Exploring a participatory multi-stakeholder engagement approach to address chronic medicine use

A thesis submitted in fulfilment of the requirements for the master’s degree in
Pharmacy (M. Pharm) in the Faculty of Science, School of Pharmacy of the
University of the Western Cape

By

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November 2023

KEYWORDS

Chronic medicine use

Diseases experiences of patients with chronic diseases

Community-based health research

Multi-stakeholder collaboration

Health Education Institutions

Community

Community health workers

Non- governmental organisations

Participatory Action Research

DECLARATION

I, Bonheur Parfaite Nfurayase, declare that this thesis entitled '*Exploring a Participatory multi-stakeholder engagement approach to address chronic medicine use'* presents my original work and study outputs. This thesis reflects my efforts to best capture our unique research journey and findings under the supervision of Professor Angeni Bheekie, Dr Mea van Huyssteen, and Dr Cornel Hart. I vouch that I have not previously submitted this thesis for examination and have not been awarded any degree, diploma or certificate within my institution or any other. To the best of my ability, I have acknowledged and credited authors and sources contributing to this thesis write-up. Lastly, I established usage rights and creative commons licenses within academic and teaching settings for images and illustrations that are not my original work.

Signed,

Ms Bonheur Parfaite Nfurayase

17 July 2023

Cape Town, South Africa

ACKNOWLEDGEMENTS

I dedicated this thesis to Petronille Mukarugwiza.
For every sacrifice you've made to get me closer to my dreams.
For believing in me even when I struggled.
No words can describe how grateful I am to be called your daughter.
In my heart, your legacy and strength live on.
We made it, mama.

******

What a rewarding adventure this has been. I am deeply blessed with incredible people in my life, and for that, I am grateful. I want to thank three superwomen who held my hand while navigating community-based research's complex and character-building world. Prof Bheekie (Aunty Prof), thank you for gifting me a wide-eyed novel researcher seeking work that touches the heart, kindness, patience and guidance selflessly. Your consistency in believing in my abilities and reminding me of my strength as I fought with self-doubt and imposter syndrome touched me deeply. Dr Hart (Aunty Doc), I am deeply grateful for your mentorship, authentic love and willingness to go above and beyond for my holistic development. From the first time I walked into your office to the many phone calls, meetings, and lunches centred around my heart space, more than my brain space are precious memories that I hold dear to my heart. Dr Van Huyssteen (Dr V), flashbacks of your attention to detail, welcoming nature and bubbly personality remain vivid. While you were all tasked with simply being my supervisors, you gifted me with friendship, mentorship and kindness as I have never known. I am so excited for all the impactful work we will do in future.

I would also like to especially thank my dear friends: Ida Okeyo, Nadine Khotoo, Providence Niyigena, Adeline Rukondo, Blandine Mizero, Onyinye Akunne, Vuyo Cwati, Didi Mucyo, and Emmanuel Tuyishimire. Thank you for your commendable love, patience, cheerleading and never-ending grace for all the birthdays, life updates, parties and hangout sessions that I missed and turned into a support group for my struggles with finishing this thesis. I love you all very much, and now that I have submitted this thesis, I promise to arrive earlier and be more of my bubbly self. To the love of my life, keorapetse Selebogo, your never-ending love, encouragement, support and patience held me together as I walked the last mile of this journey. Thank you, Motho Waka.

Lastly, to my mother's friends and colleagues who became pillars of strength and encouragement as I mourned losing her, I remain forever indebted to you. I would also like to thank the Ada and Berti Levenstein Bursary Association for their generous support during the first two years of my master's. I would also like to acknowledge NRF for awarding me various support grants in the last three years of my master's.

ABSTRACT

Background: In South Africa, chronic diseases (CD) fall into the quadruple burdens of diseases. In 2018 the World Health Organization (WHO) reported that chronic diseases were responsible for more than fifty percent of premature deaths. This report followed South Africa's announcement in 2016 that CDs accounted for forty-nine percent of all total deaths. Globally and locally in South Africa, many progressive policies, strategic documents and interventions to address CDs remain commendable. However, the prevalence and burden of CDs on national healthcare systems and community health is concerning. Consequently, newer and revised approaches and strategies prioritising multi-government and multi-stakeholder collaborations are gaining popularity. Moreover, Participatory Action Research (PAR) and its founding principles as an approach to addressing healthcare issues are gaining momentum. Disappointingly such approaches within chronic disease contexts remain underexplored in South Africa.

Bearing these considerations in mind, we explored the use of a Participatory multi-stakeholder engagement approach to address chronic medicine use issues (CMU) within an underserved community in the Western Cape. Our collaborative research project commenced in 2018 in a unique research setting that boasted pre-established partnerships between a pharmacy School and its services partners (NGO and CHWs). These service partners connected the School to surrounding communities through one of their experiential learning programmes, Service Learning in Pharmacy (SLiP).

Research questions: Attempting to use the partnerships described above, we wanted to identify and contextualise the chronic disease experiences of patients living in Delft within a multi-stakeholder context. Essentially, we had two research questions:

1. What issues do people taking chronic medicine face in Delft?
2. How is a participatory multi-stakeholder approach useful in addressing such issues?

Methods: Subsequently, to answer these two research questions, we followed a 3-step process of engaging stakeholders; *Basic orientation*, *Consultation/ problem diagnosis* and *prioritisation and integration*. During these steps, we used participatory appraisal tools to engage the stakeholders on CMU experiences and partnership dynamics and identified preliminary interventions to address CMU issues within the Delft community.

Findings: Delft community members affected by chronic disease navigate unfriendly socio-economic conditions that negatively affect their disease experiences, health behaviours and chronic medicine adherence. Health system-related factors such as patient interactions with doctors, nurses and pharmacy personnel, chronic medicine stockouts and generic substitution, and lack of quality medicine counselling also contribute toward sub-optimal adherence.

The Health Education Institution (HEI) and Non-governmental Organisation (NGO) research stakeholders described institutional and internal organisational barriers that limited their efforts to engage with each other and the community within mutually beneficial contexts. In one instance, the HEI group suggested that the university remains detached from the realities of the NGOs, CHWs and communities. Stakeholders contextualised strained relationships between the community, HEI, NGO and some Primary Healthcare Clinics (PHCs) in Delft. Lastly, CHWs and the community stakeholders expressed disappointment at the lack of HEI and NGO visibility in Delft.

The primary research stakeholders identified four interventions to address the contextualised CMU issues.

Contribution of this study: Our unique participatory multi-stakeholder engagement approach, underpinned by creative, fun and interactive participatory appraisal tools, facilitated a radical inquiry process to contextualise chronic medicine use issues with patients with chronic disease residing in Delft. The inclusive nature of this project empowered patients with chronic diseases and offered a platform for stakeholders to solidify strained relationships. Finally, lessons learnt from our unique approach provide valuable insights for community developers, policymakers, health professionals, academics, and researchers.

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ABBREVIATIONS

ANC	African National Congress
CDU	Chronic Dispensing Unit
CE	Community Engagement
CEU	Community Engagement Unit
CHS	Community and Health Sciences
CHW	Community Health Worker
COM	Chief Operations Manager
COPC	Community Oriented Primary Care
CTSA	Clinical and Translational Science Awards Consortium
DoH	Department of Health
FGD	Focus group discussion
HCT	Healthcare Team
HEI	Health Education Institution
ICDM	Integrated Chronic Disease Management
ICSM	Integrated Clinical Services Model
IPE	Interprofessional Education
MSA	Multi-stakeholder Action
MSCW	Multi-stakeholder collaborative workshop
NCD	Non-communicable disease
NGO	Non-governmental organization
NHI	National Health Insurance
NIH	National Institutes of Health

NPC	National Planning Commission
PAR	Participatory Action Research
PHC	Primary Health Care
QPBPA	Qualified Post Basic Pharmacist’s assistant
SADoNT	South African Department of National Treasury
SANCDA	South African Non-Communicable Diseases Alliance
SANDoH	South African National Department of Health
SANDoP	South African National Department of the Premier
SLiP	Service Learning in Pharmacy
THEnet	Training for Health Equity Network
UHC	Universal Health Coverage
UN	United Nations
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UN-HLM	United Nations High-Level Meeting
UNICEF	United Nations Children's Fund
WCDoH	Western Cape Department of Health
WCGDoP	Western Cape Government Department of the Premier
W/S	Workshop
WHO	World Health Organization

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CHAPTER ONE: INTRODUCING THE RESEARCH

1.1 INTRODUCTION

In this thesis, I describe our experience using a multi-stakeholder participatory approach to explore chronic medicine use issues. Between 2019 and 2020, a series of engagements occurred between the research team (n=4), a select representative community group (n=25) from Delft Western Cape, and eight different stakeholder groups with other affiliations and skills. Such a collaborative process contextualised community issues about using chronic medicines and patients' chronic disease experiences.

Subsequently, in this Chapter, I introduce our research by defining what chronic diseases (CDs) are and why they deserve attention. Further, how they currently affect global health and how the South African health system responds. I also narrate how COVID-19 affected CDs and the role of pharmacy schools and pharmacists. I intend to showcase research gaps and opportunities in CDs with these narrations. Moreover, as a pharmacy school with pre-established partnerships within Delft, how we sought to explore and address chronic medicine use issues collaboratively. Finally, I conclude this Chapter by presenting our evolved research aims, questions, and objectives before outlining the remaining thesis Chapters.

1.1.1 **What are chronic diseases (CDs)?**

CDs or non-communicable diseases (NCDs), terms used interchangeably, describe diseases experienced over an extended time and usually due to different or a combination of factors (WHO, 2018a). They require prolonged and lifelong medicine use, fall within the quadruple burden of disease in South Africa along with Maternal, new-born and child health; HIV/AIDS and tuberculosis (TB); and violence and injury. CD's burden of disease contributes extensively to the country's mortality rate (SANDoH, 2010).

In 2021 the World Health Organization (WHO) reported that over 71% of global deaths were due to CDs (WHO, 2021b). In 2019, South Africa stated that 57.8% of all deaths were due to CDs, including cardiovascular disease, cancer, diabetes and chronic respiratory disease (SANCDA, 2019). According to the national strategic plan for preventing and controlling non-communicable diseases, deaths due to chronic diseases are preventable through evidence-based promotive/preventive and control measures (SANCDA, 2019).

1.1.2 CDs as a Syndemic

Syndemic refers to the complex interaction between health and social issues that intimately affect a disease's progression, management, and prevention (Pirrone *et al.*, 2021). Merrill Singer coined this term in the 1990s by identifying how substance abuse and the converging of violence and AIDS affected each other (Singer *et al.*, 2017). According to Pirrone and her colleagues, to fully contextualise CDs, a requirement to understand how individual (lifestyle) factors, social and community networks, living and working conditions, and general social, economic, cultural and environmental conditions co-exist and synergistically affect CDs, is imperative (Pirrone *et al.*, 2021). Hence, CDs are considered syndemic and require holistic conceptualisation of patients' chronic disease experiences (Swinburn *et al.*, 2019; Yadav *et al.*, 2020).

Furthermore, 'people living with non-communicable diseases (PLWNCDs) (Yadav *et al.*, 2020) often experience multi-morbidities and can have two or more CDs concurrently. In some cases, patients are affected by CDs and infectious diseases at the same time (Mendenhall, 2015; Hurst *et al.*, 2018). For example, in South Africa, people living with diabetes often are also affected by cardiovascular diseases, which triples the risk of developing TB (SANCDA, 2019).

The question then arises as to how the South African health system is organised and how they respond to CDs, what approaches the country uses and what role pharmacists and pharmacy schools play in such endeavours. I elaborate on these in the following section. But, first, I use literature to sketch a rough picture of how patients with CDs access and experience the fragmented health system, particularly in the Western Cape, what challenges COVID-19 imposed and how ongoing strategies to improve access and management of CDs face implementation challenges that require innovative research like ours.

1.2 CHRONIC DISEASES AND THE SOUTH AFRICAN PUBLIC HEALTH SYSTEM

The South African national healthcare system is two-tiered between the private and public sectors, with the public health sector serving 83% of the population and the private sector serving 17% (NPC, 2012). The private health sector comprises private general practices, pharmacies and hospitals, typically in urban areas unreachable to most South Africans (Mahlathi and Dlamini, 2015). In contrast, the under-resourced public health system provides healthcare through a decentralised District Health System (DHS) (NPC, 2012; Mahlathi and Dlamini, 2015; SANDoH, 2017). Like many other countries, the coronavirus disease (COVID-19) outbreak heavily affected the national health system. I elaborate on this below.

The coronavirus disease outbreak in December 2019 (Yang *et al.*, 2020) inspired global strategies and actions to protect and treat affected people (Girum *et al.*, 2020). In South Africa, the first big wave hit in March 2020; by then, a global realisation that PLWNCDs had higher risks of developing serious and potentially fatal complications when infected with COVID-19 was well known (WHO, 2020). In the Western Cape, healthcare delivery for chronic diseases was disrupted due to the pandemic (Delobelle *et al.*, 2021).

Delobelle and colleagues, in 2021, described how the national lockdown regulations resulted in limited health services (Delobelle *et al.*, 2021). There was an abrupt cancellation of non-essential clinic visits, chronic clubs (support groups for patients with the same chronic conditions) and routine laboratory tests. Many patients with chronic disease were enrolled on the CDU system, and their parcels were delivered to their homes by CHWs. This meant that patients with chronic disease had less contact with healthcare professionals at their PHC clinics, negatively affecting chronic disease management. This occurrence highlighted how healthcare service delivery changes are made without fully contextualising how these changes affect end-users (Carman and Workman, 2017; Khuzwayo and Moshabela, 2017).

Lessons from the coronavirus outbreak have influenced national policy and strategic action addressing chronic diseases and population health. I describe how the national health system is organised in the following subsections.

1.2.1 The District Health System (DHS)

The DHS oversees the healthcare services for the eight metropolitan municipalities or ‘metros’ that are assigned to each of the official provinces of South Africa (Mahlathi and Dlamini, 2015; Voss,2019b). Each metro is divided into smaller area-bound “health districts” or district municipalities, which are further subdivided into sub-districts or local municipalities (Voss,2019b). The health district offices are responsible for planning and coordinating preventative and community-based services, clinics and district hospitals, and each sub-district remains accountable for providing day-to-day primary healthcare services (Voss, 2019a). This decentralised and area-focused sub-district method was intended to grant autonomy to the sub-districts to make relevant and contextualised decisions more responsive to their local health needs (Voss, 2019b, 2019a). The DHS is not prescriptive of how each province operates its healthcare services, and I will elaborate on the Western Cape's approach next.

1.2.2 Healthcare Services in the Western Cape

In the Western Cape, healthcare services are organised into three levels: primary, secondary and tertiary, which are categorised according to the Comprehensive Service Plan (CSP) of the Provincial Government of the Western Cape (PGWC) (Bradley, 2013). Primary-level services include community-based clinics, mobile clinics, and district hospitals. In contrast, the secondary level consists mainly of regional hospitals with general specialists, and finally, the tertiary level typically includes teaching hospitals (Voss,2019b). Home and community-based care also serve as an extension of the primary level. Specialised services like emergency ambulances, specialised hospitals for TB, psychiatry, and dental all support the levels mentioned above of care (WCDoH, 2014).

Within the primary care level, services are divided between two tiers of government: The Western Cape provincial health department and the City of Cape Town health department (Bradley, 2013). The former oversees district and specialised hospitals. While the latter focuses on preventive and promotive services such as reproductive and child health, TB, HIV prevention and treatment, and the provision of pre-packaged chronic medicine parcels to patients with chronic disease, often through primary healthcare centres (Pillay and Barron, 2011). The Western Cape provincial health department processes and dispenses these parcels the through a Chronic Dispensing Unit system (CDU) (Magadzire, Marchal and Ward, 2015).

1.2.3 The Primary healthcare Level and PHC Approach

The primary healthcare level is regarded as the most essential component of the public health system because it is a significant first point of contact. Often primary healthcare services are more accessible to individuals seeking healthcare as they are located within or near their community and are provided with little to no fee payment (WCDoH, 2014). This level relies on principles of the PHC approach to render its healthcare services (WCDoH, 2014; SANCDA, 2019).

The PHC approach is grounded in the understanding that health is multifaceted and '*cannot be* *promoted in isolation from the social, economic and political environment'* of the people (WCDoH, 2014, p. 37), which resonates with the syndemic nature required for chronic disease management (Pirrone *et al.*, 2021). As such, the PHC approach encourages providing comprehensive healthcare services focused on preventative, promotive, curative, and rehabilitative care at the primary health level. The PHC services are divided into three streams: Home and community- based care (HCBC), Primary care services at the health facilities, and intermediate care (WCDoH, 2014). In 2010 the approach was re-introduced as the re-engineered PHC approach (Pillay and Barron, 2011), which fits in well with the National Health Insurance objectives (Khuzwayo and Moshabela, 2017) and Community Orientated Primary Care (COPC) (Mash *et al.*, 2019).

The core principles of the re-engineered PHC approach reframed healthcare within a population-orientated lens; that aimed to address significant causes of ill health by also prioritising non-health sector factors (social, economic, environment etc.) that affect the health of a community (Naledi, Barron and Schneider, 2011; Khuzwayo and Moshabela, 2017). The approach also introduced efficient multi-disciplinary PHC teams that worked collaboratively with the community and other private community-based health services (Khuzwayo and Moshabela, 2017). The re-engineered approach encourages local people to take ownership and personal responsibility for their health as well as the health of their communities (WCDoH, 2014).

In the Western Cape, the re-engineered PHC approach categorises health services into three streams; ward-based PHC outreach team; School health services; and district-based clinical specialist teams (Pillay and Barron, 2011). The ward-based PHC outreach team is multi-disciplinary and comprises a professional nurse;as the team leader, environmental health practitioner, health promotion practitioner an CHWs (Pillay and Barron, 2011). CHWs play a significant role in the team and act as the *'bridge between communities and healthcare services'* (Murphy *et al.*, 2020, p. 2). This team focuses on health promotion and prevention through home and community-based healthcare services (Pillay and Barron, 2011). The School health services team is mainly composed of nurses and supported by the ward-based PHC team. Presently this team focuses on screening learners for early developmental conditions like hearing and vision, immunisations, and reproductive and sexual health education to supplement existing life skills subjects (Pillay and Barron, 2011). The multi-disciplinary district-based specialist teams have a gynaecologist, paediatrician, anaesthetist, family physician, advanced midwife and paediatric nurse, and a PHC nurse. This well-rounded team prioritises reducing the high levels of infant and child mortality in the province and takes on a monitoring and evaluation role. This team ensures that treatment guidelines are followed and essential health equipment is available to healthcare professionals (Pillay and Barron, 2011).

Unfortunately, the comprehensive re-engineered PHC approach did not respond to the need for integrated healthcare for patients with chronic disease who often have multi-morbidities. For example, a patient with chronic disease needing to see a physician and physiotherapist must schedule two clinic visits and appointments. However, the 2019 national strategic plan for the prevention and control of non- communicable diseases 2020-2025, the Integrated Clinical Services Model was introduced (ICSM) (SANCDA, 2019). The introduction of ICSM allowed patients to be seen for all health issues in one PHC clinic visit (communicable and non-communicable diseases) (SANCDA, 2019). The ICSM model, in conjunction with the CDU system that is embedded within the re-engineered PHC approach, highlights the comprehensive, multi-disciplinary and integrated efforts by the NDOH to address chronic diseases holistically (Magadzire, Marchal and Ward, 2015; Mash *et al.*, 2019; SANCDA, 2019).

Sadly, the re-engineered PHC approach is somewhat silent on the role of pharmacists (Bheekie and Bradley, 2016). This is surprising as pharmacists have been described as key role-players in chronic medicine access and delivery in South Africa (Boswell *et al.*, 2018), especially during the COVID-19 pandemic (NCD Alliance, 2020). I elaborate on the role of pharmacists and pharmacy schools in assisting national strategies to address chronic diseases below.

1.2.4 The Role of Pharmacy and Pharmacists

When consulting policy, the South African National Drug Policy of 1996 describes pharmacists as well-positioned to promote the rational use of medicines to patients and prescribers because of their extensive knowledge (SANDoH, 1996). Coincidentally, community-based pharmacists are responsible for providing health education, focusing on correctly using medicines, general well-being and reporting adverse drug reactions (SANDoH, 1996; Bradley, 2013). This strategically places pharmacists in positions to significantly contribute to effective national chronic disease management (Rockers *et al.*, 2019) and support the multi-disciplinary teams of the three streams of the re-engineered PHC approach (Bheekie and Bradley, 2016).

Bheekie and Bradley outlined critical areas within the re-engineered PHC approach where pharmacists and pharmacy students are useful (Bheekie and Bradley, 2016). Generalist pharmacists with extensive knowledge of chronic medicine therapy management, medicine adherence counselling, cold chain management and the Expanded Programme on Immunisations (EPI) could offer training and support to clinical staff, adherence counsellors, ward-based PHC outreach teams and the School health services team. Pharmacists who have been trained in conducting medicine utilisation reviews could assist the district-based specialist teams in monitoring the prescribing patterns to identify and address polypharmacy, especially among patients with multiple chronic disease and prescribed multiple medicines.

Furthermore, exposing pharmacy students to communities through experiential learning programmes could contribute positively to community health. These programmes are suggested to help students collaboratively work with the community to contextualise the unique environmental, social, and economic factors contributing to ill health (Albertyn and Daniels, 2009). These collaboratively contextualised factors could form a basis of reference for pharmacy schools to adjust their curriculum and include community projects inspired by the people (Perez *et al.*, 2013). Consequently, creating a dynamic process that encourages health learning to be relevant and responsive to the realities of the community (Larkins *et al.*, 2013) would establish mutual transfer and translation of health knowledge and resources within symbiotically established partnerships between the community, PHC clinics and pharmacy schools (CTSA, 2011; Tindana *et al.*, 2015).

Hence embedding pharmacy students' clinical training, through experiential learning programmes, within the re-engineered PHC services could result in positive health outcomes. This would involve including students within the ward-based PHC outreach teams, where they would assist (under supervision) with monitoring families on TB treatment, assisting with chronic medicines adherence counselling, assessing environmental health risk factors and other tasks. The students would learn to embrace interdisciplinary collaboration and learning and further understand their moral obligation to serve communities with their acquired skills, expertise, and knowledge. These students would become graduates with a strong sense of moral responsibility who positively contribute to transforming health systems by serving society as competent health professionals (Boelen and Woollard, 2011; Egieyeh *et al.*, 2021).

1.2.5 A move toward multi-stakeholder strategies for CDs

The prevention and management of CDs have been centred around addressing lifestyle behaviours (alcohol, tobacco, diet and physical inactivity) (SANCDA, 2019), medicine adherence (Tozivepi *et al.*, 2021) and medicine access (Boswell *et al.*, 2018). Therefore, PLWNCDs are encouraged to reduce their alcohol, tobacco, sugar and salt consumption and maintain an active lifestyle (Bala and Srivastava, 2021) without fully contextualising their chronic disease experiences and health behaviours. In reality, patients in South Africa often endure long waiting times and a shortage of human resources and medicines when interacting with the primary level of care (SANCDA, 2019). This level of care also experiences a shortage of essential medical equipment and devices, poor infection control management and poor record keeping (Maphumulo and Bhengu, 2019). These healthcare service delivery issues significantly impede efforts to provide quality healthcare and services to patients at the primary level.

National policy documents prescribe using community-based and contextual approaches as a solution (WCDoH, 2014). A focus on multi-stakeholder methods that lean toward a “Whole society” and “Whole of government” paradigm is a common thread in national policies and strategies (SANCDA, 2019).

The “whole of society” approach encourages the collaboration between different sectors of society, both within the health sector and outside of it, to collaboratively work with the community to contextualise and address the syndemic nature of CDs. This paradigm is grounded in appreciating all health, social, economic, political, and environmental factors contributing to ill health. Similarly, the “whole of government” approach outlines various government sectors and departments essential to realising effective national health promotion and prevention strategies. These sectors, including multiple industries and role-players, emphasise the significance of multi-stakeholder and collaborative approaches to address CDs. Unfortunately, an in-depth understanding of people’s lifestyle choices, interactions with one another and the environment, as well as socio-political and economic contexts (Adjaye-Gbewonyo and Vaughan, 2019; Littlejohns, Smith and Townend, 2019) lack national research prioritisation (SANCDA, 2019). Hence the employment of multi-stakeholder approaches that can contribute to the holistic understanding of how patients with chronic disease navigate their chronic diseases, community and life is necessary.

1.3 RESEARCH PROBLEM

From what I have narrated above, chronic diseases remain a national and global concern. However, multi-stakeholder research that employs multi-level analysis to contextualise factors contributing to increased chronic disease mortality entirely is limited. While South Africa boasts of ‘Whole of society’ and ‘Whole of government’ national policies and strategies (Further described in Chapter Two) to address CDs, they face implementation challenges. This is further aggravated by the limited research conducted with patients with chronic disease as research partners, who could better contextualise their chronic disease experiences.

These research gaps require multi-stakeholder collaborative research to identify chronic medicine use issues and ways to address them.

In the following sections, I narrate our research setting by describing our project’s primary stakeholders, how they had pre-established partnerships through an experiential learning programme hosted within a pharmacy School and previous interactions within National Research Foundation research activities. I also describe the collaborative process of uncovering our research topic, aims, questions and objectives. I conclude this Chapter by outlining the remaining Chapters of the thesis.

1.4 RESEARCH SETTING

Our research topic was inspired by an existing partnership between the School of Pharmacy at the University of the Western Cape and an NGO in Delft. This partnership was developed mainly through the School’s experiential learning programme and NRF research activities. In this section, I describe the community of Delft, the participating NGO and the experiential learning programme Service Learning in Pharmacy (SLiP) that connects all these stakeholders. I also describe the NRF research activities and their contributions to our research.

1.4.1 Community setting: Delft

Delft is located within the northern Tygerberg substructure of the Western Cape health metro (WCDoH, 2019). The geographical area is divided into three health Wards, 13, 20 and 106, with unique social and health issues. There are three public health facilities in Delft: Delft CHC in Ward 13, Delft South CDC in Ward 20, and Symphony Way CDC in Ward 106. There are some variations in the health services that each facility offers to the community; for instance, Delft CHC provides 24-hour trauma and maternity services, as well as child health and adult curative services during extended hours of 16:00 till 21:00 on weekdays and 08:00- 13:00 on Saturdays. While the later offers primary health care services to the community. Interestingly there is a greater focus on chronic diseases at Delft CHC and Symphony Way CDC than at Delft South (WCDoH, 2019). Figure 1.1 on the next page presents a map of Delft.

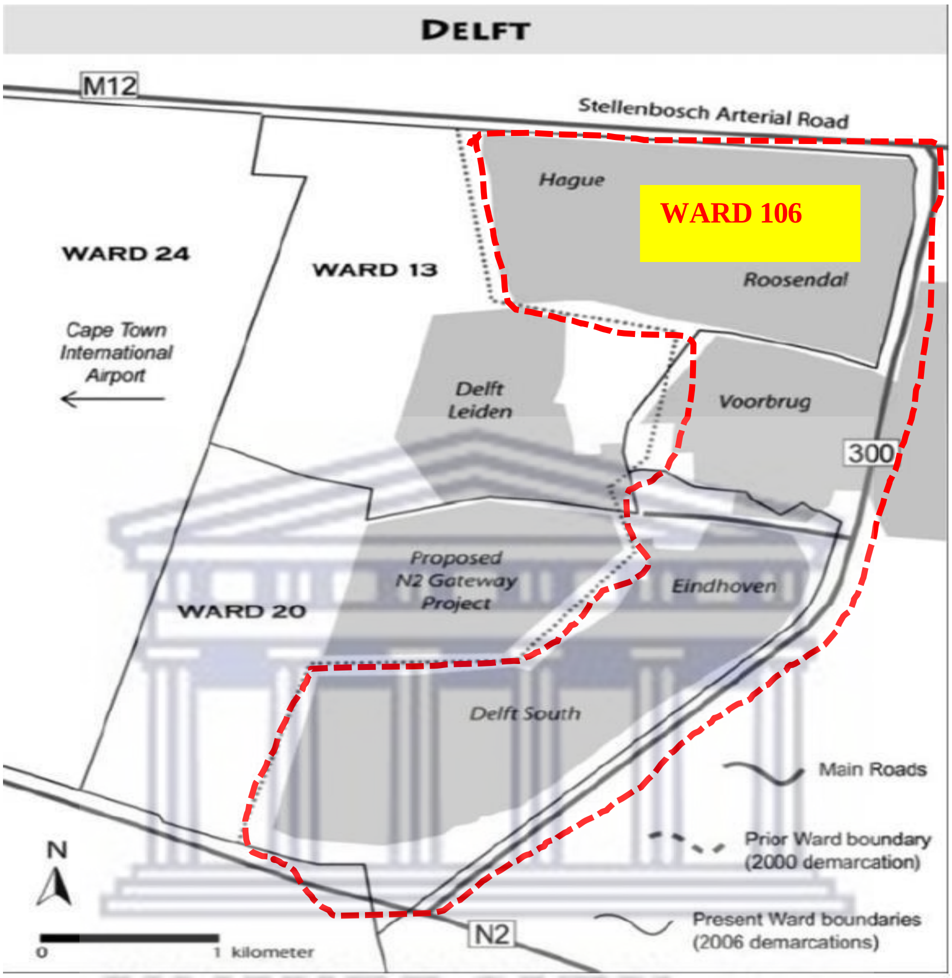


Figure 1. 1 Map of Delft (adapted from (Millstein and Jordhus-Lier, 2012)

1.4.2 NGO setting

NGO X (name omitted to maintain confidentiality) has been operating in Delft since 2015 and offers home and community-based health services, mainly through CHWs across the area. The NDOH primarily funds the organisation. Presently the organisation collaborates with the three primary healthcare facilities in Delft to manage a variety of comprehensive community health and HIV/ AIDS and TB projects, namely: (i) HIV/ Aids, STI and TB (HAST), (ii) Community-Based Services (CBS) and a (iii) Catch & Match digital health program. The NGO also runs a Social Crime Prevention program and a Victim Empowerment project funded by the

Department of Social Development and serves to respond to the escalating crime and gender-based violence in the community. Figure 1.2 below showcases an annotated organogram of the organisation offered by the NGO's CEO.

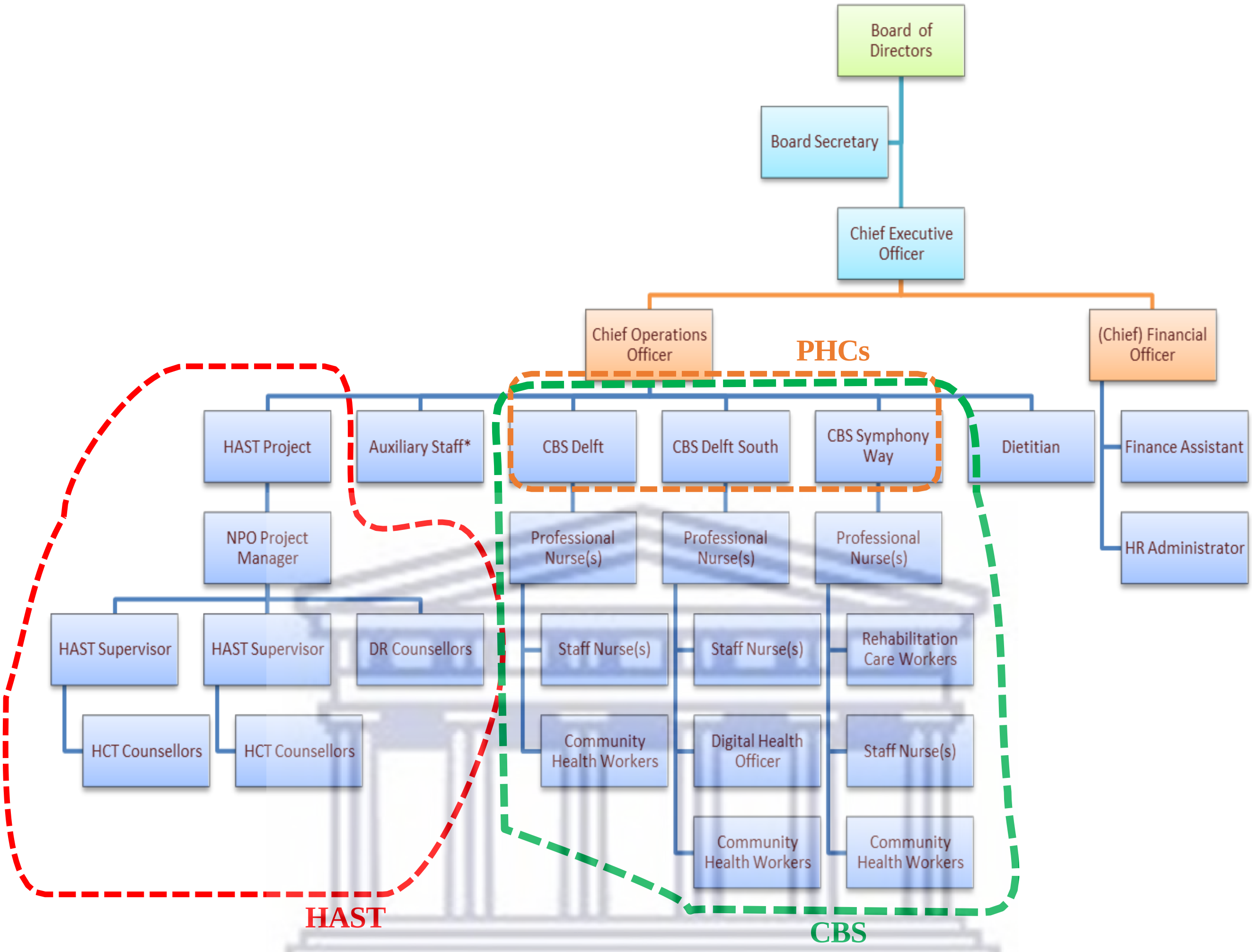


Figure 1. 2 Organisational organogram Of NGO service partner

<u>Key for figure 1.2</u>

HAST- HIV/ Aids, STI and TB

CBS- Community-Based Services

NPO- Not-for-Profit Organisation (interchangeably used with NGO)

HCT- HIV Counselling and Testing

DR- Drug Resistance

HR- Human Resources

PHCs- Primary Health Clinics

Important consideration: Typically, *HCT* and *DR counsellors* are CHWs with diversified roles and job functions. I elaborate on the role and function of CHWs within the different programmes in Table 1.

The HAST programme (circled red) is primarily facility-based and employs HIV Counselling and Testing (HCT) counsellors to conduct HIV/Aids and STI testing and counselling. This programme also employs Drug Resistance (DR) counsellors who conduct TB testing. Additionally, DR counsellors work with other CHWs to identify drug-resistant TB through high-risk patient community tracing activities. The project manager and supervisors support the counsellors and programme activities. Table 1 showcases the HAST programme activities.

The CBS programme (circled green) is community-based and primarily functions through a referral system that splits between the three health facilities (PHCs) (circled orange). Staff nurses are stationed within the three primary healthcare facilities and are overseen by professional nurses who work between the NGO office space and facilities. When a health professional (professional nurse or staff nurse) identifies a patient needing CBS services at a PHC, they are assigned a CHW, who then schedules a home visit. At this initial home visit, CHWs assess home and social conditions, provide health promotion and refer patients to health facilities and other healthcare professionals such as physiotherapists, dieticians etc. and other social services. Additionally, CHWs determine the degree of home-based care services and support the patient and family will need at the same initial visit. Afterwards, the assigned CHWs visit the patient's homes, providing critical home-based care and health promotion. Table 1 below summarises the CBS programme activities.

Unfortunately, the exact manner in which the NGO works with each primary healthcare facility was not inquired.

Table 1 HAST and CBS programme activities performed by CHWs

HAST- Facility-based activities	**CBS- Home/Community-based visits activities**
Pre and post-HIV testing and counselling. TB screening STI screening	Blood pressure and glucose screening Medicine adherence assessments of referred patients. Provide health education.

Distribute female and male condoms. Mediate support groups Mediate medicine adherence clubs Sex education health talks	Distribute CDU parcels Scheduled home visits to provide basic home care: i. Bed baths ii. Wound care iii. General grooming iv. Nutrition advice (Dieticians) Unscheduled door-to-door home visits to: i. Assess living conditions. i. Observe social issues. ii. Check children's immunisation status iii. Refer suspected TB cases to PHC.
Supervisors attend weekly MDTs at PHC facilities to present cases, flag defaulters, and escalate complex patient/ family cases.	

Table 1 Key

HAST- HIV/ Aids, STI and TB

CBS- Community-Based Services

STI- Sexually Transmitted Infections

TB- Tuberculosis

CDU- Chronic Dispensing Unit

MDT-Multidisciplinary meetings

PHCs – Primary Health Clinics

The NGO was first approached by SLiP staff in 2014 and asked to host a group of first-year students. At the time, the organisation was based in Matroosfontein and served the community of Elsies River. The organisation's move to Delft in 2015 did not affect the established relationship with the School, and students continued to conduct their SLiP learning activities in Delft. Following this, the School and NGO signed an MOU in 2016.

1.4.3 Pharmacy School's experiential learning programmes

The School of Pharmacy falls within the Faculty of Natural Sciences at the University of the

Western Cape in Cape Town. It is located about seven kilometres from the community of Delft. It is the only Pharmacy School in the province offering the Bachelor of Pharmacy (BPharm) degree. The School has two significant experiential learning programmes, namely: SLiP and Patient Care Experience (PaCE) (Adeleye, 2019).

The SLiP programme started between 2001 and 2002 as part of the Community Higher Education Services Partnership (CHESP) initiative (Bheekie, Adonis and Daniels, 2007; Van Huyssteen, Bheekie and Obikeze, 2013). At this time, the program focused on exposing fourth-year BPharm students to tertiary-level hospitals and primary healthcare facilities and excluded other year groups. The fourth-year students were expected to develop prescription analysis, manufacturing, and medicine packaging skills (Bheekie *et al.*, 2011). However, in 2013, upon the mandate of the South African Pharmacy Council (SAPC), the programme expanded to include all other year levels (van Huyssteen and Bheekie, 2015).

