in Chapters 6 and 7 facilitated identification of many factors shaping patient trust in doctors in the study settings (Table 10). Two issues emerged that have implications for how trust improvement interventions may need to be designed in LIA. First, some of the factors shaping patient trust in rural Tanzania (e.g. doctors' behaviours and technical skills and health system resources) resonate with those reported in other contexts (Chapter 3). This implies that when designing interventions for trust improvement in LIA, these factors need to be addressed more broadly, and that some of the trust improvement interventions addressing these factors in HICs may be transferable to rural Tanzania and vice versa (Chapter 6). Second, some of the factors shaping patient trust in rural Tanzania indicated that context matters when seeking to design interventions for improving trust. Novel factors that negatively or positively shaped patient trust in doctors in Western care, such as patients' faith in medications, patients' expectations of cure and the interplay between Western and traditional care have not received adequate attention in other contexts (Chapter 7). Patient access to both Western and traditional healers contributing to medical pluralism (157, 163, 190, 191, 194, 195, 546, 555) and widespread concerns about resource constraints (150-153, 186, 200, 610) are possible explanations for why these novel factors emerged in this context. The discussion of these novel factors in Chapter 7 indicated there may be no single intervention that can effectively improve patient trust in doctors. It became evident that combining interventions focusing on patients and providers alongside those focusing on

health systems and beyond may be more fruitful when seeking to improve patient trust in doctors in the LIA context.

Some of the existing literature has recommended a range of interventions, most of which may be relevant to LIA. These include addressing:

- (i) Patient factors shaping trust, such as improving their health information and literacy (404), the choice of doctor and continuity with care (247, 364).
- (ii) Provider factors shaping trust, such as improving their communication skills, openness, honesty, caring and confidentiality and demonstration of technical competence (247, 364, 379, 408, 422).
- (iii) Health system factors shaping trust, such as improving access to doctors' care (247, 364) and issues related to the cost of care (374).

While these interventions may be useful, they mainly focused on what happens within medical care settings. However, the findings of this study (in particular patient access to both Western and traditional care, heightened influence of social networks and traditional healers, patient perceptions and expectations of hypertension cure and limitations of Western care) suggest a need for more contextualised and combined interventions that go beyond what happens during patient-doctor encounters in medical care settings.

It is not the intention of this thesis to undermine the value of focusing on patient-doctor encounters within medical care settings alone. Rather, the intention is to suggest that trust improvements interventions in rural LIA contexts need to extend beyond patient-doctor relationships to health system barriers and regulatory weaknesses that continue to contribute to patient distrust in doctors in Western practice. For example, it may be

illogical to solely focus on either patient literacy or doctors' communication as a means of increasing patient trust in doctors and adherence when patients lack financial access to prescribed medications and traditional healers continue to use the media to devalue doctors in Western care for their inability to completely cure hypertension. Seeking to strengthen trust in patient-doctor relationships without addressing health system and regulatory issues may yield unsuccessful results, particularly in rural settings where there are major concerns about poor access to Western care options amid an abundance of traditional options. This brings me to two other considerations when designing effective trust improvement strategies in LIA. First, there is a question as to whether it is feasible to implement interventions solely focused on improving patient trust in doctors in LIA given concerns regarding limitations of funding and multiple priorities (659-670). Clearly, while trust improvement interventions in LIA may need to form a component of broader public health interventions/programmes, some of the interventions I propose below may be feasible even within the context of resource limitations (e.g. a checklist that reminds doctors what patients desire to see during encounters, Section 9.4.6). Second, the disadvantages of trust must be considered when designing trust improvement interventions. Participants in this study cited disadvantages of trust for patients (e.g. increased vulnerability to doctors' malpractice or impacting patient health outcomes) and for doctors (including inflated self-pride and increased workload) (Chapter 8). Apart from theoretical ideas of Thom *et al.* (292) and Gilson (472), the disadvantages of trust have not received attention in previous studies and were not considered in the previous interventions reviewed (Chapter 3). A practical implication is that trust improvement interventions may need to be designed in such a way that they do not result in these disadvantages, or they include remedial strategies against the negative consequences of trust when used as a lens for NCD

response. The following section presents specific medical practice and policy recommendations for improving trust in LIA.

9.4 Specific recommendations for designing trust improvement interventions

Informed by the wider literature and the findings of the present study, these recommendations reflect important or contextual issues that impact trust in patient-doctor relationships in LIA, some of which have not received sufficient attention in previous interventions. The recommendations are offered in consideration of:

- i. Health system factors: the interplay of Western and traditional practice and barriers to NCD care in LIA.
- ii. Patient factors: expectations of hypertension cure and faith in medications
- iii. Patients' religiosity and religious institutions.
- iv. Provider factors: behaviours, technical competence and reputation in the community.

9.4.1 Interplay of Western and traditional practice

The most important practically relevant finding with respect to how trust is constructed and experienced in rural Tanzania stems from identification of the interplay between Western and traditional care as a factor shaping patient trust (Chapter 7). The findings of this study showed that some traditional practitioners continued to offer promises of complete cure for conditions that are conventionally deemed incurable. These promises heavily contributed to patient distrust in doctors in Western practice, medical pluralism or discontinuation with Western care. This occurred in a context of widespread traditional healing across LIA and all over Africa. A recent review by Liwa *et al.* (159) reported a

prevalence of 25%–65% of traditional medicine use for hypertension care in LIA.

Consequently, researchers in Africa are increasingly advocating for the integration of traditional medicine within Western the healthcare system (672- 677), partly because some have documented its effectiveness, such as in HIV management (678). However, there are also concerns about the interaction of traditional medicine with and negative impact on adherence to biomedical medication, necessitating strong regulations (133, 159, 163, 649, 679-682). Some African countries have developed national policies for traditional medicine (627, 683), and the WHO has recently called for 'Regulation of Traditional Medicine in Africa' (684). However, emphasis is largely placed on policies and regulations ensuring safety, efficacy and quality of traditional medicines. While these efforts are still needed, my findings indicate many issues in the interplay of Western and traditional practice specifically relate to traditional herbalists' advertisements through different forums in Tanzania, where medical professional bodies hold much stricter views of self-promotion of doctors in Western practice (287, 632, 634, 635). This suggests a need to regulate self-advertisement of traditional healers, whose activities impact acceptance, uptake and continuity with NCD care provided by doctors in Western practice. Therefore, where traditional practices contribute to patient distrust in doctors who provide scientifically-proven biomedical interventions, it is recommended that regulations related to traditional herbalists' self-advertisement and promises of chronic disease cure are strengthened. Regulation of traditional healers may need to be implemented alongside efforts to educate the general public on the nature of and what to expect from biomedical NCD care, and the negative consequences of medical pluralism. In general, there is much to be done to counter the strong influence of traditional healers in rural LIA. In addition to regulating traditional healers and public education, promoting PCC approach to Western healthcare delivery may

be needed. Doctors in Western care may need more training on how to talk with patients who practice medical pluralism and offer person-centered care so that they do not default from Western care.

