

# VU Research Portal

## Patients, providers, and systems

Angwenyi, V.

2020

### **document version**

Publisher's PDF, also known as Version of record

[Link to publication in VU Research Portal](#)

### **citation for published version (APA)**

Angwenyi, V. (2020). *Patients, providers, and systems: local models for chronic care and self-management support in southern Malawi*. [PhD-Thesis - Research and graduation internal, Vrije Universiteit Amsterdam].

### **General rights**

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

### **Take down policy**

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

### **E-mail address:**

[vuresearchportal.ub@vu.nl](mailto:vuresearchportal.ub@vu.nl)

# **CHAPTER 3**

---

## **Research design**

In Chapter 1, the increasing burden of chronic conditions (both communicable and non-communicable diseases) in the sub-Saharan African region, and how health systems are responding was outlined. While a number of models and frameworks exist to guide better coordination of chronic care, several bottlenecks and contextual factors inhibiting their implementation were identified. In Chapter 2, the theoretical concepts guiding this thesis were presented. Both chapters highlighted the need for more empirical research, in order to understand how local health systems are responding to chronic care, especially in primary healthcare settings, which serve as the first point of care in most parts of rural sSA. In this chapter, we present the central research question and sub-questions formulated. In subsequent sections, we outline the research approach, describe the study setting, study design and data collection approaches, and conclude with a presentation of the ethical and research validity issues observed.

## **CENTRAL RESEARCH QUESTION AND SUB-QUESTIONS**

The central research question for this thesis is:

*What local innovations and practices exist for the self-management of patients living with chronic conditions, and how do they contribute to patient outcomes and to the delivery of responsive chronic care at primary care level in Malawi?*

Addressing this question involves studying local innovations and practices of self-management, and deepening the understanding and contextualisation of challenges and opportunities that currently present themselves within local health systems in resource-limited settings, as these are being reoriented towards delivering responsive chronic care at scale at primary level. This question is highly relevant to the sSA setting, tasked with delivering quality services to a growing population in need of long-term chronic care but within a context of multiple health systems constraints. Three sub-questions were formulated to answer the central research question:

1. *How is chronic disease self-management conceptualised by patients and providers of care, and what factors contribute to variations in experiences and practices in resource-limited settings?*

Chapters 1 and 2 highlighted how different health system contexts influence how chronic care is organised. Within sSA settings, the prominent role of community caregivers working alongside healthcare professionals was featured. This sub-question seeks to investigate the operationalisation and contextualisation of self-management and patient empowerment concepts, which are cornerstones for chronic disease management. We explore perspectives of chronic patients and providers of care (in clinics, community, and home settings) on these concepts, with illustrations of self-management practices and coping strategies when faced

with multiple (care) challenges as a provider or patient. We utilise Bandura's social-cognitive theory [1], to further unpack the self-management construct by drawing from patients lived experiences.

2. *What models of care and innovations exist within community and primary care settings to support delivery of chronic care, and what is their potential impact on patient self-management outcomes in resource-limited settings?*

In Chapter 2, chronic care models currently in use were reviewed and key principles transferable to resource-limited health system context identified. By reflecting on these conceptual models, that is, Wagner's chronic care model [2], and the WHO Innovative Care for Chronic Conditions Framework [3], it permits us to interrogate and deepen our understanding of what principles or features are present within our study context (rural Malawi). Under this sub-question, we explore the practice of chronic care, with a focus on self-management support resources in facility and community settings. It involves studying the different initiatives in existence, the providers of care, and forms of support provided to patients with chronic conditions. Particularly, we study community home-based care programmes, a prominent feature within the delivery of community-based care in Malawi, drawn from the HIV model of care. In order to evaluate the impact of these interventions on self-management outcomes such as health behaviour, health status, and self-efficacy, we conduct repeat surveys with chronically ill patients receiving home-based care followed for 12 months.

3. *How are local health systems and processes currently structured, and what adaptations may be required to enable responsive quality care for patients with multiple chronic conditions in resource-limited settings?*

In most sSA settings, primary care is offered at two tiers of the health system; community and primary healthcare facilities as described in Chapter 2. This sub-question aims at a closer investigation of how chronic care services are organised within these two levels. We apply a systems approach and draw on the integrated care framework [4], to explore how services for both chronic communicable conditions (such as HIV) and non-communicable diseases are coordinated, and identify gaps and opportunities for improving the efficiency of organising such health services in a primary care setting. The need for a supportive policy environment is critical in the coordination and delivery of care at different tiers of a health system. To this end, we examine the introduction and implementation of Malawi's first-ever national community health strategy [5], and analyse its significance in reorienting Malawi's community health actors and structures, and the implications for delivering chronic care at scale in the future.