Starting in 2013, the first-year SLiP program focused on social determinants of health, environmental health and the making of Oral Rehydration Solution (ORS) as a response to seasonal high local incidents of diarrhoeal disease in the Tygerberg sub-district in Cape Town (van Huyssteen and Bheekie, 2015; Cwati, 2020). Subsequently, the second-year program introduced in 2014 focused on TB screening, cardiovascular risk assessments and maternal and child health (MCH) (Adeleye, 2019; Cwati, 2020). The third-year program focused on pharmaceutical procedures such as: '*manufacturing, prepacking, triaging, preparing prescriptions, labelling medication, handing out medication, ward rounds, stock control, checking for expired stock, procurement, consultations, and group education activities*', was launched in 2015 (Essack, 2020, p. 25). The fourth-year programme was rebranded to PaCE and launched in 2016 (Essack, 2020).

Noteworthy was the ongoing efforts to incorporate national and locally prioritised diseases (TB, CDs, MCH and seasonal diarrhoea) within the SLiP programme. This highlights the School's long-standing intention to respond to local and national health agendas (van Huyssteen and Bheekie, 2015; Adeola *et al.*, 2021).

The rebranded fourth-year experiential learning programme intended to train students in identifying, addressing and preventing patient medicine therapy-related problems (Adeleye, 2019). The learning activities were divided between primary healthcare facilities and hospitals. These activities included, amongst others: designing patient education posters; conducting medicine history and reconciliation; designing pharmaceutical care plans based on identified drug-related problems; and designing and conducting pharmacy and medicine-related training sessions for healthcare professionals (Essack, 2020).

Noteworthy, the process of allocating service learning sites for the School to conduct SLiP and PaCE programs within the Tygerberg subdistrict remains complicated (Essack, 2020), recalling that the two-tiered healthcare services at primary health facilities are sub-divided between the Western Cape provincial health department and City Health (Bradley, 2013). Consequently, pharmaceutical services are located within these various divisions, which can confuse roles and responsibilities for healthcare professionals facilitating experiential learning (Essack, 2020). To address this, a formal Memorandum of Agreement between the School and Metro District Health Services (MDHS) is signed every 4-5 years, and the terms are renegotiated annually (van Huyssteen *et al.*, 2020). However, in 2016 this agreement was renegotiated with the provincial pharmaceutical services office with input from MDHS pharmacists (Essack, 2020). This negotiation led to including provincial and city health facilities as service-learning sites for SLiP and PaCE.

I now present the service partners and partnerships within the SLiP programme below. This may clarify how I encountered the NGO.

1.4.3.1 Service Partners and Partnerships

The SLiP program relies on symbiotic and reciprocal partnerships within a triad partnership between the university or school, community, and health services (Essack, 2020). However, for different year groups, the composition of each service partner varies, which is determined by the nature of the service-learning activities that students need to achieve and the learning site.

Table 2 showcases the School’s experiential learning programme activities, learning sites and service partners. This table illustrates the School’s leaning toward collaborative partnerships for addressing community health needs through community engagement.

A careful analysis of Table 2 reveals that the School of Pharmacy works with an NGO partner for the first-year SLiP programme. This typically involves students, accompanied by CHWs, walking through the community of Delft and visiting selected households. The students are encouraged to record their observations on a prescribed community survey or worksheet form focusing on the community's environmental, social and hygiene factors. In addition, students also complete mandatory reflections with a reflective assignment piece.

Interestingly, research into the experiential learning programme started in 2015, focusing on exploring the triad partnership between the SLiP Service partners. One project pertained to understanding the community health needs identified by SLiP service partners within the Cape Metropole Community Health Forum (CHF) (Cwati, 2020). This research identified a clear link between the CHF and clinic committees involved in PHCs. Subsequently, the project inspired a research workshop in early 2018 (Boswell *et al.*, 2018). At this workshop, I first encountered the NGO and my research interest in chronic diseases emerged. I elaborate on this more in the following subsection.

Table 2 Experiential learning programs, learning sites and service partners

Program	Student year	Learning activities	SLiP Partners/ Role-players	Learning sites
SLiP	1st	Semester 1 Community health: Social determinants of health.	SoP SLiP staff First-year pharmacy students CHWs belonging to NGO Selected community members Community leaders	Community-based: Community site and patient homes
		Semester 2 Environmental health: preparing ORS	SoP SLiP staff Various SoP academic staff Various city health sub-district staff First-year pharmacy students Environmental health practitioners	Community: informal settlement visit UWC SoP laboratory
	2nd	Semester 1 TB and CV risk assessment screening	SoP SLiP staff City health sub-district staff Second-year pharmacy students Primary health clinics: clinic manager and nurses Selected patients in the general waiting area of primary health clinics	Primary health clinic

		Semester 2 MCH	● SoP SLiP staff ● Various city health sub-district staff ● Second-year pharmacy students ● Primary health clinics: clinic managers and nurses ● Mothers visiting primary health clinics	● Primary health clinic
	3rd	Patient & population-based pharmaceutical skills development	● SoP SLiP staff ● Third-year pharmacy students ● Pharmaceutical services, sub-district managers, facility managers ● Pharmacists facilitating learning in the pharmacy ● Patients	● Primary healthcare clinics and hospitals

<u>Key</u>

ORS- Oral Rehydration Solution
CHWs- Community Health Workers
UWC- University of the Western Cape
MCH- Maternal and Child Health
SoP- School of Pharmacy
IPC- Infection Prevention Control

1.4.4 Previous research projects' Contributions

As a guest at the 2018 research workshop, I was grouped with various other participants, and our in-depth group discussion revealed significant concerns with the current dispensing, delivery, and health education of chronic medicines. As the presenter for my team, I became attached to these concerns, and my interest in understanding the experiences of patients with chronic disease was sparked.

Following that workshop, I met with my supervisor (AB), an academic within the School of Pharmacy, a pharmacist, and the co-founder of the SLiP programme; we sourced advice from various colleagues, including my first co-supervisor (MvH), who was also an academic pharmacist within the School and who had experience working with traditional healers to understand indigenous knowledge of medicines and wellbeing. Other colleagues from different departments (faculty of Arts and EMS) also assisted us in understanding emancipatory and participatory research methods further and the use of systems thinking. Later I met up with my second co-supervisor (CH), a community development practitioner and research methodology expert. During one of our meetings, we eventually realised the appropriateness of using Participatory Action Research (PAR).

Noteworthy is how after commencing our research project and recruiting the NGO as a stakeholder, I was invited to serve as a non-executive board member of the organisation's board. This position allowed me to engage and interact with the organisation outside the research project, consequently offering insight into the organisational culture and realities that the NGO faces in the community. I address issues of potential bias and how I navigated my roles as a student within the School, a board member of the NGO, and a researcher in Chapter Six of this thesis.

I discussed the experiential learning programmes and previous research projects' contributions to developing our research topic in previous sections. I now further hone in on how these converged below.

1.4.5 Research Origin and dynamic nature of Participatory Action Research (PAR)

Essentially, our research topic emanated from the research team's shared understanding of the need for us to advance our ongoing inquiry and appease our moral imperative to serve the community of Delft and its people. Delft is close to the School and is a learning site for the SLiP programme. We were curious to understand the health of people living in Delft compared to other vulnerable communities further from the school. Further discussions with the NGO and the research team and literature directed our research to explore the experiences of patients with chronic disease in Delft.

A reference population was also needed to further conceptualise the School's social accountability status. We wanted to investigate the impact of our teaching, research, and service activities through a PAR approach. The first-year SLiP programme has been responsible for the ongoing partnerships between the school, NGO, CHWs and some community members. We then wanted to use a multi-stakeholder participatory approach to identify, conceptualise and address chronic medicine use issues in the community. Concurrently through the same inquiry, we anticipated continuing our ongoing venture to seek feedback from service partners on our partnerships.

Typically, a participatory multi-stakeholder approach is co-developed with research partners; the research questions, aims, and objectives are often not predetermined. Instead, these are co-developed, defined, and refined by research stakeholders as the project progresses (Bradley, 2013). As we commenced our research, we had the research topic described above and had already selected the four main stakeholder group categories. However, they still needed to be recruited, and research objectives and aims were yet to be re-negotiated with stakeholders. This occurrence is typical in PAR research, where the research questions, objectives and focus are renegotiated with participants as the research progresses (Musesengwa and Chimbari, 2017).

Consequently, our proposal writing period and application for ethical approval took much work. The scientific and standard way of drafting a proposal requires researchers to have set research topics, aims, objectives and methods that do not change throughout the research. Due to the unstructured and dynamic nature of our PAR research, ours evolved with time as the priorities and interests of stakeholders changed. Other PAR researchers report that in some cases, the entire research focus can change during the research to align with the community's and stakeholders' priorities (Mosavel *et al.*, 2005; Salimi *et al.*, 2012; Majid *et al.*, 2018).

1.5 RESEARCH DESIGN, AIM, QUESTIONS AND OBJECTIVES

We chose to use an exploratory qualitative design that drew on PAR methodologies. We wanted to partner with stakeholders involved in the first-year SLiP programme and were interested in chronic disease research. We used participatory tools such as games, role-play, group activities and discussions to share experiences, identify issues, and develop ways to address them. This process, we imagined, would allow us to collaboratively explore and conceptualise chronic medicine use issues in the community of Delft. This was done through focus group sessions or workshops with the primary stakeholders (the School, NGO, CHW and community members). Following these focus groups, data retrieved was presented at two multi-stakeholder collaborative workshops attended by both the primary and recruited role-players.

Our research aim was to identify chronic medicine use issues that patients encounter and ways to address these through a multi-stakeholder approach. At that time, we had the following research questions:

1. What issues do people taking chronic medicine face in Delft?
2. How is a participatory multi-stakeholder approach useful in addressing such issues?

Additionally, yet subtly, we saw our research as an opportunity to understand how service partners and the community perceived the role of the school.

From our research, we hoped to achieve the following objectives:

1. To describe the chronic medicine use (CMU) issues patients living with chronic diseases experience in Delft.
2. To contextualise partnership dynamics between the School and primary research stakeholders.
3. To describe key lessons learnt using a multi-stakeholder approach to address chronic medicine use issues.

I present the thesis outline below to spark the process of understanding how we achieved our research objectives.

1.6 THESIS OUTLINE

In this Chapter, I introduced the research and offered a brief background on CDs and the South African health system. I narrated our unique research setting and outlined the research problem and design. I also presented our research aims, questions and objectives before presenting this thesis outline below.

In Chapter Two, I present an in-depth analysis of global and national policies and strategies concerned with CDs. I also outline the challenges South Africa faces to achieve effective CD management. Thereafter, I describe the PAR approach, its research principles, and its applicability to our unique research settings.

Consequently, in Chapter Three, I describe how we selected and recruited the key stakeholders (research participants) involved in our study. I also describe how we developed our unique 5-stage data collection process (*Participatory multi-stakeholder engagement approach*) and five Participatory appraisal tools (data collection instruments). Moreover, I also narrate how each tool was used in the different stages of our engagement approach and data management methods. I conclude this Chapter by highlighting our research's ethical considerations, quality and transferability.

Then in Chapter Four, I present our findings in two parts. In part one, I describe Delft's community contexts and offer insight on how patients with chronic disease navigate the community and health services. I also describe how primary stakeholders perceive their community role and contextualised service delivery challenges before outlining their partnership dynamics. Then in part two, I present contextualised disease experiences of patients with chronic disease living in Delft, first from the perspective of community members (patients with chronic disease) themselves, then from that of the other health workers and stakeholders (research participants) within our study. Furthermore, I outline the role of additional health role-players concerned with chronic medicine use in Delft, according to our research stakeholders. Lastly, I describe the contextualised stakeholder (participant) recommendations useful in addressing the identified CMU issues.

Then in Chapter Five, I reflect on our findings and contextualise them within a patient-centred context that explores the unique congruency between patient motivation, disease ownership and adherence and the influence of social-economic factors within a fragmented national health system. Additionally, I also highlight the relevance of collaborative health research within the community health setting. Lastly, I outline the limitations of our study before concluding the Chapter.

Finally, in Chapter Six, I reflect on our research process, and offer my observations and reflections before outlining key lessons learnt.

CHAPTER TWO: LITERATURE REVIEW

2.1 INTRODUCTION

In Chapter One, I described chronic diseases, how they currently affect health and why they deserve attention. I also explained how South Africa organises its public health system and manages CDs. This has set the stage for understanding healthcare within a South African context. In this Chapter, I draw from effective global strategies, policy documents and United Nations High-Level Meetings concerned with CDs. I also explore how they have significantly influenced South African policies and strategies. Further, I present PAR, its principles, and its suitability for community-based collaborative research.

2.2 GLOBAL TRENDS, SIGNIFICANT POLICIES AND STRATEGIES

NCDs were put onto the global agenda page in the 1970s (Weisz and Vignola-Gagné, 2015; Heller *et al.*, 2019). Then in 2000, WHO released the global strategy for preventing and controlling NCDs (WHO, 2000). What followed was the WHO Framework Convention on Tobacco Control (FCTC) in 2003 (WHO, 2003b) and the global strategy on diet, physical activity and health in 2004 (WHO, 2004). These actions demonstrated that the some members of the global community was starting to understand the importance of modifiable risk factors that affect CDs (Mikkelsen, 2015).

Four years later, in 2008, the WHO released the annual World Health Statistics Report, which revealed a significant increase in the prevalence and mortality of CDs, despite the above efforts (WHO, 2008b). This was followed by the 2008-2013 Action plan for the global strategy for the prevention and control of CDs in the same year (WHO, 2008a). This document, containing objectives targeting challenges that affect the prevention and management of CDs, was regarded as a road map for countries to follow to strengthen their efforts to prevent, manage and monitor CDs (WHO, 2008a; Mikkelsen, 2015). Additionally, the document highlighted the need for collaboration with non-health sector stakeholders as a suitable approach to better respond to the multi-morbidity of CDs (United Nations, 2011). Following this, the WHO released the global strategy to reduce the harmful use of alcohol in 2009, and then the first WHO global status report on CDs in 2010 (Mikkelsen, 2015). More recently, the Global Action Plan for the Prevention and Control of NCDs 2013-2020 was released in 2013 (WHO, 2013). This document contained nine global targets and six objectives (WHO, 2013). Governments can use global targets, objectives and 'best buys' to better respond to the modifiable risk factors perpetuating CDs (WHO, 2017). Boxes 1 and 2 present the WHO's six objectives and nine global targets to be reached by 2025, respectively. These were adapted from '*The global action plan for the prevention and control of non-communicable diseases 2013-2020'*.

Box 2. 1 WHO'S objectives for the prevention and control of CDs (WHO, 2013)

1. To raise the priority accorded to the prevention and control of non-communicable diseases in global, regional and national agendas and internationally agreed development goals, through strengthened international cooperation and advocacy.
2. To strengthen national capacity, leadership, governance, multi-sectoral action and partnerships to accelerate country response for the prevention and control of non- communicable diseases.
3. To reduce modifiable risk factors for non-communicable diseases and underlying social determinants through creation of health-promoting environments.
4. To strengthen and orient health systems to address the prevention and control of non-communicable diseases and the underlying social determinants through people-centred primary healthcare and universal health coverage.
5. To promote and support national capacity for high-quality research and development for the prevention and control of non-communicable diseases.
6. To monitor the trends and determinants of non-communicable diseases and evaluate progress in their prevention and control.

Box 2. 2 WHO's voluntary global targets for the prevention and control of CDs (WHO, 2013)

1. A 25% relative reduction in risk of premature mortality from cardiovascular diseases, cancer, diabetes, or chronic respiratory diseases.
2. At least 10% relative reduction in the harmful use of alcohol, as appropriate, within the national context
3. A 10% relative reduction in prevalence of insufficient physical activity.
4. A 30% relative reduction in mean population intake of salt/sodium.
5. A 30% relative reduction in prevalence of current tobacco use in persons aged 15+ years.

6. A 25% relative reduction in the prevalence of raised blood pressure or contain the prevalence of raised blood pressure, according to national circumstances.

7. Halt the rise in diabetes and obesity.

8. At least 50% of eligible people receive drug therapy and counselling (including glycemic control) to prevent heart attacks and strokes.

9. An 80% availability of the affordable basic technologies and essential medicines, including generics, required to treat major non-communicable diseases in both public and private facilities.

Parallel to the abovementioned policies and strategies, the WHO hosted high-level collaborative meetings between 2011 and 2018. These meetings resulted in global political declarations and inspired most countries' national strategies and policy amendments. I elaborate on these below.

The first United Nations High-Level Meeting (UN-HLM) on NCDs (2011) highlighted the need for a paradigm shift in contextualising and addressing NCDs (UN General Assembly, 2012; Oni *et al.*, 2019). The meeting formed the backbone for the multi-sectoral policies and plans (Mikkelsen, 2015) and understanding of the modifiable risk factors contributing to CDs, namely, tobacco and harmful use of alcohol, unhealthy diets and physical inactivity.

The second UN-HLM (2014) explored the significant policy implementation challenges and highlighted a need for coordinated global Multi-Sectoral Action (MSA) and national resources (UN General Assembly, 2014). The formation of the NCD Alliance in 2017 catalysed efforts targeted to address CDs (WHO, 2008a, 2008b; Adjaye-Gbewonyo and Vaughan, 2019).

Then, the third UN-HLM for NCDs (2018) focused on evaluating the progress made to combat CD mortality globally and encouraged governments to further prioritise CDs through political commitment (WHO, 2017). This resulted in a political declaration that accepted that global action and commitments to address CDs were insufficient (United Nations, 2018). The WHO highlighted that more progress was needed toward achieving sustainable development goal 3.4, aiming to reduce CDs prematurity by one-third by 2030 (WHO, 2018a).

2.2.1 Guiding Elements for Strategies and Approaches to Address CDs

The global objectives and targets also offered guiding elements underpinning strategies and objectives to address CDs. I describe these below.

2.2.1.1 Integrate into pre-existing strategies for other diseases

The action plan seems to focus on four CDs; cardiovascular diseases, cancer, chronic respiratory diseases and diabetes and their risk factors. However, these often co-occur with other diseases (WHO, 2013, 2018b). Thus, the UN and WHO recommend integrating CD interventions into pre-existing functioning strategies and approaches for other diseases (WHO, 2017; NCD Alliance, 2021). I highlight how some African LMICs responded to these recommendations (Mwagomba *et al.*, 2018; Owino, 2019).

In Swaziland, HIV and CD service delivery is integrated, and patients are comprehensively screened for diabetes, hypertension and cervical cancer within the programmes previously reserved for HIV alone (Mwagomba *et al.*, 2018). Similarly, in Uganda, CD management has been integrated with the programmes and services previously reserved for maternal, newborn and child health, sexual and reproductive health and rights, mental health, and HIV (Adeyemi *et al.*, 2021).

While in Kenya, CD management is integrated into community-based services previously reserved for MCH and School health, with the hope that this approach will better respond to the alarming disease burden of CDs, HIV, TB, Malaria and other infectious diseases the country faces (Adeyemi *et al.*, 2021).

2.2.1.2 Universal Health Coverage (UHC) and Sustainable Development Goals (SDGs)

Universal Health Coverage aims to achieve affordable healthcare services for people and communities by 2030 and has re-emerged as a global health goal (Fusheini and Eyles, 2016). This was further fuelled by the United Nations High-Level Meeting on UHC in 2019 (United Nations, 2019b). Broadly Fusheini and Eyles suggest that UHC means '*all people receive the health services they need, including health initiatives designed to promote better health, prevent illness, and provide treatment, rehabilitation, and palliative care of sufficient quality* *to be effective while at the same time ensuring that the use of these services does not expose the user to financial hardship'* (Fusheini and Eyles, 2016).

Consequently, UHC supports reframed interventions and national strategies that are holistic and responsive to the intimate dance between health and social and economic inequalities that underpin and interact with CDs (Russo, Bloom and McCoy, 2017; Munday *et al.*, 2018; Oni *et al.*, 2019). Therefore, the achievement of UHC significantly relies on the achievement of the relevant, sustainable development goals; end poverty, quality education, gender equality, decent work and economic growth, infrastructure, reduce inequality, justice and peace, and partnerships (Munday *et al.*, 2018; Nugent *et al.*, 2018; United Nations, 2019b) (Munday *et al.*, 2018; Nugent *et al.*, 2018; United Nations, 2019b). Furthermore, Primary Healthcare is regarded as the vehicle for successfully achieving UHC (United Nations, 2019b), particularly within a CDs context (United Nations, 2018; NCD Alliance, 2021).

2.2.1.3 Primary Healthcare (PHC) as a Vehicle for Successful UHC

Primary level care, as described in Chapter One of this thesis, remains the first point of contact for people wanting to access their national health system in most countries (United Nations, 2019a). PHC provides comprehensive promotive, prevention, rehabilitation and palliative care near where people live and work (WHO and UNICEF, 2018). It does this through three interrelated components: 1) comprehensive, integrated health services, 2) multi-sectoral policies and action, and 3) engaging and empowering people, families and communities to self-manage their health (WHO and UNICEF, 2018; WHO, 2021b). These components underpin UHC; as such, it is unsurprising that PHC is critical for achieving UHC (United Nations, 2019b; WHO, 2021b).

Interestingly, the recent global re-commitment to PHC, inspired by the WHO due to UHC, sparked the global conference on Primary Healthcare in October 2018, 40 years after the famous Alma-Ata declaration (WHO, 2021b). The resulting fresh and commendable Declaration of Astana is now driving global and national efforts to strengthen health systems and refuel political re-commitment to PHC (WHO, 2021b, 2021a).

Notwithstanding how principles of social justice, equity and participation underpin PHC, thereby also embedded within the UHC tune, health remains a fundamental human right

(United Nations, 2019a). The WHO emphasises the importance of patient autonomy and inclusivity within CD health management strategies (WHO and UNICEF, 2018). I elaborate on this further in the following subsection.

2.2.1.4 Engaged and empowered people and the Role of Multi-Stakeholder Action (MSA)

According to the WHO and UNICEF, *'people want and expect to have a say in the planning of health priorities and how these priorities are implemented in their community'* (WHO and UNICEF, 2018, p. 18). This statement signifies people's willingness and desire to participate in health service delivery and governance (WHO, 2018a). Sadly, however, in most LMICs, health education and access to information remain suboptimal (United Nations, 2018), consequently affecting people's ability to be well-informed and empowered participants and contributors to local and national CD management (WHO, 2013).

Unsurprisingly, global policy supports providing health education to patients with chronic disease to empower them to make informed decisions surrounding health risk behaviour and self- management of chronic diseases (United Nations, 2018). Additionally, meaningful community and patient engagement are suggested to help identify and contextualise the needs and preferences of the people holistically (WHO and UNICEF, 2018). A well-known example is how patient advocacy and involvement within HIV/AIDS management in different countries have contributed to lowering the price of their medicines, mobilising leadership to get new medicines approved, fighting against discrimination and overturning discriminatory laws (UNAIDS, 2018; WHO and UNICEF, 2018). Such processes increase patient satisfaction and improve patient responsiveness and health outcomes (WHO and UNICEF, 2018).

Sadly, for CD research, community-based engagement processes rooted in MSA remain underexplored (NCD Alliance, 2021). This is surprising because a significant component of effective CD management relies on the daily modifiable risk behaviours that patients navigate and factors that may lie outside the health sector (Bala and Srivastava, 2021). As such, there is an urgent need to understand people's lifestyle choices, interactions with one another and their environment, and the socio-political and economic contexts and how these influence patient health behaviours (Yadav *et al.*, 2020; Pirrone *et al.*, 2021). Multi-stakeholder collaboration or MSA and inquiry could aid with the holistic comprehension of people's health behaviours and how to positively influence them (Mendenhall, 2015; Pirrone *et al.*, 2021).

The national tobacco and sugar control strategies showcased successful MSA coordination that positively contributed to better CD management. These rely on partnerships between different stakeholders to positively influence people's health behaviours. Such 'health-in-all-policies' (HiAP), similar to the 'whole-of-government' and whole-of -Society' approaches, cut across different sectors to systematically understand the health implications of the decisions people make and how to collaborate to protect people from harmful health impacts and inequality and improve population health. WHO encourages countries to adapt these strategies and approaches to their unique socio-economic and developmental contexts (WHO, 2013). Ironically, MSA against CDs in Africa is suboptimal and nascent even with this leeway (Juma *et al.*, 2019; Oni *et al.*, 2019). Most LMICs are wrestling with policy translation and implementation challenges (United Nations, 2019a), burdened by aggressively unresolved health, social and economic inequalities (WHO, 2018b; United Nations, 2019a).

The following section examines how South Africa has adapted and incorporated the global CD guiding elements and strategies into their national efforts to address CDs.

2.3 CD POLICY AND STRATEGIES IN SOUTH AFRICA

This section identifies leading national policies and strategies to address CDs in South Africa. I also elaborate on National Health Insurance (NHI) and the recently reintroduced Community Oriented Primary Care (COPC) approach. In 1994 the country experienced a significant victory as we emerged from the era of racial discrimination, segregation, and inequality (Ndinda *et al.*, 2018). However, scars of unequal healthcare, resource distribution and access remained (ANC, 1994). South Africa was plagued with infectious diseases (Russo, Bloom and McCoy, 2017) and HIV & AIDS and these (contributing the greatest to the country's mortality rate) were prioritised over NCDs (Ndinda and Hongoro, 2017). An NCD Directorate in the Department of Health (DoH) was created in 1996, but tangible actions to address CDs needed more direction and implementation (Ndinda *et al.*, 2018). Then in the years that followed, over 40 policy documents and guidelines to address CDs' syndemic nature and multi-morbidity emerged (Ndinda and Hongoro, 2017; Ndinda *et al.*, 2018). Table 3 highlights significant milestones achieved through select documents and guides released between 2010 and 2017.

2.3.1 Trends and significant events for CDs

Table 3 selected national and provincial policy documents addressing CDs between 2010 – 2017

Policy document	**Year released**	**Key points identified**
National Department of Health Strategic Plan 2010/2011 - 2012/2013 (SANDoH, 2010).	2010	• Described the quadruple burden of diseases to include (i) HIV and AIDS (ii) Communicable diseases (iii) Chronic Diseases (iv) Violence and injuries • Called for the 'revitalisation' and strengthening of the PHC approach. • Identified PHC principles: (i) Equity, (ii) Quality (iii) Community involvement (iv) Intersectoral collaboration
Human Resources for Health. South Africa Strategy for Health (Matsoso and Strachan, 2011).	2011	• Introduced 'Task shifting' and redefined the roles and functions of healthcare workers. • Called for the integration of IPE and collaboration at academic institutions and health facilities.
National Development Plan 2030 (NPC, 2012).	2012	• Called for the immediate prioritisation of extensive community engagement and intersectoral action to address community health issues.
Strategic Plan for the Prevention and Control of Non-communicable Diseases 2013-2017 (SANDoH, 2013).	2013	• Highlighted the need for multi-stakeholder collaborations and action to address CDs • Contextualised the 'Whole of government' and 'Whole of Society' approaches to better fit South Africa

Healthcare 2030- The Road to Wellness-Western Cape Provincial Policy (WCDoH, 2014).	2014	• Further contextualised the use of the 'Whole of society' approach for building and maintaining strategic partnerships for MSA • Contextualised and called for adopting a 'person-centred' approach to health and wellness. • Recommitted to prioritising approaches that improve disease ownership and self-management in patients with chronic disease. • Advocated for the need for improved and strengthened M&E strategies. • Advocated for the significance of health systems research that contextualises the patient disease experience.
Provincial Strategic Plan 2014-2019 for the Western Cape (WCGDoP, 2014).	2014	• Identified approaches to strengthen social protection services in vulnerable communities. • Called for the "whole-of-society" approach to intentionally place people, patients and communities at the forefront of MSA. • Emphasised the significance of developing a wellness index to measure community resilience and assets. • Highlighted the need for community-based educational programs to promote health and wellness.
National Health Insurance White Paper_gazette (SANDoH, 2017).	2017	• Narrated how social determinants of health affect the population's health significantly and hence require MSA to address • Described the establishment of the multi-sectoral National Commission to address CDs • Contextualised NHI and its attempts to protect people and households from out-of-pocket medical expenses. • Linked the achievement of UHC in South Africa to NHI implementation

Key for table 3

CDs- Chronic diseases

IPE- Interprofessional Education

PHC- Primary Healthcare

UHC- Universal Health Coverage

M&E- Monitoring and Evaluation

MSA- Multi-stakeholder Action

SA- South Africa

NHI- National Health Insurance

2.3.2 South African CD Policies and Strategies: significant considerations

South Africa’s efforts to strengthen the PHC system and integrate CD management into pre-existing and practical strategies to address other diseases are commendable. For instance, the Integrated Chronic Disease Management (ICDM) model released in 2011 called for the integration of health promotion activities for HIV, TB and NCDs (Adeyemi *et al.*, 2021). This model advocated for population screening, facility reorganisation, clinical management support, and assisted self-management of diseases through patient education (Adeyemi *et al.*, 2021). The ICDM model was included in the famous 'ideal clinic' initiative rolled out in 2014 and probably contributed to the ICSM model launched in 2019 that I described in Chapter 1.2.4 (Mwagomba *et al.*, 2018; SANCDA, 2019).

Furthermore, upon careful inspection of Table 3, it is evident that national efforts to manage and address CDs align with global strategies (Mayosi *et al.*, 2009; SANDoH, 2010). National strategies encouraging a move from 'provider-centred' toward 'patient-centred' approaches further echo global efforts to promote the self-management of CDs and their risk factors and empower people to make better health choices (SANCDA, 2019). Strategies and approaches like National Health Insurance (NHI) and Community Oriented Primary Care (COPC) are propelling the country toward the successful attainment of UHC (Fusheini and Eyles, 2016). I elaborate on these further in the following sub-sections.

2.3.2.1 National Health Insurance (NHI)

The NHI financing system aims to provide South Africans access to personalised quality and affordable healthcare services (SANDoH, 2017). It is proposed that this will be done by strategically pooling national funds to purchase healthcare services so that all healthcare services (PHCs, hospitals, specialised services etc.) are nationalised and regulated by the government (Pauw, 2022). The imagined reality is that healthcare will be people-centred and integrated to respond to health needs (Moosa, 2022). Bearing in mind the socio-economic inequalities that plague South Africa, NHI is painted as a solution to addressing these inequalities that negatively affect access and quality of healthcare services (Pauw, 2022). Additionally, it is seen as the vehicle for achieving UHC and is well within its implementation stage in the country (Cashin and Dossou, 2021).

2.3.2.2 Community Oriented Primary Care Approach for Western Cape

The Community Oriented Primary Care (COPC) approach originated in South Africa in the 1940s (Mullan and Epstein, 2002; Moosa, 2006) as an innovative approach that converged epidemiology, primary care, preventive medicine and health promotion (Longlett, Kruse and Wesley, 2001). The Metro District Health Services (MDHS), a component of the Western Cape Government, describes COPC as a continuous process of providing PHC to a defined community based on their assessed health needs (Mash *et al.*, 2020, p. 2). The iterative process has four stages, as illustrated in Figure 2.1 below.

Figure 2. 1 COPC process (Liaw et al., 2015)

Stage 1: <u>Define the community of interest</u> involves inquiring about a community's demographic characteristics, environment, health status, and available health and social services (Epstein *et al.*, 2002, pp. 1–2). This critical stage seeks to explore the significant health-related issues of a community collaboratively, then holistically understand them (Stage 2) and develop contextualised interventions (Stage 3) (Epstein *et al.*, 2002; Mullan and Epstein, 2002).

The COPC process heavily depends on multi-disciplinary collaboration between healthcare professionals, community advocacy groups, NGOs, health education institutions and other stakeholders or partners outside the health system (Moosa, 2006; Bam *et al.*, 2013). Positively, the community is involved at each stage of the process (Bam *et al.*, 2013; Liaw *et al.*, 2015), and community participation is constantly prioritised (Moosa, 2006).

In the Western Cape, the revised COPC framework was developed through a participatory action research (PAR) process that employed multi-stakeholder collaboration and is well into its implementation stage (Bam *et al.*, 2013; Mash *et al.*, 2020). This revised COPC framework has been reintroduced to four Western Cape communities; Mamre, Nomzamo, Eastridge and Bishop Lavis, where a collaborative process to actualise COPC in the community is ongoing (Mash *et al.*, 2020). In late 2019 the process of reintroducing the COPC framework to the community of Delft was started (WCDoH, 2019).

Not surprisingly, COPC relies on the Ward-based Primary Healthcare Outreach Teams (WBPHCOT). As Chapter One describes, these teams are composed mainly of CHWs who interact with the community directly (Mash *et al.*, 2020). In Delft, CHWs work under an NGO affiliated with the health department, and their role in successfully implementing COPC and CD management in the community is enormous.

2.3.2.3 The role of CHWs, NGOs and Pharmacists in CD Management

CHWs often work in the same communities they live in; as such, they have a deep and personal awareness of the ethnic, linguistic, socio-economic and cultural factors influencing people's health behaviours (Scott *et al.*, 2018; Tseng *et al.*, 2019). CHWs have health training to offer primary health education, promotion and disease-specific counselling. This occurrence means they are strategically advantaged to positively influence community-based efforts for health promotion, infection prevention, home-based disease management, and improving continuity of care (Tsolekile *et al.*, 2014). It is, therefore, not surprising that they play a critical role in the successful implementation of COPC and effective CD management in the Western Cape.

Similarly, community-based health NGOs have greater access to the community than formal health facilities and can exploit this position to offer necessary community-based health services (Mash *et al.*, 2019). For instance, in South Africa, NGOs work with PHC clinics/nurses/staff?? to host health awareness drives, mediate alternative central close-to-home CDU pick-up spots and offer home-based care in the comfort of patient homes (WCDoH, 2019).

Disappointingly, NGOs are said to be dependent on aid from the government and international organisations. This occurrence influences the NGO's autonomy in that they are conflicted with serving the donor's interests to the detriment of their communities (Shivji, 2006). Additionally, they are considered vulnerable to external and political influences that adopt a "pro-poor" approach that casts the community as an external participant in the health system with no power of influence (Frenk, 2010; Michel and Matlakala, 2013). This is unfortunate as NGOs are strategically advantaged to conduct asset-based assessments with the community (as an equal partner) to profile it and contextualise people's health issues (Shivji, 2006; Michel and Matlakala, 2013). Such collaborative approaches between communities and NGOs have significant value and can ensure increased participation and patient satisfaction (Frenk, 2010).

Pharmacists are integral to chronic medicine access and delivery (Boswell *et al.*, 2018). The South African National Drug Policy of 1996 outlines that pharmacists can promote the rational use of medicines to patients and prescribers because of their extensive knowledge (SANDoH, 1996; Gray, Suleman and Pharasi, 2017). Community-based pharmacists are responsible for providing health education focusing on the correct use of medicines and reporting adverse drug reactions (SANDoH, 1996). These functions position pharmacists to significantly contribute to effective chronic disease management and efforts to achieve universal health coverage (Rockers *et al.*, 2019).

2.3.2.4 The Role of HEIs in Community-based CD Research

Social accountability of higher education institutions describes '*the obligation to direct their education, research, and service activities toward addressing the priority health concerns of the community, region and/ or nation they have a mandate to serve*' (Boelen, Heck and WHO, 1995, p. 3). Hence, health education institutions must remain socially accountable to their surrounding communities (Frenk *et al.*, 2010; Boelen, Dharamsi and Gibbs, 2012; Larkins *et al.*, 2013). As such, they aim to produce graduates who will serve society as competent health professionals to address the population's health needs and can positively contribute to transforming health systems (Boelen and Woollard, 2011; Egieyeh *et al.*, 2021). These graduates are wholesomely described as Change Agents (Bheekie and Bradley, 2016).

In her thesis, Bradley H suggests that relationships between health services and academic institutions fast-track research activities that attempt to strengthen local and national health systems (Bradley, 2013). Pharmacists linked to academic institutions are then suitably positioned to collaborate with various stakeholders to drive multi-disciplinary and multi-stakeholder approaches to address health disparities in their surrounding communities (SANDoH, 1996; Bheekie and Bradley, 2016).

However, in South Africa, universities are often described as '*extensions of European universities*' that have yet to fully emerge in the African reality (Albertyn and Daniels, 2009, p. 422). Empowerment theories instruct researchers to focus on developing people's ability to be self-sufficient and act in their interests (CTSA, 2011; Musesengwa and Chimbari, 2017). Therefore, acknowledging local people's contribution to knowledge generation remain vital to Community Engagement (Roy, Baker and Kerr, 2017).

2.3.2.5 The Role of Communities in CD research

Communities must be equipped to take responsibility for their health and wellness and abandon their passive roles as health service recipients (WCDoH, 2014). Educational institutions generally report community-based research initiatives with minimal input from the community (Judkins and LaHurd, 1999; Roy, Baker and Kerr, 2017) . However, for successful learning and service delivery, the community must be considered an essential and equal active partner within the research process and community improvement conversation (Tsolekile *et al.*, 2014).

2.3.3 Challenges for Effective CD management in SA

Reflecting on our research problem in Chapter 1.3 and previous discussion points from this Chapter, South Africa is experiencing a disjoint relationship between policy formulation, its implementation, and its applicability to the realities of the South African people (Ndinda *et al.*, 2018).

The COPC approach shows promise; however, the need for more political commitment to its implementation is problematic. This is further exacerbated by poor intersectoral collaboration when identifying, contextualising and addressing community health needs. Perhaps due to the lack of clear-cut defined roles that stakeholders and role-players have in implementing COPC (Friesen *et al.*, 2018; Mash *et al.*, 2019). The snail-pace adoption of CHWs into the formal health system and lack of role clarification is frustrating and negatively affect their ability and willingness to fully support the successful implementation of COPC in their communities (Murphy *et al.*, 2020).

National policies and strategies that target alcohol, tobacco and substance abuse control seem to focus on regulating production and distribution rather than on the more complex social and health issues (Ndinda and Hongoro, 2017). Similarly, those attempting to address physical inactivity need to address the problems of inadequate education on the importance of physical activity and the lack of infrastructure and spaces for communities to exercise safely (Oni *et al.*, 2019). Policies on unhealthy diets seem more progressive (SANDoH, 2015). The famous action to increase the sugar tax in the country employs and relies on ongoing MSA (SADoNT, 2016), a first for the country since 1994 (Ndinda *et al.*, 2018).

Not surprisingly, CD policy development seems fragmented, and this could be because of the disabling silo-working practices within different government departments and sectors (Mayosi *et al.*, 2009; Basu *et al.*, 2019). Additionally, government hesitancy to engage industry and gain buy-in support perpetuates industry interference from major companies. This in turn further delays policy implementation and hinders progressive MSA efforts to address CDs holistically.

The country is a leading champion in advocating for a democratic nation that is people-centred and demands more inclusivity and citizen participation in national agendas (WCDoH, 2014). As such, PAR approaches to address CDs require further exploration, and I elaborate on PAR, its definition and its principles in the following section.