9.4.2 Barriers to NCD care

The institutional challenges faced by hypertension patients in rural Tanzania emerged in Chapter 6 as contributing to distrust in both doctors and healthcare facilities. Concerns related to institutional characteristics of healthcare facilities (level, ownership, accessibility), resources (medications or doctors), quality of care and cost-mediated barriers to care emerged as impacting patient trust regarding from who (doctor) and where (facility) to seek care, adherence to medications and whether or not to return for follow-ups, particularly among rural patients. As suggested above, these findings indicated that the success of patient and provider focused interventions for improving trust as a means of promoting patient uptake, adherence and continuity with hospital care in rural LIA cannot be guaranteed if institutional barriers to NCD care are not concurrently addressed. As recommended in Chapters 6 and 7, improving trust also needs to address health system issues (e.g. increasing the number of PHC facilities in rural areas and decentralisation of NCD services, universalisation of insurance) and challenges faced by insured patients pertaining to availability of medications and pricing, and enrolling more service providers in insurance schemes. This implies that researchers and public health experts need to see trust improvement as rooted in the totality of patients' experiences within medical practice, and not merely a product of interpersonal aspects of patient-doctor encounters.

9.4.3 Patients' expectations of hypertension cure

Chapter 7 indicated that many patients and providers described patients' expectations of complete hypertension cure as a factor shaping trust in doctors. These accounts were offered in a context where only symptomatic relief and disease control can be achieved through doctors' biomedical interventions for hypertension management in Western practice (8, 11, 118). A possible explanation of these accounts was inadequate patient knowledge about NCDs, which is common across LIA (157, 163, 685, 686). Knowledge about NCDs can be positively impacted by providers' messages to patients in relation to the nature of and what to expect from biomedical management. When comparing explanatory models and stroke treatment seeking behaviours between rural and urban contexts in Tanzania (in the context of patient access to both Western and traditional practices), Mshana *et al.* (157) suggested that, 'many people may abandon biomedical treatment because they do not see themselves being cured' (p49). Mshana *et al.* (157) further suggested that 'it is essential [for providers] to explain, from the outset, the limitations of treatment versus rehabilitation and prevention' (p49). However, recent research in LIA (including Tanzania) continues to indicate that providers in PHC facilities are inadequately equipped with the resources to offer sound NCD care, including knowledge-based tools such as technical guidelines and manuals (150, 152, 611). Further investigations may be required to establish whether provider communication of messages of relief and control to patients clouded by expectations of complete NCD cure risks losing their trust. Nevertheless, the findings of this study offer evidence that suggests a need for standardised NCD messages for providers' communication with their patients and the broader community. The media may play a significant role in dissemination of these messages as they have wider presence in the community in the study settings.

9.4.4 Patients' faith in medications

Chapter 7 indicated that patient faith in medications rooted in their ability to facilitate positive treatment emerged as fuelling patient trust or distrust in providers. On one hand, patient faith in traditional medications emerged as potentially shaping trust in Western doctors and their medications in a negative direction. Patients' social networks were important in constructing more patient faith in traditional medications and healers in rural Tanzania. Some literature has identified patients' social networks as the source of health information and the first point of contact for health-related concerns (687-690), and demonstrated their impact on patients' behaviours and health outcomes in chronic disease and mental health (385, 691-694). For example, in examining how patient and family preferences can be incorporated into evidence-based medicine, Siminoff (690) suggested that information from patients' families and friends can influence their healthcare decisions and may bring conflicts in patient-doctor relationships. In South India, patient social networks were documented to shape patient trust by informing their competence-based judgments of providers (469). The accounts related to patient faith in medications in rural Tanzania indicated that social networks largely constructed patient distrust towards Western doctors and their medications. Therefore, a policy- and practice-based approach consideration could be generating standardised education tools targeting patients' social networks regarding the value of and what to expect in biomedical NCD care. On the other hand, patient faith in Western medications based on their therapeutic effectiveness emerged as shaping satisfaction-based trust in a prescribing doctor. These accounts emerged where some doctors were cited to prescribe less potent drugs for cost reasons. Regardless of whether these accounts pointed to faith in medications as a new facet of trust (Chapter 7), trust improvement strategies may not to be successful if patients have limited financial accessibility to effective medications in the LIA context. A policy consideration

could be implementing trust improvement interventions alongside those seeking to address patients' financial barriers to effective NCD medications in LIA context.

9.4.5 Patients' religiosity and religious institutions as partners

Patient religiosity emerged in Chapters 6 and 7 as a crucial factor shaping their trust of Western doctors and avoidance of traditional healers. This finding is consistent with Tarn *et al.* (214), who showed that greater religiosity was associated with increased trust among Japanese and Japanese Americans. The role of religion in health has been mainly examined in relation to mental wellbeing (695-698). There appear to be mixed findings and views in relation to the role religion plays in patient trust in doctors in Western care. Religiosity has been documented to influence health behaviours, risk screening and healthcare seeking behaviours in African Americans (699, 700), health promoting behaviours (701-705) and health outcomes (706). In Africa, religious beliefs about disease causation, diagnosis and healing are said to influence the choice of where to seek care, whether Western, spiritual or traditional healing (707). In contrast, recent studies have shown no relationship between religion and uptake of health services in general and HIV-related maternal health services in Nigeria (708) or preferences for traditional and Western practices in Ghana (709). More studies are needed to shed light on how religiosity shapes patient trust in doctors. However, when improving patient trust of doctors envisages promoting the acceptance of Western practice as a strategy for NCD response in rural LIA, there appears to be some value in considering religious institutions as partners in moving people from traditional healers and promoting engagement with Western medicine.

9.4.6 Provider behaviours, perceived technical competence and reputation

Chapter 3 indicated that provider behaviours and competence dominated the scholarly discussion and was the focus of interventions on patient trust in doctors. In rural Tanzania, provider behaviours, demeanour, perceived technical competence and reputation emerged as important in shaping patient (satisfaction-based) trust in doctors (Chapter 6). These findings suggest that trust improvement interventions in rural LIA seeking to address provider factors may need to ensure doctors maintain good reputation in the community by demonstrating good behaviours, demeanour and technical actions during encounters with patients. A number of interventions recommended in previous literature (above) may be of use in the LIA context. However, the following practice and policy interventions may be considered to further improve patient trust in doctors in LIA.