## **RESEARCH APPROACH**

### **A transdisciplinary framing**

The overall research project was situated in a broader research call for ‘Transdisciplinary solutions for Global Health challenges in low- and middle-income countries (TGH)’, funded by the European Commission (EMJD 2015–1595). The transdisciplinary approach is an emerging field of scientific inquiry, which cuts across disciplines with different epistemic cultures, promotes methodological inquiries that transverse academic boundaries, and encourages collaboration in knowledge production of complex real-world problems [6]. For the purpose of this research, an interdisciplinary team was established which consisted of academics with expertise in the fields of social sciences, public health, general medicine, life sciences, and health systems and policy. The team collaborated closely with practitioners in Malawi, including district health officials and managers of community-based organisations, who were involved in the design and implementation of the research. The study built on previous research on the delivery of chronic care to HIV patients in the region, including Malawi [7].

### **Method of inquiry**

We applied a case study approach, using concurrent mixed-methods data collection [8, 9]. According to Yin [9], a case study approach is recommended for investigating a contemporary phenomenon in-depth and within a real life context. Case study approaches are particularly useful when there are multiple variables of interest and when boundaries between the phenomenon and the context in which it occurs are not clearly evident [9]. It utilises multiple sources of information for establishing a deeper understanding of the study topic. For this research, the case unit was a single district in Malawi (Phalombe), with multiple-units of data collection (community/faith-based organisations and health facilities), as illustrated in Figure 3 below. Empirical data collection was guided by a social-constructivist approach [8], which aims at co-production of knowledge between the research participants and researchers, by means of extensive interactions between them, in order to understand the social realities and processes of the topic under study.

The overarching purpose of the study in Malawi was to use primary data to inform the conceptualisation of self-management practices and support for chronic conditions within the community, and primary care settings in resource-limited settings in sSA. Furthermore, the local evidence generated could be used to inform policies and strategies for delivering responsive, quality care for a growing population in need of long-term care.

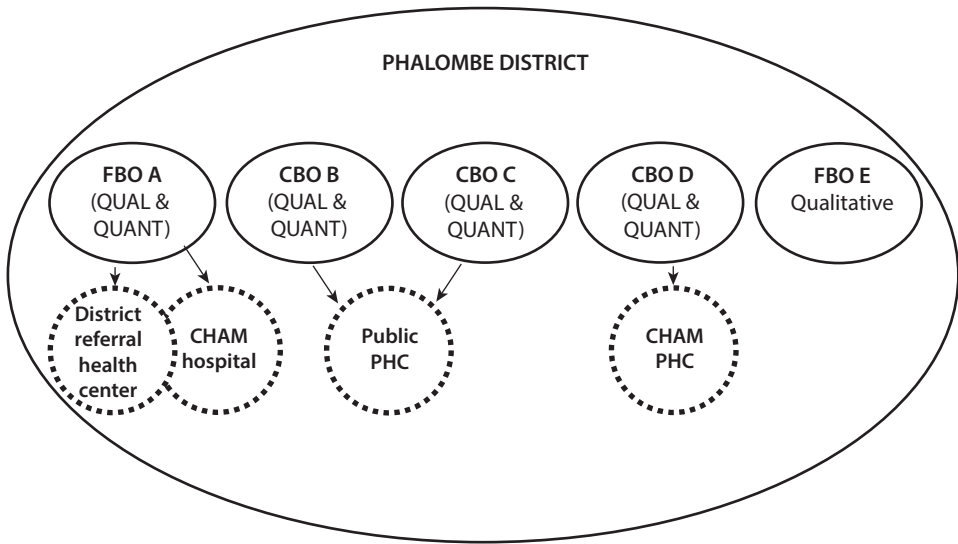
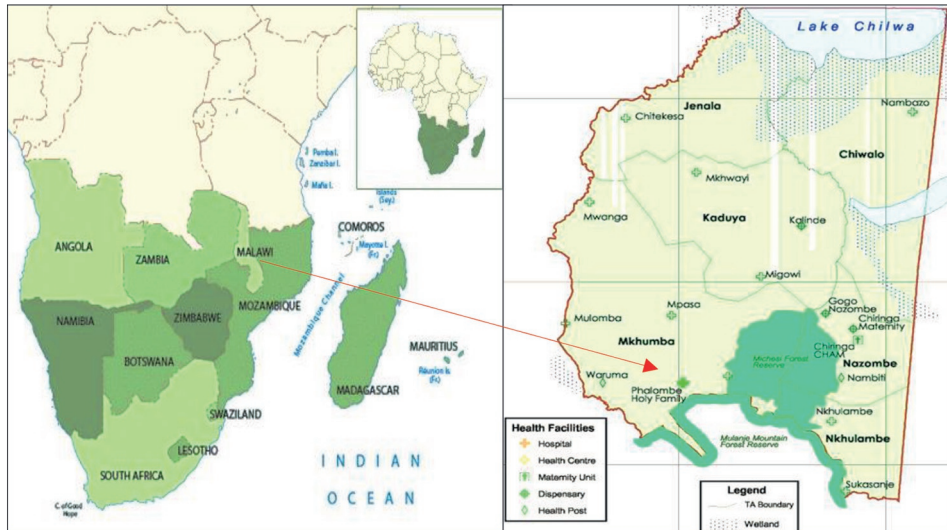