2.4 PAR AS A RESEARCH APPROACH

Participatory Action Research (PAR) methods usually prioritise research stakeholder empowerment through collaborative learning processes (Byrne, 2004). The PAR approach is often dynamic and adaptive to the ever-changing research setting and stakeholder contexts. As such, it benefits community-based health research that requires flexibility and holistic considerations of people's everyday realities (Bradley, 2013). Interestingly, PAR does not have a commonly accepted definition. Instead, it draws from Kurt Lewin's 1946 proposed 'spirals of Planning, Actioning, Observing and Reflecting' and Paulo Freire's 'emancipatory approaches' (Read, 2012). This encourages inspired researchers to uphold certain principles, such as valuing participation, developing iterative processes that engage stakeholders several times, and using reflection (Bradley, 2013). These principles are similar to those of Community Engagement, and I define this below.

Albertyn and Daniels describe Community Engagement (CE); *'as initiatives and processes through which the expertise of the higher education institutions, in the area of teaching and research, are applied to address issues relevant to its external communities'* (Albertyn and Daniels, 2009). The Higher Education Quality Committee (HEQC) of South Africa also subscribes to this definition (Mtawa, 2014).

Noticeably, the collaboration between HEIs and their surrounding communities forms a vital element of CE (Mtawa, 2014). This collaboration facilitates the mutual transfer and translation of knowledge and resources within a symbiotically established partnership that is non-exploitative (Albertyn and Daniels, 2009; CTSA, 2011; Tindana *et al.*, 2015).

In her thesis titled: '*Applying a participatory action research model to assess and address community health concerns among tribal communities in Gujarat, Western India: the potential and challenges of participatory approaches',* Read proposed a modified PAR-inspired methodological framework for conducting her research (Read, 2012). She further highlighted how the model was helpful in helping identify the health needs of the community and subsequently started the process of collaboratively identifying and actioning interventions to address the issues. Figure 2.2 below showcases this model.

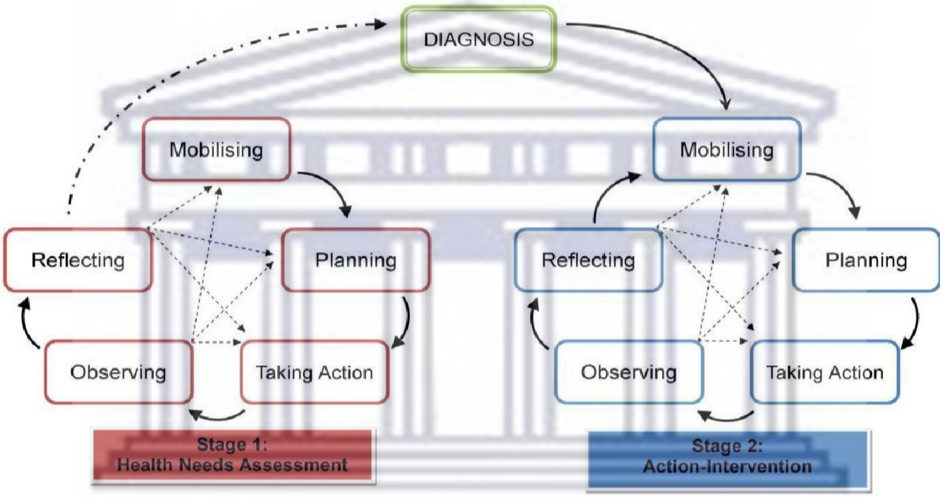


Figure 2. 2 Clancy Read's PAR methodological model (Read, 2012, p. 26)

In stage 1 (*health needs assessment*), the researchers typically work with the community and relevant stakeholders to collaboratively identify priority health issues (Read, 2012). In stage 2 (*action-intervention*), interventions to address the identified and prioritised health issues from stage 1 are developed and implemented with the community (Read, 2012). In Chapter Three, I elaborate on how we adapted our data collection method from this model.

2.4.1 Participation and community voice in PAR

In PAR, participation is the degree to which stakeholders become involved in the research process, from research topic conceptualisation to data collection and analysis (Geilfus, 2008).

This is viewed as a dynamic and ever-evolving process that gives the decision-making power to the community and stakeholders (CTSA, 2011; Geilfus, 2008; Musesengwa and Chimbari, 201 ; Tindana *et al.*, 2015). For instance, in some research, project objectives are predetermined by the researchers, but participants significantly influence how the research process is adjusted as it progresses (Geilfus, 2008).

In South Africa, the patient's rights charter highlights the constitutional right for patients to participate in decision-making that affects their health directly and indirectly (UN General Assembly, 2012). In PAR, the hope is that by engaging participants and facilitating the process of investigating the reality of their lives, participants learn to develop contextualised and appropriate strategies (Byrne, 2004; WCGDoP, 2014).

2.4.2 Critical reproductive research strategy's appropriateness within PAR

Critical researchers aim to explore the status quo, focusing on critiquing and exposing the unfavourable social contexts of people. Not surprisingly, these researchers often seek to address (emancipate people from) issues that contribute to social ills, often due to a dynamic interplay of social, cultural, and political domination (Malhotra, 2017).

Coincidently, critical realists departing from Marxist orthodoxy lean toward 'reproductive' and 'intensive' research designs and strategies (Malhotra, 2017). This makes it suitable when seeking to explain the underlying mechanisms of stakeholder engagements and relationships, for instance, between HEI and the community, and how these relationships contribute to knowledge production and translation (Malhotra, 2017). This inquiry aligns with the PAR paradigm, which seeks to be emancipatory and encourage people to determine their social constructs. We approached our research project from a Critical reproductive and intensive Participatory Action Research lens.

2.5 CHAPTER SUMMARY

In this Chapter, I drew from global policy and strategies to describe the guiding elements that underpin national strategies and efforts to address CDs. I outlined vital policy documents and strategies South Africa relies on to address the country's high disease burden. Additionally, I showcased the country's challenges in implementing and actioning national strategies. My intention with these descriptions and narrations was to showcase the suitability and necessity of PAR strategies that could hold value in addressing these challenges and the burden of CDs.

CHAPTER THREE: RESEARCH DESIGN & METHODOLOGY

3.1 INTRODUCTION

I outlined our research problem, questions, aims, and objectives in Chapters One and Two of this thesis. I also highlighted the suitability of Participatory Action Research (PAR) as an approach for our ongoing inquiry. In this chapter, recalling how unique our research setting is, I describe how we identified, recruited and engaged with stakeholders and role-players. I also highlight how we designed and adjusted our data collection process and instruments (PAR tools) by drawing from different PAR models, theoretical influences and participatory tools. Furthermore, I highlight how we managed and analysed our data and the ethical considerations. Lastly, I dissect the validity and reliability of our research process within the PAR lens. My intention with this Chapter is to set the stage for understanding the inquiry process to answer our research questions and attain our findings, which I present in Chapter Four.

3.2 RECRUITING THE RESEARCH STAKEHOLDERS (RESEARCH PARTICIPANTS)

In section 1.4 of this thesis, I described our research setting extensively. There, I revealed the link between the School of Pharmacy and an NGO service partner operating in the community of Delft. In this section, I will describe our process for identifying and recruiting primary research stakeholders (participants) and other role-players.

The primary stakeholder groups of our research were:

A. Health education institution (HEI) or School of Pharmacy
B. Non-governmental organisation (NGO)
C. Community health workers (CHWs)
D. Community representatives

In Chapter One, I described these particular stakeholder groups' roles in the SLiP programme. Further, how our inquiry sought to contextualise partnership dynamics between the School of Pharmacy and its SLiP service partners. These stakeholders being key to our research, were regarded as the primary stakeholders who directed the recruitment of others. The literature describes our recruitment process as convenience sampling that falls within the non-probability selection principles (Saumure and Given, 2008). Interestingly a key advantage of employing such methods to recruit research stakeholders (participants) is the increased accessibility stakeholders have toward the research process, as well as their increased willingness to participate and lead the recruitment process (Saumure and Given, 2008; Mtawa, 2014).

Recalling our research questions and objectives, we intended to recruit research stakeholders that fell within the following criteria:

i. Had some association or link within the SLiP programme and engaged with pharmacy students.
ii. Had some experience collaboratively working with different stakeholders in the community or through student experiential learning activities.
iii. Had a basic understanding of community engagement and experience working with community members in a health and health promotion setting.
iv. Had a basic understanding of what chronic diseases are and currently diagnosed with a chronic disease.

Considering these umbrella criteria, I now elaborate on how we identified, selected and contacted our primary research stakeholders and other role-players.

3.2.1 Health Education Institution (HEI) group (School of Pharmacy)

For the health education institution (HEI), the overall target was the students and academic staff of the School of Pharmacy at the University of the Western Cape. Therefore, we used the following inclusion and exclusion criteria below.

The inclusion criteria for the academic staff:

- Based within the School of Pharmacy
- Play an active role in the SLiP programme
- Had previously interacted with the NGO service partner through the SLiP programme

The exclusion criteria for the academic staff:

- From outside the School of Pharmacy
- Not involved in the SLiP programme

- No connection or previous interactions with the NGO service partner.

Considering the above inclusion and exclusion criteria, I recruited two academic staff members who helped me recruit a specific group of students. These staff members coordinated the SLiP programme and Community Engagement (CE) elective module and were the supervisor and co-supervisors for this research project. I elaborate on the CE elective module below before outlining the student inclusion and exclusion criteria below.

The CE elective module was started in 2018 with the help of the two staff members recruited for our research. The elective allowed enrolled fourth-year pharmacy students to conduct participatory research with the NGO group operating in Delft. As such, the NGO and some CHWs were already aware and familiar with the fourth-year CE elective students. I saw this as an opportunity and recruited these specific pharmacy students as the student representatives within the HEI stakeholder group. I outline their inclusion and exclusion criteria below:

Student inclusion criteria

- Pharmacy students at the University of the Western Cape
- Pharmacy students registered for the CE elective module (module code: PHA427) in 2019
- Previously participated in the SLiP programme in previous year levels.

Student exclusion criteria

- Students from other faculties
- Pharmacy students not in fourth-year
- Fourth-year pharmacy students not registered for the CE elective module (module code: PHA427) in 2019

Considering the above, the previously identified academic staff (n=2) supplied me with the email addresses for the fourth-year CE elective student group (n=6) for the 2019 academic year. I sent the student group an email with the research stakeholder invitation letter (Appendix A). These documents clearly outlined our research and anticipated roles for stakeholders. The HEI group, which was composed of eight members (2 academic staff and 6 students), was the first to participate in closed focus group sessions on the 06th and 17th of February 2019. I elaborate on these focus group sessions, activities and instruments used in section 3.3 of this Chapter. In Chapter Six of this thesis, I reflect on why the HEI group had two engagement sessions as opposed to the other groups who only had one session.

3.2.2 Non-governmental organisation (NGO)

The target NGO at the onset of our research project was working with the academic staff and CE elective students. Given our umbrella recruitment criteria, these considerations meant that the identified organisation fit well with our research project.

Toward the end of 2018, I emailed the organisation's CEO and Chief Operations Manager (COM) with the help of the academic staff. I asked for an in-person meeting to further explain my research project and their anticipated role. Then at the start of 2019, I sent the recruitment email to the COM and CEO (Appendix B).

As shown in Figure 1.2 in Chapter 1.4.2, a natural division between the management, supervisors and CHWs is evident in the organisation's organogram. Due to this occurrence, I worked with the COM to recruit stakeholder representatives and participants. She used a nuanced approach that divided the NGO group into two groups. One group mainly included the management and operational staff and some CHWs, while the second group included mostly CHWs and a professional nurse who was working closely with the CHWs. I elaborate on our inclusion and exclusion criteria for the NGO group below.

Inclusion criteria for NGO group

- Working exclusively for the chosen NGO
- Previous interaction with School of Pharmacy students
- Awareness of the SLiP programme
- Previous interaction with fourth-year CE elective students

Exclusion criteria for the NGO group

- Not working for chosen NGO
- Unaware of the SLiP programme

With these considerations and after the in-person meeting, the COM selected representatives for the NGO group. In total, the NGO group was comprised of:

3 project managers

2 project coordinators

2 supervisors

3 CHWs

2 administrators

1 Chief Operations Manager (COM

Therefore, thirteen members made up the NGO group. The COM recruited them using WhatsApp and shared the research stakeholder invitation letter and engagement dates. As a result, the NGO stakeholder group had their focus group session on 13th March 2019.

3.2.3 Community Health Workers (CHWs)

Similarly, the COM recruited the CHW group via WhatsApp, using the same inclusion and exclusion criteria for the NGO. The COM recruited the following:

4 CBS CHWs

3 Lay counsellors (also CHWs)

1 Professional nurse

Like the NGO group, the COM shared the research stakeholder invitation letter and engagement dates. In addition, this eight-member group had their focus group session on 23rd May 2019.

3.2.4 Community members

At the CHWs' focus group session, I asked that each group member recruit 2 to 3 community representatives. Interestingly, CHWs recruited community members from support groups and medicine adherence clubs that they mediated. I outline the inclusion and exclusion criteria CHWs used below:

Inclusion criteria for community members:

- Living in the Delft area
- Part of a support group mediated by CHWs working for the chosen organisation
- Enrolled on the organisation's home-based visit system
- Affected with a chronic disease and taking chronic medicines
- Willing to discuss chronic disease experience in an open setting with researchers

- Ready to engage with different research stakeholders on chronic medicine use issues and personal experiences

Exclusion criteria for community members:

- Not living in Delft
- Not affected by a chronic disease and not taking chronic medicines
- Not willing to discuss chronic disease experience with researchers and other stakeholders

Bearing these considerations in mind, the CHWs recruited twelve community members from the Delft community. The CHWs used varied ways to recruit the community members; some invited community members from chronic support groups that they mediated and others through their regular home visits. In addition, I gave each CHW three research stakeholder invitation letters at their focus group session, and they used this to recruit the community members.

Once the CHWs had recruited their chosen community members, they gave me their names and contact details. Then, closer to the community workshop, I called each community member to introduce myself and remind them of essential information (workshop time, that transport was available and confirming if they were familiar and comfortable with the chosen central pick-up point). After that, I did not see the community members till the day of their workshop.

On the day of the community workshop (10th July 2019), I arranged a bus from the university's transport services to transport the group from a central pick-up point and back. I accompanied the bus driver to go collect the community group. Upon arriving at the main pick-up point, I was surprised to see 5 non-community members attending the community group. The extra 5 members included

1 project coordinator

3 CHWs

1 administrator

The COM and CHWs suggested that these extra group members would help the community feel more comfortable and confident to engage. For most of the community members, it was the first time they came to the university and engaged with researchers in an academic setting. Stakeholders are expected and encouraged to take charge of the recruitment process in participatory research. In total, seventeen-group members (including the 5 NGO staff members) formed the community group. I elaborate on my observations of the community workshop and how I navigated this engagement in Chapter Six of this thesis.

3.2.5 Other recruited role-players and stakeholders

Bearing in mind that I had collected a register at each engagement with the four primary stakeholder groups. By the time I concluded the community workshop, I had the primary stakeholder contacts and used these to finalise details for the first multi-stakeholder collaborative workshop (MSCW) held on 17th July 2019. Appendix C shows the invitation email for the first multi-stakeholder collaborative workshop.

3.2.5.1 Stakeholders for the First Multi-stakeholder Collaborative Workshop (MSCW I)

Fifty-three people attended the first MSCW. However, stakeholders had recruited other people, and I was unaware of these modifications until the day of the workshop when I noticed new and unfamiliar people.

At the first MSCW, primary stakeholders (through the group activities) identified other role-players that they felt could add value to our research. So, I invited these role-players to the second MSCW, which was eventually held on 17 January 2020. I elaborate on this below.

3.2.5.2 Role-players for the second multi-stakeholder collaborative workshop (MSCW II)

After the first MSCW, I used insight and my workshop notes to formally identify the role-players that the primary stakeholders had suggested could add value to our project. These identified role-players fell within the following groups:

1. Higher Education Institution (the university)
2. Primary health clinic (PHC)
3. Clinic committee
4. Health Forum
5. Medicine courier company
6. Delft Law Enforcement
7. Western Cape Provincial Department of Health

For most of the people falling within the groups above, I was able to source contact information from the primary stakeholders. Once I had contact details in the form of cell phone numbers and emails, I sent out a mass email (Appendix D) and made telephonic calls to the identified role-players and the primary stakeholders. We postponed the second MSCW three times because aligning the availability of such a large and diverse audience proved challenging. Finally, the second MSCW occurred on 17th January 2020, six months after the first MSCW, and included fifty people. I elaborate on this process, and the critical lessons learnt in Chapter Six.

Noticeably the group compositions of the primary stakeholders evolved as our research progressed. As a result, it was difficult to formally identify the frequency of attendance for each group representative, even when using the attendance registers. However, advantageously, I collected every attendant's roles and functions in the community. Table 4 below captures all the people who contributed to our research and their stakeholder groups or affiliations.

Table 4 Composition and affiliations of research stakeholders and role- players

	Community Function	**Number (n)**	**Affiliation/ Stakeholder group**
1	Community member	25	Community members from the Delft community
2	Community Health Worker (CHW)	12	Members working for chosen NGO linked to the School of Pharmacy through the SLiP programme
3	Lay counsellor	4	
4	Project manager	4	
5	CHW team supervisor	3	
6	Practising Nurse	3	

7	Administrator	2	
8	CEO	1	
9	Pharmacy lecturer	2	School of Pharmacy (health education institution) and higher education institution (rest of university)
10	Public health lecturer	1	
11	Pharmacy student	6	
12	UWC community engagement unit representative	1	
13	Primary healthcare facility manager	2	Representatives working at one of the three identified PHCs based in Delft.
14	Pharmacist	4	
15	Qualified post-basic Pharmacist’s assistant (QPB)	2	
16	Health promoter	2	
17	Medicine runner	1	
18	Clinic committee representatives	1	PHC clinic committee
19	Tygerberg sub-district health forum representative	1	Delft health forum
20	Medicine courier company representative	5	Medicine courier company
21	Law Enforcement representative	1	South African Police Service (SAPS)- Delft
22	Specialised health services representative	1	DoH, City Health
Total number of stakeholders engaged		**84 people**	**9 groups**

In this upcoming subsection, I narrate our data collection process and PAR tools used.

3.3 DATA COLLECTION PROCESS

Reflecting on the principles of PAR described in Chapter 2.4, data collection approaches rooted in PAR aim to involve research stakeholders in the inquiry process holistically. As such, PAR involves reiterating methods of identifying community issues, developing contextualised interventions, implementing them and then reflecting. These processes are often cyclical and repeated throughout the research process, allowing both researchers and stakeholders an adaptive, immersive, hands-on, and change-driven experience. Figure 3.1 below showcases an annotated PAR cyclical process often used in community-based and health systems research.

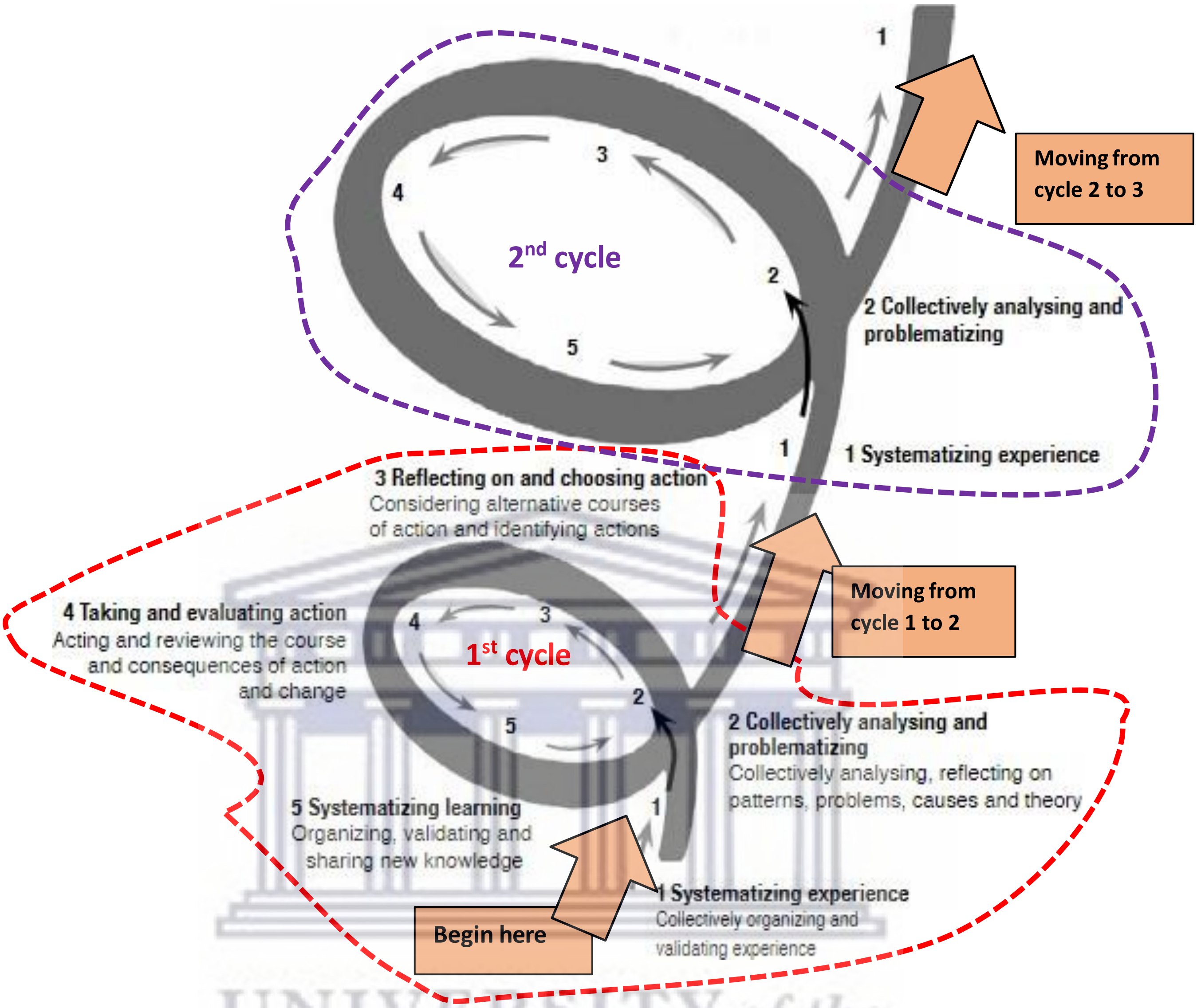


Figure 3. 1 The cyclical and spiral process of PAR (Loewenson et al., 2014, P. 13)

3.3.1 PAR Models and theoretical aspects that inspired our unique approach

Considering the PAR cyclical process above, we drew from Clancy Read's (2012) PAR methodological model (Read, 2012) and elements from the Dialogue Model (Mafuta *et al.*, 2017), and Participatory Technology development (van Veldhuizen, Waters-Bayer and de Zeeuw, 1997) to develop a data collection approach that suited our unique research setting. Before presenting our data collection approach and process, I elaborate on Read's and the latter models below.

3.3.1.1 Clancy Read's PAR model

Recalling my brief description of Clancy Read's methodological model in Chapter 2.4, the model presented a two-stage process (Figure 2.2) to identify and address the health needs of five villages within the Valsad District in Gujarat State, India (Read, 2012). Their process relied on a collaborative approach with research partners (including the community members) to address health needs by implementing selected interventions and actions. Reflecting on the cyclical process of PAR explained in Figure 3.1 above, Read's model showed us two cycles. I elaborate on their two stages (cycles) below.

During stage one, or the first cycle, under the *mobilising* step, researchers identified and engaged with community leaders to gather basic information about the communities and set objectives. After that, during the *planning* step, the research team determined what information they would source and from which stakeholders. During this step, the researchers determined the most suitable inquiry methods and required resources. Finally, during the '*taking action'* step, researchers held community meetings and used PAR tools to engage, collect data and identify significant health problems in the community. The '*observing'* and '*reflecting'* steps concurrently occurred with the mobilising, planning and taking action steps.

At the end of stage one, the researchers analysed the collected data. Additionally, they conducted key informant interviews. This process yielded reports translated into the local Gujarati language and disseminated back to the key informants and each community at the start of stage two. This intermediate stage was called the diagnosis stage and was used to link the first PAR cycle (stage one) to the second (stage two).

Subsequently, during stage two, under the *mobilising* step, researchers interacted with each of the five villages differently. Researchers could only interact with the community leader for one village, not the community members. For the remaining villages, varied, somewhat limited interactions with the communities occurred. During these engagements, researchers presented the findings from the diagnosis stage and sought guidance on addressing these prioritised health needs. Afterwards, researchers narrated their failure to plan and take action steps. Finally, the researchers under the *observing* and *reflecting* step shared how they instead leaned on key informant interviews to understand further what went wrong and how to improve future engagements. The key lessons learnt from the PAR process concluded the second cycle.

What was unique about Read's PAR approach was that researchers did not set the health priorities from the onset. Instead, research partners and, to some extent, lay community members directed the dynamic research agenda throughout the research process, staying true to the prominent feature of PAR-type projects (Abma and Broerse, 2010). Differently so, the Dialogue Model (DM) proposes that researchers set the health priority from the onset and that research stakeholders and community members act in a consultant role to guide the research process (Abma and Broerse, 2010; Elberse et al., 2012). I elaborate on how this model was used to contribute to public health interventions to improve maternal and child health service delivery in the Republic of Congo below.

3.3.1.2 Dialogue model (DM)

The Dialogue model (DM) explores complex health research topics affecting diverse people and stakeholders (Abma and Broerse, 2010). The DM is often employed to create a platform where different research stakeholders engage and participate through intentional dialogue on predetermined health topics that require intervention (Elberse *et al.*, 2012). A significant feature of DM is that it prioritises patient (end-user) involvement in health research processes to improve acceptance of public health interventions and outcomes (Caron-Flinterman *et al.*, 2006; Broerse *et al.*, 2010).

The DM model proposes a research process involving six phases in a somewhat linear progression. These phases include i) Initiation and preparation; ii) Consultation, iii) Prioritisation; iv) Integration; v) Programming; vi) Implementation (Abma and Broerse, 2010; Broerse *et al.*, 2010; Elberse *et al.*, 2012).

Mafuta and his colleagues adjusted these six phases of the DM to suit their unique research setting (Mafuta *et al.*, 2017). This setting relied on a pre-existing health partnership between two health zones, which were then deliberately chosen as the primary research stakeholders (Mafuta et al., 2015, 2017). The resulting adjusted DM merged the integration and prioritisation phases, resulting in five progressive phases (Mafuta *et al.*, 2017).

During the initiation and preparation (*exploration* and *preparation*) phases, the researchers defined the research partners, including two organisations and other stakeholders involved in maternal and child health. Four research partner groups were established, and formal MOUs through informed consent were signed (Mafuta *et al.*, 2017). The inclusion criteria for research partners relied on findings from a previously conducted exploratory study and context analysis that aimed to investigate the dynamic factors that impact the organisational mechanisms and efforts to achieve social accountability through initiatives (Mafuta *et al.*, 2015, 2017).

Subsequently, during the *consultation and prioritisation* phase, researchers conducted separate focus group discussions with the four research partner groups to determine the reliability of the results from the context analysis and exploratory study done previously in 2015 (Mafuta *et al.*, 2015, 2017).

Then during the *integration and prioritisation* phase, collaborative multi-stakeholder engagements involving all the research stakeholder groups reassessed the previously identified community health issues relating to the management of maternal health and services and suggested interventions (Mafuta *et al.,* 2017). At these collaborative engagements, researchers used participatory tools and engagement techniques (Abma and Broerse, 2010; Elberse *et al.*, 2012) to develop a single integrated intervention proposal (Abma *et al.*, 2017; Mafuta *et al.*, 2017). Interestingly, during this phase, researchers could draft proposal reports highlighting the prioritised health issues and imagined interventions for both health zones (Mafuta *et al.*, 2017). These proposal reports were shared with all research stakeholders and added significant value for the subsequent phase in the process.

The *programming* phase also involved collaborative multi-stakeholder engagements through workshops and used the proposal reports to refine and finetune the community interventions (Mafuta et al., 2017). Furthermore, the involvement of national health stakeholder representatives (e.g., officers from the Ministry of Health) attempted to align better the anticipated socially accountable interventions to the local and national health contexts of the two health zones (Caron-Flinterman *et al.*, 2006; Elberse *et al.*, 2012; Mafuta *et al.*, 2017). Interestingly, during this phase, researchers reported that they encouraged stakeholders to integrate the prioritised and fine-tuned interventions within pre-existing operational national health strategies responding to the country's disease burden; after critically examining the feasibility and applicability (Mafuta et al., 2017). In addition, an intervention proposal highlighting the need to increase community voice and participation and improve health sector accountability toward local people was drafted (Mafuta *et al.*, 2017). However, researchers did not conduct the *implementation* phase as this was seen as a mandate for local government.

3.3.1.3 Elements from Participatory technology development (PTD)

The third element of PAR this research project drew on originates from agriculture and rural development projects, which attempted to work with people to define and contextualise local farming systems, community issues and opportunities for change and improvement. These projects employed the Participatory Technology Development (PTD) process. Through PTD, development workers can facilitate engagements between researchers, organisations, farmers and the local people (van Veldhuizen, Waters-Bayer and de Zeeuw, 1997). These engagements use participatory tools and techniques to develop sustainable farming technology interventions that address and improve local farming and community life.

Typically, the PTD process is linked to the social change process, which involves 4 phases and relies on a modified spiral process of a training model sharing similarities with the PAR cycle. However, interestingly PTD sees the engagement process as a training opportunity for development workers and local people. This key feature of PTD aims to equip local people with dialogue, facilitation and participatory skills and resources through their participation in the research process. Thereby encouraging an environment where people identify and contextualise their local farming issues and confidently develop interventions to address them. I outline the four phases of the PTD below.

During phase one (*Basic orientation*), field staff (developmental workers and researchers) are trained and oriented on the basic skills needed to facilitate the PTD process successfully. Subsequently, they work with the farmers and facilitate critical reflection sessions that focus on exploring the farmers' local contexts. In these sessions, farmers reflect on their experiences working with other farmer groups (men versus women groups), previously used farming approaches and gaps. Additionally, the PTD process and its principles are also discussed with farmers, thereby creating spaces to assess the approach's suitability to the contexts of the farmers and community.

Subsequently, during phase two (*Toward an agenda for action*), field staff work with farmers and community members to collaboratively identify local problems and opportunities. These problems are not limited to farming but extend across aspects that farmers and local people prioritise. During this phase, field staff facilitate closed group and multi-stakeholder engagements geared toward encouraging people to select promising options and interventions they want to try and achieve and implement. What is most commendable about this phase is that field staff and researchers fully comprehend and prioritise that farmers naturally build and perform their experimentation to change and improvise their farming systems. Therefore, farmers and local people are encouraged to jointly analyse the community issues and ways to address them. Simultaneously, farmers and local people are trained to use participatory tools to plan out identified and desired interventions. This process supports a harmonious process of increasing the farmers' and local peoples' self-reliance, awareness of their creativity and innovation and confidence concurrently.

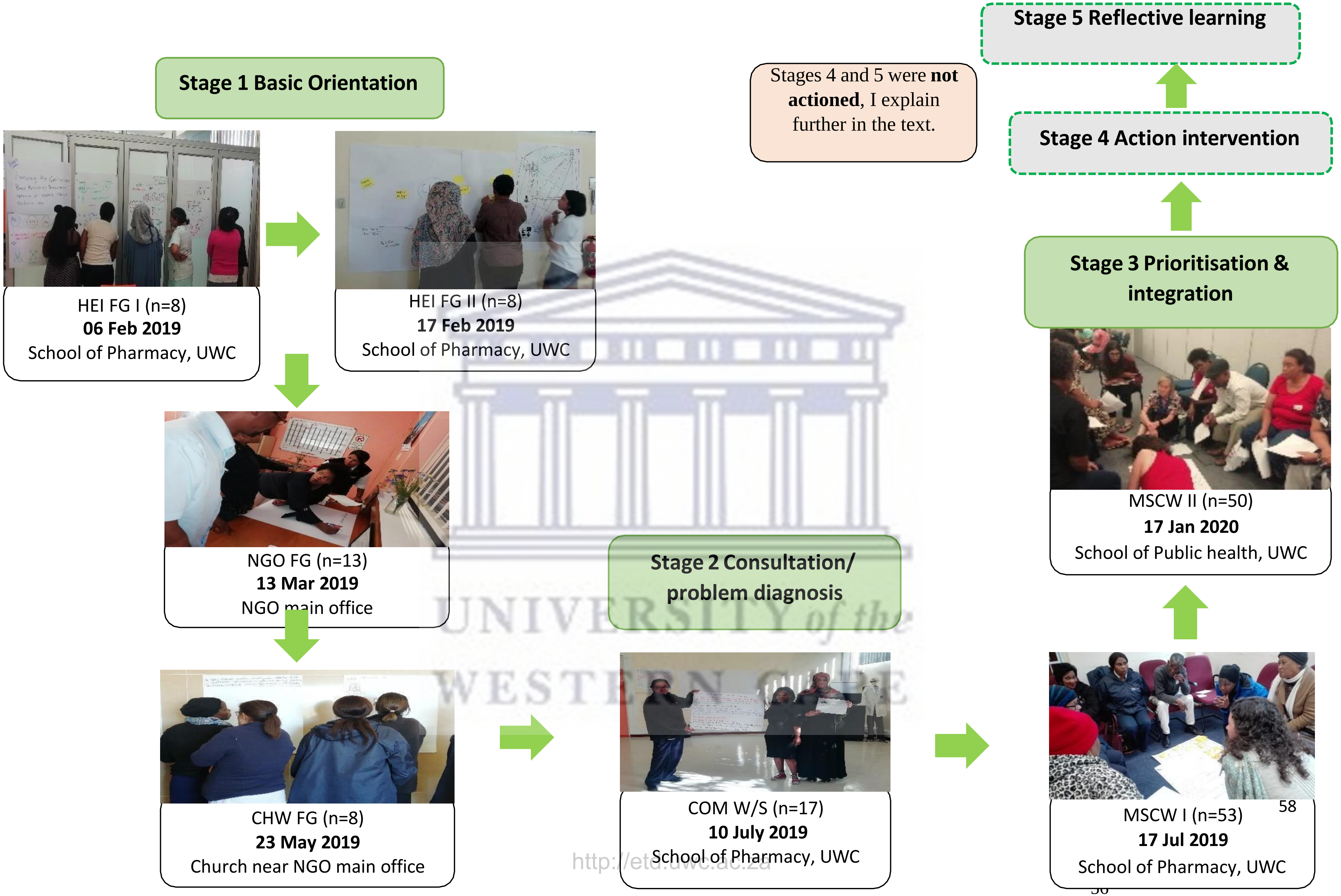
After that, in phase three (*Farmers' experimentation*), farmers and local people implement the prioritised options and interventions from phase two. During this phase, field staff support and co-facilitate the ongoing monitoring and evaluation interventions with the farmers and local people.

Finally, during phase four (*Spreading and consolidating the PTD process*), farmers share the outcomes of the interventions with each other, donor organisations, researchers and neighbouring communities. This process allows farmers to share new ideas based on experience, adding more credibility and trust to their suggestions. Further, stakeholders are equipped to continue the process beyond the scope of research or project timelines.

3.3.2 Our data collection process (Participatory multi-stakeholder engagement approach)

Our participatory multi-stakeholder engagement approach borrowed elements, phases and PAR tools from the previously described PAR approaches and models. In this subsection, I outline our five-stage process: Basic orientation, Consultation/problem diagnosis, Prioritisation and integration, Action intervention and Reflective learning, and the participatory tools used at each stage. I elaborate on the five PAR tools (data collection instruments) in the following Chapter 3.4. I outlined the composition of each stakeholder group and how we recruited them in previous subsections of this Chapter. Additionally, in Appendixes H to M, I present the session outlines used for each stakeholder engagement; I used these outlines to guide our sessions and, when used with this Chapter, will allow you to better integrate the PAR tools and how we administered them. Figure 3.2 visually showcases which stakeholder groups were engaged, dates and locations throughout our five-stage process.

Figure 3. 2 Stages of participatory multi-stakeholder engagement and research timeline



3.3.2.1 Basic Orientation

For this stage, we aimed to explore the organisational functions and realities of the primary stakeholder groups. This stage borrowed heavily from phase one of the PTD process and *'the change process'* activity (van Veldhuizen, Waters-Bayer and de Zeeuw, 1997), and I saw it fit only to engage three of the four primary stakeholders; HEI, NGO and CHW groups.

For this stage, we wanted to understand the organisational contexts of the stakeholders mentioned above and their partnership dynamics with each other and the community. We also, to some extent, wanted to pre-empt their willingness and readiness for collaborative inquiry to address chronic medicine use. Furthermore, we wanted to identify what chronic medicine use issues stakeholders were aware of and their perspectives on it.

Similar to the DM and how stakeholder groups were kept and engaged separately during the initial phases (Mafuta *et al.*, 2017), we also held our groups apart during this stage. We hoped that the closed nature of the engagements would contribute to fewer power dynamics within the stakeholder groups.

Consequently, during the Basic Orientation stage, I facilitated four focus group sessions with the stakeholder mentioned above (two sessions for the HEI group and one for the NGO and CHW groups, respectively).

For the HEI group their first session lasted about 2 and a half hours and was held on the university premises at the School of Pharmacy, and I used one PAR tool: The Journey of Change. The second session with the HEI group, which lasted for about 3 hours, was held at the same venue as the first, and I used three PAR tools: i) Robot, ii) Map of Exchange, and iii) Thoughts Pool-CMU.

Recalling how the operational manager was heavily involved in recruiting representatives for the NGO and CHW group, the suggestion to only conduct one extended engagement session with each group as opposed to two like the HEI group was well received. Additionally, the Robot tool was omitted as this was seen as a transition tool between two engagements and since the NGO and CHW groups only had one session, using this tool was anticipated to take away from the session time. I elaborate on this when I explain the Robot tool in the following Chapter 3.3.5.

Hence for the NGO group, we facilitated a closed focus group session at the NGOs offices that lasted about 4 hours. During this session, I used three PAR tools: i) The Journey of Change, ii) the Map of Exchange, and iii) Thoughts Pool- CMU.

Similarly, for the CHW group, we facilitated a closed focus group session at a church affiliated with the NGO and near the premises of their offices. This session lasted for about 4 and a half hours, and I further adjusted the three tools used for the HEI and NGO group to suit the contexts of the CHW group better: i) The Journey of Change, ii) the Map of Exchange, and iii) Thoughts Pool -CMU.