- i. Many patients indicated that the reputation of doctors in social networks and the community shaped trust in them. To maintain doctors' positive reputations, the first recommendation is to train providers/doctors in strategies for identifying dissatisfied patients and managing dissatisfaction before patients exit consultation rooms or healthcare settings to the community. Second, it may be necessary to establish patient-friendly mechanisms to collect information about negative experiences or dissatisfaction and collaboratively address them. According to the WHO (710 p5), this can be achieved through a range of patient engagement strategies including frequent surveys, informal feedback, exit interviews and/or focus group discussions. Such information may offer an opportunity to understand patient preferences, desires and values, and has the potential to improve service delivery quality and positivity towards providers (710-713).

- ii. Patients in this study identified various doctors' behaviours and technical skills they desire to see during therapeutic encounters for trust development. Therefore, interventions such as generating a clinical consultation checklist to remind doctors of the behaviours, demeanour and technical actions desired by patients to ensure standardised care is offered throughout patient-doctor relationships (initial encounters and follow-up visits) may be considered.
- iii. Participants' characterization of doctors as either trustworthy or untrustworthy (Section 6.2.2) further suggests that there is much to be done in the healthcare profession and medical education in terms of promoting moral and ethical conduct among healthcare workers. Continuing professional development programs centered on strategies for improving patient-provider relationships and upholding moral and ethical principles of care may be considered for in-service doctors. However, to ensure that doctors who enter medical practice are well equipped with essential skills to develop and maintain their patients' trust before entry into medical services, health care training institutions may need to consider revisiting their training curriculum to give equal emphasis to doctors' interpersonal and technical skills, ethics of care and moral conduct.

9.5 Recommendations for further research

Given the need for trust improvement interventions for NCD response in LIA, the question remains as to how evidence of success of such interventions will be established. This brings me to the issue of measures of patient trust in doctors and other areas for further research.

9.5.1 Generating measures of trust

Measures of trust are required to generate evidence of effectiveness of any trust improvement interventions. This thesis raises an important question about whether we can expect measures of patient trust largely developed in HICs (Chapter 3) to yield enough information about patient trust in all its meanings in rural Tanzania. As noted in Chapter 5, patient trust in doctors in rural Tanzania was characterised as meaning: i) *expectations of providers* before the encounter; ii) *patient satisfaction with what happens* during the encounter; and iii) *patient satisfaction with doctors' treatment outcomes* after the encounter. These distinct meanings suggest that when generating measures of patient trust in doctors in LIA we also need to ask: i) what meaning do they appear to be measuring? and ii) what do they make of other meanings?

There are also questions as to whether: i) to generate a new measure of trust, addressing the dimensions/content areas of all the meanings of trust in LIA; or ii) to make modifications to existing measures from HICs as others have done (445, 466). Some researchers in HICs identified common dimensions/content areas across existing measures of trust, such as provider's honesty, communication, competence, confidence, fairness, confidentiality and fidelity, as well as system trust (248, 439, 461-463). These dimensions/content areas reflect a range of provider factors identified as shaping trust in the present and previous studies (Chapter 3). When viewed from the perspective of what trust means in rural Tanzania, they appear to tap into the satisfaction-based meaning of trust grounded in provider behaviours and technical competence observed during therapeutic encounters (Chapter 5). In other words, the common dimensions/content areas in existing measures of trust in HICs do not appear to reflect the expectation-based meaning of trust before an encounter, or the satisfaction-based meaning of trust (rooted in

satisfaction with doctors' treatment outcomes) after a therapeutic encounter. Therefore, what is being measured as patient trust in doctors in HICs may not reflect all of the specificities of what trust means in the LIA context. This suggests that researchers may need to consider a new measure that takes into account all the three meanings of trust that emerged in the LIA context.

9.5.2 Areas for further research

Further research may be needed in LIA countries (including rural Tanzania) to generate more evidence for designing trust improvement interventions. Questions that need more investigation include whether strengthening trust in patient-doctor relationships could quantitatively lead to improvements in: i) adherence and health outcomes and ii) other aspects of care, such as patient-centred care, communication and satisfaction with general care.

Furthermore, this study has shown that most patients combine Western and traditional medicines for hypertension management, often contributing to poor adherence to medication and defaulting from Western to traditional care. Several questions remain unanswered on this issue. In seeking to investigate this issue further in Tanzania and other LIA countries, research questions that could be asked include: i) whether stringent regulation of traditional healers could reduce medical pluralism; and ii) whether reduction of medical pluralism may quantitatively contribute to adherence and patient retention in Western practice.

9.6 Strengths of this research

This thesis focused on a low-income rural setting where there is limited evidence on the topic of patient trust in doctors. In so doing, it bridged the gap between what is known in high-income and urban contexts and the unknown in low-income rural settings. It addresses some of the criticisms of past research on patient trust in doctors (Chapter 3) by: i) examining three different research questions that are often investigated separately, and offering evidence suggesting what trust meant to research participants to provide a useful lens to analyse factors shaping trust and its benefits; ii) involving patients and doctors from both Western and traditional care enabling a wide focus beyond the existing literature; and iii) examining the benefits of trust beyond patients to providers and health system.

This thesis contributes understanding in several areas that have received limited attention in previous trust research: i) why trust matters for NCD response in the rural LIA context; ii) the meaning of trust for research participants (expectation- and satisfaction-based meanings), which offers a useful basis for bringing the experiences, voices and perspectives of patients and providers from a specific rural Tanzanian context to the question of what is trust; iii) the disadvantages of trust for patients and doctors; iv) a detailed analysis of novel factors shaping trust in rural LIA (the interplay between Western and traditional practices, patients' faith in medications and patients' expectations of cure) that have not been identified in previous studies; and v) a detailed analysis of context-specific factors shaping trust in a rural LIA context, which indicates a need for combined interventions.

9.7 Limitations of this study

This exploratory study was conducted in Shinyanga, a region where I have spent most of my professional career and continue to reside. Being a medical doctor and public health expert in the study settings may have attracted some patients to take part in the study and/or impacted their responses. Moreover, most participants in this low-income rural setting are of the same ethnic group (Sukuma as a common vernacular and Swahili as a national language) and use both Western and traditional care for NCD management. Most providers who participated in this study were identified by patients or self-identified as trustworthy, which limited the opportunity to examine the perspectives of the 'untrustworthy' providers. Also, peer engagement was used to counter the potential impact of language translation on the results, however, such possibility cannot be completely eliminated. Having worked as healthcare service advocate in Tanzania might have also impacted the choice of themes, related sub-themes and codes that I considered most appropriate, the interpretations of participants' accounts and the conclusions in seeking to answer the research questions. Therefore, where transferability of the findings for NCD response and health service improvement is envisaged, the results of this study may not be applied without consideration of the role that diverse social, economic, cultural and linguistic backgrounds play in shaping patient trust in those contexts as well as the researcher's role in the research process.