Figure 3 — A summary of the study units and methodological approaches applied

## STUDY SETTING

The setting for this research project was Phalombe District, located south-east of Malawi and near the border with Mozambique, as shown in Figure 4. Malawi is a small land-locked country with a population of approximately 17 million people in 2017, of which 2.3% (393,587) reside in Phalombe district [10]. Over 80% of the Malawian population live in rural areas with a predominantly agricultural economy, with high unemployment and poverty levels. The Lomwes are the main ethnic group and languages commonly spoken are Lomwe and Chichewa, which is the official national language. Phalombe is a relatively new district. It was previously part of Mulanje district, and was declared a district in 1996. Administratively, Phalombe has six Traditional Authorities (TAs), further sub-divided into 46 Group Villages (GVs), and 450 villages.



**Figure 4** — Map of Malawi and Phalombe district

SOURCE: Google Maps™ and Phalombe District Health Sector Multi-year Plan 2013–2016

### Phalombe district healthcare system

There are 15 health facilities to serve the residents of Phalombe [10] operated by government and faith-based organisations. These include a private hospital, 11 health centres, 2 dispensaries, and a maternity unit. Government health facility services are fully subsidized (free-for-user), while private health facilities operated by the Christian Health Association of Malawi (CHAM) operate on a user-fee policy [11]. The only hospital in Phalombe district is the Holy Family Mission Hospital, which is a paying faith-based hospital, sub-contracted by the government to provide subsidized services. Phalombe Health Centre is a government referral facility located at the district headquarters. Due to its limited capacity and resources, patients requiring specialized care are referred to Holy Family Mission hospital or to Zomba Central hospital in the neighbouring district.

**Table 2** — Phalombe district healthcare systems

<b>HEALTH FACILITIES; LEVEL AND OWNERSHIP</b>		
Secondary Care (hospital*)	Provides secondary care including promotive, preventive, curative, laboratory, in-patient care and minor surgeries  Operated by general doctors, clinical officers, registered nurses, medical assistants, health surveillance assistants  Serves between 30,000–40,000 people	1 CHAM/private Holy Family Mission Hospital  1 district government health centre/Phalombe health centre (acts as a government referral facility)
Primary care (health centres, dispensaries, health posts and maternity units)	Medical assistants, nurses and in some places clinical officers, supported by HSAs and allied staff.  Provides primary curative and preventive care, which includes diagnosis, treatment, immunization, macronutrient supplementation, maternity, health education, and hygiene and sanitation promotion.  Outreach services are offered in communities and in village health posts  Serves between 10,000–30,000 people	7 MoH/public health centres (Migowi, Nambazo, Nkhulambe, Chitekesa, Mkhwayi, Mpsa, Gogo Nazombe)  3 CHAM/private health centres (Chiringa, Sukasanje – categorised as community hospital, Mwanga)
	Dispensaries offer preventive, promotive, outpatient, curative and outreach care.	1 MoH/public dispensary (Kalinde)
		1 CHAM/private dispensary (Mulungu Alinafe)
	Maternity units focus on maternal health services. Operated by medical assistants, nurses and HSAs	1 CHAM/private maternity unit (Chiringa Maternity)

### Phalombe district health and demographic profile

In Phalombe, the number of people living with HIV is 62,612 in 2018, which accounts for 15.5% of the district population. In addition, there is a growing burden of NCDs (especially cancers and cardiovascular diseases) [10]. In Phalombe, life expectancy is at 42.5 years for males and 46.5 years for females [10]. While the average length of school attendance in Malawi is 11 years, only 8.6% of the population in Phalombe complete primary school.