3.3.2.2 Consultation/Problem Diagnosis

We only engaged the community stakeholder group in a closed workshop during this stage. We sought to explore the group's perspectives toward the other research stakeholders and their chronic disease experiences. This stage was inspired by Read's model (Read, 2012) and elements from the DM (Mafuta *et al.*, 2017), which rendered it unique and significantly influenced the direction of our research process.

Elements from Read that inspired our research process included the *taking action* step during stage one (Health needs assessment) and guided the way in which researchers conducted community meetings to identify the significant health issues people faced (Read, 2012). Furthermore, during the *diagnosis stage*, researchers attempted to confirm the accuracy of the collected data and identify the community's health needs. Additionally, by drawing on the DM's consultation and prioritisation phase, researchers were able to confirm the relevance of collected information with stakeholders (Mafuta *et al.*, 2017).

We hoped that by engaging the community group with modified PAR tools, we would be able to contextualise CMU further by uncovering relationship dynamics with the other stakeholders and health services in Delft. Additionally, we wanted to explore the disease experiences of the community members and identify the major issues surrounding the use of chronic medicines. We also hoped to pre-empt the community groups' willingness to participate in the collaborative process of addressing chronic medicine use issues in Delft.

Consequently, during the consultation/problem diagnosis stage, I facilitated one extended community workshop that lasted about 4 hours on the university premises at the School of pharmacy. In addition, I used modified versions of the PAR tools and techniques during previous engagements with the other primary stakeholders; i) The journey of change, ii); Map of exchange, and; iii) Thoughts Pool- CMU.

3.3.2.3 *Prioritisation and Integration*

For this stage, the DM and PTD process inspired me to conduct collaborative multi-stakeholder workshops (Mafuta *et al.*, 2017; van Veldhuizen, Waters-Bayer and de Zeeuw, 1997). We did this to collaboratively prioritise the main chronic medicine use issues identified by the primary stakeholder groups and identify elementary intervention ideas. Additionally, during this stage, we recruited other role-players outside the primary stakeholder groups to participate in the research.

Recalling how, during the *DM Integration and prioritisation stage*, researchers reported conducting engagements that pulled all the previously isolated stakeholder groups together and sought to identify integrated interventions to address the previously identified MCH community issues (Mafuta *et al.*, 2017). Similarly, during phase two of the PTD process, researchers worked with farmers and community members and facilitated stakeholder engagements geared toward developing practical interventions to address local farming and community issues (van Veldhuizen, Waters-Bayer and de Zeeuw, 1997).

Consequently, in this *Prioritisation and Integration* stage, we hoped that by pulling the primary stakeholder groups together and creating a collaborative space, we could revise the previously identified chronic medicine use issues, and stakeholders would identify opportunities. Additionally, during this stage, we hoped to allow stakeholders to expand on their perceived relationship dynamics with each other in the presence of all.

Hence, we conducted two multi-stakeholder collaborative workshops (MSCW). In previous subsections of this thesis, I outlined the attendants for each workshop. The first MSCW (n=53) lasted about 4 hours on the university premises at the School of Pharmacy. I used four PAR tools; i) Purple, Blue, Red and Green (PBGR) game, ii) Thoughts Pool- CMU revisited, iii) Thoughts Pool-Dreaming together, and iv) Thoughts Pool- where are we now?

Throughout the first workshop, stakeholders mentioned other role-players they felt needed to be involved in our research. This occurrence allowed me to enhance my insights further and finalise who else to invite to the second MSCW.

Subsequently, for the second MSCW (n=50), we combined the primary stakeholders with a much broader and inclusive audience of health role-players operating in the Delft community. Interestingly, fewer of the original stakeholder groups were present at the second MSC because more people had been invited. This, we believe, allowed us to explore fresh perspectives.

The second MSCW lasted about 6 hours and was held on the university premises at the UWC's School of Public Health, and I used three PAR tools that were mostly adjusted from the previously mentioned tools: i) Map of exchange- focusing, ii) Thoughts Pool- CMU, and iii) Thoughts Pool- Ideal CMU management. I outlined the additional role-players that attended the second MSCW in previous subsections, and Table 4 captured all research stakeholders and role-players involved in our project.

Noticeably, we were unable to action stages 4 (*Action intervention*) and 5 (*Reflective learning*) of our research process. Since stages 1-3 spanned over a considerable amount of time (February 2019 – January 2020), we presumed that actioning stages 4 and 5 would require even more time, which spanned beyond the timeframe of our study. Additionally, we also anticipated that collaboratively analysing and contextualising the extensive data collected from stages 1-3, paramount for successful actioning stages 4-5, would require an extended research timeframe and resources outside the anticipated research budget required for this Master's study. In the following subsections, I elaborate on the anticipated actions for stages 4 and 5 if we were to have been successful in our attempts.

3.3.2.4 Action Intervention

The PTD (van Veldhuizen, Waters-Bayer and de Zeeuw, 1997), DM (Mafuta *et al.*, 2017) and Read's Model (Read, 2012, p. 26) inspired this stage. This phase was intended to support the stakeholders (inclusive of the role-players from the second MSCW in stage three) to refine and further develop an intervention(s) to address a chronic medicine use issue(s) prioritised by the research stakeholders from previous research stages.

Recalling how, during the *farmers' experimentation* phase of PTD, farmers and local people implemented interventions while the field staff (researchers) co-facilitated engagements with the stakeholders as a monitoring and evaluation technique (van Veldhuizen, Waters-Bayer and de Zeeuw, 1997). Additionally, how during the *programming* phase of the DM, researchers facilitated collaborative engagements that sought to finetune the community interventions identified in the previous stage (Mafuta *et al.*, 2017). Finally, recalling how this phase yielded an intervention proposal was circulated back to the stakeholders in the final phase of their research (Mafuta *et al.*, 2017). Similarly, during the *'Action-intervention'* stage of Read's model, researchers attempted to share the previous stage's findings with communities, identify ways to address the prioritised health issues and seek interventions (Read, 2012).

In the *Action-Intervention* stage, we anticipated three focus group sessions and one workshop with the primary stakeholder groups. We hoped these engagements would further develop identified interventions to address the prioritised chronic medicine use issues. After that, we imagined a third collaborative MSCW with the primary stakeholders. We hoped stakeholders would collaboratively identify a unanimous intervention strategy based on their prioritised chronic medicine use issues. We also hoped that the primary stakeholders could identify which other role-players were key in actioning and supporting their intervention strategy during this engagement. We would then invite these to a fourth MSCW.

3.3.2.5 Reflective Learning

Read's model (Read, 2012) and the PTD process (van Veldhuizen, Waters-Bayer and de Zeeuw, 1997) inspired this stage. Recalling how during the Action-intervention stage of Read's model, under the *observing and reflecting* step, researchers conducted key-informant interviews and identified key lessons from their engagement process (Read, 2012). Similarly, during the *Spreading and consolidating* phase of PTD, farmers were encouraged to share the progress and outcomes of implemented interventions with one another and other relevant role-players (van Veldhuizen, Waters-Bayer and de Zeeuw, 1997). Furthermore, researchers reported that farmers often shared new ideas and had deciding power on how to continue the engagement process during the *spreading and consolidating* phase of the PTD process (van Veldhuizen, Waters-Bayer and de Zeeuw, 1997).

Consequently, during the *Reflective Learning* stage, we had hoped to support the primary stakeholders in organising collaborative workshops to reflect on the research process and implement ongoing interventions collectively. We anticipated two MSCWs that would be planned, facilitated and recorded by the representatives from the primary stakeholder groups. As researchers, we hoped to support these ventures by providing facilitation training, financial support necessary for the logistical and planning elements of the MSCWs, and data collection and analysis training. In addition, we imagined that this stage would further equip stakeholders to continue the participatory process even far beyond the scope of our research.

3.4 PAR TOOLS

Participatory Action Research (PAR) tools and techniques describe interactive, people-centred instruments and methods to facilitate dialogue between people. PAR tools form a significant part of successful engagements between diverse stakeholders over complex issues such as health and chronic medicine use (de Brún *et al.*, 2017). In previous Chapters, I described PAR, its principles and its relevance to our research. Consequently, we used five main PAR tools and techniques to facilitate dialogue and engagements with stakeholders and role-players within our five-stage research process (approach) outlined above. Our five PAR tools are.

1. The Journey of Change
2. The Map of Exchange
3. Thoughts Pool
4. Purple, Blue, Red and Green (PBGR) game
5. Robot

In the previous subsection, I identified which tool was used during each stage of our five-stage research approach. Recalling how different PAR approaches and models inspired each stage, I present the main PAR tools and techniques in this subsection and highlight where these tools were sourced and the inspiration behind them. I also outline how I adapted each tool to suit the different stakeholder groups during various engagements. This action is in line with how practitioners in PAR are encouraged to use the least number of tools for vast and varied engagements.

3.4.1 The Journey of Change

Recalling the PTD process, the Journey of Change tool was inspired by the change process questions (van Veldhuizen, Waters-Bayer and de Zeeuw, 1997, p. 6) and *'characterising'* the existing farming system's learning activity tool (van Veldhuizen, Waters-Bayer and de Zeeuw, 1997, p. 36). These activities were described to be essential prerequisites for organisations to achieve meaningful engagements with the farmers and local people. Through the activities, stakeholders were encouraged to reflect critically on different aspects of their organisations and their readiness for the PTD process and change (van Veldhuizen, Waters-Bayer and de Zeeuw, 1997).

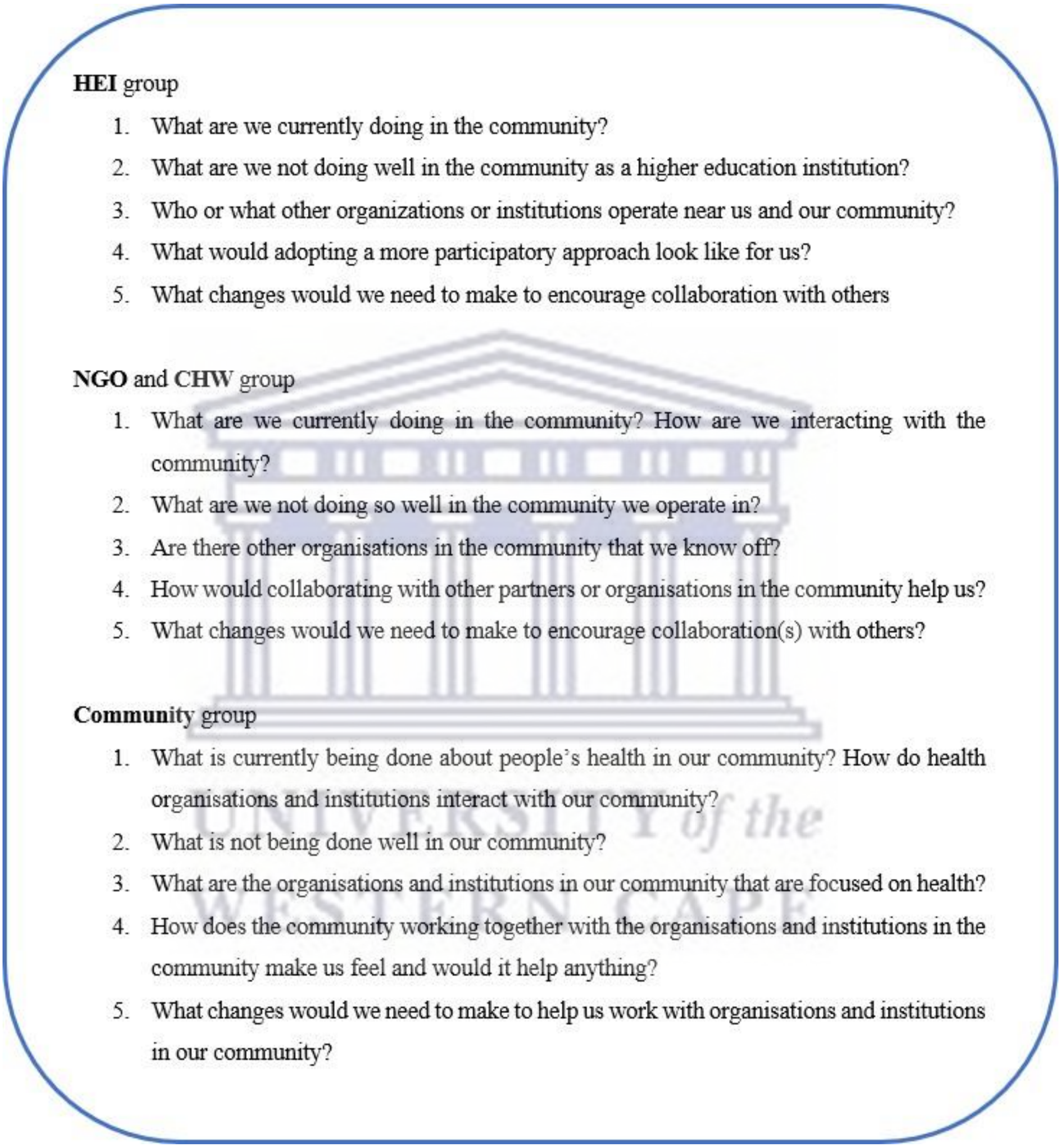
Below, I outline the '*change process questions*' described as useful in assessing the readiness for collaboration and change within organisations (van Veldhuizen, Waters-Bayer and de Zeeuw, 1997).

- Outline the active approaches and operational methods used to work with communities and their limitations.
- Assess the suitability of PTD to organisational contexts, its ability to address limitations and internal organisational adaptations or changes necessary to incorporate PTD.
- Identify key personnel to be at the forefront of efforts to attempt, document and facilitate a PTD approach and the required training.
- Assess the need and possibility for cooperating and collaborating with other organisations within the same region for PTD and their willingness to participate.

The *'characterising the existing farming system'* learning activity probed farmers to critically reflect on their farming systems and identify advantages and disadvantages. Researchers attempted to facilitate dialogue between farmers that highlighted the main characteristics of traditional agricultural systems and identified an opportunity for change and improvement. During this 60–80-minute activity, the trainers (facilitators) introduced the topic and questions to be answered to the entire group. After that, the group was divided into smaller groups of two or three members, given pens, markers, newsprint, cards and paper, and allowed to discuss their answers to the questions separately before presenting them to the rest of the group using the blackboard (van Veldhuizen, Waters-Bayer and de Zeeuw, 1997).

The Journey of Change tool used a variation of five questions to elicit discussions amongst stakeholder groups. I used these questions to probe stakeholder groups to reflect on their operational functions in the community and within respective partnerships. Box 3.1 below showcases these questions and how we adjusted them for each of the stakeholder groups.

Box 3. 1 The Journey of Change tool probe questions



HEI group

1. What are we currently doing in the community?
2. What are we not doing well in the community as a higher education institution?
3. Who or what other organizations or institutions operate near us and our community?
4. What would adopting a more participatory approach look like for us?
5. What changes would we need to make to encourage collaboration with others

NGO and **CHW** group

1. What are we currently doing in the community? How are we interacting with the community?
2. What are we not doing so well in the community we operate in?
3. Are there other organisations in the community that we know off?
4. How would collaborating with other partners or organisations in the community help us?
5. What changes would we need to make to encourage collaboration(s) with others?

Community group

1. What is currently being done about people's health in our community? How do health organisations and institutions interact with our community?
2. What is not being done well in our community?
3. What are the organisations and institutions in our community that are focused on health?
4. How does the community working together with the organisations and institutions in the community make us feel and would it help anything?
5. What changes would we need to make to help us work with organisations and institutions in our community?

To administer the Journey of Change tool, we divided the stakeholder group into four smaller groups (usually 2-4 members). Then each smaller group was given a question from questions 1-4, flipchart paper and markers. Each small group was assigned about 10-15 minutes to discuss their allocated question using the stationery provided or any other creative way they felt comfortable with (roleplay, storytelling etc.). Afterwards, groups presented their answers to other smaller groups, and an open discussion followed. The presentations and discussions typically lasted between 10-15 minutes, which allowed us to run through questions 1 through 4 in about 40-50 minutes.

Interestingly running through question 5 took between 20-30 minutes, potentially because it was posed to the entire group and discussions simultaneously occurred with recording the group's responses on combined flipchart papers. Figure 3.3 illustrates the Journey of Change in action during various engagements.

Figure 3. 3 The Journey of Change in action

KEY for Figure 3.3

Left: CHW stakeholder members working on their allocated question in their small group

Centre: HEI stakeholder members working on their respective questions in their small groups

Right: Community members working on their respective questions in their small group

3.4.2 The Map of Exchange

A valuable and well-known resource often used in participatory development projects, particularly within agriculture, is the 80 Tools for participatory development (Geilfus, 2008, pp. 142–145). This resource offers practitioners and alike a list of activities, games and instruments to facilitate engagements between farmers, local people and researchers. These resources , grounded in participatory appraisal principles, were the driving inspiration for the Map of Exchange tool, the Thoughts Pool and the facilitation style of our engagements with stakeholders and role-players. I elaborate on which elements we borrowed from the extensive resource to develop our unique Map of Exchange tool below.

The Map of Exchange tool was adapted from two existing tools: *'Map of Exchanges'* and *'Communication/exchange problem census'* (Geilfus, 2008, pp. 142–145). The former tool is used to help farmers identify the flow of materials and communication between the different role-players in their communities. Additionally, the tool can pinpoint areas of concern and which communication channels require remedying. The communication/exchange problem census tool encourages farmers to analyse the identified challenges affecting communication channels with other actors and role-players by asking specific probing questions. Below, I elaborate on the administration of these two tools before describing our Map of Exchange tool.

The administration of the Map of exchanges tool involves asking participants to identify the actors they engage with and exchange materials with, using a blackboard, paper, markers and newsprint. After that, the group is encouraged to use arrows to showcase what is exchanged between the actors and the flow of these exchanges. This activity is suggested to last between 1-2 hours. Similarly, the communication/exchange problem census takes the same group of participants that completed the Map of exchanges and encourages them to now identify any issues within the exchange process between various actors. Again, this activity is suggested to last 2 hours.

Consequently, our unique **Map of Exchange tool** sought to combine the formerly mentioned tools and facilitate visually capturing the nature of communication, the flow of resources and the challenges encountered between relevant actors familiar to the primary stakeholder groups. Recalling our unique research setting and pre-established partnerships between the primary stakeholder groups through the SLiP programme, we pre-populated the tools with six actor groups: community, PHC, CHW, student, health education institution and NGO.

To administer the Map of Exchange tool, I gave every group member an A4 printed page containing a blank Map of Exchange (see Box 3.2). After that, I gave the group 3-5 minutes to showcase who interacted with whom on their A4 sheets using provided markers. While the group was doing this, I placed A4 pages, each showcasing one of the six actor groups, around an ample blank space on the wall that was created by combining four flipchart papers. I placed actor groups in the same order as on the A4 handouts given to the group members. Figure 3.4 below showcases the Map of Exchange in action. Once the group had completed their individual maps of exchange, I facilitated combining and transposing these onto the large combined Map of exchange. This process took between 10-15 minutes. Once all relationships and interactions were identified, I then asked group members to comment on the interactions, communication and relationships between actors, and in most cases, a unanimous decision to use variations of 'good', 'bad' and 'room for improvement' to describe these links emerged. This process lasted between 30-35 minutes, and for each assigned description, we would discuss it as a larger group. The total duration of this tool was around 45 minutes to 1 hour.

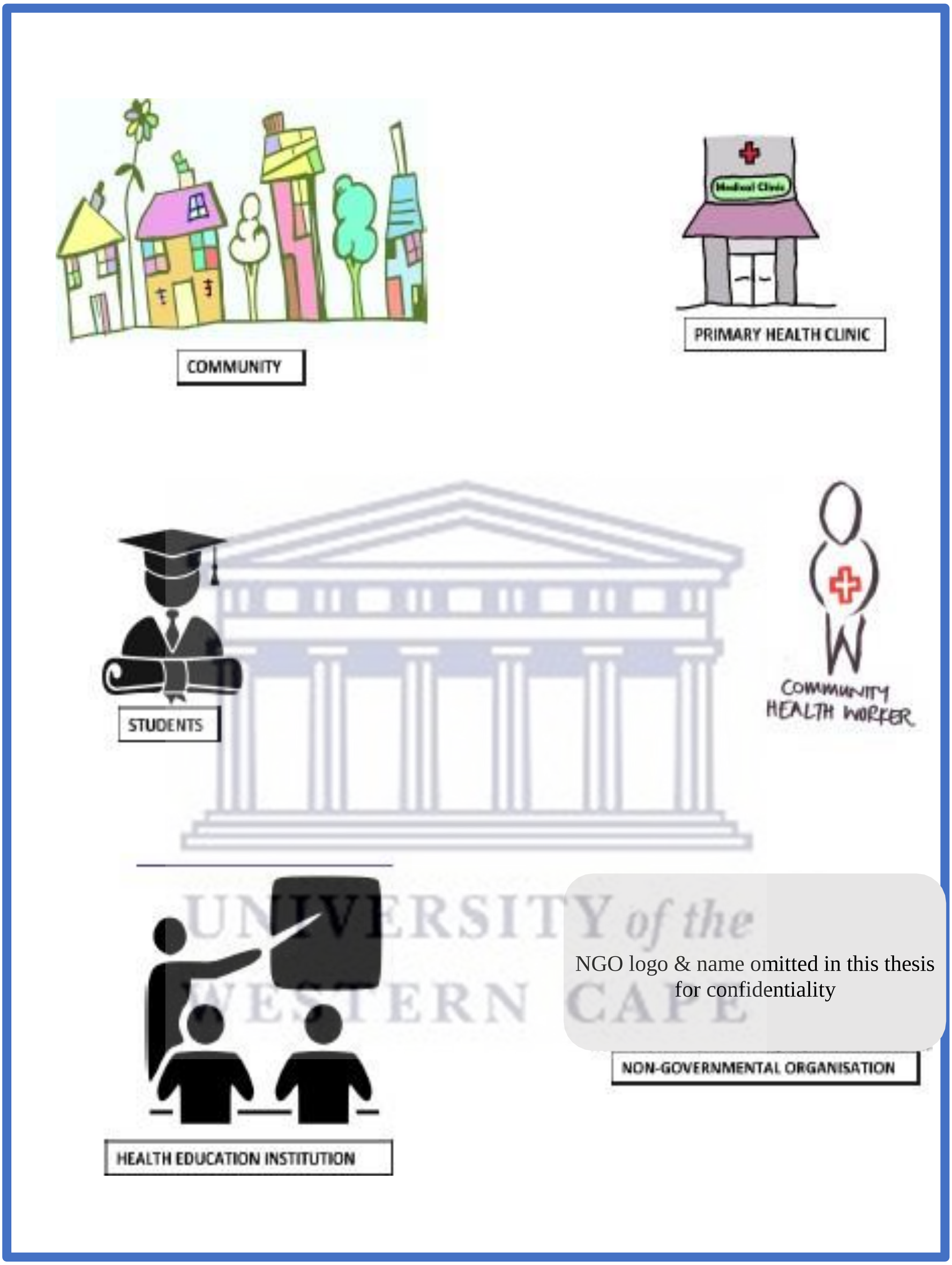
Figure 3. 4 The Map of Exchange in action

Key for Figure 3.4

Left: CHW group member illustrating the relationship between students and the community

Right: Community group member assessing relationships between partners

Box 3. 2 Blank mini Map of Exchange



3.4.3 Thoughts Pool

The Thoughts Pool tool was inspired by the *'Brainstorming session'* exercise from 80 tools for participatory development (Geilfus, 2008, p. 33). This exercise is useful when practitioners want to rapidly collect different ideas and perceptions from a large group of diverse people for a particular idea, proposal or event. This exercise is praised for encouraging participants to be more open and have dynamic discussions, which overcomes a known limitation of structured and semi-structured interviews and focus groups. Typically, the exercise begins by presenting an open question on an issue to a group of people. Afterwards, group members are given cue cards and asked to write their ideas, opinions and/or feelings on the cue cards, making sure to use one card per idea and keeping their responses below three lines or sentences. Once each group member has completed this task, the facilitator collects the cards and pins them onto the blackboard as they read each card out loud. As the cards are being read out loud and pinned to the board, the facilitator can group cards expressing the same idea around the same area of the board. Once all the cards have been collected and placed on the board, the group can decide to discuss further and/or brainstorm topics and ideas that arise from the cards. Interestingly no specified time frame or duration for this tool was suggested in the resource book (Geilfus, 2008, p. 33).

Consequently, with our **Thoughts Pool tool**, I modified the tool into four variations throughout our project i) Thoughts Pool-CMU used with HEI, NGO, CHW and Community groups during their closed focus group sessions; ii) Thoughts Pool- where are we now, used at the first MSCW with the various workshop participants, iii) Thoughts Pool- Dreaming together, used at the second MSCW with the various workshop participants; and iv) Thoughts Pool- Ideal CMU also used at the second MSCW. I elaborate on how I administered these tools below.

To administer the Thoughts Pool-CMU, I started by distributing cue cards (usually 3 or 4 cards per person), Prestik™ and markers. To help with this task, I asked that group members distribute the cards amongst themselves. At the same time, I drew a visibly large circle enclosing the word 'CMU' meant to represent chronic medicine use in the centre of combined flip-chart papers. After that, I presented the topic to the group by asking them to use the cards and markers to write down their first thoughts, opinions, experiences and/or feelings when they saw the word CMU and/or chronic medicine use. I gave the group about 5-10 minutes to complete this task and reminded them to use one card per thought and to keep responses short. Afterwards, I asked group members to walk up to the board and stick their cards around the working area. This task took about 10-15 minutes as group members often read the other cue cards already on the wall before sticking theirs. In some cases, they would place their cards near similar cards. Once every group member had placed their cards on the wall, I asked the group to assess the Thoughts Pool, and from there, I facilitated various pocket discussions between group members prompted by the cue cards. Our discussions bouncing between different yet important topics, lasted between 30-45 minutes, thereby allowing the total duration of this tool to last between 1 hour and 30 minutes or more. Figure 3.5 below illustrates the Thoughts Pool-CMU tool in action. I used the same method to administer other modified Thoughts Pool exercises with different groups and at different engagements.

Figure 3. 5 Thoughts pool-CMU in action

KEY for Figure 3.5

Left: Community group member sticking cards on CMU Thoughts Pool
Centre: HEI group members sticking cards on CMU Thoughts Pool
Right: NGO group members sticking cards on CMU Thoughts Pool

3.4.4 The Purple, Blue, Red and Green (PBGR) game

During the Basic Orientation and Consultation/ Problem Diagnosis stages, I observed that stakeholders enjoyed ice-breaker activities and often responded positively. With this consideration, I developed the Purple-Blue-Red-Green game, abbreviated to PBRG. I intended to use this tool at the first MSCW, which combined the four primary stakeholder groups involved in our research from the onset. I used the game to elicit discussions exploring the stakeholders' willingness to work together and collaborate to solve common problems. In turn, I hoped the game would further support the Map of Exchange tool and allow us to understand the limitations and opportunities for improved stakeholder communication, interaction and collaboration. The game was not played at the second MSCW, and this is because the broader range of different role-players present at the workshop was not necessarily involved with our project from the onset. We anticipated that because of this occurrence, the additional role-players would not have the necessary context to participate fully in the game. I elaborate on how I administered the game below.

To administer the PBRG game, I split the participants of the first MSCW into four groups, each having between 10-15 people. To divide the large group, I drew different coloured circles (Purple, Blue, Red or Green) on the blank register. As participants signed the register, they would know which team (colour) they belonged to. When the large group split into various smaller groups, I manually adjusted the team so that each team had accounted for an equal balance of representatives from all four primary stakeholders. Once the teams were somewhat balanced, I encouraged the groups to get to know each other and develop a creative group name that they later shared with the rest of the larger group. These activities took about 10-15 minutes. Once the groups had all introduced themselves, I asked each group to send me a representative to collect instructions and tools for the activity. Outside the workshop venue, I spoke to each group representative separately and explained an imaginary scenario:

Their group was on a burning island, and their only hope to escape was to board a boat that belonged to a kind fisherwoman (myself). However, I required a hot meal and fresh drinking water to allow their group to board my boat. The catch, however, was that they had to imagine that their island only had the item contained in their allocated gift bag, which was one of four things; i) a big pot with a lid or ii) uncooked potatoes and carrots, or iii) a 2-litre water bottle, or iv) a lighter, salt and black pepper). So the groups would need to work together and strategize how to use their allocated supplies to meet the fisherwoman's demands, board the boat and escape danger.

Once I had explained the imaginary scenario to each group representative and handed them their bag with supplies, I allowed them to go back inside the workshop venue. There, the groups started strategising. This process took about 10-15 minutes, and I walked around the venue to probe each group. Once the groups were done discussing their ideas, I explained the imaginary scenario to all the groups and encouraged each team to present their strategy. As expected, all groups failed to follow the instructions and would include the use of other items and resources they imagined their island would have. As groups presented, laughter filled the room as they gave their creative yet humorous strategies. This process lasted between 25-30 minutes.

After every group had failed, a CHW raised that to win the game; the groups had to work together as each team had a different yet critical part of what was needed to meet the fisherwoman's demands. I agreed with the CHW and then probed the group to identify what elements of the game they could relate to their interactions, communication and resource-sharing habits within their respective partnerships as primary stakeholders concerned with CDs healthcare services.

3.4.5 Robot

Like the PBRG game described above, I developed the Robot tool myself. Having understood the significance of reflection throughout our data collection process, I anticipated that I would facilitate critical reflection sessions throughout the engagement process with stakeholders. Initially, I expected to engage each primary stakeholder on two different occasions within the Basic Orientation and Consultation/Problem diagnosis research stages. Subsequently, I anticipated using the Robot tool to guide a reflective process at the start of the second focus group session with primary stakeholders. However, only the HEI stakeholder group had a second focus group session in the Basic Orientation stage, so I used the tool once with this group during their second focus group session. I described how I administered this tool below.

I drew three large circles on A1 flipchart papers stuck against the wall to administer the Robot tool. After that, in the centre of each circle, I wrote different words; in the first circle, I wrote 'Recall' on a pink sticky note card; for the second circle, I wrote 'Reflect' on an orange sticky note card; for the final circle, I wrote 'Move on' on a green sticky note card. These three circles were meant to mimic a classic Robot that communicates expected actions for motorists (Red- stop, orange- slow down, green- safe to go and move).

Drawing from this, I used the first circle (Pink) to probe the HEI group to share their thoughts and memories from their first focus group session a week earlier. I did this by handing out 2-3 pink sticky note cards and markers to each group member and, after explaining the tool and its purpose, asked that the group use the cards to *'Recall'* any thoughts and memories that they still had in their heads from the previous session. It is important to note that this was done after I had recapped and summarised the last focus group session. I gave the group about 5 minutes and invited them to walk up to the circle and stick their pink note. Afterwards, I gave them 2-3 orange sticky note cards and asked the group to 'Reflect' on their feelings and emotions from the previous session. The group was encouraged to stick their orange cards in the orange circle as with the pink cards. For this task, group members were done within less than 4 minutes.

I then used the sticky notes as props to facilitate an in-depth discussion with the group and unpack their feelings surrounding their first session, research topic, and perceived role as primary stakeholders. This lasted for about 35 minutes.

The green 'Move on' circle was made at the end of the session after the Map of Exchange and Thoughts Pool-CMU was done. For this task, I asked the group to use the provided green sticky note cards to write down how they felt we could move forward from both focus group sessions as a collective. Initially, I had not planned to administer the Robot tool in segments but in one setting where the pink circle was followed by the orange and then green. However, after briefly reviewing the words that the group had written in the *Recall* and *Reflect* circles, I felt a need to address them so as not to lose their significance. Surprisingly through our discussions, an organic leaning to wanting to discuss the partnerships between the School and community service partners emerged. This allowed a natural process of completing the Map of Exchange and Thoughts Pool-CMU before circling back to the green 'Move on' task. Figure 3.6, on the next page, showcases the resulting Robot tool in action. Following that, the next subsection describes what data we collected, how we managed it and our qualitative data collection analysis techniques.

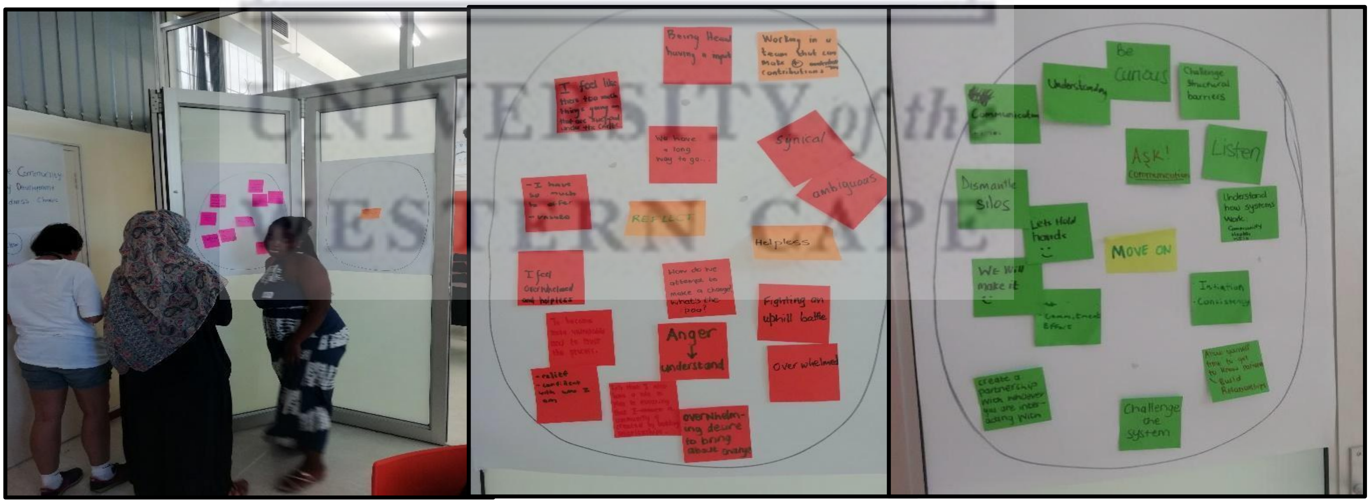


Figure 3. 6 Robot tool in action_ HEI focus group session II

3.5 COLLECTING, MANAGING AND INTERPRETING DATA

Recalling the five-stage process, you may have observed that we had seven contact sessions. These sessions were audio recorded from start to finish using a voice recorder. Additionally, I took pictures and brief videos throughout each session, mainly focusing on capturing people while they were discussing the given task within their groups, their presentations and the resulting A1 flip-chart posters. What then resulted at the end of our data collection period were seven audio recordings, a full gallery of pictures and videos, and completed A1 flip-chart posters, written-on cards, sticky note cards and used handouts. We stored these on a secured google team drive that was password protected. I also kept a personal journal and a research file containing session outlines, registers and important information documenting significant decisions that affected data collection procedures and research direction.

Consequently, I could use the audio recordings, collected session materials and my reflection journal to reassemble and recreate the stakeholder engagement sessions even after data collection had ended. Typically, I would attempt to recreate each session by hanging up the A1 flip-chart posters and cue cards. After that, I would listen and transcribe the audio recordings while noting further observations and reflections I had not captured during the live engagements. As I transcribed, I would include pictures taken during engagements in the transcription document. Often, I would annotate these images so they linked with the transcribed text. What resulted was a lengthy document that fused transcription, image annotation and reflection in one. Moreover, I included transcribed data and images from the research meetings held before and during our data collection process. This action allowed us to capture our real-time research process, data and reflections.

Not surprisingly, for PAR research projects, the data management, analysis and interpretation often include a combination of text, written words, symbols and visuals that represent the dynamic realities of people (Pain, Whitman and Milledge, 2011; Bradley, 2013). Word-based techniques help organise heavily text-based data and can identify themes for qualitative data interpretation (Ryan and Bernard, 2000). I elaborate on how I used the *Compare and contrast* (Ryan and Bernard, 2000) and a variation of *typology and matrix analysis* techniques below (Lofland et al., 1995; Ratcliff, 2015).

3.5.1 Compare-and-contrast

The compare-and-contrast technique encourages analysts to draw themes from data by looking at how the texts and evidence are similar or different from each other (Ryan and Bernard, 2000). It also encourages the analysts to ask critical questions that allow them to reflect on their biases. I explain how I used this technique in our research below.

Recalling the lengthy document containing the transcribed and annotated raw data. I reviewed this document and used the compare-and-contrast technique to analyse each engagement session systematically. For ease of reference, I changed the font colour of each engagement session so it would be easier to separate sections and engagement events.

After reading sections of the transcribed text and capturing annotations and images relating to a PAR tool and session activity, I selected key messages (codes) and copied and pasted them into a different document. In this separate document, I drew a table and pasted the selected and copied messages, making sure to group similar messages and texts relating to the same topic in one block. After sorting and grouping the key messages for a particular section or PAR tool; for instance, the first question of the Journey of Change with the HEI group, I would gauge if the following key messages required a new table. However, I ensured that the different key messages for each block spoke to one topic of discussion point (sub-theme). I conducted the same process for each engagement session and used the session outlines to order them.

Consequently, after sorting, copying and pasting raw data from an engagement session (e.g., HEI FG 1), long tables containing different groups (blocks) of themes resulted. I was then able to do the same for the remaining engagement sessions.

3.5.2 Typology and matrix analysis

Typology and matrix analysis techniques are classification systems that identify patterns and themes from large sets of visual and text-based data. Analysts use these techniques to present data findings that capture a holistic understanding and realities of research participants (Jackson, 2008; Lofland *et al.*, 1995). This technique also favours presenting analysed data through flowcharts and diagrams (Ratcliff, 2015).

Recalling the long tables of grouped key messages from the *compare-and-contrast* technique explained above. I was then able to group similar blocks (sub-themes) from different stakeholder groups and engagements. Thereafter, I grouped similar sub-themes electronically to develop the main themes from the sub-themes. After that, I could identify overarching and supporting themes from the pictures collected and annotated in the lengthy document. This process allowed me to trace sub-themes across the different stakeholder groups, PAR tools and engagement sessions.

3.6 ETHICAL CONSIDERATIONS

The University of the Western Cape (UWC) Biomedical research ethics committee approved our research study (Reference: BM18/7/15) on 27th September 2018 (Appendix E).

We sought permission from the stakeholders via email and telephone after obtaining UWC ethics approval. I outlined how I recruited each stakeholder for each engagement in previous sections of this Chapter. At the start of each focus group session and workshop, I presented general information to the stakeholders on the research project title and the data collection process. This was supported with detailed information sheets (Appendix F) and informed consent forms (Appendix G) that stakeholders were encouraged to sign. We highlighted information about the stakeholders' rights to voluntarily participate in the study, assurance of confidentiality and anonymity in the information sheets and consent forms. We also stressed that stakeholders would not suffer harm if they decided to terminate their involvement in the study.