Moreover, this study did not explore all of the patient demographic factors shaping trust. Although previous studies established associations between patients' individual characteristics (e.g. age, gender, race, ethnicity and marital status) and their trust in doctors (Chapter 3), the analysis of participants' accounts in the present study only identified

patients' income, religiosity, residence (rural vs. urban), knowledge and social networks (Chapters 5–7) as shaping patient trust in doctors in rural Tanzania. Future quantitative studies could provide more definitive evidence of whether patients' age, gender, race, ethnicity and marital status shape their trust in doctors in rural LIA.

9.8 Reflections

Conducting this research provided an invaluable contribution to my postgraduate research learning experience. From designing the study, data collection and analysis to writing the results chapters, it facilitated an understanding of the nature of qualitative inquiry and the concept of patient trust in doctors. It helped me to learn that undertaking research can be both rewarding and frustrating. As public health expert and a medical doctor, this research helped me to acknowledge that I often take patient-doctor relationships for granted by attributing my own perception of what is technically good to patients, whose desires and perceptions may be different from my expert judgment. The research results helped me to learn that my actions and behaviours as a medical doctor in therapeutic relationships may limit patients' ownership of the prescribed interventions, thereby fostering distrust, non-adherence and discontinuity with hospital care. The research also unmasked some key issues that helped me to evaluate my own practice, professional values, desires and goals, and offered guidance for my future practice and career prospects.

The findings of this thesis have been communicated to medical practitioners and the broader scientific community in Tanzania, Australia and beyond. The first output involved an oral presentation during the 30th Annual Joint Scientific Conference organised by NIMR in October 2016 in Tanzania. The presentation stimulated many questions from medical

practitioners and local and international researchers on how strengthening trust in patient-doctor relationship can be used as a vehicle not only for NCD response, but to create positive patient experiences in medical care. This was followed by a seminar presentation entitled 'Patient trust in doctors in low income rural Africa: does it matter?' at the Global Health @ UNSW in 2017. This brought together UNSW experts to provide crucial comments on the research, and facilitated improvement of the results chapters. At the beginning of 2018, the content of Chapter 8 was published in the Tanzania Journal of Health Research. The published paper can be accessed online by audiences outside Tanzania, and offers justifications for strengthening patient trust in doctors as a means of improving patients' healthcare seeking, adherence and continuity with NCD care. A link to the published paper was sent to key stakeholders who participated in the study and across different professional networks. Most recently, the content of Chapter 6 was accepted for the 6th Annual Congress and Medicare Expo on Primary Healthcare in Tokyo Japan. The abstract has been published in the accepted abstract book and can be accessed online. Finally, the content of Chapter 8 has been accepted for a poster presentation at the 5th Global Symposium on Health Systems Research in the UK. With the WHO as a co-sponsor, that conference guarantees dissemination of the research findings to key stakeholders at the global level.

Much needs to be done in terms of using the findings of this qualitative inquiry to inform the design of future quantitative inquiries, as described in (487, 531). Now that I have a growing awareness of patient trust in doctors, I make a commitment to seek for opportunities and partnerships to implement the recommendations and explore the topic further in Tanzania. I also intend to continue sharing the research findings in different

professional forums and be an advocate on the topic within and beyond Tanzania in the hope of attracting more researchers, providers and policy makers to view trust as an important lens for NCD response and also improving the totality of patients' healthcare experiences.

9.9 Conclusion

The broad aim of this thesis was to establish whether patient trust in doctors could form part of the effort to improve NCD response in rural LIA. The goal of this investigation was to understand the potential value of patient trust in doctors in LIA and offer recommendations for its improvement. The thesis is the first study to examine the question of what trust means, what factors shape trust and whether trust matters in terms of the perceived benefits of trust in a rural LIA setting.

The challenges of NCD response globally, in LIA and Tanzania require optimal implementation of the WHO policy actions and cost-effective interventions. Although many LIA countries are embracing these WHO cost-effective interventions, concerns about poor patient-doctor relationships in medical practice continue to hinder their success. This thesis suggests that improving patient trust in doctors may strengthen patient-doctor relationships and contribute to addressing the challenges of NCD response including: poor healthcare seeking, non-adherence and poor continuity with care, which LIA countries continue to face. It further suggests the benefits of improving patient trust as including providers and healthcare systems, rather than being limited to patients. Moreover, the findings of this thesis indicate that attempting to improve trust by focusing on patients and providers alone in a context where Western practice competes with traditional healers for chronic disease

management amid many institutional barriers to care may yield unsatisfactory results. Therefore, a call is made in this research that trust improvement strategies addressing patients and provider factors in rural LIA need to be implemented alongside those addressing patient barriers to healthcare access and efforts to regulate self-promotion of traditional practice. In addition, given the current funding priorities in LIA, financing of isolated trust improvement interventions may not be possible. Therefore, most trust improvement interventions may need to be integrated within broader public health, medical and policy interventions. Nonetheless, some of the proposed interventions may require no or minimal funding to implement.

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APPENDICES

Appendix I: Key milestones in the global NCD response from 1999 to date

YEAR	FORUM/EVENTS	COMMITMENTS AND POLICY PRIORITIES
1999	WHO consultative recommendations for the Global Strategy for the Prevention and Control of NCDs	Mapping NCDs epidemics and guidelines for risk factor exposure reduction and strengthening biomedical care were developed
2000	The 53rd World Health Assembly endorses the Global Strategy for the Prevention and Control	Member states committed to generating a local information base to facilitate action, establishing programmes for health promotion, prevention and control of NCDs, and tackling issues beyond the health sector
2002	The 2002 Johannesburg Declaration on Sustainable Development: UN Member States committed to address NCDs and CVDs	Response to NCDs and CVDs in LMICs became a central agenda
2008	The World Health Assembly endorses the Action Plan for the Prevention and Control of NCDs 2008–2013	Six objectives: Priority raising and integration of NCDs in policies, establishing and strengthening national policies and plans, promoting interventions for reducing modifiable risk factors, promote research, promote partnerships and monitoring and evaluation
2009	United Nations Ministerial Declaration: Economic and Social Council Economic and Social Council	Recognition of the economic and social impacts of NCDs in LMICs
2011	First global ministerial conference on healthy lifestyles and NCDs control in Moscow.	Emphasis on NCDs prevention and placing initiatives to prevent NCDs in national health plans
2012	Political declaration of the High-level Meeting of the UN General Assembly on the	Member state commitment to improve diagnostic services, human resources, public-private partnership to increase affordability and strengthen healthcare infrastructure for