### Identification of community-home based care (CHBC) programmes

In Malawi, CHBC programmes have played a prominent role in extending HIV care to households and communities since 1980s. These are nationally recognised structure for delivering home-based care to chronically-ill patients [12]. Hence, we focused on these programmes as the central entry-point for our study. As the model of interest,



identification and selection of CHBC programmes was guided by the following criteria:

- CHBC programmes that were operational for over 10 years
- CHBC programmes that offered a wide range of services including preventive, treatment, care and self-management support
- CHBC programmes that covered different populations such as rural, peri-urban and urban communities, and community members from different socio-economic strata
- CHBC programmes that were managed and financed by different types of organisations such as non-governmental organisations, faith-based or community-based organisations

Using the above criteria, the study team engaged in extensive consultation with researchers and key contacts of organisations working in Malawi. In Phalombe, we selected five community and faith-based organisations (CBO/FBOs) based on their exposure to a pilot-project which focused on strengthening the capacity of CHBC volunteers to deliver community-based chronic care. Through the CHBC volunteers, the project offered medical and psychosocial support to chronic patients and provided economic livelihood support to vulnerable households. CHBC volunteers were trained in home-based care and management of chronic conditions. This project was implemented by the Archdiocese of Blantyre Health Commission between 2013 and 2015, and was funded by Cordaid International (Netherlands). Each of these CBO/FBOs operated within the catchment area of a health facility where their patients could access healthcare services. These link facilities included a district referral health centre, one public health centre, a Christian Health Association of Malawi (CHAM) hospital, and one CHAM health centre, which were also studied (see Box 1 for further details).

**Box 1 — Characteristics of CBO/FBOs selected for the research**

CHARACTERISTICS	FBO (A)	CBO (B)	CBO (C)	CBO (D)	FBO (E)
Year established	1996	2006	2008	2009	2005
<i>Location, accessibility and proximity to district headquarters</i>	At district headquarter (hired office, near to CHAM hospital)	>50 KM, poor road access (CBO land, 7 km from PHC facility). Near CBO B	>55 KM, poor road access (CBO land, very near PHC facility). Near CBO C	>40 KM, along main highway (CBO land, 10 km from CHAM PHC)	>30 KM, near main highway (hired office, next to CHAM PHC)
<i>Linked health facility(s)</i>	CHAM Hospital District referral health centre	Public health centre	Public health centre	CHAM health centre	CHAM health centre
<i>Villages covered (population size)</i>	12 (9,198)	6 (6,889)	9 (6,196)	7 (6,321)	6 (4,697)
<i>No. of active community health volunteers</i>	51	52	32	29	22
<i>Linked patient support groups</i>	4	1	3	2	2
<i>No. of chronic patients (total beneficiaries)</i>	326 (618)	91 (538)	242 (500)	133 (499)	42 (270)
<i>CBO/FBO thematic area</i>	HIV/AIDS; CBCC; OVC; HBC; safe motherhood; hygiene and sanitation; elderly and disabled; human and child rights; youth; gender; environment/climate change and agriculture; livelihood support				
ACRONYMS: CBCC: community-based childcare centres; CBO: community-based organisation; CHAM: Christian Health Association of Malawi; FBO: faith-based organisation; HBC: home-based care; OVC: orphans and vulnerable children					

## A CONCURRENT MIXED-METHODS RESEARCH DESIGN

The overall research design was a concurrent mixed-methods study, with a qualitative component engaging a range of study participants and a quantitative component covering a repeated survey-design administered to chronically-ill patients enrolled in CHBC programmes. Data were collected between March 2016 and May 2017, through an iterative process. Below we describe each of the methods used, while specific details on the methodology are presented in corresponding chapters of the thesis.

### Qualitative methods, sampling and instruments

#### *Structured observations*

In the initial phase of data collection, we conducted structured observations in the selected CHBC programmes and health facilities. Observations aimed at familiarising

ourselves with, and capturing the range of activities that took place within the CHBC programmes. In health facilities, the purpose was to document and describe the care process and services offered. A structured observation checklist was used to capture and document observations in health facility settings – see also Appendix 1A.