Noteworthy is that from the onset of our research and stakeholder engagements, we did not provide the full details of the data-collection process and PAR tools we would use. Although we were transparent with stakeholders that the PAR process is a dynamic, ever-evolving process (Bradley, 2013), we did not fully know the entire data collection and research process from the onset. Below I highlight pertinent ethical considerations that arose during data collection.

3.6.1 Stakeholder Censorship, Power and Biases

Recalling how I outlined the roles and job functions of the group members involved during the various engagement sessions. Noticeably, the primary stakeholder groups combined more senior and management members with operational staff and lay community members. For instance, in the HEI group, students were paired with their lecturers and research supervisors. While the

NGO group also included CHWs, and the Community group included CHWs. These occurrences were evident to the group members, and we suspected that issues of power and censorship would arise.

Recalling the NGO group, it would be naïve to ignore that CHW may have personally censored their contributions during the session. Perhaps fearing that if they spoke negatively about the NGO, they could have compromised their job security. Similarly, with the HEI group, students could have held back out of fear of their lecturers and research supervisors. Unfortunately, these realities come with the territory of multi-stakeholder participatory research that is collaborative, and all research data is then accepted with some degree of bias.

Our interactive and participatory engagement sessions often involved group work and creative outputs. These simple actions created a somewhat game-like and informal environment. Additionally, our sessions' unstructured format, which relied on facilitated discussions, allowed me to deflect attention from leading speakers and toward the quieter speakers. While this consideration does not eliminate the degree of accepted bias surrounding our data, it allows some surety that we attempted to manage power dynamics and prejudice.

3.6.2 Data Management, avoiding fabrication and Plagiarism

I transcribed, analysed, and interpreted the raw data to reduce the chances of breaching confidentiality and anonymity. To the best of my ability, I used codes to identify the stakeholders during transcription and avoided fabricating, plagiarism and misrepresenting data collection processes, management and analysis. Where I used work that was not mine, I attempted to acknowledge and reference original authors accordingly.

Having read the presented sections above, you have an in-depth understanding of our research setting, how we recruited stakeholders, the data collection process and the PAR tools and techniques used. I also outlined the ethical considerations in this section. Subsequently, in the following section, I describe the quality and transferability of our research. I present this here to better couch the following findings Chapter.

3.7 QUALITY AND TRANSFERABILITY OF RESEARCH METHOD

In PAR, the usual constructs used to determine the validity and reliability of a research process in typical qualitative research tends to undermine the participative, dynamic, and action-oriented nature of multi-stakeholder engagements (Herr and Anderson, 2005). As such, PAR reports the research journey and findings concurrently (Winter, 1987), recalling our lengthy document capturing the data collection process and the data. Consequently, PAR Scholars suggest that addressing transparency, member checking, triangulation, and self-reflexivity better suits PAR and multi-stakeholder collaborative research (Bradley, 2013; Gilson et al., 2011; Green and Thorogood, 2004; Meyer, 2006). I drew on the same constructs to highlight the quality of our research.

3.7.1 Transparency

I kept detailed and honest accounts of the methods, tools and choices used and made throughout the process to maintain transparency within the research process (Green and Thorogood, 2004). Throughout the research process, I made many decisions; some were made with the research team through extensive discussions and brainstorming before engaging stakeholders. In addition, I kept a personal journal detailing events, changes, emotions, and reflections during the data collection stage of this research. The research file contained copies of changed meeting dates, focus group outlines, workshop outlines and agendas, while the journal recorded my reflections and observations throughout the research process. These were then used to develop this Chapter and honestly capture our data collection process and use of PAR tools.

3.7.2 Member checking

This process ensures effective feedback mechanisms or systems that allow stakeholders to confirm and verify the main findings and contribute to decision-making throughout the research process (Bradley, 2013; Meyer, 2006). For example, I consulted stakeholders when deciding to omit an activity from the session due to time or stakeholder preference was necessary. During each session, I would also start by sharing a summary of the research progress and the preliminary findings.

We felt that summaries and revision discussions at the start of the sessions, as opposed to session reports or documents, were more effective and inclusive of people with varying literacy levels and limited access to electronic and email services. In addition, these processes allowed correction and amendment of my interpretation of the data and encouraged input from stakeholders about how to adjust the research process. An official stakeholder report capturing our research process and findings was drafted and distributed to the primary stakeholders for comment (Nfurayase, 2021).

3.7.3 Triangulation

This strategy typically suggests the use of different resources and sources to gather information (Mtawa, 2014). Our study used 5 PAR tools and techniques with different stakeholder groups and contexts. We were also able to conduct closed focus group sessions with the four primary stakeholders as well as collaborative workshops. Segregating the stakeholders during the Basic Orientation stage and then bringing them together again in the prioritisation and integration stage allowed for opinions from various participants in different contexts and under other interactions.

3.7.4 Critical self-reflexivity

Self-reflexivity is a process that encourages researchers to be self-aware and cognizant of their perceptions, biases and preconceived opinions or resolutions throughout the research process (Haynes, 2012; Goemans *et al.*, 2019).

The people-centredness of this project exposed me to many different contexts, discussions, environments, and emotions that were complex and unfamiliar. I used a reflective journal and attended debriefing sessions with the research team to maintain focus and reflect on the research process. Debriefing and regular reflection became crucial components that ran parallel to the research journey. I fully capture this process in Chapter Six of this thesis. These processes allow authentic storytelling of the research processes, methods, and journey.

3.7.5 Transferability of our research

In PAR, the transferability or generalizability of research attests to the ability to transfer research findings from one context to another (Zuber-Skerrit and Fletcher, 2007; Bradley, 2013). This then encourages obtaining research findings that can contribute to and be useful in other research contexts or greater society.

In our project, we attempted to explore the use of a multi-stakeholder participatory approach to address chronic medicine use. As a result, we were able to develop a stakeholder engagement research process that could be useful with a different set of stakeholders and topics altogether.

While the same results cannot be obtained if the research process was to be repeated under the exact conditions, I believe the contributions of this study hold value for community engagement processes and community-based chronic medicine use intervention development.

3.8 CHAPTER SUMMARY

In this Chapter, I narrated our recruitment process and outlined the inclusion and exclusion criteria for the research stakeholder groups. Further, I describe how I drew from literature to develop our unique five-stage data research approach and the five PAR tools used to facilitate dialogue and data collection. I also outline our data management and analysis techniques before presenting the ethical considerations for our study. Finally, I concluded this Chapter by highlighting our research's quality, validity and transferability. In the next Chapter I present our findings.

CHAPTER FOUR: FINDINGS

4.1 CHAPTER PREFACE AND INTRODUCTION

In Chapter Three, I described how we collected data, our instruments (tools) and our analysis techniques. Having done so, I offer our research findings through themes and subthemes in this Chapter. Noteworthy, PAR researchers traditionally report the research findings as narratives that attempt to capture the research process and actions in a stepwise manner. However, recalling how we borrowed different elements from different PAR models, methods and approaches and somewhat cultivated a unique research process inquiry, this Chapter deviates from tradition.

Instead, I draw from different time points, PAR tools and engagements with stakeholders to present the findings as research themes underpinning our inquiries. My intention with this deviation is to illustrate a findings Chapter that does not merely present the research process but one that holistically captures the unified voices of stakeholders and allows room for comparison and contrast of relevant key opinions.

Additionally, considering our highly contextualised results, an awareness of the role-players concerned with CMU in Delft, their function and relevance to our study is imperative to fully understand our findings. I elaborate on this in the following subsection.

4.1.1 The role of relevant health role-players in Delft

During the second MSCW, participants identified 24 role-player groups in the Delft area through a mapping exercise. During this exercise, the large group was encouraged to call out different role-players that they felt were involved and concerned with chronic medicine use in the community. I present the 24 role-player groups engaged with CMU in Delft and their perceived function or influence in Table 5.

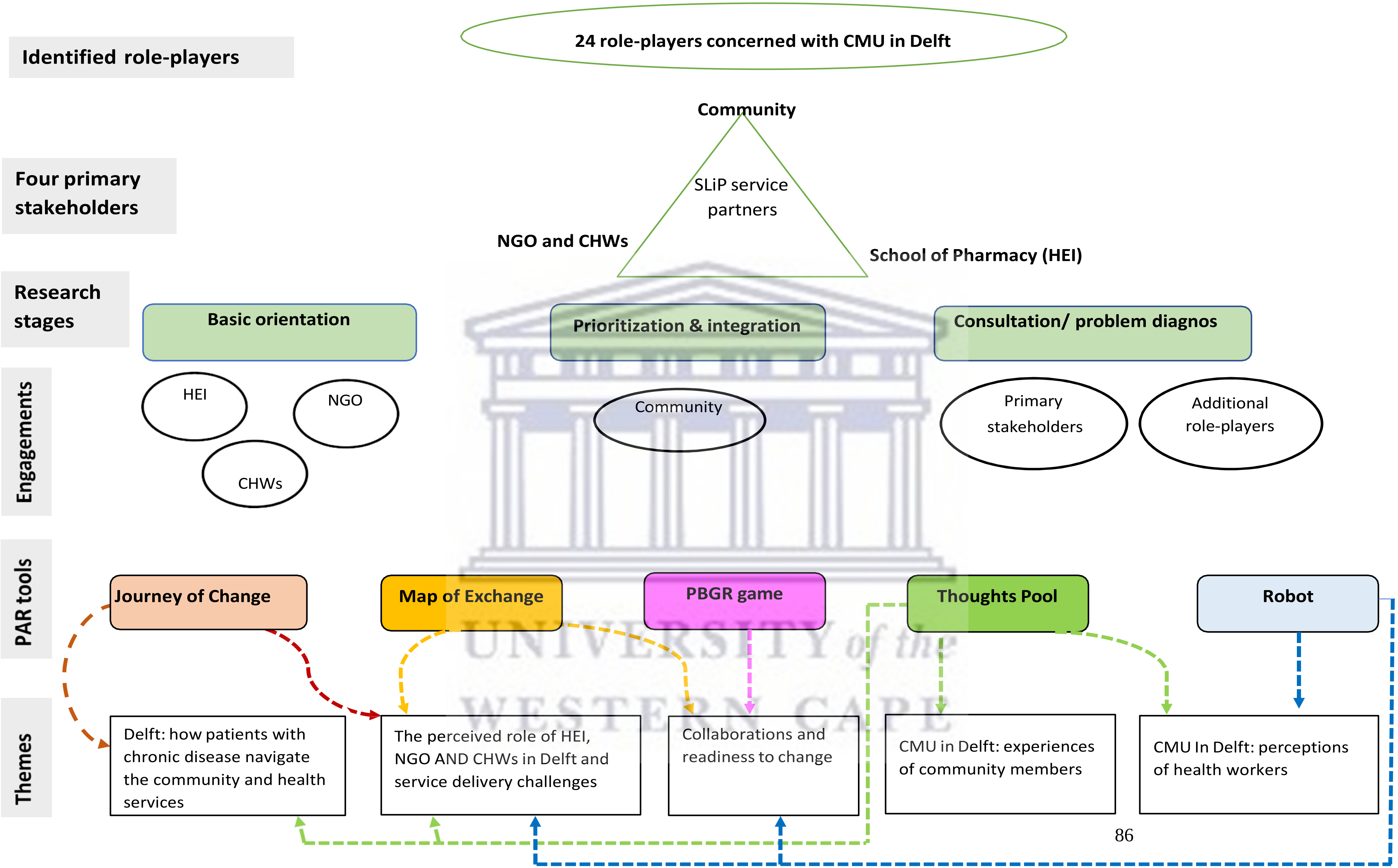
Consequently, the four primary stakeholders of our research span from these 24 role-players groups identified at the second MSCW. And it was by engaging these four primary stakeholders, using five PAR tools, that we were able to derive research data that informed the five overarching themes underpinning our findings. Figure 4.1 links the stakeholder group engagements to the PAR tools and overarching themes.

Table 5 Function of role-players engaged with CMU in Delft

	Categories of role-players	**Described (perceived) Function**
1	Department of Health (DoH) - Cape Medical Depot	Western Cape provincial health authority that oversees operational processes on the health services and reports to the National Department of Health Supply Primary Health Care clinics with chronic and acute medicines
2	City of Cape Town (COCT)	Local health authority responsible for the delivery of basic primary healthcare services
3	Primary healthcare facilities/clinics	Provide an array of healthcare services to community members in the community. Maintains DoH and CoCT function within each facility.
4	South African Pharmacy Council (SAPC)	Regulatory body responsible for ensuring that pharmacies, pharmacists, pharmacist's assistants and education meet the required professional standards in service delivery.
5	Medicine courier service: - Medi Post - DSV	Packaging of CDU chronic medicine parcels for delivery at facilities Delivery of medicines and other related pharmaceuticals to facilities and in communities
6	Medicine collectors/ Pill collectors	Informal collection of medicines for patients, friends and / or family members from health facilities and charge a collection fee. Often CDU packets are not open to check for accuracy.
7	Clinicians e.g. doctors, clinical nurse practitioners	Provide healthcare to patients during clinic visits
8	Community Health Workers (CHWs)	Dynamically involved in all aspects of CMU (from the NGO and clinic perspectives) in patient disease management, counselling, and medicine delivery, and facility-based activities.
9	Patients- end users (community members)	Interact with all identified role-players in dynamic ways for healthcare and are users of medicines (chronic and acute).
10	Clinic committee, Heath forums and other community advocacy groups	Represent community interests in meetings and community engagement forums and workshops with DoH
11	Private sector general practitioners	Provide non-specialised healthcare services to the local community
12	Traditional healers	Provide alternative holistic health services and products to community members
13	Corporate Pharmacies (Clicks and Dis-chem)	Private sector retail community pharmacies that require out-of-pocket payment (or patients with access to medical insurance) to receive pharmaceutical and basic primary healthcare services to the local community
14	Health clubs - ARV clubs - Support clubs - Senior citizens clubs	Support clubs based in facilities run by CHWs and nurses for adherent patients. Offers counselling, peer support and can collect CDU parcels at club meetings. Support groups run by NGOs in the community for a variety of different health and related conditions. Provides a platform for seniors with similar interests to interact with each other through outings or similar engagements. As well as interacting with health facilities in the area.

15	Gangsters (drug lords and/ or taxi feuds)	Negatively impacts patients' CDU collection experiences as they are robbed when coming from facilities with chronic medicines
16	Police stations	Issue of affidavits for stolen medicine to be used as evidence at facilities for reissue of medicines
17	Law enforcement	Escort CHWs and ambulance personnel into dangerous areas (hot spots) in the community and maintain community safety and peace.
18	NGOs that service the Delft community - Anova Health - Kheth'Impilo (KI) - Touching Nations - Mashitembela - Philani - Hope - The Caring Network - Omega	NGOs with various roles and specified health services to the community.
19	Research NGO - Task- Stellenbosch	Provides TB positive patients with medication and health information. Also conducts research on enrolled patients.
20	UCT medical students	Conducts research in the community
21	Churches - Omega Centre (West Bank) - Zoey Church (Delft)	Churches that act as offsite chronic medicine collection points. These act as decentralised collection sites
22	Schools (primary and high)	Offer healthcare information to School children periodically
23	University of the Western Cape, School of Pharmacy	Offers experiential learning through the SLIP and Community engagement programmes for pharmacy students to engage with community members and provide health information
24	Transport: taxis (private sector), buses (public sector)	Protests affect the ability of patients to travel to health facilities

Figure 4. 1 Operational framework for findings, PAR tools and contribution to themes



4.1.2 Chapter outline and important considerations

I have structured this Chapter to prioritise the voice of community members who participated in our research. This is because their lived experiences are crucial in determining the quality of healthcare, and consequently chronic medicine access and use which is the focus of this thesis. Hence, I use the community workshop as a baseline for this Chapter and themes. Remaining contributions from other primary stakeholders' groups like the HEI, NGO and CHW as well as role-players at both MSCWs supplement the findings presented in this Chapter.

Additionally, I have divided this Chapter into two parts to allow easier digestion. In part one I present how patients with chronic disease in Delft navigate their community and health services. Furthermore, I present the perceived community function of other primary stakeholders before I describe their relational dynamics with the community and each other. Then in part two I present the community's CMU experiences before presenting the perceptions of health workers involved in our research. I also outline the stakeholder recommendations to address the contextualised CMU issues.

Consequently, it would be valuable to read this Chapter with Figures 3.2 and 4.1 that shows the various stakeholder engagements throughout our research process and links the PAR tools to overarching themes. Furthermore, Appendix N presents a research participant table and is useful for tracking participant contributions to the quotes used in this chapter.

Another consideration for this Chapter is the basic anatomy of each quotation used to supplement stakeholder/participant contributions toward a theme or discussion point. I present a few examples of quotes and annotate them below.

Example one:

So, there are some places where we go to and some places where we don't go to… so obviously there's places that we don't know yet. And then UWC has got this beautiful strategic plan that is just flowers everywhere, ahm but I don't think any student has ever seen a strategic plan have you **…** ***[waited for participants to respond- some participants shook their heads and looked uncertain]*** ***1*** *. No. So how would the community outside have seen it? Lecturer, L1, HEI focus group I, 06 February 2019* **2**

Notes:

1- [ ] captures participant body language or action observed

2- Description at end of every quote, identifies the speaker, their speaker code, affiliation and engagement date

Example two:

.... It's the community that is being left out… and I will go back, back and back to Cipla… that is a living example of place something there…but no consultation happening to the community…and now you expect this thing to work…remember what we said earlier also that the community is being used…there you see it… (like a dumping site, we will dump resources, dump funds and when we done we leave)[3] *...yes exactly.- Project manager P1, NGO focus group, 13 March 2019*

Notes:

3- (non-italicised words) Capture facilitator comments/ additions as speaker spoke

Example three:

I am now thinking in particular, at our last CBS meeting (meeting held monthly between DoH representatives, NGO management, PHC facility managers, Nurses and CHWs to address regional health targets and challenges) [4] *…It's like they almost wanna use your abilities and your strength but they don't wanna take the time and acknowledge you... - Project manager P1, NGO focus group, 13 March 2019*

Notes:

4- (*italicised words*) capture additional information to better comprehend speaker's contribution

I described important consideration for this chapter, subsequently in the following sections I present our research findings in two parts as previously alluded to.

FINDINGS Part ONE

4.2 NAVIGATING THE COMMUNITY AND HEALTH SERVICES IN DELFT

In Chapter Three, I described how I facilitated a workshop with the community group during our research process's consultation/ problem diagnosis stage. During this workshop, community members described their community contexts and chronic disease experiences. In this section, I present these findings and describe the perceptions and experiences of Delft community members when interacting with healthcare services, and general community issues.

4.2.1 Influence of social-economic issues on everyday life

During their workshop, community members described the troubling social-economic issues plaguing Delft. Figure 4.2 below showcases a group’s presentation outlining their response to the second question from the Journey of Change exercise, I elaborate below.

What is not being done well in Community

- People not being educated regarding the illnesses so they use medication without right information.
- Doctors don't do medisal checkups they just write new prescriptions
- We wait for ambulance for hours.
- Crime escalting due to lack of education.
- Children are being force out of schools [illegible] tell them to [illegible] to gangsterism.
- No sport facility in our areas.
- No support for our drop-out youth.
- Adults don't take care of their elelery people in the community or their families.

If we stand together we can bring change.

What is not being done well in our community?

Group handout during the Journey of Change exercise.

Community group presenting their answers to handout shown above.

Figure 4. 2 Socio-economic issues in Delft: Journey of Change_ Community group

Community members expressed great concern at the escalating crime and gangsterism in Delft. One member went on to suggest that the high crime and gangsterism in the area contributed to why ambulances often hesitated and took too long to come into the community.

Another member linked the increased crime rate to the lack of education and youth development activities in the area. Going on to share how often the youth dropped out of School to join gangs and participate in criminal activities. One member shared his experience of managing his troubled teenage son amidst limited information and social support services in the area, I share his quote below.

> *In Delft…well we thought about…any organisation related to gangsterism, drug use, rehabilitation centres…do they actually know which organisations to go to, or who you can actually go and speak to or a social worker or something like that…I think that is why…there is a lack of communication… and if there are, I don't know if there are… I have a very naughty son, we had to take him all the way to Vredendal about 300 km, but thanks he is achieving something there…okay it's good that it's so far away, but we actually don't, as we all know we're not all well off. That is why we are in that situation all the time. So, like if we could…just research…or get someone to assist us to go to these organisations, to know who they are and if they could help us. Like actually come to us and not you go there…why you take the problem there, why not come to the area where the problem is. - Community member C3, Community workshop, 10 July 2019*

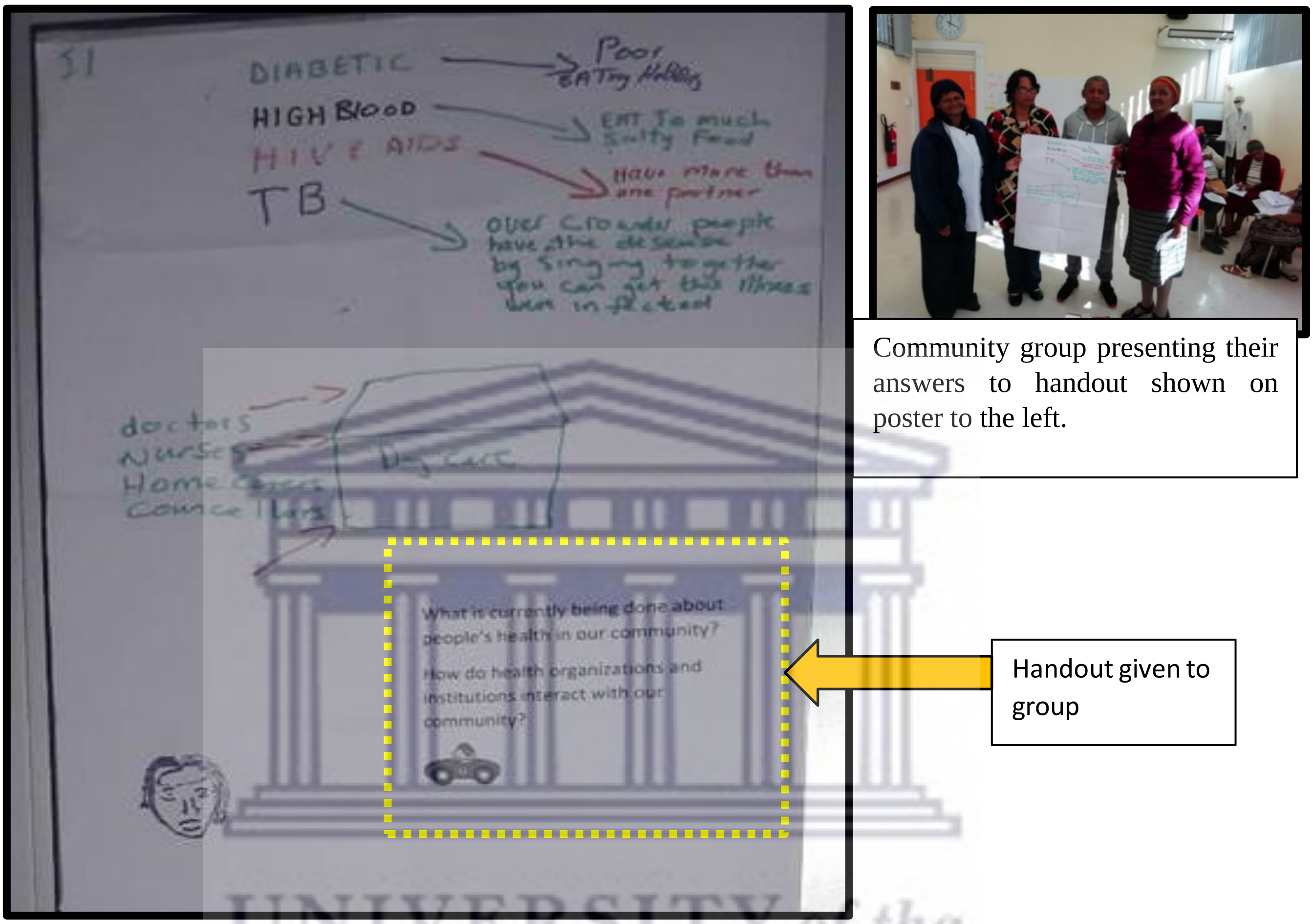
The above quote highlighted the limited social support services available for young people living in Delft. Another member extended this to the elderly population and how they were not being taken care of and neglected by their family members and community, further stressing the lack of essential services in the community, noted in her quote below:

> *And we don't get helped… So where do we go… In our community in Delft there is very little services rendered to the underprivileged in the community. -Community member C1, Community workshop, 10 July 2019*

Notwithstanding the limited educational, youth development and social support services in the area, community members reported the lack of proper sport facilities and safe spaces to exercise, thereby predisposing them to lifestyle-related chronic diseases and infectious diseases.

4.2.2 High prevalence of HIV/AIDS and TB worsened by uncontrolled CDs

The community group expressed great concern at the high prevalence of HIV/AIDS and TB amidst untreated diabetes and high blood pressure. Figure 4.3 captures a groups' presentation during the Journey of Change exercise.



What is currently being done about people's health in our community?

How do health organizations and institutions interact with our community?

Community group presenting their answers to handout shown on poster to the left.

Handout given to group

Figure 4. 3 Main health challenges in Delft: Journey of Change, Community group

Community members shared their observations of how people living with diabetes and high blood pressure were not taking their health seriously. Members went on to reveal that affected people often had poor eating habits (including the use of foods containing high salt like soups or spices with high sodium levels) and consumed excessive alcohol. One member warned that unhealthy foods were the cheaper option for most people and that most people were living in poverty.

Similarly, community members expressed concern for the increased spread of HIV/AIDS as a result of poor safe sex practices. Additionally, how the spread of TB was worsened by overcrowding, improper housing, lack of cough etiquette and unhygienic practices while using public transport.

Furthermore, community members expressed concern that health workers seem to not prioritise the holistic health of patients with chronic disease and how often they did not offer patient education and referrals to relevant social support services. Most concerning, is that the group felt doctors copied and pasted previous prescriptions of chronic medication without conducting comprehensive medical assessments. One community member expressed her negative experience below.

> *There is so many people on chronic medication, and it doesn't get taken seriously by our health workers at the hospitals…these are also things that need to be taken up… I feel there is a great need for change…for the last 40 years I've been suffering with a disease and so many people know me in the community, and I am always there to assist in the community for anyone…how many times have I walked out to the hospital and even applied for a grant already and get declined for it. Which is a chronic since a child…I can't go and work every day due to my illness…these are things that need to be noted. I mean what is the use of having a chronic illness and getting chronic medication all your life and it doesn't get seen. - Community member C1, Community workshop, 10 July 2019*

4.2.3 Health services available in Delft and fragmentation

The community group identified different health and social services in the community during the Map of Exchange exercise, I briefly outline these below:

- Three primary health clinics:
    i. Delft 24-hour Community Health centre (CHC)
    ii. Delft South Community Day Centre (CDC)
    iii. Symphony CDC)
- Three Non-governmental organisations:
    i. Touching Nations
    ii. Masithembela
    iii. Healthcare (Caring Network)
- Support groups:

    i. Churches,
    ii. Day care centres,
    iii. Old age support groups
- Sport clubs

The group expressed that Symphony CDC was effectively providing quality services, while Delft 24-hour CHC was overcrowded, had longer waiting times for collection of medicines and was ineffective in responding to the health needs of the community. I elaborate on the community's interaction with PHCs and other stakeholders in Chapter 4.4.

Noteworthy is how one community member highlighted the apparent lack of communication between the different service providers in the Delft area. Additionally, how social support services lacked empathy for the community and the harsh realities people faced. Another member compared the attitude of support service providers to universities that conduct research and send students to the area, disappointingly suggesting that universities exploit community members to achieve research and learning objectives without substantial benefit for the people. I quote her below:

> *They don't come and… have like open days in the community. They don't come… to see what the community is about… they don't do nothing. They just want to come learn. - Community member, C1, Community workshop, 10 July 2019*

Having described the major social, service and health issues that community members face in Delft. I would now like to better contextualise the primary stakeholders' organisational realities and perceived community functions in Delft in the next section 4.3. This will allow you to better understand the following section 4.4 that explores the relational dynamics between the community and other primary stakeholders.

4.3 THE PERCEIVED ROLE OF HEI, NGO AND CHWs IN DELFT

In this section, I present findings from interactions with the HEI, NGO and CHW groups relating to their perceived role and function in the Delft community and the challenges they experience.

4.3.1 HEI- University participants

During the HEI focus group, I used the Journey of Change tool to inquire about the groups' perceived role and function in the community. Figure 4.4 captures one group's presentation.

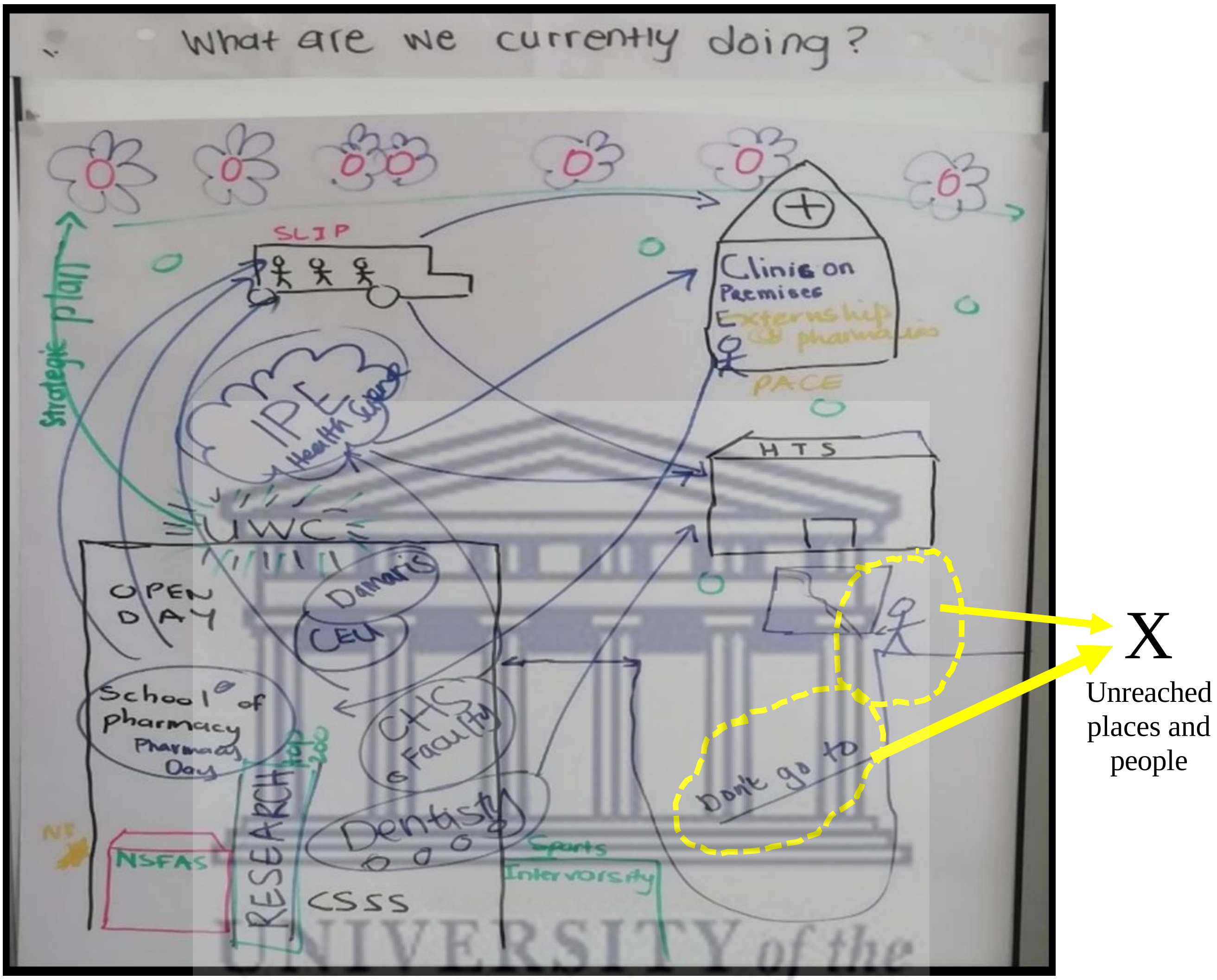


Figure 4. 4 Tower of power: university's fragmented efforts to reach the community

The HEI group identified two main community functions that the School of Pharmacy performs:

1. Sends pharmacy students to PHCs and hospitals through the SLiP, PaCE and externship programmes.
2. Sends pharmacy students to schools and communities to carry out health promotion activities through the SLiP programme

For the other departments and divisions within the university, the HEI group highlighted the work done by the Community Engagement Unit (CEU) that focused on working with communities to conduct outreach and research activities. Additionally, the Inter-professional Education Unit (IPE) located within the Community Health Sciences (CHS) faculty, was described to provide opportunities for health students to interact with communities through their academic programmes, while the Dentistry faculty was praised for their efforts to provide basic dentistry services to community members through their student practical training programmes.

While the university seemed involved with the community, one lecturer pinpointed that there were vulnerable places and people who were not reached through the academic and research activities of the university (annotated as "X" on Figure 4.4). Such discrepancies underpin how the strategic plan of the university highlighted community engagement as a goal but had no tangible efforts to promote and prioritise this goal with academics and students. I quote her below.

> *So, there are some places where we go to and some places where we don't go to… so obviously there's places that we don't know yet. And then UWC has got this beautiful strategic plan that is just flowers everywhere, ahm but I don't think any student has ever seen a strategic plan. Have you [waited for participants to respond- some participants shook their heads and looked uncertain]. No. So how would the community outside have seen it?-Lecturer, L1, HEI focus group I, 06 February 2019*

Consequently, the apparent failure for the university to reach people in Delft, given its close proximity, and fully engage the community negatively affect how people viewed and engaged with the university. I elaborate on how departmental fragmentation within the university contributes to this observation in the following subsection.

4.3.1.1 Service fragmentation and silo working within university

During the HEI focus group a lecturer highlighted the departmental fragmentation within the university and how apparent it seemed that departments work in isolation and don't share resources or ideas with one another. Consequently, departments engage the community separately and at different times. I share her quote below:

> *So, we have recently received that email from the vice chancellor that we are already in the top 200 research universities… So some of those researchers have lovely little projects outside in the community.*

> *Yes, also in their little bubbles. So, we like to be in bubbles, hey. There's Damaris and her community engagement unit and there are CHS faculty that does their own thing. So, there is a lot of separate arrows. The interprofessional teaching and learning unit who's linked to CHS (Community Health Sciences faculty) that also does their thing, so there's a lot of (separate) arrows… but there's not one arrow that links UWC. Small little isolated ones that links it everywhere. So, everybody has their little thing that they do in the community, ahm but it's inside of a very well demarcated area, inside the silos. And then research is obviously spreading out very prominently, very valued, ahm which further isolated things from each other. -Lecturer, L1, HEI focus group I, 06 February*

The university was named the 'Tower of Power' by the same lecturer:

> *Yes, so that is regarding access to people from the community who can't afford it, come to our lovely tower. Can you see the tower… the tower has got a lot of bubbles in it?- Lecturer, L1, HEI focus group I, 06 February*

4.3.1.2 HEI internal challenges affecting community engagement

During the Journey of Change exercise, the HEI group described the different challenges that plagued the university and student community. Figure 4.5 below captures these.

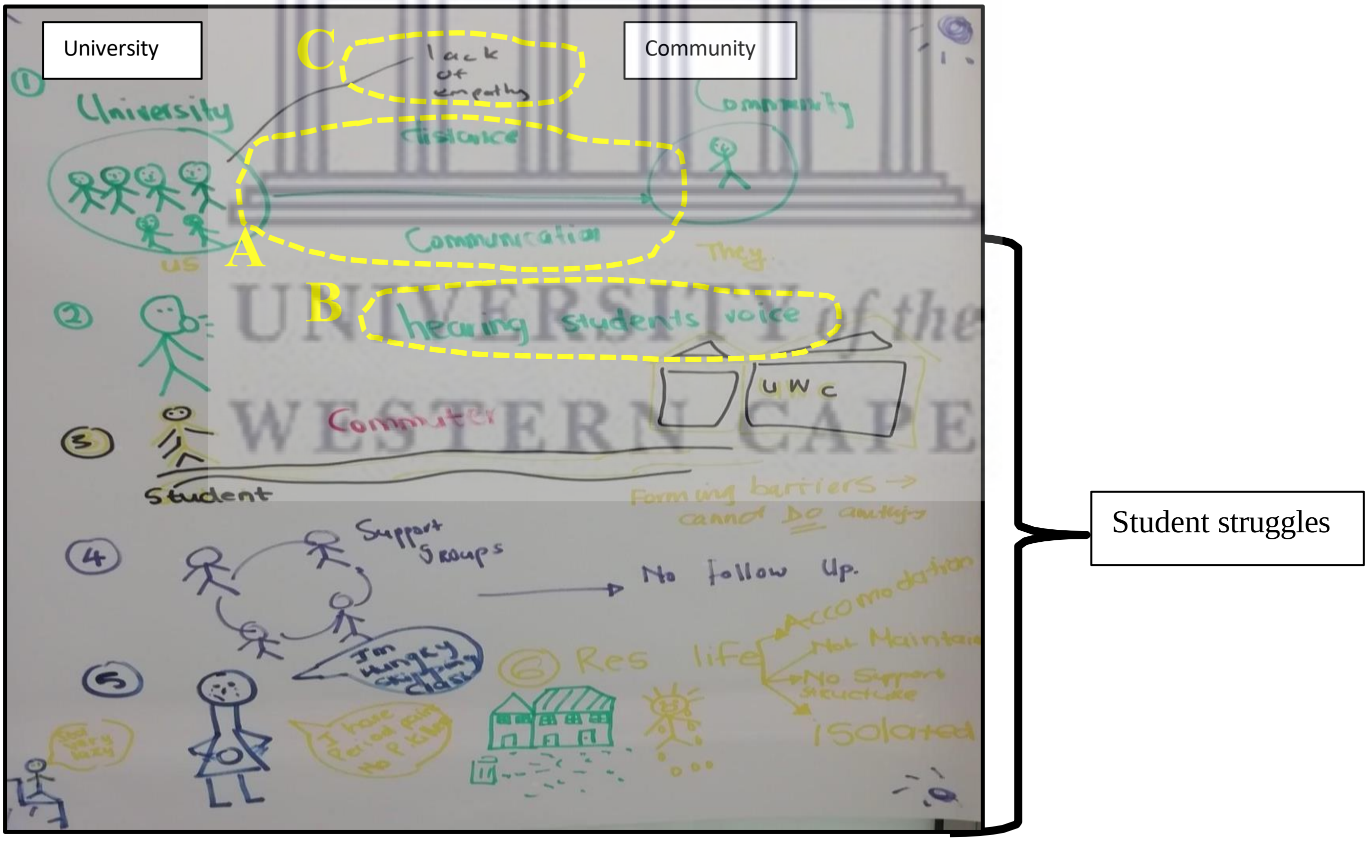


Figure 4. 5 Internal challenges within the university and student issues

Four main challenges affect the ability of the HEI group to effectively engage with the community:

1. The university remains detached from the realities of the community, this was symbolised by the word ‘distance’ written between the line connecting the university and the community Figure 4.5 above (**yellow circle A**). This distance was suggested to be worsened by the lack of continued dialogue (“communication”) with the community to determine acceptability of student tasks and research. As one pharmacy student emphasised:

> *So, this is us as the university. We are all together and this is the distance between us and the community...this is communication. How do we speak to the community and what do we address...? In the sense that the university will send the students to the community right, to do a certain task and complete it. But now how do the community feel about that? Have you ever said how do you guys feel about us coming here, it's always going going every year…? You know I think communication is crucial there. And so, we’re not really hearing what they feel about the whole idea. So, it's about us doing what we have to do, check check…- Student, S4, HEI focus group I, 06 February 2019*

2. Student struggles dynamically affect class attendance and overall student well-being. These issues were suggested, by a lecturer, to remain unprioritized and inertly further suppress the voice of the students as seen in Figure 4.5 (**yellow circle B**) above. Issues include:
    a. Inability to commute to university due to lack of funds or living too far and not having been placed in university residence.
    b. Disruptive painful menstruation prevents female students from attending class.
    c. Food insecurity leaves some students with no food to eat, which negatively impacts their ability to focus during class.
    d. Lack of support for residence students to voice their struggles with food security, gender-based violence (GBV) mental health and need for academic support.
    e. Strained lecturer-student relationships.
    f. Poor student-student relationships.
    g. Lack of proper and effective referral system for mental health support.