	Prevention and Control of NCDs.	procurement, storage and distribution of medicine
2013	The 66th World Health Assembly endorses the WHO Global Action Plan for the Prevention and Control of NCDs 2013–2020.	Six objectives and nine voluntary targets. An emphasis on prevention, treatment and control of CVDs, drug therapy and strengthening health systems
2014	The WHO Global Coordination Mechanism on Prevention and Control of NCDs (GCM/NCD) established	To enhance coordination, multi-stakeholder engagement and action across sectors
2014	The WHO releases global status report on national progress on voluntary global targets.	Increasing burden in Africa. Emphasis on the Best Buys as a cost-effective tool. Four priority actions devised: public health policies, service integration, promotion of workplace wellness and enhancing medication adherence
2015	The WHO GCM/NCD holds a dialogue on how to support countries in their national efforts to build domestic solutions	A focus on solutions based on local insights and global perspectives
2016	WHO NCD working group meetings	Inclusion of NCDs in other working group programme areas. Renewed emphasis on early detection, diagnosis, treatment and care
2017	The 70th World Health Assembly endorses the updated set of best buys and other recommended interventions for NCDs.	A new set includes 16 “best buys” interventions within the WHO global action plan for the prevention and control of NCDs 2013–2020. A priority placed on LMICs
2018	The UN General assembly to convene a third high-level meeting on NCDs to review progress on voluntary targets	To review progress on implementation of the best buys

Source: Generated from multiple WHO reports

Appendix 2: Status of the 2013–2020 voluntary targets on NCD response by 2014
(a focus on CVDs in Africa)

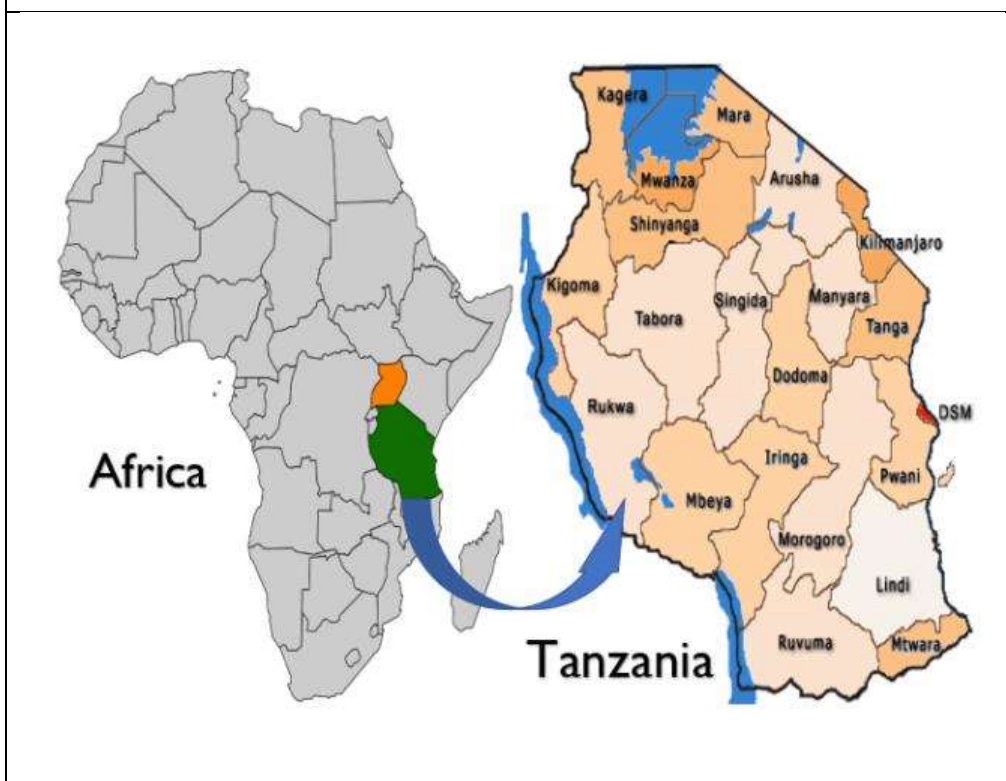
VOLUNTARY TARGETS (to be reached by 2020)	STATUS AS OF 2014 (FOCUS ON AFRICA)
A 25% reduction in risk of CVDs mortality	Low-income countries have almost double the burden of NCDs deaths between 2000 and 2012. In 2012, age-standardised NCDs deaths per 100,000 population were higher in LMICs (625) compared with high-income countries (397). Age-standardised NCDs deaths per 100,000 population in the African region (650) exceeded that of the US (438)
At least 10% reduction in harmful use of alcohol	Africa is the 4th region among those with higher per capita alcohol consumption (6.0%), and is nearly the world average (6.2%) but less than the US (8.4%)
10% reduction in prevalence of insufficient physical activity	The prevalence of insufficient physical activity in Africa is 21% compared with 32% in the American region; however, it is rapidly increasing due to Westernisation of lifestyles
30% reduction in mean population intake of salt/sodium.	Insufficient data exist on salt intake progress in Africa. High success in Finland and UK, with Finland noticing a 65% reduction in age-adjusted mortality from coronary heart disease over the last four decades
30% reduction in the prevalence of current tobacco use in persons aged 15+ years	Africa region has lowest (12%) average regional rate for tobacco smoking compared with the European region (30%); however, this is more likely to increase because of weak implementation of the 'best buys'. Only 95% of the 95 countries had at least one 'best-buy' measure, and only 40 countries implemented for the first time one or more best-buy measures between 2010 and 2013
25% reduction in the prevalence of hypertension	Prevalence of hypertension in 2014 was highest in Africa (30%) and lowest in the US (18%). The percentage of countries reporting policies, plans or strategies on behavioural risk factors is lowest in the African region. In high-income countries: Hypertension awareness is 80%,

	treatment is 75% and control in 50%, but data are unfavourable in Africa (refer to subsequent sections)
Halt the rise in diabetes and obesity.	Obesity is increasing in all countries. In 2014, 39% of adults aged 18 years were overweight. The worldwide prevalence of obesity nearly doubled between 1980 and 2014
At least 50% of eligible people receive drug therapy and counselling	Over 80% of CVDs occur in LMICs. In 2013, 85% of high-income countries reported offering risk-factor screening and disease management in their PHC systems. But there is weak utility of risk-factor screening and disease management tools in LMICs
80% availability of affordable technologies and essential medicines	Availability of NCDs medicines in LICs is public: 54.1% and private: 68.0% compared with HICs (public, 70% and private, 60%)

Source: adapted from WHO (1)

Appendix 3: Demographic characteristics and map of Tanzania

Tanzania is the largest East African country. It is bordered by Uganda and Kenya to the North; Zambia, Malawi and Mozambique to the South; Democratic Republic of Congo, Rwanda and Burundi to the West; and the Indian Ocean to the East. The country is multiethnic and multilingual, with more than 120 ethnic groups and vernaculars, although Swahili (the national language) is spoken by more than 90% of the population (714). The 2012 population and housing census projected the population at 44.9 million (543, 548, 715), with current projections of over 51 million.