### ***Desk review***

Throughout the study, we reviewed and synthesised published grey and scientific literature, and reports from the district and other parts of Malawi. The review included an analysis of district implementation plans and health records; clinical guidelines for HIV and NCDs, and relevant policy documents such as the National Health Sector Strategic Plans. Information obtained provided a broader contextual understanding of the district and Malawi at large, with reference to the organisation and delivery of chronic care. We regularly reviewed scientific literature in the field of self-management, chronic care, and health systems published in the region and globally.

### **Interviews and focus-group discussions**

We selected healthcare providers and managers (n=15) from five out of fifteen health facilities in the district as interview respondents, using purposive and snowballing techniques [13]. Selection aimed for representation and diversity by gender, health worker cadre (clinical, non-clinical, and health managers with varying responsibilities in chronic care), and health facility category (public and private; PHC and referral facilities). A structured topic guide was used to explore among health managers and healthcare workers their understanding, perceptions and role in self-management support, organisation of chronic care, and support resources in community settings – see Appendix 1B and 1C.

We also selected patients for interviews (n=10) and focus group discussions (n=4; 31 respondents) through purposive and snowballing techniques (Green & Thorogood, 2004). Patients were identified from the same CBO/FBO registers, with selection aimed at ensuring representativeness in gender, diversity of chronic conditions and/or comorbidities, and residency. A structured topic guide was used to explore patients' perceptions and experiences of chronic care services within facilities, interaction and communication with healthcare providers, and resources for self-management support at home and in community setting (see also Appendix 1D and 1E).

Furthermore, community-based caregivers such as volunteers in CBO/FBOs were selected purposively to participate in focus-group discussions (n=4; 24 respondents), to understand their roles and services they provide under CHBC programmes. Additionally, we sampled four HIV-expert patients from four health facilities to learn their roles in HIV care and other forms of self-management support. We interviewed 10 family caregivers responsible for the daily caregiving responsibilities of patients living with chronic conditions. A sample of topics covered is included in Appendix 1F and 1G.

### ***Learning visits and meetings***

Beyond the CHBC programmes, we visited an additional five non-governmental organisations (NGOs) implementing health programmes and activities within the study district. Organisations were identified through snowballing techniques and referrals from healthcare providers and managers working in the district. The purpose of these visits was to familiarise ourselves with the scope of these programmes, services and support provided for chronic patients within health facilities and community settings, funding arrangements, and the nature of collaboration with the district health office and other partners in supporting chronic care services. Discussions with representatives from these organisations were open-ended, guided by the above themes. Information was recorded through detailed handwritten notes.

### **Quantitative methods, sampling and instruments**

The quantitative component was a repeated survey among chronically-ill patients, newly enrolled into CHBC programmes. Hypothetically, we wanted to establish whether exposure to or receipt of CHBC made any difference over time in how patients managed their conditions. Our study outcomes of interest were changes in health status, self-efficacy, and self-management behaviour.

Survey sample size estimation was computed based on the ability to detect a 12-month mean change of at least 0.5 (SD 2.4) in self-efficacy scores [14], a significance level of 5%, at 95% power after accounting for 30% attrition. Survey inclusion criteria were patients aged 18 years and above, with one/more diagnosed chronic condition(s), and newly registered in one of the CHBC programmes. We engaged with CBO/FBOs that were actively providing home-based care, hence one FBO was excluded from the main survey component of the study. Eligible patients were identified from CBO/FBO registers, with recruitment happening concurrently in four CBO/FBOs. Volunteers in the selected CBO/FBOs visited eligible patients to book appointments, followed by a visit from the research team visit to provide patients with detailed study information and administer consent. We enrolled 140 patients at baseline, and interviewed them after months three, six, and twelve in order to assess whether exposure to or receipt of CHBC made any difference over time in how patients managed their conditions. The same set of questions were administered in every survey round. The survey was interviewer-administered using an electronically programmed application (Open Data Kit®) which was uploaded to a secure web-based database.

The survey instrument consisted of adapted validated scales from the chronic disease self-management programme [15, 16], behavioural risk-factor questions from a Malawian NCD STEPS survey [17], and modified questions from other literature [18, 19], further described in Appendix 2.

### **Data management and analysis**

Data from in-depth interviews and focus group discussions were captured using digital voice recorders and field notebooks. All audio files were transcribed verbatim and translated to English. Personal identifiers in interviews and questionnaires were replaced with codes. Data were kept secure in locked cabinets as well as in password-protected computers, which were only accessible to research team members.