3. Students highlighted how there were limited resources to operate safe spaces for them to fully express their struggles. A lecturer agreed and suggested that there was a lack of empathy (Figure 4.5, **yellow circle C**) within the university and suggested a need for more creative, humanistic, and empathetic approaches to address student and community issues.

> *It seems like there's a distance between the lecturers and the students, but also between the students and the students… So maybe the caring part is a little bit missing, caring for each other and having a culture of caring at the university-Lecturer, L2, HEI focus group I, 06 February 2019*

4. Lecturers indicated that there was a lack of strong forums to champion processes of challenging systemic influences which disregard students' struggles and the community's voice. One lecturer suggested that these issues would remain ignored until such a forum was created.

> *So, it is the structural barriers (the 'overwhelmingness' of shortening the distance) ... yes that' what can I do', 'I am actionless', you know...which is typical in universities...these are the structures in the university, these are the policies. So, we hide behind the policies, we use the policies as shade against the policies… Yet policies need to be challenged. But we are not challenging the policies enough… So, until we have a forum that is strong enough to challenge the systems within the university, to address the grassroots level points that have been raised now, it is conveniently stashed away, as a coping mechanism for those that are interfacing with the group that is experiencing (them). -Lecturer, L2, HEI focus group I, 06 February 2019*

Having described the challenges that students face above, the group agreed that an organic process to address these internal challenges were necessary that would allow the university to respond to the disconnect and distance that exists with the surrounding communities. However, a student highlighted that the lack of formal feedback mechanism between the School and community, may have contributed to the School offering services that were irrelevant to the community. I highlight her quote below:

> *So, this is us as the university. We are all together and this is the distance between us and the community [some shaking head in disappointment] ...this is communication. How do we speak to the community and what do we address? Ahm, how are we? Okay, we have SLiP right. Okay SLiP also falls into the category. In the sense that the university will send the students to the community right, to do a certain task and ahm complete it. But now how do the community feel about that? Have you ever said how do you guys*

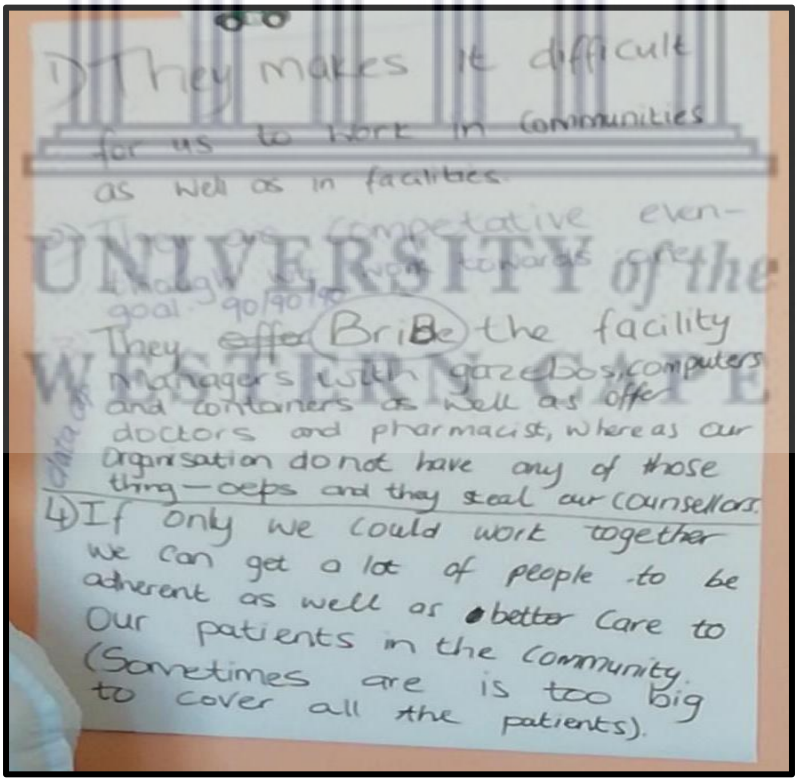
> *feel about us coming here, it's always going going every year? You know I think communication is crucial there. And so, we're not really hearing what they feel about the whole idea. So it's about us doing what we have to do, check check.- Student, S4, HEI focus group I, 06 February 2019*

Therefore, considering the above narrations, the HEI group is undoubtedly aware of the service fragmentation within the university. Consequently, this awareness paired with the overwhelming plethora of internal challenges affecting lecturers, students and operational mandates, deter progressive efforts to reach and impact surrounding communities.

In the following section, I narrate the experiences of the NGO and CHW groups when working with communities and also highlight the challenges they encounter.

4.3.2 NGO and CHWs

The NGO faces an array of internal and external challenges that affect their ability to effectively provide health services to the community. Figure 4.6 shows one groups' presentation outlining the difficulties the organisation faced when working in Delft. The different functions that the NGO performs in the community were previously described in Chapter Three of this thesis.



1) They makes it difficult for us to work in communities as well as in facilities.
2) They are Competative even- though we work towards one goal 90/90/90
3) They ~~offer~~ BriBe the facility managers with gazebos, computers and contaners as well as offer doctors and pharmacist, whereas our Organisation do not have any of those thing — oeps and they steal our counsellors.
4) If only we could work together we can get a lot of people to be adherent as well as better Care to Our patients in the Community. (Sometimes are is too big to cover all the patients).

Figure 4. 6 Main challenges NGO face when working in the community

The destructive behaviours of competing NGOs in Delft were highlighted as a prominent issue that negatively affects health service delivery to the community during the NGO focus group. Additionally, during the CHW focus group, other challenges that affect health service provision to the community were described. I elaborate further in the following subsections.

4.3.2.1 Competing NGOs in the Delft area

The NGO group complained about how the competing NGOs enticed facility managers and PHC staff with incentives, which resulted in PHC staff redirecting more patients to the competing NGO. Supervisors shared their experiences of witnessing the competing NGO poach the organisation's more competent CHWs by offering them better salary packages. A project manager added that duplication of community health services was amplified by competing NGOs who were offering the same services. One CHW suggested that this encouraged community members to vet different NGOs based on the offered incentives, which she felt further disempowered people and perpetuated the handout mentality of community members. I quote her below:

> *… we don't have incentives and people's mentality is like this…I must get something for my attention…now you come there and give them R20.00 airtime…I give nothing because I don't have funds for anything. So, they benefit from R20.00 airtime and you come there and give them a hot dog roll. They are hungry…our community…there's poverty in our communities…you offer a 'Worse rolikie' (hotdog), I offer them nothing…You will get more people than me… It's bribery, because to know your status, to know your health status, you don't have to take a bribe. You shouldn't say give me something to know your health status, but because of our community's mentality; I must get something…It's like I do you a favour for you to come and test me. - Community health worker Ch2, NGO focus group, 13 March 2019*

4.3.2.2 CHW professional confidence, support and incorrect patient information

One CHW described the difficulty of locating patients, due to incorrect capturing of the patient's address, contact details and medicine therapy details on referral forms received from hospitals and PHCs. I quote her below:

> *Like when we receive the referrals from the health facilities; sometimes there are wrong addresses. Sometimes as they mention ROTF- risk of treatment failure, so that patient we must go to them in community … to do the education to them and to check how they are taking their meds, but now we can't*

> *reach them…they end up dying…because they became defaulters and at the end of the day they fail their treatment…- Community health worker Ch3, NGO focus group, 13 March 2019*

These administrative issues increase the workload of CHWs and further affects the confidence CHWs have in their professional competence. During the CHWs focus group, one nurse described how CHWs exhibited low confidence in their professional capabilities and skills, noted in her quote below:

> *From the perspective of working in the hospitals and now working in an NGO…I always tell the carers that they don't realize how well equipped and skilled they are. Because some of these carers… that do wound training, I can honestly tell you that some of them do wound care much better than a staff nurse in hospital… It comes down again to feeling inferior…they do not realize how well equipped they are…coz they just thinking I'm just a carer…– Nurse N1, CHW focus group, 23 May 2019*

In the same CHW focus group a CHW expressed concern at the lack of debriefing and counselling sessions for CHWs who are exposed to emotionally harsh and traumatic realities in the community, and I quote her experience below:

> *I was working in this house…this mama is a CVA patient, she had this grandchild…he smuggled the drugs…selling drugs from mama's house…now we have to go to this client's house, and every time I give a report I put it in my report. And the mama say Yhuu I did not even know there was so a lot of drugs in my next room coming out of this blazer jacket… if you are in such a house and the police come raid that house, they will take you with, they will take you with… and so I said Lord what am I going to do, because this mama needs the help, because every time she just getting another stroke, because the grandchild… It's only the mama and the grandchild, no one else in the house… so me and my colleague we went there all the time… next to mama this guy was shot dead, and two houses back, two houses from mama there's another guy, this Friday this one was shot dead and the Saturday morning two houses from mama, that guy was shot dead…- Community health worker Ch4, CHW focus group, 23 May 2019*

4.3.2.3 NGOs reliance on main donor and organisational autonomy

During the NGO focus group, a project manager expressed concern at how the department of health (DoH) was the organisation's main donor and how the organisation's functioning and community activities was prescribed by DoH. According to the project manager, this was concerning, because DoH does not fully understand the dynamic and ever-changing community contexts and extent of required interventions like the NGO. I quote her below:

> *I am now thinking in particular, at our last CBS meeting (meeting held monthly between DoH representatives, NGO management, PHC facility managers, Nurses and CHWs to address regional health targets and challenges) …It's like they almost wanna use your abilities and your strength but they don't wanna take the time and acknowledge you... Let us sit around a table and share ideas and that is for even with our partners, our funders… it's like they give you stuff to do but they don't really know the implementation of it… When you go and implement it in the community and working on grass root level it doesn't look as beautiful as it was on paper…so I think respect is, yes we need to respect them, but they also need to respect us, because at the end of the day they need us…to turn around our poor health situation. - Project manager P1, NGO focus group, 13 March 2019*

Consequently, this heavy dependence on few funding agencies (or sponsors) and lack of organisational autonomy limits the NGO's ability to diversify the CHW roles to better serve the needs of the community, as one project manager outlined:

> *… the only fear and I think that's amongst us… is the invisible lines that's there… because we only have one funder… although they don't say it, but they pull the strings, because you cannot cross their boundaries yet we have all the skills…* Name ommited *s have a lot of skills but we cannot really tap into the skills right now…but soon we will do it because of only the one funder and once they hear you've crossed borders, it's almost like they come in like a principle and they want to give you a spanking- Project manager P1, NGO focus group, 13 March 2019*

Furthermore, during the CHW focus group, a CHW expressed that the NGO efforts and significance in their partnership with DoH is undermined. She suggested that DoH is highly output driven and focuses on meeting predetermined targets that are subsequently imposed on the NGO and CHWs. I quote her below:

> *They're chasing numbers, they're chasing after stats… DoH and our employers -Community health worker Ch6, CHW focus group, 23 May 2019*

4.3.2.4 Exploitation of community by government and NGOs

Health services remain highly politicized in Delft. During the NGO focus group, a supervisor suggested that government and their officials' visibility in the community increases around election time. Further that during the election period, health service delivery improves slightly, then later returns to the sub-optimal level. The supervisor raised concern that this yo-yo effect further aggravates the governments' exploitation of the community. I quote her below:

> *Another concern is how it's close to elections… you see people, you hear people, and everyone is visible…Now my concern is after the elections…they disappear like mist…they disappear with their promises- Supervisor Su1, NGO focus group, 13 March 2019*

Similarly, during the same focus group a project manager suggested that the lack of two-way feedback communication between the community and other stakeholders (inclusive of government) worsened ongoing exploitation and abuse of the community by both the government and researchers who viewed the community as a 'dumping site' for projects.

> *.... It's the community that is being left out… and I will go back, back and back to Cipla… that is a living example of place something there…but no consultation happening to the community...and now you expect this thing to work…remember what we said earlier also that the community is being used…there you see it…(like a dumping site, we will dump resources, dump funds and when we done we leave)…yes exactly.- Project manager P1, NGO focus group, 13 March 2019*

The afore-mentioned challenges plague the community and have led to people finding alternate ways to support each other. A project manager during the NGO focus group attested to the resilience and positive spirit of community members amidst the lack of quality health services, high crime rates and gangsterism. I quote her below:

> *There is positive things coming out…yes we do have drug abuse, yes we do have gangsterism, yes we do have violence, yes we do have an unemployment rate. But our community is so positive we have tried every time something new...this is part of the community to benefit each other and with the support of each other we do survive- Project manager P1, NGO focus group, 13 March 2019*

In section 4.2, I presented the experiences of Delft community members when navigating the community and health services in the area. Subsequently in this 4.3 section I presented the organisational realities of the remaining primary stakeholder groups (HEI, NGO and CHWs). My intentions with these narratives were to allow you to gain insight into the internal challenges that the aforementioned primary stakeholder groups face when engaging with the community in response to the observations the Delft community members expressed during their workshop.

Consequently, from these insights, I now present merged findings from different stakeholder groups and engagement points relating to how the primary stakeholders communicate and share resources with one another in the following 4.4 section. It would be important to note that the majority of these findings emerged from the Map of Exchange exercise conducted with the primary stakeholder groups.

4.4 COLLABORATIONS AND READINESS TO CHANGE

Figure 4.7 below captures the community group's Map of Exchange. I use this community workshop output as the primary reference point and supplement it with other stakeholder's Map of Exchange outputs (HEI, NGO and CHWs). Having highlighted the ultimate importance and value of the community voice in PAR research, as noted in previous Chapters, the other maps were used as secondary sources. Subsequently this section reveals relational dynamics between the primary stakeholder groups (Community, HEI, NGO and CHWs) and how they engage with the PHCs in the Delft area. It is important to note that during this exercise the students were separated from the university staff, units and divisions within the university.

As a guide to understanding Figure 4.7, pay special attention to the colours the community group used to connect the different stakeholder groups; **Red** denoting '*bad*', **Purple** as '*needing work*'/ '*room for improvement*' and **Green** as '*good*'. These considerations will be important while reading this section.

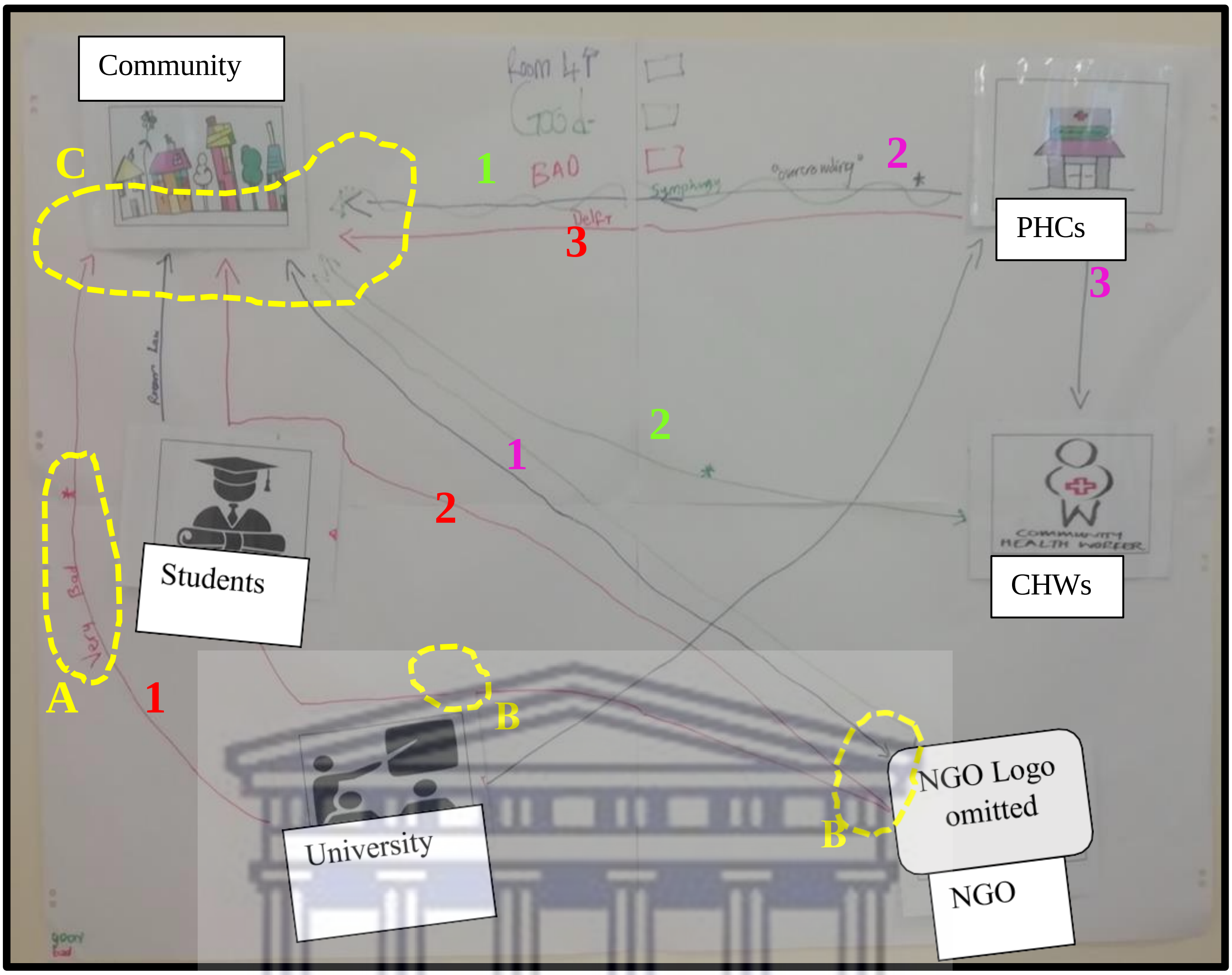


Figure 4. 7 Delft community's relationship with other primary stakeholders: Map of Exchange- community stakeholder group

4.4.1 Community with the university (HEI) and pharmacy students

The community group described their relationship with the university and the community as 'very bad' denoted by **Red line 1** and **yellow circle A** on Figure 4.7 above. One community member disappointedly raised that the university as a whole was exploitative and *'used'* and valued the community only for research outputs. I quote her below:

> *A lot of universities come to do research, that's all they do. Because why… they have tasks to complete here and…when their tasks is completed and they ask their questions and so now they can go do their thesis or whatever then they're done with the community… We are used…we feel used. - Community member C1- Community workshop, 10 July 2019*

In the same breath, the community group also described their relationship with the pharmacy student as parasitic. One community member felt that students used the community to achieve learning outcomes through their experiential learning outcomes and desert them thereafter, I quote her below:

> *They don't come and… have like open days in the community. They don't come… to see what the community is about… they don't do nothing. They just want to come learn. - Community member C1, Community workshop, 10 July 2019*

Further, the **Red line 2** and **yellow circle B** on Figure 4.7 above, highlights how students go via the university, who then go through the NGO to reach the community. By adopting this prescribed 'via-via' route was described to be indicative that students choose not engage the community directly on their own accord, which one CHW, during the CHW focus group, also highlighted in her quote below:

> *I feel disgusted about it, because when they need my community then I'm good for them, because they need their marks, they need their practicals to do their exams and pass. But when my community assists them with all their assignments, with all their practicals, then they're good. But when they do that they don't come back to my community…and say thank you… or give an hour or a day…or offer free time to the community-Community health worker Community health worker Ch2, CHW focus group, 23 May 2019*

During the community workshop one member expressed concern that after graduating students did not return to their communities, to plough back their acquired knowledge. Additionally, such students missed opportunities to positively influence (or mentor) the youth in Delft who needed guidance and inspiration to make better life choices. I highlight his quote below:

> *They're are to inspire our youth and tell them, listen here this is the way out forward. This is how you do it and this is what you have to do to achieve your goals. They need more motivation…What I am saying is that if they are empowered and they have their degrees or whatever they don't look back to the community. It's just, okay, I'm done with them, I'm moving forward. - Community member C3, Community workshop, 10 July 2019*

Coincidentally, during the HEI focus group one lecturer confessed to undoubtedly understanding the university's damaged relationship with the community due to mistrust and past exploitation. I elaborate on how HEI group members perceived their own relationship with the community below.

During the second HEI focus group, one lecturer described the difficulty of building trust with the community while conducting research and highlighted the need to prioritise practices that empower people with whom research is being conducted. I quote her below:

> *When you go into the community as an outsider… to understand the community well, you've got to be an insider. So, until you're not immersed with them… it's built over years and time. And if you're researcher you don't have that luxury and they know that. So, at the times they will share information that will make you happy so that you meet your research criteria… so that you can get done, go… and like whatever skills you impart onto that community… if you can impart the skills to them and they take control over it, then you know you've done it. and when they call you, then you know even with your vulnerability was used constructively… it isn't bad, but to get to that bridge and work with the processes… understanding culture, understanding the rituals, respecting that and working with that without being judgmental. - Lecturer, L1, HEI focus group 2, 17 February 2019*

Figure 4.8 below captures the HEI's Map of Exchange output during their second focus group. One lecturer used Red line 1 to capture the fragmented relationship between pharmacy students and the community, while another lecturer highlighted a missed opportunity for students to learn advocacy from community members. **Yellow circle A** on Figure 4.8 ('advocacy ed') captures this contribution and I quote her below:

> *I think, also…the other thing that the community can teach the university is advocacy. Because the community is very powerful in changing things... They can move… for example… just take HIV. If it wasn't for the community, we wouldn't have the ARV program… so the community is very powerful and there's a lot of resources there. And as a higher education institution those are skills that we just do not have or as the School of pharmacy… maybe the other bubbles in the tower have it… I haven't seen it. - Lecturer, L2, HEI focus group 2, 17 February 2019*

Interestingly, the same lecturer highlighted the schools' relationship with the NGO was slowly mending the broken relationship with the community and served as a 'lifeline' to re-establish trust within the community. **Yellow circle B** on Figure 4.8 captures this and I quote her below:

> *I never thought that we would have a lifeline in the community… and this crisis that we are going through at the moment, has taught me that it's not only* NGO name omitted *,we also have so much support there [motioning to the Primary Healthcare Clinic]… So this crisis has brought out support systems that we did not even know that we had… If I had to look on the bright side… to try and help us with this whole City of health crisis. - Lecturer, L2, HEI focus group 2, 17 February 2019*

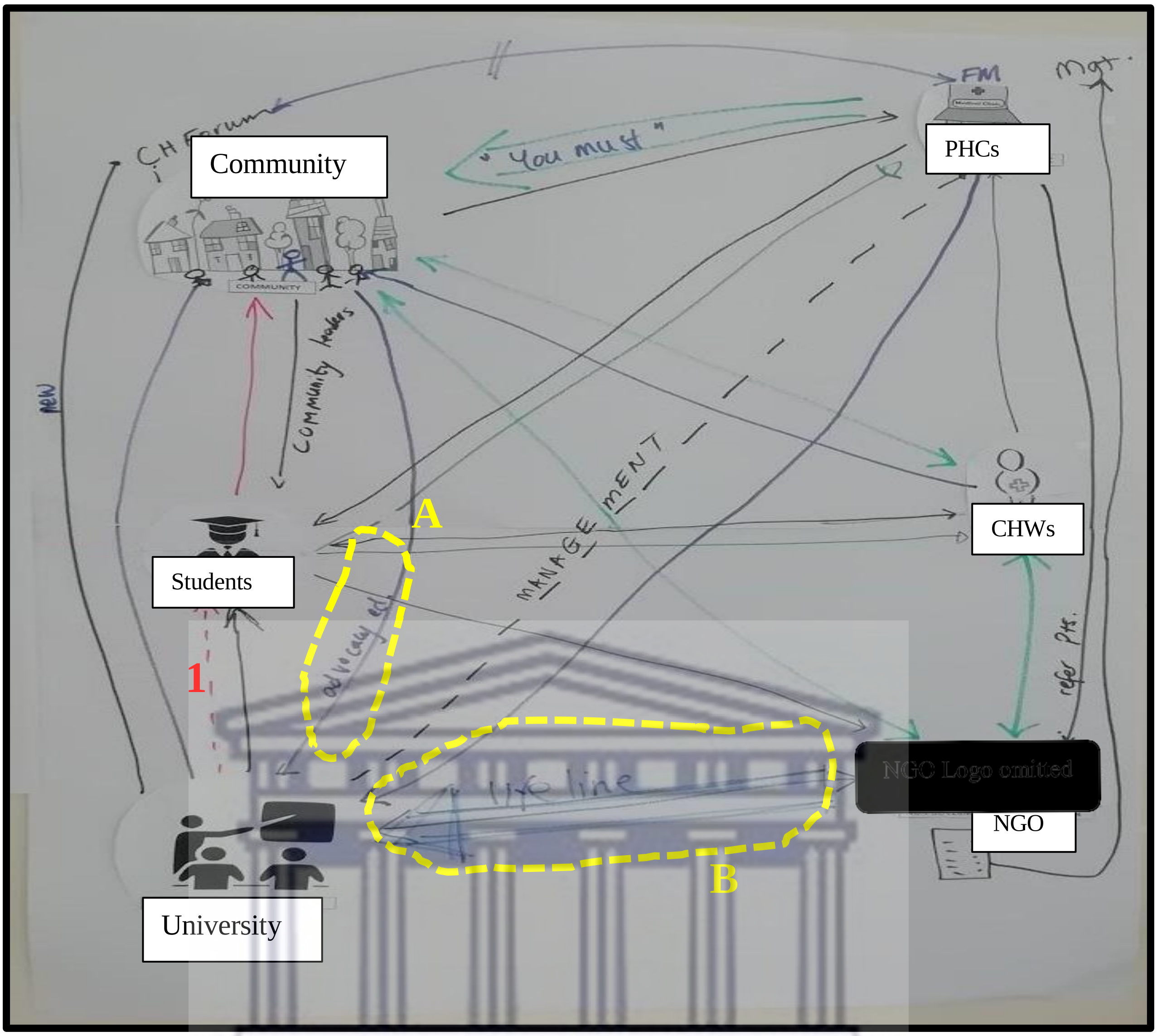


Figure 4. 8 NGO act as lifeline for HEI and community relationship: Map of Exchange- HEI stakeholder group

4.4.2 Community with PHCs

During the community workshop, one member of the team shared how the service delivery differed at the various facilities in the Delft area. This was briefly described in subsection 4.2.3 of this Chapter and this section adds more context.

One community member during the Map of Exchange exercise, described Delft 24-hour CHC as overcrowded and speculated that this was because people from different regions of Delft would access the facility. She then highlighted that their relationship with the facility has room for improvement; denoted as **Purple line 2** on Figure 4.7. I quote her below:

> *I think Delft Hospital is overcrowded, because people are coming from Westbank, from all over the Delft area, its very very full there. So, I think that hospital needs another hospital somewhere nearby…because it's overcrowded... Room for improvement because of management is doing their duties toward the community. So, there is a huge lack of communication…at that facility, and it needs to be resolved, urgently because why, more people is getting sick, more people is dying because of even the facilities fault- Community member C2, Community workshop, 10 July 2019*

In contrast, another community member praised Symphony CDC for their excellent service, denoted as **Green line 1** that is noticeably intertwined with **Purple line 2** that was explained above, but she expressed dissatisfaction with Delft South CDC, captured as **Red line 3** on Figure 4.7. I quote her below:

> *The Symphony clinic, there is a huge difference in service rendered by the staff there than at Delft. At Delft you will be sitting for hours. The facility is filthy dirty, the bathrooms is dirty, the floor is unhygienic and its sick people already at the hospital. Also, how come for a moment the in charge don't see that, how can you sit from morning till evening for medication at the Pharmacy, that's unacceptable; that's for Delft. But at Symphony clinic the service is excellent, it's extremely extremely good, the way they render a service to the community. So that means to say the in charge is doing their job well unlike Delft clinic…very sick and frail people is evens laying on the floors there at Delft… - Community member C1, Community workshop, 10 July 2019*

4.4.3 Community with NGO and CHWs

The community group during their workshop expressed their disappointment at the lack of visibility of the NGO in Delft. Their relationship with the NGO was described to require room for improvement, denoted as **Purple line 1** on Figure 4.7. One community member described how the NGO operated in isolation from other community and social support services, which she said stripped away opportunities for holistic responses to community health needs. I quote her below:

> *Everybody is just caught up in their own…everybody is just doing what they must do…the church is just doing… you come to church, you get your blessing and there you go. They do not worry about the bigger community. - Community member C1, Community workshop, 10 July 2019*

Similarly, during the first MSCW, a CHW described an observation which highlighted the need for communication between different NGOs and community health and support services to streamline service delivery in the Delft area. I quote her below

> *This exercise is encouraging to all of us. Yes, we're different characters, we NGO, we community healthcare workers, we counselors, but whoever we are in our career, most important is communication if we communicate to each other. Please it shows us again that we all lack communication skills… with communication skills we can go a mile… nobody is on their own island. - Community health worker Ch4, CHW focus group, 23 May 2019*

Not surprisingly, during the community workshop a nurse shared her observation that CHWs had a good relationship with the community, denoted as **Green line 2** on Figure 4.7. She attested it to the holistic way in which CHWs respond to patient health needs, noted in her quote below:

> *Everybody just do what they must do, what they're there for… we as home-based carers, we're not there for only one thing at the moment…we are all over. So, we are the people that pick up the problems in the community and the clinics, they just focus on giving medication and making you healthy. – Nurse N2, Community workshop, 10 July 2019*

4.4.4 Perceived relationship between CHWs with NGO management and PHCs

Noticeably the community group did not touch on the relationship between the NGO and CHWs. However, during the CHW focus group, the relationship between the CHWs and NGO was discussed. I present these findings below.

The NGO experienced major restructuring toward the end of their 2018 financial year. During that period CHW work hours were changed from half day to an eight-hour workday. This change paired with the unstructured and informalized roles and functions that CHWs had in the community, negatively affected their ability to maintain a positive professional identity. This also contributed to low staff morale that was accompanied by feelings of low self-worth and confidence in their competence, as previously described in Chapter 4.3.2.2.

During the CHW focus group one CHW felt that NGO management did not communicate changes timeously to better support them through the aforementioned organisational change. I quote her below:

> *As in now… As I can remember yesterday all of us wanted to take our bags home, that's why I highlighted that black one [referring to black line between CHWs and NGO on their Map of Exchange diagram, denoting unfavourable relationship between NGO and CHWs] needs work… But then this*

> *morning…there was communication…it was better… and…there was a common understanding why change has to happen, which we kinda of meet each other halfway. But we are waiting for the way forward to see how it is going…so communication between the management team and CHWs is starting, maybe a bit late because the carers are long in this service, which you will think there was supposed to be trust in the relationship and an open-door policy and communication, buts its starting now. So, it's one day at a time- Community health worker Ch4, CHW focus group, 23 May 2019*

Coincidently, during the NGO focus group, a project manager expressed awareness of the need to resolve their relationship with CHWs and with the community. She suggested that by addressing the NGO's internal challenges, the organisation would be able to move on to the external ones. I quote her below:

> *They say if you want…you must first clean inside before you go on the outside. Understanding what you are doing and understanding the mission and where your goals is. It will actually make you have ideas, let's do this, let's do this… you get what I'm saying…so I mean if you clean on the inside, it will be easier to go on the outside- Project manager P1, NGO focus group, 13 March 2019*

Interestingly, during the community workshop, a CHW highlighted the strained relationship between the CHWs and PHC facilities, denoted as **Purple line 3** on Figure 4.7. She went on to describe that PHCs do not ensure patient information is captured correctly when they refer them to the NGO for tracing and home visits, which delays the process, going on to then describe that their relationship needed work.

In sections 4.2 till 4.4 of this Chapter, I dived deeper into how Delft community members affected by chronic disease navigate life in their community. I described their experiences with social-economic issues and their influence on HIV/AIDS and TB amidst the high prevalence of chronic diseases. I also described the community groups' experiences when interacting with their primary healthcare services, before zooming in on their relationship with the HEI, NGO and CHW stakeholder groups. These narrations further contextualise the everyday realities of patients with chronic disease and the primary stakeholders of this research in relation to medicine use and access.

FINDINGS Part TWO

In the following section 4.5 I examine chronic medicine use issues experienced by the Delft community members. Following the same trend as before I prioritise findings from the community workshop to attempt to capture the voice of the community and supplement these using data from other stakeholder groups and engagements. Then in section 4.6 I draw from experiences of the NGO, HEI and CHW research stakeholder groups, and other role-players present at the first and second MSCW to offer other insights.

Thereafter in section 4.7, I present the collaborative recommendations, to address the perceived chronic disease issues, before concluding this Chapter.

4.5 CMU IN DELFT: EXPERIENCES OF COMMUNITY MEMBERS

During the community workshop, group members shared their chronic disease experiences through the Thoughts Pool-CMU activity. The team shared how being on chronic medication was a lifelong venture that required support and commitment from both the patient, healthcare workers and community. Members also described disruptive medicine side effects and their dislike of generic medicines. Additionally, community members described their unpleasant interactions with doctors and nurses during clinic visits and their experiences of medicine stock outs. I elaborate on these in this subsection.