Source: <https://www.worldatlas.com/webimage/countrys/africa/tz.htm>

Appendix 4: Gaps in DHIS hypertension data reporting from facilities in Shinyanga MC and DC (Oct 2014–Sept 2015)

MONTH	Facility-level hypertension data in Shinyanga MC			Facility-level hypertension data in Shinyanga DC		
	No. of hypertension patients reported to receive care	No. of facilities reporting data in DHIS (out of 29)	Percent of facilities reporting hypertension data in the DHIS	No. of hypertension patients reported to receive care	No. of facilities reporting data in DHIS (out of 46)	Percent of facilities reporting hypertension data in the DHIS
Oct 2014	161	9	31.0	70	9	19.6
Nov 2014	332	7	24.1	87	7	15.2
Dec 2014	351	11	37.9	36	8	17.4
Jan 2015	334	8	27.6	98	11	23.9
Feb 2015	65	7	24.1	65	6	13.0
Mar 2015	287	9	31.0	123	11	23.9
Apr 2015	253	7	24.1	15	5	10.9
May 2015	74	8	27.6	48	9	19.6
Jun 2015	388	8	27.6	35	8	17.4
Jul 2015	95	8	27.6	22	7	15.2
Aug 2015	93	9	31.0	45	3	6.5
Sep 2015	55	6	20.7	42	6	13.0
Total/ Average	2488	8	27.6	686	8	16.3
<p>Description: It is apparent from this table that few healthcare facilities (27.6% annual average) contributed to the 2488 patients reported to receive hypertension care in Shinyanga MC, with irregular reporting every month. For example, the regional hospital accounted for 59.5% of all patients reported to receive hypertension care in Shinyanga MC, but the hospital reported no data in 5 months: February, May, July, August and September 2015 (556). Also, it can also be seen that few healthcare facilities (16.3% annual average) contributed to the 686 patients reported to receive hypertension care in Shinyanga DC, with irregular reporting every month (556). The poor data quality rendered the reported number of patients receiving hypertension care in each facility unreliable and unsuitable criterion for facility selection.</p>						

Appendix 5: Participants information and consent form (English version)

School of Public Health and Community Medicine, Level 2, Samuel's Building, Kensington, NSW, AUSTRALIA	 
PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM	
PATIENT FORM	
Exploratory study of patient-provider trust in a low-income African primary healthcare setting in Tanzania.	

What is the research study about?

You are invited to take part in this research study. You have been invited because you are a patient who has been identified to be suitable for the study from Shinyanga Region. To participate in this project, you need to meet the following criteria:

☐ A PATIENT 1) Seeking care for hypertension 2) Not admitted in hospital and who does not have complicated comorbidity or disability.

The research study will explore your perceptions and experiences related to trust in patient and provider relationships in primary healthcare services in Shinyanga Region, Tanzania.

This study is important because it will provide information on the meaning, determinants, benefits, challenges for establishment and sustenance and strategies for improving patient trust in primary healthcare settings in Shinyanga Region.

Do I have to take part in this research study?

Participation in this research study is voluntary. If you do not wish to take part, you do not have to. Your decision will not affect your relationship with your provider/facility/health administrator/local village leaders. This Participant Information Statement and Consent Form tells you about the research study. It explains the research tasks involved. Knowing what is involved will help you decide if you want to take part in the research.

Please read/listen to this information carefully. Ask questions about anything that you do not understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative or friend.

If you decide you want to take part in the research study, you will be asked to:

☐ Keep a copy of this Participant Information Statement;

What does participation in this research require, and are there any risks involved?

If you decide to take part in the research study, you will be asked to participate in an interview that would take approximately 45–60 minutes. During the interview a member of

the research team will ask questions about your perceptions and experiences related to trust in primary healthcare settings. With your permission, we would like to digitally record the interview using an audiotape. The interviews will take place at the location of your choice, preferably near to a place where you often interact with your provider for medical care. Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study.

Will I be paid to participate in this project?

For participating in this study, we will reimburse you for your time and transport up to Tanzanian Shillings 4,500 (equivalent to AUD 3).

What are the possible benefits to participation?

We hope to use information we get from this research study to benefit others who receive care from providers in primary healthcare settings in Shinyanga and Tanzania in general.

What will happen to information about me?

By signing the consent form, you consent to the research team collecting and using information about you for the research study.

The audiotaped digital recordings are for the purposes of the research study. After the interview we will transcribe your digital recordings. We will keep your digital recordings in the form of digital files for 7 years. We will store information about you temporarily at Shinyanga Regional Medical Officer's office then transfer them to the University of New South Wales in Australia. Your confidentiality will be ensured by only using the information for the purpose of this research study and it will only be disclosed with your permission.

It is anticipated that the results of this research study will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that your research findings may be published, but you will not be individually identifiable in these publications.

You have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. You can do this by contacting a member of the research team.

How and when will I find out what the results of the research study are?


You have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback by contacting the researcher whose contact is in this form. This feedback will be in the form of aggregate summary in one-page paper. You will receive this feedback after the study is finished.

What if I want to withdraw from the research study?

If you do consent to participate, you may withdraw at any time. If you do withdraw, you will be asked to complete and sign the 'Withdrawal of Consent Form', which is provided at the end of this document. Alternatively, you can ring the research team and tell them you no longer want to participate. If you decide to leave the research study, the researchers will not collect additional information from you.

What should I do if I have further questions about my involvement in the research study?

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems that may be related to your involvement in the project, you can contact the following member/s of the research team (*contacts listed below*)

School of Public Health and Community Medicine, Level 2, Samuel's Building, Kensington, NSW, AUSTRALIA	 UNSW A U S T R A L I A
PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM	
PROVIDER FORM Exploratory study of patient-provider trust in a low income-African primary health care setting in Tanzania.	