Qualitative data were organised and managed using NVivo (Version 11, QSR international), and both thematic and framework approaches were applied to analysis [13, 20]. Initial steps involved familiarisation with the data, followed by the development of a coding framework based on inductive and deductive processes, done by the thesis author and reviewed by one of the thesis supervisors. The thesis author did all the coding, and once coding was completed categories were developed based on overarching themes. Analytical charting was done in Microsoft Word® to explore emerging patterns and refine interpretation of findings.

Quantitative data were analysed in STATA® (Version 13; StataCorp, College Station, TX, USA). Descriptive summaries were performed to describe the characteristics of survey patients. Chi-square tests for associations (or a Fisher's Exact Test for small sample size) were performed to establish the relationships between categorical variables (e.g. HIV and non-HIV patient groups) and study outcomes. To compare changes in outcomes across time-points, and using baseline scores as reference, we performed either paired student T-test or Wilcoxon signed-rank test, depending on data distribution. Due to multiple comparisons, we used statistical significance levels at Bonferroni-corrected p-value thresholds, adjusted by number of comparisons. All statistical tests were two-sided. Furthermore, multivariate analyses were performed to adjust for known or perceived confounding variables (including socio-demographic variables) in assessing the effect of exposure to self-management support interventions on study outcomes.

### **RESEARCH TEAM**

The data collection team consisted of three Malawian research assistants who worked under close supervision of the thesis author, of Kenyan nationality with extensive research experience outside the Malawian context. The research assistants had professional backgrounds in nursing, project management, and community development, and working experience in either HIV research or in HIV programme implementation. Prior to each data collection round, the research assistants underwent 10-days training on the research protocol, consent processes, study instruments, and participated in the pre-testing of tools. In addition, the research team was complemented by two interns, each pursuing a Bachelors and Master's degree from the Vrije Universiteit Amsterdam, who supported this research at different

intervals e.g. data collection and literature review. To facilitate the implementation of this research, we worked closely with volunteers from CHBC programmes who supported the study with the identification and mobilisation of research participants, and communicated issues emerging from the community related to this study. A team of four supervisors offered technical and supervisory support to the thesis author during research implementation and provided guidance during analysis, interpretation of results, and manuscript writing.

## RELIABILITY AND VALIDITY IN THE RESEARCH PROCESS

Reliability refers to the consistency, rigour, dependability, and replicability of results obtained from a piece of research, and aims to minimise errors and biases in a study [9]. Validity is concerned with methodological soundness and the extent to which research findings truly represent the phenomenon under study [8]. Concepts used synonymously to refer to research validity include trustworthiness, credibility, confirmability, and data dependability [9]. For this mixed-methods research, several steps were undertaken to ensure that reliability and validity qualities were met. First, survey instrument development was informed by a review of literature to identify scales used in other settings with established psychometric properties, which were translated and pre-tested by us for use in the Malawian context. To ensure consistency, the same research team was involved in data collection and received extensive training and close supervision. Data quality checks involved reviewing all questionnaires prior to uploading data to the server.

Qualitative data collection, by the same research team, occurred concurrently with the survey administration, which allowed for the incorporation of emerging issues and new questions identified from the survey. Taking detailed notes of observations and interactions throughout the entire fieldwork provided valuable additional information in deepening our understanding and providing 'thick' contextual description of the study setting.

The technique of triangulation was used to enhance credibility in the interpretation and presentation of research findings [21]. Data triangulation was used to compare similarities and differences of information from multiple sources such as interviews, focus group discussions, observations, and survey responses. During analysis, patterns within datasets were explored and interpretations of findings were aided using analytical charts. The final round of data collection enabled verification of initial themes and findings with focus-group participants (patients and CBO/FBO volunteers). At the end of every data collection cycle and as part of research validation, dissemination meetings and presentations were organised where preliminary research findings were shared with CBO/FBO representatives, healthcare providers and managers, and other local stakeholders for further verification.

Reflexivity and transparency of the researchers' positionality [13] was observed through the following steps: daily feedback meetings were arranged where the research team discussed data collection procedures, reflected upon emerging issues, and how their actions could have influenced the research process. By being aware of our 'outsider' status (researchers not from the same study community, of different professional and cultural backgrounds), we openly discussed how this could have shaped our interpretations of the interactions we had with research participants. We regularly documented procedural issues as well as personal reflections in a field journal. In addition, there was close consultation between the research team and local collaborators, which facilitated the management of practical issues related to the research implementation.