4.5.1 Taking chronic medicines is a long-life commitment

During the community workshop, group members expressed frustration with what they described as a long-life commitment to taking chronic medicine and its unpleasantness. One community member described the task of taking the same chronic medicine everyday with no hope for resolution and support as laborious and demotivating. I quote her below:

> *It's because why, you are using the same medication over and over and it stays the same…There is no support that they give you that can decrease the illness that you have. And when you come to the doctor it's just... Every month the same thing, Every month the same thing. Community member C1, Community workshop, 10 July 2019*

4.5.2 Disruptive side effects and medicine adherence

Another concern raised by community members, during the community workshop, shed light on the disruptive side effects of taking chronic medicine. One community member on chronic medicine for high blood pressure complained that a particular medicine disrupted her during church services. I quote her below:

> *It makes you cough…Enalapril ® yes…you can't go to church, because why. You cough and cough and the people look at you all the time…like the Pharmapress ® – Community member C4, Community workshop, 10 July 2019*

While another community member suggested that unresolved side effects pushed people to abandon taking chronic medicines altogether in her quote below:

> *Side effects make that you won't take your tablets…because if you don't feel well or if you get a rash or you start coughing, there you won't take that tablets again. Because then you see okay if I take this tablets this is happening. So that makes that you abstain from the tablets, that is the side effects. Community member C5, Community workshop, 10 July 2019*

This concern that side effects heavily prevent people from adhering to their prescribed medication, was supported by another community member who shared her own experience of taking chronic medicine. I quote her below:

> *For me I am a diabetic patient . This is my 3rd year, but sometimes that tablets make me so sick. Sometimes I don't take it for 2 or 4 or 5 days then I don't take it and still nothing happens… My sister is also diabetic but if she doesn't take her tablets again, and then she get sick… Even the high blood tablets… also sometimes makes you cough…for me sometimes I don't feel well when I take it like every day. - Community member C2, community workshop,10 July 2019*

4.5.3 Interactions with clinic staff and medicine acceptability

During the community workshop, the group raised concern that doctors and nurses at PHCs do not offer comprehensive examinations during clinic visits and prescribe the same chronic medicines repeatedly. One community member expressed her frustration noted in her quote below:

> *Then they should give you a thorough examination, because why, even after 6 months, when I come to the hospital. You know what they do, I've been attending now for 20 odd years…for this chronic disease*

> *that I have and let me tell you…Only one doctor that examined me for the time I was really sick…But for all the years it's just, oh chronic, asthmatic I am on 'dingese' (Afrikaans slang for denoting a thing or place or individual)… lets go…don't change.* - Community member C1, Community workshop, 10 July 2019

A similar observation had also been raised during the NGO focus group held before the community workshop. During their session, a CHW had suggested that the bi-annual consultation that doctors offer to patients with chronic disease was unresponsive to patient needs. She also alluded to witnessing doctors who would copy and paste previous prescriptions without thoroughly assessing the patient's disease progression. I quote her below:

> *Then the doctors is not able to change it… it's gonna be… her doctor's appointment now this month but the doctors they don't even look at you or nothing… you feel a certain way, they don't examine you, they just write the same stuff over and over again…they don't reassess you*- Community health worker Ch5, NGO focus group, 13 March 2019

Similarly, a CHW present at the first MSCW, expressed concern that doctors do not confirm medicine acceptability with patients during consultations. Describing the experience of her group member, I quote her below:

> *So, doctor will put something on the prescription sheet and then you just have to drink that tablets or the medication. Like one of our spice girls* (Chosen group name selected during the PBGR game at first MSCW) *said now, they gave her something, doctor just gave her something and it did not work for her. But they don't wanna listen to you because they think what they give to you it's the right thing to do, but that is not their body so they don't feel what you are feeling and you just have to carry on with that medication.* -Community health worker Ch3, MSW I, 17 July 2019

4.5.4 Generic substitution and patient acceptability

During the community workshop, one member described her clinic visit experiences, raising concern about unpleasant side effects of generic medicines and that the prescriber often overlooked her discomfort. She described her experience in the quote below:

> *I am not happy with the generic…People always complain about the generic…Pharmapress ®, Enalapril for example. Then you will say Pharmapress ® they still say no, I am on Enalapril and they won't take the Pharmapress ®... so I don't like this generic medication.* - Community member C5, Community workshop, 10 July 2019

Interestingly, recalling that a nurse who was present during the community workshop, as described in Chapter Three of this thesis, who challenged community members and asked if they attempted to talk to doctors and nurses to raise their displeasure of prescribed chronic medicines and generic substitutes. Her quote is noted below:

> *Does the patient actually tell the doctor look here I am fed up with taking this, can't you prescribe something, is there something better on the market. – Nurse N2, Community workshop, 10 July 2019*

In response to the nurse's question, one community member shared her experience of when healthcare workers assumed that she was intentionally not adhering to her chronic medicines during her clinic visit without understanding her context. Her quote is noted below:

> *You don't get an opportunity to do that…example now, the doctor don't see you…one of nurses or sisters or whatever see you…you know what they tell you. Like I am a severe asthmatic, there's days when I can walk up and down, there's days that I can't even pick up a broom or I get up and I am extremely tired, due to my condition, sometimes I eat and I can't even breathe… When you come to the hospital, although you take your medication, you do take your pump and now you come in with a tight chest, you know what they tell you…this person is just neglecting, they know they have this chronic disease and whatever and they still come and sit on the oxygen. That is something you can't control, it's something you can't control, it just happens. - Community member C1, Community workshop, 10 July 2019*

Another community member described his experience of engaging with his doctor and they collaboratively arrived at reducing the number of chronic medicines, thereby allowing him to adhere more easily. He suggested that scared patients do not communicate their medicine and concerns correctly with their doctors during consultations. He went on to emphasise the significance of regular and authentic communication between the doctor and patient with chronic disease for effective patient disease management, as noted in his quote below:

> *I went from 11 tablets to 3 tablets, but that is taking through your doctor and telling him look here this is what happens, and he said okay right if you use the Pharmapress ®... we can cancel that one, then we put you on something else. So, I think the best thing is to communicate with your doctor whenever you go for your appointment and insist to see a doctor…and then tell him about your side effects. - Community member C3, Community workshop, 10 July 2019*

4.5.5 Stockouts amidst stockpiles of acute medicines at patient homes

Recalling that two CHWs were present at the community workshop as previously described in Chapter Three. One concerned CHW highlighted how patients with chronic disease were given medicines initially intended to treat acute conditions together with their chronic medicines. She described her experience of witnessing piling up of unused medicines in her patients' home during their regular home visit, as described in her quote below:

> *Another thing with this chronic medication… they don't even know if you did drink the tablets for the month or if something happened. You were in hospital, so you did not take your meds. They will just give and give and give and the medication is stacking up at peoples' houses. You know I get to one person's house, there were about 20 Budaflams ® on that person's cupboard. Then I asked her what is happening here, and she said no I don't use it but they just give me…they don't ask me so they don't see if the condition is improving, if they can make a decrease in the medication. - Community health worker Ch4, Community workshop, 10 July 2019*

This description surprised a community member who explained why patients with chronic disease share medicines due to stockouts and chronic medicine shortages at the pharmacy, as reflected in her quote below:

> *Because you come to the Pharmacy. Then on your sticker they say come back in two weeks, now you struggled to get to the Pharmacy in the first place. Now they tell you…Its not available can you come back in two weeks…But if you don't keep whatever you have left at the end of the month and situation like that arises, where they can't give you tablets, that you actually need every day and it's not available…That is why…I am taking that persons medicine, that person is giving me of his, because the tablets aren't available.- Community member C1, Community workshop, 10 July 2019*

4.5.6 Use of Complementary and Alternative Medicine (CAMs)

During the community workshop, members identified four commonly used natural products to supplement prescribed chronic medicines. I outline these with their scientific names below:

- Wilde Als (Artemisia afra)
- Aloe Vera (Aloe barbadensis Mill)
- Buchu (Agathosma)
- Mugwort (Artemisia vulgaris)

Community members, CHWs and nurses confirmed that these were readily available in Delft and used to assist in the treatment of high blood pressure, diabetes, arthritis and to increase vitality. Unfortunately, I was not able to explore further the exact use and sources of the natural medicines during the community workshop because of time constraints.

However, during the workshop, one community member shared that she experienced less side effects after converting from using western medicines to CAMs. In the same breath she warned against the incorrect use of CAMs by sharing her personal experience in her quote below:

> *I made a mistake once, I used to drink a whole glass of that* (referring to Aloe Vera, previously described by another group member) *in the morning and at night-time. And then one morning I got up and I felt like I am gonna die and I just rushed to the jam… and I take the jam out with my hand…and I ate it…and I was sitting and afterwards I thought no I am not gonna die… So, I made a mistake by drinking too much aloe- - Community member C5, Community workshop, 10 July 2019*

While a CHW, present during the workshop, also expressed her concern for the concurrent use of prescribed chronic medicines and CAMs in her quote below:

> *My concern in the community is some people knows they is on medication, but they use herbs and then they're also on this medication… I don't say you should not do it, but they mix it and it's not good for your heart. - Community health worker Ch4, Community workshop, 10 July 2019*

Interestingly, during the HEI focus group, a lecturer suggested that healthcare professionals disregarded the role of CAMs in chronic disease management. She instigated that there was an unfair preference for western medicines over CAMs within local prescribing systems that is reflected in her quote below:

> *This allopathic versus complementary alternative medicines… I think the whole structure in the way the CDU or chronic medicines is seen in the community… is a very western prejudice, so it discounts any type of value that that community has about health and how they seek healing and things like that… It is very one-sided power relationship, because there's really no conversation about it… take this, there's nothing else, don't take that…finish. - Lecturer L1, HEI focus group II, 17 February 2019*

In this section I narrated the main CMU issues identified by the community group during their workshop. Subsequently, in this following section 4.6, I draw from other stakeholder and role-player engagements and illustrate their converged perceptions of issues affecting patients with chronic disease.

4.6 CMU IN DELFT: PERCEPTIONS OF HEALTH WORKERS

In this section, I describe how stakeholders perceived motivation and disease ownership from patients with chronic disease. I also highlight their perceived patients' experiences and engagements with healthcare workers when using local primary healthcare services. Furthermore, I narrate the concerns the stakeholders raised describing the challenges patients with chronic disease experience during their CDU parcel collection. Lastly, I outline the stakeholders' perceived influence of socio- economic issues that affect the health and medicine use among community members.

4.6.1 Motivation and disease ownership of patients with chronic disease

Recalling that during the community workshop, group members expressed dissatisfaction with the ad nauseam routine of taking chronic medicines daily. It was interesting to observe that during the CHW focus group, one CHW suggested that patients with chronic disease became tired of taking the same medication every day. She raised concern at how some patients start believing that death is inevitable, and tend to value medicine adherence less. Consequently, she suggested that patients with chronic disease experience low motivation and start to neglect the significance of their medicines. I quote her below:

> *Like my mother she is moss (Afrikaans slang used to denote the word 'also' in this instance) chronic…now she sometimes say, enough! I don't want this tablets anymore! I am tired. Everyday tablets, tablets, tablets. I am old. I am gonna die soon, I don't care anymore and I have too much pain. I don't worry, this tablets is doing nothing. - Community health worker Ch2, CHW focus group, 23 May 2019*

In response to the above, another CHW suggested that for patients with chronic disease to have improved disease experiences, they needed to accept their chronic status. She went on to suggest that patients with chronic disease found it easier to embrace the daily activities and medicine regimens prescribed by the doctors and healthcare workers when they accepted their disease status. However, she cautioned the CHW group that successfully completing the aforementioned tasks is difficult for most patients with chronic disease. Describing her mother's experience, I quote her below:

> *My mother, till even now, she was never sick…she belonged to the senior's club and she has medals. She use to run 100 meters and she was very active…now that she is old she is having all this (chronic illnesses) …she never accepted her illness… She can't take it that she can't do the things that she likes anymore…She don't wanna accept that she have diabetic… That's why sometimes she is not adherent,*

> *she don't care…she don't even want to come to the clinic…because she is in denial. - Community health worker Ch5, CHW focus group, 23 May 2019*

To support the above CHW, a nurse maintained that effective chronic disease management within the health system required patients to be more proactive with clinic attendance and maintain prescribed medicine adherence activities. I quote her below:

> *And it all depends on the client themselves…you do your best…you can stand on the clients'' head and say go to the clinic and kick and chase…and it all depends on himself if he is going to adhere. – Nurse N1, CHW focus group, 23 May 2019.*

4.6.2 Navigating local healthcare services in Delft

Stakeholders in our research described the challenges they anticipated patients with chronic disease experienced while navigating the local primary healthcare services in Delft. These challenges included long waiting times, lack of support structures and inadequate chronic disease management systems, language barriers and frequent medicine stock outs. I elaborate on these below.

4.6.2.1 Lack of support structures and systems that encourage feedback

During the second HEI focus group, a pharmacy lecturer after commending the national and local efforts that prioritised creating support structures for HIV/ AIDS in communities, suggested that the same methods could be useful for CMU in Delft. I quote her below:

> *Diseases of the lifestyle like diabetes and hypertension… like you know with the HIV program you have peer support groups; you had such an extensive network of people that were operating… and there suddenly this non-communicable disease were sort of side-lined, HIV took centre stage… so now we need to build a parallel system to what HIV had to non-communicable disease to give you that support structure that is required… peer support groups… exercise group, adherence groups- Lecturer L1, HEI focus group II, 17 February 2019*

Echoing the pharmacy lecturer, a project manager, during the NGO focus group, suggested that Delft has limited support systems to promote positive experiences for patients with chronic disease. Further that less opportunities exist to alleviate stigmatisation and encourage medicine adherence. She described the significance of '*treatment buddies'* in her quote below:

> *With treatment buddies, why I don't have a treatment buddy and why I'm not adhere also is disability… Disabled, I am disabled so I can't take the medication myself and I don't have a treatment buddy and I'm staying alone…no support- Project manager P1, NGO focus group, 13 March 2019*

Worried, the same project manager, raised concern that some patients with chronic disease were experiencing high stigma in the community, perhaps explaining why patients hesitated to join support groups. She relayed how some patients were not honest with CHWs during home visits out of fear of being stigmatised, which is reflected in her quote below:

> *If people see I take my TB tablets, they gonna 'StigMe' out. – Project manager P1, NGO focus group, 13 March 2019*

Moreover, during the second MSCW, a facility manager suggested that patients maintain high discontent for public sector PHC service delivery. She suggested that patient feedback mechanisms are not valued and monitored, which she believed aggravated patients' anger and unwillingness to raise concerns and complain about service delivery. I quote her below

> *Most of these clients that are on…CDU system, they getting frustrated with our systems, long waiting times, yes, we have excess pressures, but how do we make it look better. I mean we all know it but implementation? Is it done, do we monitor to get feedback, as we said now clients do…you feel comfortable to complain, to give compliments, to give suggestions [motioned to audience to give answers]* (some shook their heads in disagreement). *We have got all these resources, we shouldn't be really be having a problem with health information…already we knew the stockouts , that information was supposed to be communicated even in a group setting...at least by the time a client collects their medication or whichever point they know that there is a possibility…even if maybe we doing those health promotions are we just doing it because it's a job that's I must do it? Are the clients getting the message that they are supposed to be getting…those are the gaps - Facility manager F1, MSCW II, 17 January 2020*

4.6.2.2 Communication and language barriers

During the CHW focus group, a CHW raised concern that the language preferences of patients with chronic disease were not being met at local primary healthcare facilities. She attested that this created a language barrier that affected patients negatively, as noted in her description of a patient being spoken to in English while her medicines were being dispensed. I quote her below:

Not even…foreigners. Our own people, people are born and breed Afrikaans now you come talk English, you don't worry if they understand whatever…take two tablets three times a day and blah blah blah…the person don't understand what you're saying- Community health worker Ch1, CHW focus group, 23 May 2019

4.6.2.3 Medicine stockouts

Additionally, during the same CHW focus group, the same CHW raised concern that patients often had to return to the PHCs with an IOU ("I owe you") note as a result of medicine stockouts. She suggested that the process was strenuous, and negatively affected patients with chronic disease; especially the elderly and differently abled. I quote her below:

No stock…They give a IOU slip at the pharmacy, you must come every week…you must get taxi fare to get there every week… and there is no stock, so you will go a month without… it's dangerous to walk every week… It's elderly people, people with disabilities. - Community health worker Ch1, CHW focus group, 23 May 2019

In response to the concern of medicine stock outs, a facility manager, during the second MSCW, expressed her disappointment in the local primary healthcare system and their failure to communicate with patients with chronic disease timeously. She suggested that clinics had the necessary resources for pharmacies to be well aware of potential medicine stockouts well-in advance and hence could warn patients. I quote her below:

We have got all these resources, we shouldn't really be having a problem with health information…already we knew the stockouts , that information was supposed to be communicated even in a group setting…at least by the time a client collects their medication or whichever point they know that there is a possibility. -Facility manager FI, MSW II, 17 January 2020

4.6.3 Medicine adherence counselling and the role of pharmacists.

During the HEI, NGO and CHW focus group sessions, stakeholders highlighted the importance of chronic medicine adherence counselling and the significant role of the pharmacist. However, some challenges to offering patients quality counselling was noted, which I elaborate below.

4.6.3.1 The importance of medicine and adherence counselling for patients with chronic disease

During the second HEI focus group, a pharmacy lecturer, described the systemic and structural barriers that impose on most pharmacists' ability to engage with patients with chronic disease more humanly. She painfully reflected that pharmacists hide behind these structural and physical barriers, such as the outpatient dispensing window to avoid providing patients with medicines and adherence counselling, as illustrated in her quote below:

> *What we have noticed, is the structural systems in which chronic disease management operates… because they have decided what is good for the people… this is how we going to streamline… that is why the pharmacists must be in that window and the rest of us will look at the pharmacist on the other side of the window…closed-up behind this window, that is a mechanistic way of working… a mechanical way… you know robots… barricaded…selfish… I don't know if it's structurally imposed barriers or self-imposed barriers, but we use it to our advantage as a power mechanism. Because if this is my medicines, then I got something you want from me… this is the social object over which I got power over you… so we use the medicines as a power tool with the communities, while on the other side of the bars… You want something from me, it's for your health, it's in my hands, I got control… so structurally we as pharmacists haven't challenged the system… we've accepted it, to such an extent that we don't have a voice anymore… and we still accepting the status quo. - Lecturer L1, HEI focus group II, 17 February 2019*

This observation was similar to another concern raised by a project manager during the NGO focus group, who noted that due to stock availability pharmacy personnel had subsequently changed chronic medicine dosage regimens, which had negative effects on the patient's understanding of such abrupt changes. I quote her below:

> *The patient don't understand how they need to take their tablets… whether it's because the folders is still packed, and they're just quick. And the tablets work in milligrams… Now they don't have a 25, they usually got a 25, now they get 12.5. which means they need to take 2 now…but how do you explain that to a mommy of 78 years old… it's very difficult to explain…so is op ma (Afrikaans phrase denoting: it is left just like that with no explanation). - Project manager P1, NGO focus group, 13 March 2019*

4.6.3.2 Challenges of offering medicine and adherence counselling to patients with chronic disease

During the second HEI focus group, a pharmacy student suggested that the pharmacist did not offer patients with chronic disease counselling, because they assumed that they were previously counselled during their first chronic medicine dispensing event. He highlighted the negative consequences he witnessed when he encountered a patient who had not received adequate medicine counselling, which is noted in his quote below:

> *Sometimes, the pharmacists, they do not really counsel you, because they think that you know what you should be taking… this other woman came up to me and she was like; "I don't know why I'm taking this, but the doctor gave me this and I don't know". She came a week later, and she hadn't taken her pills yet, so at that time… They assume that they already know. – Student S1, HEI focus group II, 17 February 2019*

In the same focus group, another pharmacy student suggested that some patients feared pharmacists and in return offered false confirmation that they understood how to correctly administer their chronic medicines. I quote her below

> *It's easy to just say Yes… if they don't elaborate and they just say yes, it can just be yes to get away, yes so that they don't seem dumb. – Student S5, HEI focus group II, 17 February 2019*

While, another pharmacy student suggested that other patients maintained incorrect chronic medicine administration convictions due to a lack of counselling. She relayed her father's experience in her quote below:

> *My dad is diabetic… he has to go get his medication every month…now he says I don't take my medication every day because my sugar detector… says my sugar level is fine and low, so I don't take my tablets everyday… that's obviously because of lack of counselling… somebody did not tell him that okay its fine, even if your sugar level is low, but you can develop so and so, he just thinks it's okay to not take his medication, because he doesn't know the consequences of not taking it.- Student S1, HEI focus group II, 17 February 2019*

Responding to the above, a pharmacy lecturer, suggested that pharmacists work in highly stressful environments with high patient loads in the public sector and that they do not offer the necessary counselling because they don't have time, as noted in her quote below:

> *Also, the type of counselling… MI (motivational Interviewing) is great, but have I got the 5 minutes to engage with open ended questions… so it's the type of counselling- Lecturer L1, HEI focus group II, 17 February 2019*

This was echoed during the CHW focus group, where a CHW also highlighted how pharmacies are often dealing with high patient load and that pharmacists hastily dispense chronic medicines to patients without encouraging them to engage and ask questions. She suggested that the pharmacist and pharmacy personnel seem to be frustrated when interacting with patients with chronic disease, which is evident in her quote below:

> *They just take it from the pharmacist, and the pharmacy is so full, and that pharmacist is so agitated with them… just want to get rid of them… you see so the patient is not at all comfortable to ask the pharmacist to check…they don't have time for them… it's just take here and good riddance- Community health worker Ch3, CHW focus group, 23 May 2019*

4.6.4 Chronic dispensing unit (CDU) parcel collection challenges

The CDU system allows patients with chronic disease who are considered stable (as determined by a qualified doctor) to collect their pre-packed chronic medicine parcels monthly. Such patients then avoid long waiting times at the pharmacy, and the pharmacist's workload is significantly reduced. During the CHW focus group session and second MSCW stakeholders described the challenges of the CDU system, I elaborate on these below.

4.6.4.1 Enrolment onto CDU system

During the second MSCW, a pharmacist's assistant suggested that doctors mostly enrolled patients with chronic disease on the CDU system without fully considering their holistic benefit. She alluded that doctors enrolled patients out of convenience in her quote below:

> *The physician [doctor] has specific requirements, has specific criteria that they need to look at, that is prior to indicating that a patient is going to be a CDU patient…basically the decision making is in their hands…if the right patient is enrolled on to the CDU that will improve…and not just oh, it's easier because the book is in front of me, let me just do it on here …it needs to be time and effort put into the decision whether the patient is going to be a CDU patient or not. – Pharmacist's assistant Pa2, MWS II, 17 January 2020*

4.6.4.2 Generic substitution in enclosed CDU parcels

A generic medicine maintains the same active ingredient chemical composition and quality to the original medicine; it may however have a different packaging and differ in shape, colour, and size. When a generic medicine is issued to a patient that was either previously on the original or another generic medicine, generic substitution has occurred.

During the CHW focus group, a CHW warned that when generic substitution was unannounced in the medicine adherence counselling, during CDU parcel collection, it led to patients with chronic disease becoming confused about their therapy. She described how patients with chronic disease often assumed the generic drug was perceived as a new drug treatment and they would then either refrain from taking it or take it concurrently with left-over medicines from previous months. She added how CHWs helped patients with chronic disease understand generic substitution during home visits in her quote below:

> *Most of the time, the patients, they do take the medication from them, because they don't want to hang around there. But now they go home, and we have to guide them. Then they tell, but this is not my tablet, I am not used to this… so we sit down with them and we explain to them, look here this is amlodipine, it's just a different name and a different package, a different provider that make it, it's the same thing. Okay now they take their tablet because you explain it to them why they should. - Community health worker Ch2, CHW focus group, 23 May 2019*

4.6.4.3 CDU collection, understanding parcel information and medicine runners

During the second MSCW, a CHW suggested that patients are not thoroughly educated on how to check their parcels for errors and omissions and the importance of patient literacy is evident in her quote below:

> *The reason why the people also have boxes and bags of medication at home, for every service provider that has been changed and then the people go fetch their chronic medication. The pharmacist or the person giving it to them don't explain to them, this is the… Ridaq®. The package had just changed…the people is not educated, that's why they also have the medication at home because it's not the same packet like last week. They just give your tablet and there you go, and because many of our people is not educated, they can't read and write, especially the older people, there is no one to follow up on them…illiteracy is a big thing also Community health worker*, Ch3, MSW II, *17 January 2020*

Responding to the CHW, two pharmacist's assistants highlighted two instances respectively that made providing counselling difficult during the same MSCW. I highlight these below.

The first pharmacist's assistant suggested that some patients with chronic disease collected their CDU parcels at non-facility-based (decentralized) sites. She then highlighted that the dispensers at these locations do not open and check the CDU contents or offer counselling, as noted in her quote below:

> *You have these offsites, where the parcel goes straight to, for our one its Westbank. So, it doesn't come to the Pharmacy, so we don't open the parcel, so now the brands has changed in there… It's actually the tenders and the companies that's making our patients unstable… It's not we're putting unstable patients on CDU; they're becoming unstable due to these different brands. Pharmacist's assistant Pa2, MSW II, 17 January 2020*

Similarly, another pharmacist's assistant described instances where CDU parcels were given to '*medicine collectors*' (trusted community members who volunteer to collect CDU parcels for patients in their community for a small fee) on behalf of patients with chronic disease. She described how they did not offer medicine counselling in such an instance so as to maintain patient confidentiality. I quote her below:

> *How we work in Pharmacy, you need to explain to the patient how to use the medication and I know we do say that if a packet has changed, this has changed. A big problem is that most of the time collectors come, there is still the thing of patient confidentiality, we don't know if the collector know or…say the packet has changed if the patient don't know they must come back, because we can't really tell the collector this is the water tablet, the patient use it for blood pressure- Pharmacist's assistant, Pa1, MSW II, 17 January 2020*

4.6.5 Influence of social-economic issues

During the NGO and CHW focus group sessions, members raised concern at the high levels of poverty and crime and the influence of substance abuse in the Delft community. I present the group's perceived influence of the aforementioned factors on the chronic disease experience of community members below.

4.6.5.1 Poverty, crime and gangsterism

A supervisor, during the NGO focus group, suggested that the high levels of poverty in Delft affected community members' access to nutritious food options that promote treatment adherence. Further, patients with chronic disease, who are prescribed strict diets, struggled to maintain these while living with families who did not share the same dietary preferences. I quote her below:

> *Lifestyle changes…especially when it comes to the diabetics… They need to change their lifestyle, but they're still poor. Some people are so poor, they can't now, they need to buy food for the family, they can't just buy food for themselves- Supervisor S1, NGO focus group,13 March 2019*

Similarly, during the CHW focus group, a CHW raised concern at the worsening crime, gangsterism and violence in Delft. She suggested that these realities affected patients with chronic disease dynamically, and highlighted how some patients felt unsafe while walking to go fetch their chronic medicines. In contrast, she empathised with some patients who, out of desperation under the guise of poverty, willingly sold their chronic medicines to gangsters to source money to buy food. I quote her below:

> *And poverty is so real in our community hey…they know who is coming to the clinic, because you can watch, and you sell your tablets, you sell your TB tablets or ARVS, and they sell it to you for food money. Poverty is real in our community- Community health worker Ch1, CHW focus group. 23 May 2019*

4.6.5.2 Substance abuse

During the NGO focus group, members raised concern on the widespread abuse of alcohol and substances in Delft. A CHW related how patients would confess to mixing their medications with harmful recreational drugs like Tik (common street term for methamphetamine), which is explained in her quote below:

> *The TB medication, like the Ranitab® and Rifafour ® neh… what we discovered is that some guys there in our area they are using that tablet to mix with their drugs…the Tik…so each time the pill count is correct and then I ask him did you drink these tablets and he said no not today, I used those two tablets to mix…they sommer (Afrikaans word denoting 'just') tell you. – Community health worker Ch3, NGO focus group, 13 March 2019*

Then during the CHW focus group, a nurse raised concern for how patients with chronic disease concurrently use alcohol with their chronic medication and how some skipped taking their medicines when planning to drink. I quote her below:

> *Then there is also the party animals etc.…I am a regular drinker and on a Wednesday its our braai night and then we have alcohol, so which means I skip…yeah I don't use my medication with alcohol- Nurse N1, CHW focus group. 23 May 2019*

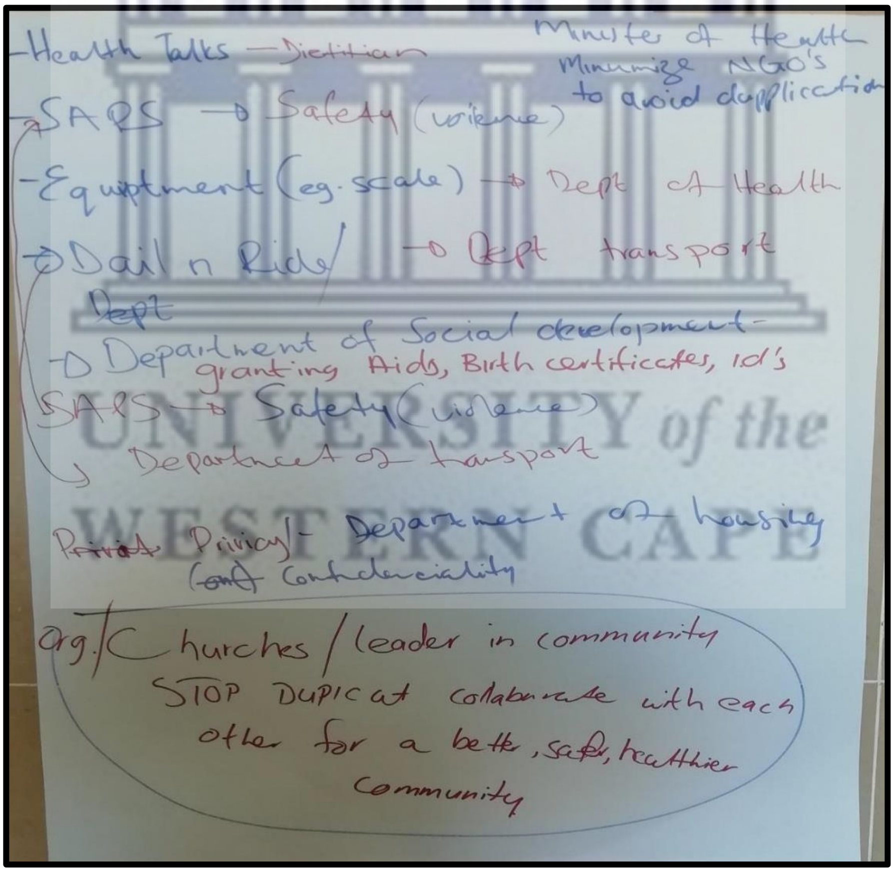
In this section I narrated the CMU issues from the perspectives of the health workers who participated in our research. Stakeholders narrated how patients with chronic disease struggle to maintain positive health seeking behaviour when their overall motivation and morale is low. I outline the research stakeholders' recommendations in the following section.

4.7 RESEARCH STAKEHOLDERS' RECOMMENDATIONS

During the HEI, NGO, CHW and community focus groups and workshop, stakeholders suggested ways to address the identified and contextualised chronic medicine use (CMU) issues. Then during the first and second MSCW, participants were tasked with formally identifying ways to address the CMU issues previously described. In this section, I converge from all engagements within our research to present four envisioned interventions that stakeholders described as having value in addressing the CMU issues.

4.7.1 Role-players need to collaborate to address CMU issues

Having interacted with different role-players in Delft, CHWs during their focus group suggested that isolated role-players concerned with CMU needed to work together to respond to the health and social needs of the community of Delft. One smaller group presented how different organisations and role-players could work together in Figure 4.9 below. I formally capture these narrations in Table 6.



- Health Talks — Dietitian
Minister of Health
Minimize NGO's
to avoid dupplication
- SAPS → Safety (violence)
- Equiptment (eg. scale) → Dept of Health
→ Dail n Ride/ → Dept transport
~~Dept~~
→ Department of Social development - granting Aids, Birth certificates, Id's
SAPS → Safety (violence)
Department of transport
~~Private~~ Privicy/ - Department of housing
~~(Conf~~ Confedenciality
Org./Churches / leader in community
STOP DUPICat collaborate with each
other for a better, safer, healthier
community

Figure 4. 9 How health role-players can collaborate to address CMU in Delft_ CHW focus group

Table 6 Role-players with resources and skills to address CMU issues in Delft

Dieticians	To accompany CHWs during home visits and provide real-time nutrition and diet information, as well as referrals were necessary.
South African Police Services	Be visible and work closely with CHWs to ensure their safety when doing field work.
Department of Health	Provide CHWs with health assessment equipment such as weighing scales to support the health assessments conducted during home visits. Employ CHWs directly within the department of health? to stabilize their job security and formalize job description.
Department of Transport	Provide support when a patient needs to be taken to a facility, in cases where patients are disabled are otherwise not able to travel to a health facility. An example of an existing service called dial-a-ride was mentioned as something that could be investigated for patients with chronic disease.
Department of Social Development	Fast track services for more vulnerable patients, such as fast-tracking grant applications, birth certificates and IDs
Department of housing	Provide safe housing for Delft residents. Overcrowding negatively affects patient confidentiality and increased risk of TB and other infectious diseases spreading faster.
Minister	Streamline NGOs and standardise structures and protocols in the Delft area, to reduce the duplication of services in the community.

Similarly, during the NGO focus group, a project manager, attested that communication and regular engagements between different NGOs concerned with CMU in Delft remained an effective way to combat duplication of service and mend broken trust. She recalled how *Indabas*, previously hosted by the City of Cape Town, allowed different NGOs to meet and engage with each other. She called for these to be reintroduced, as reflected in her quote below:

> *There was these Indabas that City use to have… and it wasn't a day to test people with… but it was a day where I come up with my NGO. I put up my table, my whatever and I present my organisation…. We would actually be networking with one another and that made our work in the past easy… and I think many a times City and Province have moved away with all these things and made our lives as NGOs difficult with networking… So, then we come like foreign people in one big city…and then it's actually duplicating and it becomes a competition all in this one bucket. But in actual fact we need one another to make our work successful. And it has worked in the past… I mean we've been successful in our outreaches in the past, in our service delivery, just by having these Indabas on one specific month, or… per quarter… and then you would also see new people or new NGOs that popped up… and you were willing to even offer your services to that new NGO. I remember we were a conduit to another NGO… and it worked…it really worked. So maybe if we can go back…-Project manager P1, NGO focus group, 13 March 2019*

4.7.2 Informal health workers act as bridges between patients and health system

During the first MSCW, participants described the importance of informal health workers in the community. Consequently, CHWs, health promoters, medicine collectors and community champions were recommended to intimately understand the health needs of patients with chronic disease in the Delft community. I elaborate on this below.

It was suggested that CHWs understand patients' health and social-economic conditions intimately because most lived in Delft themselves. Consequently, during their focus group, CHWs suggested that they could take on a more formal role in engaging with doctors and nurses because they could holistically relate patient dissatisfaction with medication or side effects to doctors following home visits.

Then, during the first MSCW, a pharmacist's assistant suggested that trained health promoters could provide health information to patients and run awareness campaigns in primary health facilities, to supplement the limited medicine counselling offered by pharmacy personnel.

In the same breath, a project manager suggested the need for a formal process to elect community champions, who would maintain the community's interests during community health meetings. I elaborate on the community meetings below.

4.7.2.1 The role of independent community meetings: 'Closing the Loop'

During the first MSCW, participants highlighted the need for independent and regular 'community health' meetings to deliberate pertinent matters affecting patients with chronic disease, primary health services and overall community wellbeing. These meetings were linked to fast-tracking medicine delivery, improving access and adherence to medicines.

Informal health workers (health promoters, medicine collectors etc) act as the 'community's voice' and connect patients with chronic disease to primary health facilities, and the formal health work force. Their convergence and collaboration with other significant stakeholders at the proposed community health meetings was described to hold value in fast tracking chronic medicine management and delivery issues within Delft. One group during the first MSCW illustrated key personnel that would be required to attend these independent community health meetings. I capture their proposal in Figure 4.10 below

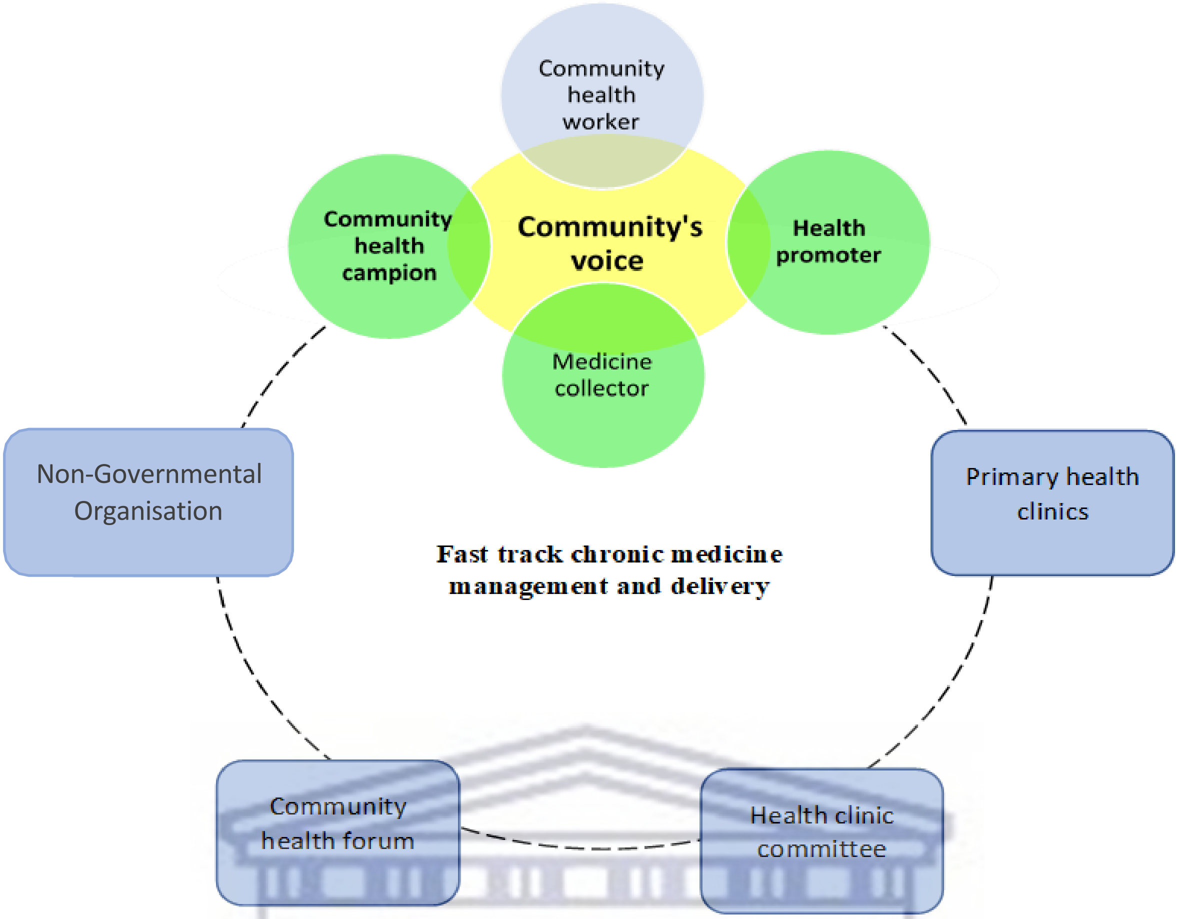


Figure 4. 10 ‘Closing the Loop’ through independent community health meetings, as adapted from MSCW I, 17 July 2019

A project manager during the first MSCW proposed that regular independent community meetings in attendance by the identified role-players in Figure 4.10, would function to fast-track chronic medicine delivery and access. She suggested role-players could deliberate on pertinent matters affecting patients with chronic disease and health facilities during these meetings, further serving to connect patients to health facilities while maintaining their interests within the health system. Interestingly, she described this process as ‘Closing the Loop’.

4.7.3 Strengthening social protection policies and public services

During the first MSCW, participants proposed ways to address socio-economic issues and the importance of strengthening social protection policies for patients with chronic disease. I elaborate on these below.

i. Community halls could be used to train people to do beadwork, sewing, and other basic hand crafts. Thereafter, community members would be able to sell finished products to the public and generate income.

ii. All senior citizens in the community who qualify for pensions, could be enrolled onto a community initiative that provides food parcels. There was a reluctance to give money to senior citizens because they often shared their funds with grandchildren and extended family members.

iii. The unemployed youth could be encouraged to walk the elderly to go collect their CDU parcels. Additionally, the youth could be enrolled into gardening to ensure food security and generate income.

iv. The existing community sport grounds could be improved to encourage the community's willingness to exercise and keep fit. Additionally, community-based sport codes and teams could be introduced to contribute to positive community cohesion.

4.7.4 Addressing CDU parcel collection challenges

During the first MSCW, a CHW highlighted the difficulties patients face when collecting their CDU parcels. Stakeholders from the first and second MSCWs proposed four interventions to address CDU collection challenges. I elaborate on these below.

i. The door-to-door delivery of CDU parcels (by using facility delivery vehicles and formally recognized medicine collectors).

ii. Formally recognize medicine language interpreters who would work with the pharmacy personnel to interpret medicine information in the patients' home language and overcome language barriers.

iii. Develop community-based tablet fetching clubs or support groups for patients who collect their CDU parcels on the same day of the month and have similar chronic diseases. These patients could walk or commute to go and fetch their CDUs together and lessen their chances of being robbed.

iv. Maintain regular community health outreaches that support community cohesion and allow sharing of health information with community members in a fun and interactive way. These multi-disciplinary outreaches could encourage community members to bring any medicine or health-related questions to share with the healthcare professionals.