What is the research study about?

You are invited to take part in this research study. You have been invited because you are a provider of healthcare or an administrator who has been identified to be suitable for the study from Shinyanga Region.

To participate in this project, you need to meet the following criteria:

- ☐ You are a provider in Western care who offers medical care to patient(s) known to be hypertensive.
- ☐ OR a traditional provider who offered care to patient(s) known or considered to be hypertensive.
- ☐ OR health administrator in a facility in which patients received care for hypertension disease.

The research study will explore your perceptions and experiences related to trust in patient and provider relationships in primary healthcare services in Shinyanga Region, Tanzania.

This study is important because it will provide information on the meaning, determinants, benefits, challenges for establishment and sustenance and strategies for improving patient trust in primary healthcare settings in Shinyanga Region.

Do I have to take part in this research study?

Participation in this research study is voluntary. If you do not wish to take part, you do not have to. Your decision will not affect your relationship with your provider/facility/health administrator/local village leaders.

This Participant Information Statement and Consent Form tells you about the research study. It explains the research tasks involved. Knowing what is involved will help you decide if you want to take part in the research.

Please read/listen to this information carefully. Ask questions about anything that you do not understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative or friend.

If you decide you want to take part in the research study, you will be asked to:

☐ Keep a copy of this Participant Information Statement.

What does participation in this research require, and are there any risks involved?

If you decide to take part in the research study, you will be asked to participate in an interview that would take approximately 45–60 minutes. During the interview a member of the research team will ask questions about your perceptions and experiences related to trust in primary healthcare settings. With your permission, we would like to digitally record the interview using an audiotape. The interviews will take place at the location of your choice, preferably near to a place where you often interact with your provider for medical care. Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study.

Will I be paid to participate in this project?

For participating in this study, we will reimburse you for your time and transport up to Tanzanian Shillings 4,500 (equivalent to AUD 3).

What are the possible benefits to participation?

We hope to use information we get from this research study to benefit others who receive care from providers in primary healthcare settings in Shinyanga and Tanzania in general.

What will happen to information about me?

By signing the consent form, you consent to the research team collecting and using information about you for the research study.

The audiotaped digital recordings are for the purposes of the research study. After the interview we will transcribe your digital recordings. We will keep your digital recordings in the form of digital files for 7 years. We will store information about you temporarily at Shinyanga Regional Medical Officer's office then transfer them to the University of New South Wales in Australia. Your confidentiality will be ensured by only using the information for the purpose of this research study and it will only be disclosed with your permission.

It is anticipated that the results of this research study will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that your research findings may be published, but you will not be individually identifiable in these publications.

You have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with

which you disagree be corrected. You can do this by contacting a member of the research team.

How and when will I find out what the results of the research study are?

You have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback by contacting the researcher whose contact is in this form. This feedback will be in the form of aggregate summary in one-page paper. You will receive this feedback after the study is finished.

What if I want to withdraw from the research study?

If you do consent to participate, you may withdraw at any time. If you do withdraw, you will be asked to complete and sign the 'Withdrawal of Consent Form' which is provided at the end of this document. Alternatively, you can ring the research team and tell them you no longer want to participate. If you decide to leave the research study, the researchers will not collect additional information from you.

What should I do if I have further questions about my involvement in the research study?

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact the following member/s of the research team:

Research Team Contacts:

What if I have a complaint or any concerns about the research study?

If you have any complaints about any aspect of the project, the way it is being conducted, then you may contact:

Complaints Contact:

Form for Withdrawal of Participation

I wish to WITHDRAW my consent to participate in the research proposal described above and understand that such withdrawal WILL NOT affect my relationship with the health providers, facility or the government.

Participant Signature:

Appendix 6: Interview guide (English version)



STUDY ON PATIENT-PROVIDER TRUST IN SHINYANGA, TANZANIA

INTERVIEW GUIDE—ENGLISH VERSION

Pre- interview preparation

- Prepare information sheet about the objectives of the study
- Pre-test audio recording equipment (s)
- Prepare a pen and paper

Opening the interview

- Introduce yourself
- Greet the participant (according to Tanzanian norms)
- Clarify to participants about the consent, offer a participant copy and ask permission for interview and audio recording
- Offer a description of the purpose of the study, the interview and audio recording and answer all participants' concerns
- Record verbal consent at the beginning of the interview

Interview session

Participant category: Patients

After you have introduced the purpose of the study and the purpose of the interview, ask/record the date and place of interview, participants' age, gender, occupation, marital status, Religion, residence, level of education and average daily expenditure.

Interview questions:

First, I would like to understand **how you make choices of where to seek care for hypertension**. Please tell me what made you decide to seek care from the provider you met during the recent/current visit. Prompts: Factors influencing provider choices? Alternatives? Expectations?

Let us talk about **your experiences during the current/recent visit to a provider for hypertension care**. Can you describe what steps you passed through to receive care and how did the provider handle your health problem? **Prompt:** duration and quality of interaction, participation in making a treatment plan? Likes and dislikes? **Prompt:** Were you satisfied with the services? Why? What could have the provider done better?

Now, based on these experiences, **would you say you trust the provider who you received care from?** Why? **Prompt:** Familiarity with provider: visited before, how long have you known each other, compare today and past experience?

Next, **how would you tell that a certain patient trusts a provider?** **Prompt:** What does patient trust in their provider means to you? What are the signs of trust?

Consider when you were a patient 10 years ago, do you think trust is decreasing or increasing? Why?

Considering this health facility (or health facility in a village), what is your opinion(s) about the health facility, health workers, health providers and health care services in general
Prompt: Likes and dislikes? Trustworthiness of the facility, providers and health sector in general

Think of a time when you met any provider who made you trust/ or distrust him/her? **Prompt:** Who, where, when, reasons for trust or distrust?

Now, why do you think patients need to have trust in their providers? **Prompt:** **Benefits of trust to patient him/herself, provider, facility and health sector in general?** Any disadvantages?

As a patient in Shinyanga Region, can you talk about the challenges you face in building and sustaining trust with providers? **Prompt:** What can be done by patients, providers, health leaders and the government to address these challenges?

Is there anything else you would like to tell me about trust between you and your provider? Who was the provider who you received care from in the current/recent visit.....?

Participant category: Providers

After you have introduced the purpose of the study and the purpose of the interview, ask /record the date and place of interview, Participants' age, gender, education and qualifications, average patients per day and facility level and ownership (for Western care)

First, I would like to understand what kind of services you are offering here to hypertension patients. **Prompt:** Services offered to hypertension patients?

Consider the patients who seek care here, why do you think they come to you for hypertension care? **Prompt:** What do you do if you cannot manage them?