To strengthen external validity and generalizability of research findings to other contexts, we compared study findings with the published literature, particularly from the sub-Saharan African region. For instance, we compared self-management practices with the literature on chronic disease self-management and on conceptual frameworks around self-management processes. Findings of the integrated approaches to chronic care were compared with the literature on health systems strengthening and models of chronic care in Africa and globally.

## **ETHICAL CONSIDERATIONS**

Ethical approval for this research was obtained from the Vrije Universiteit Amsterdam, The Netherlands (EMGO+; WC2015-080, 27–Oct–2015), and the National Committee on Research in the Social Sciences and Humanities, Malawi (P.11/15/64, 10–Dec–2015). Formal permission to implement this research was obtained from the Malawian Ministry of Health at the national level, and from the Archdiocese of Blantyre Catholic Health Commission, the Phalombe district health office, and the Phalombe District Commissioner. Prior to implementation, we organised meetings with local leaders, representatives from health facilities, and volunteers from community/faith-based organisations (CBO/FBOs) to introduce the study and seek permission for its implementation in their respective communities.

Trained research assistants explained the purpose and contents of the study in the local language (Chichewa), and obtained written informed consent from study participants (see Appendix 3). For study participants who were not able to read and/or write, an independent witness of their choice was present during consent administration and signed consent forms on their behalf. Each participant was given a copy of the information sheet and the signed consent form. In the survey, the study team re-explained study information and obtained written informed consent for every round of data collection, as well as crosschecked participant's willingness to continue with the study. This additional step was included due to the longitudinal

nature of the survey and an awareness that an individual's understanding and decision to participate in research could change over time; hence, the ethical obligation of ensuring that participants were presented with opportunities of study information exchange and choice of participation.

Patient interviews and the administration of the surveys were mostly conducted in homes (or at patient's preferred location such as a nearby CBO/FBO office) to minimise inconveniences and promote privacy and confidentiality in discussions. Discussions lasted between 45 minutes and one hour. In the case of health workers and managers, we secured interview appointments during less busy times at their place of work. Participants were provided with a small reimbursement to cover transport and light refreshment. At the end of the study, all survey participants received a small package of household items to express the team's appreciation. Community health volunteers from CBO/FBOs who assisted the research team with mobilisation and booking of appointments with survey participants were reimbursed for their time based on locally agreed rates.

All data were stored in password-protected computers and hard copies kept in lockable cabinets, accessible only by the research team. Study participants' information was kept confidential and anonymised; that is, identifiable information was replaced with codes. Engaging chronic patients as research participants required taking additional measures. We did not expose any research participant to harm during the research, nor disclose information on patient's health status to anyone. Some questions asked such as health status and medical history triggered memories about past events. Interviewers were objective in listening to patient's accounts and at the end of discussions crosschecked if there were any concerns or questions, which were then documented for further action. For issues raised that concerned treatment or clinical management of patient's condition, the interviewers encouraged and advised patients to seek further assistance from healthcare personnel. During meetings with CBO/FBO volunteers and healthcare personnel, the researchers summarily shared issues that emerged during the home visits and required further action.

## OUTLINE OF RESULTS CHAPTERS

The results chapters are organised into two parts, further illustrated in Table 3. **Part I** focuses on self-management micro-practices, support initiatives and outcomes for chronically ill patients. Firstly, **Chapter 4** presents a qualitative account of patients' experiences with self-management and strategies devised for dealing with their chronic condition. **Chapter 5** explores perspectives of patients and care providers on the role of self-management support and patient empowerment in the delivery of chronic care. **Chapter 6** compares self-management outcomes among patients with different chronic conditions enrolled in CHBC programmes. Chapters presented in



the second part examine the organisation of chronic care, that is, current practices, innovations, adaptations, and policy directions for chronic care. In **Chapter 7**, we present perspectives of different actors operating within the Malawian health system on the practicalities and dilemmas of delivering integrated chronic care at primary care level. **Chapter 8** analyses Malawi's recently launched national community health strategy and the implication of the proposed community health system for delivering chronic care at scale in the future. **Chapter 9** discusses the research, policy and practice implications of the research findings presented in **Chapters 4 to 8**. Here we reflect on how the central research question and sub-questions were addressed, and situate this within the existing body of evidence.