Think of a patient who is currently receiving care or have just received care from you for hypertension. Let us call him/her patient X. How did you arrive to the treatment recommendations you offered? **Prompt:** Steps to treatment decision? Duration of interaction? How did the patient participate in treatment plan? **Prompt:** Do you think the patient will adhere to plan? Why?

Now, based on the experiences during interaction, would you say that X trusts you? Why?

Prompt: What could you have done better to increase X trust in you?

Prompt: Familiarity with patient, visited before, how long have they known each other?

Prompt: Do you think patient will return to see you? Why?

Next, how would you tell that a certain patient trusts you? Prompt: What does patient trust in their provider mean to you? What are the signs of trust?

Can you share previous experiences with any patient that made you feel that s/he trust/ or distrust you? Prompt: Who, Where, Reasons for feeling trusted or distrusted

Considering health services in Shinyanga, what is your opinion(s) about the trustworthiness of the health providers, health facilities and healthcare services in general? Why?

Now, why do you think patients need to have trust in their providers? Prompt: Benefits of trust to patient him/herself, provider, facility and health sector in general?

As a provider in Shinyanga Region, can you talk about the challenges that patients face in building and sustaining trust with providers? Prompt: What can be done by patients, providers, health leaders and the government to address these challenges?

Is there anything else you would like to tell me about trust between patients and their providers?

THANK YOU

Appendix 7: UNSW Ethical Clearance



Human Research Ethics Committee (HREC)
The University of New South Wales
UNSW Sydney, NSW, Australia, 2052
E: humanethics@unsw.edu.au

W: <https://research.unsw.edu.au/human-research-ethics-home>

02-Sep-2015

Dear Associate Professor Anura Jayasuriya,

Project Title	Exploratory study of Patient-Provider trust in a low-income African primary health care setting in Tanzania
HC No	HC15535
Re	Personnel Modification Request dated 28.08.2015 adding Professor Heather Worth.

The modification to this project submitted on was approved by the HREC Executive on 01-Sep-2015.

If this project is a multicentre project you must forward a copy of this letter to all Investigators at other sites for their records.

Should you require any further information, please contact the Ethics Administrator at:

E: humanethics@unsw.edu.au

W: <https://research.unsw.edu.au/human-research-ethics-home>

The HREC Executive wishes you every continued success in your research.

Kind Regards

A handwritten signature in black ink, appearing to read "Heather Worth".

Professor Heather Worth
HREC Presiding Chairperson

Appendix 8: NIMR Ethical Clearance



THE UNITED REPUBLIC OF
TANZANIA



National Institute for Medical Research
3 Barack Obama Drive
P.O. Box 9653
11101 Dar es Salaam
Tel: 255 22 2121400
Fax: 255 22 2121360
E-mail: headquarters@nimr.or.tz
NIMR/HQ/R.8a/Vol. IX/2024

Ministry of Health and Social Welfare
6 Samora Machel Avenue
P.O. Box 9083
11478 Dar es Salaam
Tel: 255 22 2120262-7
Fax: 255 22 2110986

07th October 2015

Dr. Kahabi G Isangula
C/O Dr Tumaini M Nyamuhanga
School of Public Health, MUHAS
P.O. Box 65001
Dar es Salaam

CLEARANCE CERTIFICATE FOR CONDUCTING MEDICAL RESEARCH IN TANZANIA

This is to certify that the research entitled: Exploratory study of Patient- Provider Trust in a Low-Income African Primary health Care Setting in Shinyanga, Tanzania (Isangula K G *et al*) has been granted ethical clearance to be conducted in Tanzania.

The Principal Investigator of the study must ensure that the following conditions are fulfilled:

1. Progress report is submitted to the Ministry of Health and the National Institute for Medical Research, Regional and District Medical Officers after every six months.
2. Permission to publish the results is obtained from National Institute for Medical Research.
3. Copies of final publications are made available to the Ministry of Health & Social Welfare and the National Institute for Medical Research.
4. Any researcher, who contravenes or fails to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine. NIMR Act No. 23 of 1979, PART III Section 10(2).
5. Sites Shinyanga Region.

Approval is for one year: 07th October 2015 to 06th October 2016.

Name: Dr Mwelecele Malecela

Signature 
CHAIRPERSON
MEDICAL RESEARCH
COORDINATING COMMITTEE

CC: RMO
DED
DMO

Name: Prof. Muhammad Bakari Kambi

Signature 
CHIEF MEDICAL OFFICER
MINISTRY OF HEALTH, SOCIAL
WELFARE

Appendix 9: NIMR Data Transfer Authorization: Signature Page

SIGNATURE PAGE

FOR RECIPIENT:

RECIPIENT's Authorized Signatory

Signature

Professor Raina Macintyre

Printed Name and Title

Mailing Address for MATERIAL:

The University of New South Wales, School of Public Health and Community Medicine, Samuels Bld Level 2, Botany Street, Randwick, NSW Sydney Australia 2052

Tel: +612 93855311 Fax:

Email: r.macintyre@unsw.edu.au

RECIPIENT's Authorized Investigator: I acknowledge and understand the terms of this Agreement.

Signature

A/Prof. Rohan Jayasuriya

Printed Name and Title

Mailing Address for Notices:

UNSW Sydney NSW 2052
The University of New South Wales, School of Public Health and Community Medicine, Samuels Bld Level 2, Botany Street, Randwick, NSW, Sydney Australia 2052

Tel: +61215195448 Fax:

Email: r.jayasuriya@unsw.edu.au

FOR PROVIDER:

PROVIDER's Authorized Signatory

Signature

Dr Tumaini M Nyamhanga

Printed Name and Title

Mailing Address for MATERIAL:

Muhimbili University of Health and Allied Sciences, PO Box 65454, Dar Es Salaam

Tel: +255713254000 Fax:

Email: tumaininyamhanga@yahoo.com

PROVIDER's Authorized Investigator: I acknowledge and understand the terms of this Agreement.

Signature

Dr. Kahabi G. Isangula

Printed Name and Title

Mailing Address for Notices:

Mlepa Street, Ndala Ward, P.O. Box 1252, Shinyanga, Tanzania

Tel: +255754030726 Fax:

Email: kaisa079@yahoo.com

CERTIFICATION

Authorized Official: CHAIR MRCC.

Signature

DR MWELI FELE N. MALESELA

Printed Name and Title: DIRECTOR GENERAL

Mailing Address: P.O. Box 9663, DSM

Tel: +255222121400 Fax: +255222121360

Email:

Date

16/02/2016



Agreement No. _____

Page 9 of 10