**Table 3** — Overview of results chapters and research questions addressed

THESIS RESULTS SECTION	RESEARCH QUESTION	THESIS CHAPTERS				
		4	5	6	7	8
<i>I. Self-management micro-practices, support initiatives, and outcomes for chronically-ill patients</i>	1. How is chronic disease self-management conceptualised by patients and providers of care, and what factors contribute to variations in experiences and practices in resource-limited settings?					
	2. What models of care and innovations exist within community and primary care settings to support delivery of chronic care, and their potential impact on patient self-management outcomes in resource-limited settings?					
<i>II. Organisation of chronic care: current practices, innovations, adaptations, and policy directions</i>	3. How are local health systems and processes currently structured, and what adaptations may be required to enable responsive quality care for patients with multiple chronic conditions in resource-limited settings?					

## REFERENCES

1. Bandura A. *Self-efficacy: toward a unifying theory of behavioral change*. Psychological review, 1977. 84(2): p. 191.
2. Wagner EH, Austin BT, and Von Korff M. *Organizing care for patients with chronic illness*. The Milbank Quarterly, 1996: p. 511-544.
3. World Health Organization. *Innovative care for chronic conditions: building blocks for actions: global report*. 2002. Available from: <http://www.who.int/chp/knowledge/publications/icccglobalreport.pdf>. [cited 2014 18 Dec].
4. Valentijn PP, Schepman SM, Opheij W, and Bruijnzeels MA. *Understanding integrated care: a comprehensive conceptual framework based on the integrative functions of primary care*. Int J Integr Care, 2013. 13: p. e010.
5. Government of Malawi. *National Community Health Strategy 2017 - 2022: Integrating health services and engaging communities for the next generation*. 2017, Ministry of Health: Lilongwe-Malawi.
6. Gray B. *Enhancing transdisciplinary research through collaborative leadership*. Am J Prev Med, 2008. 35(2 Suppl): p. S124-32.
7. Aantjes CJ. *Drawing from what they know : how primary health and community care adaptations for HIV can serve patients with other chronic conditions*, in Athena Institute, Faculty of Sciences. 2015, Vrije Universiteit Amsterdam: The Netherlands.
8. Creswell JW. *Research design: qualitative, quantitative, and mixed methods approaches*. 2014.
9. Yin RK. *Case study research: design and methods 5th ed*. Thousand Oaks, 2014.
10. Malawi Ministry of Health. *Phalombe District Health Sector Multi-year Plan 2013 -2016*. 2013.
11. Government of Malawi. *Health Sector Strategic Plan II 2017 - 2022: Towards universal health coverage*. 2017: Ministry of Health Lilongwe - Malawi.
12. Government of Malawi. *National Community Home Based Care Policy and Guidelines*. 2011, Ministry of Health,; Lilongwe.
13. Green J and Thorogood N. *Qualitative Methods for Health Research* ed. D. Silverman. 2004, London: SAGE Publication Ltd.
14. Lorig K, Ritter P, Stewart AL, Sobel DS, Brown Jr BW, Bandura A, Gonzalez VM, Laurent DD, and Holman HR. *Chronic disease self-management program: 2-year health status and health care utilization outcomes*. Medical care, 2001. 39(11): p. 1217-1223.
15. Lorig K and Laurent D. *Primer for evaluating outcomes*. 2007. [https://www.selfmanagement-resource.com/docs/pdfs/primer\\_2017.pdf](https://www.selfmanagement-resource.com/docs/pdfs/primer_2017.pdf).
16. Self Management Resource Centre. *English Evaluation Tools; Self-Management Behaviors*. <https://www.selfmanagementresource.com/resources/evaluation-tools/english-evaluation-tools>.
17. Msyamboza KP, Ngwira B, Dzowela T, Mvula C, Kathyola D, Harries AD, and Bowie C. *The burden of selected chronic non-communicable diseases and their risk factors in Malawi: nationwide STEPS survey*. PLoS One, 2011. 6(5): p. e20316.
18. Modeste M, Regis R, and Majeke SJ. *Sources and types of information on self-care symptom management strategies for HIV and AIDS*. curationis, 2014. 37(1): p. 1-9.

19. Schulman-Green D, Jaser SS, Park C, and Whittemore R. *A metasynthesis of factors affecting self-management of chronic illness*. *Journal of advanced nursing*, 2016. 72(7): p. 1469-1489.
20. Ritchie J and Spencer L. *Qualitative data analysis for applied policy research* in *Analysing Qualitative Data*, A. Bryman and R. Burgess, Editors. 1994, Routledge. p. 173-194.
21. Miles MB and Huberman MA. *Qualitative data analysis: An expanded sourcebook*. 2nd Edition ed., 1994: Sage Publications.