4.8 CHAPTER SUMMARY

In this Chapter, I described the chronic disease experiences of community members living in Delft. I identified the challenges patients with chronic disease encounter while using primary health services and medicine use issues. I also described the community groups’ experiences when interacting with their primary health services before zooming in on their relationship with the HEI, NGO and CHW stakeholder groups. Furthermore, I outlined the recommendations developed at the first and second MSCW to address the perceived chronic disease issues.

CHAPTER FIVE: DISCUSSION

5.1 INTRODUCTION

In Chapter One of this thesis, I highlighted the need for multi-level analysis, inclusive of patients with chronic disease as research partners. I postulated that our unique participatory multi- stakeholder approach (described in Chapter Three) would allow us to identify and contextualise chronic disease experiences of patients living in Delft, stakeholder dynamics between primary stakeholders and chronic medicine use (CMU) issues. We had two research questions:

1. What issues do people taking chronic medicine face in Delft?
2. How is a participatory multi-stakeholder approach useful in addressing such issues?

We wanted to explore if applying PAR community-based methods would contribute to the following:

i. Collaborative understanding of CMU issues and patient disease experiences in Delft
ii. Understanding the partnership dynamics between the School of Pharmacy and the primary research stakeholders.
iii. Extracting key lessons learnt from using a multi-stakeholder approach to address CMU issues

Subsequently, in this Chapter, I reflect on our findings and draw from literature to explore the dynamic interplay between motivation, disease ownership and adherence for patients with chronic disease. Furthermore, I explore the influence of community and social contexts on the overall diseases experience of patients with chronic disease. Lastly, I also postulate the significance and role of collaborative research to contextualise community health research. Then, I conclude this Chapter by outlining the limitations of our study.

5.2 REFLECTING ON OUR RESEARCH FINDINGS

A closer look at Chapter Four reveals that we had two parts. In part one, I presented findings describing the community contexts of patients with chronic disease living in Delft and the partnership dynamics of the primary stakeholder groups. While in part two, I built on the community contexts described by the community group and healthcare workers to further contextualise CMU issues. In this section, I revisit these findings.

5.2.1 Delft community contexts

Our findings suggested that patients with chronic disease living in Delft face a plethora of social and economic issues. Community members further described the high prevalence of HIV/AIDs and TB in the community. Coupled with narrations describing the escalating crime and gangsterism in the area, overall chronic disease experiences of community members in Delft were negatively described.

For the partnership dynamics, the HEI group described the unfavourable service fragmentations within the university and their negative effect on their perceived community function. At the same time, the NGO group raised concern for competing NGOs in the Delft area and the negative implications of their reliance on DoH as their primary donor. While interactions between the community and CHWs were described in a positive manner, the NGO group highlighted the systemic influences that affect CHWs' professional confidence.

5.2.2 CD experiences and medicine use issues

Healthcare workers further contextualised the effects of high poverty and harmful substance abuse on chronic disease management. Community members described their negative experiences at primary healthcare centres while interacting with PHC-based healthcare professionals. Major concern was raised for how doctors did not holistically engage patients to understand their chronic disease experiences, and pharmacists rushed medicine counselling amidst overwhelming issues community members face when collecting CDU parcels. Additionally, community members highlighted side effects, pharmacy stockouts, lack of medicine counselling and generic substitution amidst unfavourable community contexts as deterring factors contributing to poor adherence.

Consequently, our results suggested that both external and internal factors contribute to the overall disease experiences of patients with chronic disease. Moreover, patient medicine adherence is complex and requires a holistic understanding of contextualised disease experiences.

Considering my reflections above, in the following sections, I elaborate and discuss two aspects drawn from our findings:

i. The patient's chronic disease experience and treatment adherence
ii. The role of collaborative health research for community-based health

5.3 EXPERIENCE OF PATIENTS WITH CHRONIC DISEASE AND ADHERENCE

The WHO describes adherence as '*the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a healthcare provider'* (WHO, 2003a, p. 3). Interestingly, Scholars, suggest that an intimate relationship between health-system, socio-economic, patient related, therapy related and conditions related factors all dynamically influence adherence (Fernandez-Lazaro *et al.*, 2019). In South Africa, the National Adherence Guidelines for Chronic Diseases (HIV, TB and NCDs), commonly known as AGL, inspired by the WHO, contextualised and grouped barriers of adherence into two categories; Patient-related barriers and Health system-related barriers (SANDoH, 2016).

Interestingly, studies conducted in LMICs, suggest that global and national guidelines merely offer guidance on barriers that influence adherence, often without consulting patients, and do not prioritise understanding patient beliefs and perceptions on medication adherence and intervention acceptance (Kvarnström *et al.*, 2021; Chauke *et al.*, 2022).

Other authors suggest that medication adherence is dynamically intertwined with the way in which patients with chronic disease experience their community and interact with the health system, and healthcare providers (Fernandez-Lazaro *et al.*, 2019; Kvarnström *et al.*, 2021; Chauke *et al.*, 2022). We named this dynamic interplay of an individual's contexts, interactions, behaviour, and choices as the *patient's chronic disease experience* throughout our research.

Our findings offered contextualised narratives from patients with chronic disease and healthcare providers that offered insight into the complex realities and considerations that affect not only medicine adherence, but overall chronic disease experiences. Consequently, four inter-connected considerations emerging from our findings, allowed us to fully contextualise the chronic disease experiences of patients with chronic disease. I outline these below before expanding on them and relating them to literature in the following subsections:

1. Community and social contexts
2. Motivation, disease ownership and adherence of patients with chronic disease
3. Interaction with doctors and pharmacists at PHCs
4. Collection of CDU parcels and medicine acceptability

5.3.1 Community and social contexts

Our findings exposed the high crime rate, poverty and gangsterism in the Delft area, and how these contribute to an unfavourable community setting for patients with chronic disease. Furthermore, CHW's shared how patients would confess to mixing their chronic medicines with harmful recreational drugs like Tik and/ or sell their medicines to gangsters to source money to buy food, and potentially alcohol and drugs. Interestingly, literature suggests that patients with chronic disease are simultaneously affected by interconnected socio-economic circumstances (Kvarnström *et al.*, 2021).

For instance, high levels of poverty in the community affects access to nutritious food options, transport money to go fetch medicines from facilities (Makhado and Mongale, 2019) and capability of making out-of-pocket purchases for essential medicines not available at the PHCs (Adefolalu and Nkosi, 2013; Munday *et al.*, 2018). This occurrence then transposes social, economic and health services barriers.

Reflecting on CHW experiences whereby patients confess to mixing their chronic medicines with harmful recreational drugs like Tik, they recalled that in some cases patients willingly sell their medicines to gangsters to source money to buy food, and potentially alcohol and drugs. While other patients remain highly fearful when going to fetch their chronic medicines, gangsters will rob them, particularly of ARVs. Our findings suggest that the effects of poverty in the community, coupled with overwhelming crime, violence and gangsterism, contribute to unpleasant community experiences. This we postulate affects the motivation of patients with chronic disease to maintain positive health choices. Interestingly, in 2020 the NCD alliance, reported that patients with chronic disease overwhelmed by the plethora of social and economic challenges posed by the Covid-19 pandemic, abused alcohol and substances (NCD Alliance, 2020). Consequently, this illustrates the complex journey that patients navigate chronic diseases amidst the interwoven dynamics of poverty, crime, gangsterism and alcohol and substance abuse.

5.3.2 Motivation, disease ownership and adherence of patients with chronic disease

Our findings suggested that the chronicity of chronic diseases and ad nauseam daily routine of taking medicines contributes to patients experiencing feelings of *'wanting to give up'* or '*what's the use of adhering'* as articulated by patients with chronic disease in the previous Chapter.

Literature suggests that a significant correlation between patient chronic disease motivation, disease ownership and adherence exist (Martos-Méndez, 2015; Kvarnström *et al.*, 2021; Chauke *et al.*, 2022). Further, the requirement for a patient to change their lifestyle due to the chronic disease diagnosis and side effects, weighs down the motivation for patients with chronic disease to remain adherent to prescribed medicines and lifestyle changes (Adefolalu and Nkosi, 2013; Mohammed, Moles and Chen, 2016). Consequently, there is a relationship between the perceived self-efficacy and adherence, and in 1991 Bandura contextualised this further and explained that people hold certain beliefs about their ability to successfully perform behaviours required to produce specific outcomes (Bandura, 1991). Hence in the context of CDs, Scholars suggest that patients with chronic disease who believe in their ability to successfully complete and follow medicine and lifestyle adherence tasks and instructions will do so with ease (Martos-Méndez, 2015; Peters *et al.*, 2019).

In contrast, other Scholars suggest that when a patients with chronic disease lose motivation to continue prescribed medicines and/or maintain positive health behaviour, they experience a lowered sense of disease acceptance and ownership and choose to abstain from making proactive choices that positively affect their health (taking medicines as prescribed, or maintaining lifestyle modifications), in turn reducing their likelihood of adhering (Mohammed, Moles and Chen, 2016; Lemay *et al.*, 2018).

Additionally, literature suggests a dynamic correlation between the self- efficacy of patients with chronic disease and the support that they receive from family, friends and society (Martos-Méndez, 2015). Where Scholars suggest that when patients with chronic disease have poor or low levels of social support, they have higher chances of failure when attempting to maintain positive health behaviours that reduce poor adherence (Hoth *et al.*, 2007).

Literature's take on the influence of self-efficacy, importance of support structures and patient motivation, collaborate our findings. Patients with chronic disease who have been taking the same medicines over an extended period of time struggle with maintaining enough motivation to stay adherent. Considering the dynamic influence of self-efficacy, motivation and diseases ownership, it is important that doctors, pharmacists and other members of the health team prioritise interventions that seek to increase patient motivation and diseases ownership (Farley, 2020).

5.3.3 Interaction with doctors and pharmacists at PHCs

Literature suggests that the way in which patients with chronic disease interact with healthcare professionals at the PHC level affects their chronic disease experiences (Fernandes *et al.*, 2020; Chauke *et al.*, 2022). Our findings suggested that patients with chronic disease get dismissed and/or receive unempathetic treatment from doctors, when they attempt to communicate unwanted side effects from prescribed medicines. We believe patients with chronic disease may refrain from raising medicine related concerns with doctors in the future.

Literature suggests that unresolved adverse effects raised by patients with chronic disease, coupled with difficulty of navigating complex community contexts, could lead to some patients potentially actively rebelling against prescribed medicine regimens and lifestyle modifications (Kvarnström et al., 2021). Furthermore, the infrequency of opportunities that allow patients with chronic disease to raise such concerns, through the structured bi-annual visits, could negatively influence the motivation that patients with chronic disease have to remain adherent and maintain positive health behaviours and worsen frustration with the health system (Smith *et al.*, 2017; Fernandez-Lazaro *et al.*, 2019).

Similarly, our findings suggested that patients with chronic disease are not thoroughly counselled when generic substitution occurs within the CDU parcels and/or when they collect chronic medicines at the pharmacy. Literature suggests that patients with chronic disease who do not receive medicine counselling, may administer these incorrectly or refrain from taking medicines altogether (Makhado and Mongale, 2019). Further, they may stock these unused medicines at their homes, encourage medicine sharing, incorrect use, and abuse in the future (Magadzire, Mathole and Ward, 2017). Pharmacists have strategic advantage and opportunity to ensure patients with chronic disease receive complete medicine and disease information before they leave PHCs (Fernandez-Lazaro *et al.*, 2019; Rockers *et al.*, 2019). While it is known that pharmacists have an overwhelming workload (Magadzire, Marchal and Ward, 2015), not prioritising medicine counselling negatively affects the disease experiences of patients with chronic disease (Celio *et al.*, 2018; Kvarnström, Airaksinen and Liira, 2018).

Coincidentally, our findings suggested that CHW's often re-explain, in the patient's home language, correct medicine use to patients during home visits. This occurrence suggested that pharmacists do not accommodate patients of different literacy levels and with language preferences (Fernandez-Lazaro *et al.*, 2019). Alternatively, CHWs highlighted patients with chronic disease experience discomfort when expressing confusion to the pharmacists, and literature agrees that patients tend to prefer CHWs during home visits, to engage meaningfully about correctly using their medicines (Tseng *et al.*, 2019; Fernandes *et al.*, 2020).

5.3.4 Collection of CDU parcels and medicine acceptability

Our findings suggested that patients with chronic disease are not trained on how to check their CDU packets for errors or omissions. An interesting occurrence described by CHWs is that when medicine collectors come to collect CDU parcels on behalf of patients with chronic disease, they do not open packets to check contents and/or offer medicine counselling. Literature highlighted that the CDU programme was intended to reduce the workload of pharmacists and other healthcare professionals in PHCs; by enrolling stable patients with chronic disease and allowing monthly (in some cases two- or three-months supply of medicines) collection of pre-packed chronic medicines (Magadzire, Marchal and Ward, 2015). More recent literature suggests that enrolled patients with chronic disease do not receive regular medicine counselling and have infrequent doctor consultations, which could lead to poor disease progression (Magadzire, Mathole and Ward, 2017).

5.4 COLLABORATIVE HEALTH RESEARCH

Our findings uncovered the varying community functions of the primary stakeholders and offered contextualized daily realities of each stakeholder, their partnerships and readiness for collaboration. In PAR, a significant amount of time is often dedicated to understanding the research stakeholders before and during the development and actioning of research intervention (Mullan and Epstein, 2002). This process while not directly contributing to the contextualizing of CMU and chronic disease experience's themes, remains highly valuable for stakeholders involved in our project and allowed us to understand the following:

1. Understanding CMU from different perspectives
2. The role of indigenous knowledge translation in CDs
3. HEI and student led community-based driven health research
4. Challenges community-based health NGOs face in addressing CDs

5.4.1 Understanding CMU from different perspectives

The syndemic nature of CDs as previously highlighted in previous Chapters paired with the call for multi-stakeholder, transdisciplinary and collaborative research to address factors contributing to negative diseases experiences endured by patients with chronic disease in LMICs (Chauke *et al.*, 2022), created a space for our research process. We believe that the multitude of stakeholders that contributed to the identification of CMU issues in the community, offer multi-coloured perspectives. These varying perspectives to a certain extent captured context of patients with chronic disease and healthcare providers, perhaps then offering the different angles and complexities surrounding people living with and effected with chronic diseases as well as people concerned and / or involved in chronic medicine distribution, health service provision, research, and policy.

Subsequently, processes that prioritise stakeholder organisational contexts from the onset of the research process such as ours, offers opportunities for collaborative spaces where various stakeholders concerned with and affected by chosen health disparities hold interest and ownership (Mafuta *et al.*, 2017). Such open, diverse spaces, as in our project, we believe hold impeccable value in research concerned with addressing NCDs, particularly CMU and other health related research.

5.4.2 The role of indigenous knowledge in CDs and health

The collaborative spaces created in our project, enthusiastically welcomed, and encouraged diversified perspectives and ways of being. This in turn allows the community stakeholder group to share their use of complementary and alternative medicines (CAMs) in managing chronic diseases. Concern was expressed, for the potential danger of patients with chronic disease abruptly abandoning western medicines when opting to use CAMs or seeking alternative healing through traditional, cultural, and religious methods (traditional healers, herbs, prayer, and rituals) (Atinga, Yarney and Gavu, 2018; Makhado and Mongale, 2019). Having a traditional healer who also served as a facility manager for one of the PHCs, allowed a balanced understanding of how patients with chronic disease navigate their choices of seeking alternative methods of healing. This then suggests that organic, accepting, and inquisitive processes that collaborate with patients, to attempt to comprehend their use of CAMS and alternative methods of healing as adjunct to or as opposed to western chronic medicines could be useful.

Subsequently, such processes may offer holistic support for patients with chronic disease and in turn also encourage the autonomous process that allows patients with chronic disease to navigate their chronic diseases with an increased sense of autonomy and disease-ownership (Zakaria, Mohd Noor and Abdullah, 2021). The linking of PHCs, HEI’s patients with chronic disease and traditional and religious healers and complementary and alternative medicine practitioners, we postulate may offer opportunities for collaborative spaces (Chitindingu, George and Gow, 2014). Hence doctors, pharmacists and other health staff need to ask patients with chronic disease about their use of alternative medicines and ways of seeking healing (Mothibe, Mmamosheledi E. Sibanda, 2019; Chauke *et al.*, 2022). This in turn would allow healthcare practitioners to remain respectful and confidently support the diversified health choices of patients with chronic disease (Konstantinou *et al.*, 2020).

Coincidently, as we move from PHCs to community health research, our findings suggest that often the co-creation of knowledge through mutually beneficial feedback processes are not prioritised when the university and community engage. We believe this contributes to how valuable indigenous knowledge surrounding health in the community gets lost and not translated to formal research outputs (Abma *et al.*, 2017). Considering how the community group expressed painfully how they often feel used by the university and NGOs to achieve their predetermined objectives, we then postulate that 'helicopter' research and engagement is ever present in communities (Walker & Ouellette, 2006). Struthers and her colleagues capture how native American tribes view researchers as '*coming in (flying in), taking data, leaving (flying out), never to be heard from again'* (Struthers *et al.*, 2005, p. 7), which echoes the fear that CHWs expressed in their focus group over our research. This occurrence highlights the ongoing distrust that the community maintains for researchers and potentially serves to warn against research that exploits local people and remains egocentric toward embracing the indigenous knowledge that communities share with us (Struthers et al., 2005).

Furthermore, researchers often do not have enough time and resources to establish trust between themselves and the community amidst strict, often inflexible research timelines and objectives, as Walker and her colleagues propose (Walker and Ouellette, 2006). These echoes the dilemmas that HEI stakeholder's face when they set out to engage meaningfully with the community, but remain bound to strict academic and research deadlines, objectives and timeframes, often developed without consulting the community and for the benefit of the university (Abma *et al.*, 2017). Such hegemony can be dismantled if health researchers and HEIs can work collaboratively with communities as equal partners through open and flexible engagement processes (Boelen and Woollard, 2011). These processes need to remain free from bureaucratic and uncontextualized faculty and research deadlines, instead prioritising in-depth community-based research and longitudinal study designs supported by academic institutions (Boelen and Woollard, 2011).

5.4.3 HEI and student led community-based driven health research

The establishment of symbiotic partnerships between the community and HEI, in our case the university, was highlighted by the HEI group as a pivotal mechanism for redressing the mistrust that community members have toward 'the tower of power' and facilitating the transfer and translation of indigenous knowledge into formal research outputs. Perhaps more interesting is the interest that the HEI group had in attempting to work toward being a socially accountable institution. While the community and CHW group expressed their concern at how often students do not plough formal skills and knowledge attained while attending HEI's back into the community.

Subsequently, we then postulate that students who come from complex communities, may possess intrinsic embedded knowledge and understanding of their communities (Irlam, Pienaar and Reid, 2016). Thereby in turn, being able to collaboratively work with communities who may offer indigenous knowledge that may otherwise not be available through formal, discipline-based teaching to contextualise community health issues and act as advocates for addressing such issues (Luke and Morrissey, 2014). Our process draws from principles of service-learning that at its core aims to '*foster and promote social justice by cultivating reciprocal service and learning partnerships'* between students, academics and surrounding communities (Luke and Morrissey, 2014, p. 3). This process we concur with Morrissey and Luke, vastly contributes to producing students who are culturally aware, self-reflective, and responsive to the needs of the community, echoing some of the aims that socially accountable health schools aim to achieve (Luke and Morrissey, 2014).

5.4.4 Challenges of community-based health NGOs in addressing CDs

Our NGO stakeholder group related the challenges that they face when interacting with the community. These challenges highlight how they remain heavily restricted by DoH, managing competing NGOs with similar community functions amidst working in a community with a plethora of social issues inclusive of high crime and gangsterism. These, we feel all further highlight the excruciatingly difficult contexts that NGOs continually navigate and overcome to respond to the health needs of the community.

Subsequently, the ability then of the NGO to be caught 'in the action' of the community, we feel creates a space where they can comprehend and contextualise community health issues and collaboratively work with the community through asset-based and participatory action approaches to address them (Weiner and McDonald, 2013). However, as stakeholders revealed that DoH often prescribes what community function the NGO may have, strips their freedom to explore and address the real issues on the ground and could contribute to community frustration when issues are communicated, but the NGO seemingly doesn't attempt to address them (Birkinshaw, 2012; de Camargo *et al.*, 2019). Perhaps then the links that NGOs have with HEIs, as the case between the NGO and HEI stakeholder groups in our research, could function to explore community-based and centred research topics that are instigated by the NPO- who remain more in-tune with the complexities of community health than HEI's (Stoecker and Tryon, 2009). This process could aid the realigning of health education to respond to the community's needs through research activities (Bheekie, Van Huyssteen and Coetzee, 2019) that have societal relevance while also maintaining validation from academic and scientific bodies (Tandon *et al.*, 2016).

5.5 LIMITATIONS OF THE STUDY

Recalling the research questions and objectives that I outlined in section 5.1. We wanted to understand what issues people taking chronic medicines in Delft face and the usefulness of using a multi-stakeholder participatory approach to address these identified issues. In Chapter Four I presented findings that contextualised the chronic diseases experiences of patients with chronic disease living in Delft, their community contexts and factors influencing positive disease management and adherence. I further elaborated on the limited research that explores the more complex relationship between adherence, chronic disease experiences and positive health behaviours motivation. What is interesting and unique in our study is how patients with chronic disease further contextualised the unique health system and external related factors that contribute to poor adherence. These were extensively discussed in section 5.2 and 5.3 of this Chapter and allowed us to achieve our first objective: *Collaborative understanding of CMU issues and experiences of patient with chronic disease in Delft.*

Additionally, in Chapter Four and section 5.4 of this Chapter I described and contextualised the partnership dynamics between the primary stakeholders of our research (HEI, NGO, CHW and community). Our findings suggesting the urgent need for researchers to marry indigenous and western methods of managing CDs together was an interesting and unique discovery within our research and allowed us to achieve our second objective: *Understanding the partnership dynamics between the School and primary research stakeholders.*

I will further elaborate on how we achieved our third objective: *Extracting key lessons learnt from using a multi-stakeholder approach to address CMU issues,* in the final Chapter of this thesis where I reflect on our research journey.

While we were able to successfully answer our research questions and achieve our research objectives, we encountered challenges during our unique participatory multi-stakeholder data collection process. I highlight some of these challenges on the following subsections in efforts to contextualise the limitations of our study

5.5.1 Selection of primary stakeholders and equitable representation

In Chapter Three I used table four to present the different stakeholders involved within our research and their affiliations. I also discussed how each stakeholder group was recruited and their role in the research in the same Chapter. You may have noticed that for instance we had 25 community members involved throughout our research. I believe that this is a small sample size and thus it is difficult to prove that the community group's chronic disease experiences are shared with the larger community of patients with chronic disease living in Delft.

Considering that we followed convenience sampling techniques, which meant that the NGO's COM identified the CHWs, and then they selected the community group representative. This occurrence could have introduced an element of participant selection bias within our research. Additionally, because we wanted to promote diversity within our research, we did not have an inclusion and/or exclusion criterion stipulating an age range and preferred gender. Consequently, the majority of the community group visibly were female and fell within middle-age and old-age. This consideration makes it difficult to determine if the community group's CD experiences are shared with younger patients with chronic disease and men living in Delft.

Furthermore, during the second MSCW, an array of different role-players concerned with health in Delft were invited. Unfortunately, all invited guests did not attend, which perhaps limits our findings to the contexts of the involved stakeholders and potentially excludes the experiences of the others. More so role-players outside the formal public health system such as private doctor practices, pharmacies and other NGOs in the area.

5.5.2 Appropriateness of PAR approach and data collection tools.

In Chapter Three, I described our five-stage research stakeholder engagement approach and PAR tools. Additionally, in Chapter One of this thesis, I contextualised the ongoing partnerships between the School of Pharmacy and their service partners through the SLiP programme. These narrations attempted to showcase the appropriateness of our research approach and subsequently tools. I elaborate on the limitations of the PAR approach and tools below.

From our anticipated five stage research approach, we successfully completed stages 1-3 within the extended research time frame. This consideration implies that more time was needed for a successful completion of the five-stage research process. Considering that our data collection period extended well beyond one year, I postulate that if our approach was to be reapplied in a different setting or contexts, researchers and practitioners would require more time for the process. This serves as a limitation, more so, for researchers and academics who often have strict research timeframes and budget constraints, since research outputs are prioritised.

Additionally, the PAR approach warrants the use of visual tools and games to engage research partners. In Chapter Three I outlined the five data collection instruments that we used to engage the research stakeholders. While the use of these tools allowed different stakeholders with different literacy levels to engage, I observed to some degree a level of difficulty when used with the community group. For instance, during the Journey of Change exercise, the group seemed to struggle to fully comprehend the questions that were asked. This then affected the responses and experiences shared during the exercise.

5.5.3 Researcher and facilitator bias within PAR

In Chapters One and Three, I outlined how I encountered the NGO group and was invited to serve on the board of directors. Additionally, during our data collection process, I was employed within the School of Pharmacy. Serving in each of these roles while concurrently facilitating all the stakeholder engagements and interactions meant I often had to juggle the key interests of all stakeholders. Considering that I, to the best of my ability, have limited bias and/or favouritism toward one particular group, it is important not to dismiss its possibility entirely. I observed that I often favoured the community group during the collaborative workshops; this observation could imply that our results to some degree, have a level of bias.

5.6 CHAPTER SUMMARY

In this Chapter, I contextualised key findings with relevant literature. I also reflected on our research questions and objectives and outlined how we were able to successfully achieve these with our unique research approach. Lastly, I also outlined the limitations of our study and PAR tools. In the next and last Chapter of this thesis I reflect on lessons learnt from our research.

CHAPTER SIX: FINAL REFLECTIONS

6.1 INTRODUCTION

In this Chapter, I present my observations, reactions, and interpretations of our dynamic research journey. I reflect on my interactions with the primary research stakeholders and recruited role-players during the various data collection and engagement points. I also outline key lessons learnt from our research, before I offer recommendations for future research and researchers alike.

6.2 ENGAGING PRIMARY RESEARCH STAKEHOLDERS

In Figure 3.2, I presented the participatory multi-stakeholder engagement approach and research timeline. Recalling the various engagement points with the research stakeholders. I reflect on my interactions with the HEI, NGO, CHW and community group in the following subsections.

6.2.1 Interaction with HEI group

For the HEI's first and second focus group sessions, I used the same venue and set it up before the participants arrived. The decision to use the SLiP lab in the School of Pharmacy was based on availability and convenience. However, I noticed that the participants were comfortable being in the lab and showed a certain command over the space that they felt they had a connection or familiarity with. On the day of the session, I organised chairs in a campfire order surrounding a brown stool with the audio recorder placed on it (Figure 6.1).

As participants arrived, I offered them the session outline, information sheets, consent forms, and directed them to sign the attendance register. I also invited participants to help themselves to refreshments that were already prepared. I noticed that the process of eating with each other allowed for us to have informal conversations, which further contributed to strengthened rapport.

Figure 6. 1 HEI session 1 venue set-up

In the following subsections I reflect on key learning and/or lasting moments while interacting with HEI participants.

6.2.1.1 *Quick thinking, creativity and childlike wonder*

During the first FGD with the HEI, we played ice breaker that required a ball which I did not have. In the spare moment, I scuffled paper into a makeshift ball and wrapped it with brown tape to make it throwable. The brown improvised ball was placed in the middle of the circle next to the voice recorder. The ball grabbed the attention of the participants when we started the game, and they laughed as they praised my creativity. This created a fun and light energy that remained throughout the session.

Furthermore, during the Journey of Change exercise, participants approached the activity as a game and some exhibited childlike excitement over their flip charts. Interestingly, participants shared pens and markers and commented on each other's drawings with light teasing and admiration. I realised during that session that there was power in giving people markers and telling them to be as creative as they wanted to be.

6.2.1.2 *Balancing power and hierarchy within diverse group*

During the Journey of Change activity, I feared issues of power and dominance within the different pair groups, more especially between the student-lecturer pairs. However interesting shifts of power were observed, I elaborate on this below.

For the student-lecturer pairs, I noticed a change in the initially self-allocated roles at the beginning of the exercise. In one pair, the lecturer started off as the scribe and would hastily write down their thoughts on the flip-chart without seeking confirmation from the student. Whereas with the second pair, the lecturer stood back from the flip-chart and dictated what the student captured.

However, as the game progressed and the vibrancy within the room increased the initial roles reversed within the student-lecturer pairs. For instance, the lecturer that had previously dictated instructions to the student, drew flowers and visuals dictated by the student. Whereas in the second pair, the lecturer stepped back as the student interpreted the flip-chart composed by the lecturer. During the presentations, the students were selected to present.

Interestingly, the student pairs seemed to swap roles throughout the exercise, with both taking chances to write and dictate what to write on the flip chart.

This almost synchronised translation of roles and power was something that I had not planned to observe within the small closed focus group. It shifted the power balance efficiently and smoothly without the group members even understanding the great magnitude of what they had done.

6.2.1.3 PAR facilitation within rigid academic research setting

When the SLiP lab was clean and I was left alone to reflect on my interactions with the HEI group, I remember feeling a sense of accomplishment. I found myself recalling interesting articles that praised Participatory Action Research, and how it empowered and impacted participants and researchers alike. Yet, in the same breath, I was fighting the pacing thoughts that bounced between my hidden agendas as a young researcher and a growing PAR practitioner.

I felt a sense of attachment to the conversations and participants. However, this was accompanied by a crippling sense of guilt at how I seemed to rush the sessions and often probed conversations that prioritised my research objectives. My unique PAR facilitation style encouraged raw honesty and vulnerability, which allowed participants to share deeply with one another and myself. Overwhelmed with pockets of authentic experiences of participants who navigate complex institutional systems, I extracted what was relevant for my research and somewhat discarded the rest. Hence how different was I from the other researchers who extract without reserve and leave participants without solutions. What was I going to do with the information, beyond simply regarding it as data? I wondered how participants felt about this too. In the mirror, I resembled the mistrusted helicopter researcher that hovered over small villages to extract information, then like the wind packed up and vanished, leaving the people with less hope and confidence in research.

Recalling that we only achieved the first three stages of our five-stage research approach, I live with this guilt till this day. I reflect on my interactions with the NGO group in the following subsection.

6.2.2 Interactions with the NGO group

Having learnt from interactions with the HEI group, I selected the NGO’s main offices as the location and venue for their FGD. On the day of the session, I set up the venue together with the participants and arranged chairs in a campfire order, with a make-shift stool in the middle for the audio recorder. I felt like the group having set-up their own venue in an environment that was familiar, showed a sense of ownership over the space. As with the HEI FGD, refreshments, information sheets, consent forms and session outlines were given to NGO participants before we started the session officially. I share my observations and reflections in the following subsections.

6.2.2.1 Influence of group dynamics and willingness to work together

During the Map of Exchange exercise, I gave each participant a blank mini-version of the tool and instructed that they carry out the exercise on their own before we collated the group's responses. Interestingly participants expressed they were more comfortable discussing it in groups of two/ three. From this request I observed that the NGO group was fond of working in groups, which reflected the collaborative way in which they worked in their daily work.

6.2.2.2 Being regarded as an insider, the power of shared language

During the NGO’s session, participants used Afrikaans in their small groups. When I picked this up and responded to one group in Afrikaans, participants then included me in the Afrikaans group banter and teasing. When this happened, I felt more accepted and like an insider, which was comforting.

6.2.2.3 The power of co-facilitating with participants

While rounding off the Journey of Change exercise, one participant focused on the fifth question and asked a series of questions to the larger group. Once her questions were answered, she made notes on the flip chart. As this was happening, I remember feeling trusted by the group; it felt reassuring that participants were comfortable to take over and lead the facilitation process.

I reflect on my interactions with the CHW group next.

6.2.3 Interacting with the CHW group

For the CHW focus group session, I used a nearby church affiliated with the NGO as the venue. This church was within walking distance from the organisation's main offices and served as a familiar location that allowed privacy from the management team and interference. Similar to the NGO group, CHWs helped me set up the venue and I ensured to offer refreshments, information sheets, consent forms and session outlines before we started the session officially. I share my observations and reflections in the following subsections.

6.2.3.1 Self-doubt, detachment and facilitation

During the CHW FGD, a CHW while commenting on interactions between students and the community, made a statement that still haunts me. Her words tugged at a deep place in my heart; *"when you're done here, then we don't see Bonny again"*. She said those words with such defeat in her voice, as if she had accepted it as the truth yet had no power to change it. Before she made the statement, she asked me what I was studying and what I intended to do after my Master's. At the time, I was contemplating pursuing a career in a different field altogether, as I was not particularly enjoying academia. In that instance, a deep sense of fear came over me as I fought thoughts that she could see through me and all my uncertainties. I felt like she was thinking: *I see what you are doing and you just like them, they come to research and leave us more broken and hopeless than before*. Recalling that I was carrying a similar guilt from the HEI FGD, this broke my heart even further. This binary mentality: "us" (community) and "them" (researchers), underpinned my deep- seated discomfort. I remember trying at that moment to remain unshaken and attempting to steer the conversation in a direction that removed focus away from me.

I remember feeling so hypocritical when carers would be sharing, and I would have to keep to the time and sometimes ask that we move on. I felt sad that I did not know some of the areas that were being mentioned in the community. What I was recording and collecting as data was everyday life for CHWs and people living in Delft and I could conveniently walk away from it after the session. Hence, I struggled to maintain my genuine intentions to cultivate a safe space for carers to voice their thoughts and feelings, with the planned session objectives. I found myself going back and forth between allowing carers to share their thoughts even if it was not related to the questions being asked or task objectives and reminding the team of the objectives. This further contributed to increased self-doubt.

6.2.3.2 CHWs' selflessness, willingness to help and comradery

Before we started the CHW FGD, CHWs helped me set-up the venue. I remember feeling overwhelmed by how CHWs had only met me a few minutes earlier but were willing to help me. As soon as each CHW would arrive they would greet everyone, drop their bags and start helping. One CHW described that "*CHWs don't see what they do as jobs, it's their way of being, where help is needed, it is given and where care is needed it is offered*".

Seeing such comradery, ubuntu and kindness was a rewarding experience. Additionally, hearing stories of how CHWs overcame hardships, death, and traumatic experiences was humbling and grounding experience. Our FGD cultivated a space where vulnerability, support and warmth were abundant.

6.2.3.3 Attachment to Participants and research project success

During the CHW FGD, I felt deeply attached to the participants and the stories they shared. I wanted to make our project work desperately and to make a difference for the research participants. This was fueled by the overwhelming trust and vulnerability CHWs shared with me during their session.

By the end of the FGD, I felt a deep sense of conviction: 'Yes, this is what I want to be doing in my life'. I want to be a part of people's journeys as they heal, discover their greatness, and embrace differences to work together to solve common problems. I explore my interactions with the community group next.

6.2.4 Interacting with the community group

I initially wanted to host the community workshop at a venue that felt familiar to the group and potentially located in Delft. From my interactions with the HEI, NGO and CHW groups I imagined the community group would be comfortable in a well-known environment as opposed to a new one. However, the research time frame and difficulty with getting a venue in the community left me very little options. As an alternative and last resort, I hosted the community workshop on the university premises, more specifically the SLiP lab in the School of Pharmacy.

On the morning of the workshop, I went to the designated pick-up location with the bus driver and waited for community members to arrive. I personally fetched the community members because I wanted to establish rapport before the workshop began. As we pulled into the university premises, I started locating and naming the buildings we were passing and community members showed child-like excitement during their makeshift tour. Surprisingly, for most participants from the community group, it was the first time coming to the university. For the community members this was not just a drive to a workshop, it was a sort of field trip.

The SLiP lab was set up the night before and, as community participants entered the venue I handed out information sheets, consent forms and the session outline. Similar to my previous engagements with other stakeholder groups, I offered community participants refreshments before and throughout our session. I elaborate on my observations and reflections in following subsections.

6.2.4.1 Cultural influences vs nurturing personalities of seniors

For the community workshop, I organised a buffet lunch on the advice of the COM from the NGO group. On the day of the community workshop, caterers dropped off pots of food and plates. Considering that most of the community participants were visibly much older than myself I struggled to balance my role as a researcher and facilitator with that of a young individual. Culturally, in typical social settings where elders and young people are both present, often young people would see to the elders by serving food and doing chores. Hence as a Rwandan young woman raised in such settings, I naturally wanted to dish and serve the participants food during lunch time. Yet, I struggled to decide what was best in that setting and instead posed the question to the group. Interestingly, two participants suggested and offered to dish and serve everyone, which relieved my ongoing internal conflict.

While the two participants dished for everyone, I offered to assist and was lovingly dismissed and told to go set up for the next activity. I remember feeling like our session was one big social event and it felt so comforting seeing participants take up space and ownership over the space and me. Moreover, after everyone had been served, one participant while helping me take down flip-chart paper from the wall, asked if I had eaten? When I informed her that I would eat after the workshop, she quickly dismissed my statement, pulled up a chair in a loving motherly way and said; "*No Bonny you also need to eat; here sit down. I will make you a plate*". These words felt so nurturing and almost motherly and, in that moment, I found myself fighting tears. She reminded me of my grandmother in so many ways.

At lightning speed, I was given a chair, a plate of food and a glass of juice, while another participant helped me distribute the blank cue cards needed for the next exercise. For a moment, I felt like I was in my grandmother's house, visiting for the holidays. I felt loved, I felt understood, I felt like I belonged. I had the same feeling I had felt when I was with the CHW group. There and then I comprehend the spiritual wholesomeness that working with communities evokes in PAR facilitators like myself.

6.2.4.2 Managing differing opinions

During the session, two participants seemed to disagree on a few things and often would get caught in a back-and-forth dialogue over certain discussion points. After the first instance, I felt a sense of panic that the rest of the group would be affected negatively, so I devised a self-made technique borrowing elements from motivational interviewing.

After allowing both parties to each share two turns of back-and-forth statements or counter-arguments, I interjected and summarised their viewpoints. Then I interpreted the summarised information adding an empathetic lens and focusing on the underlying emotions attached to their viewpoints. Simultaneously, I linked the summary back to the actual discussion. I offer a digestible step-wise process below:

Step 1:
Summarize what each party is saying in a concise and holistic way.

Step 2:

Empathize with both parties by suggesting that both parties are right in their experiences. Ensuring to make the feelings that of the entire group and not of the parties having different views.

Step 3:
Redirect the conversation back to the topic at hand.

The above process of managing conflict proved immensely helpful and efficient at diffusing any differing opinions during the community workshop and for the two MSCWs.

6.2.5 Language barriers

During the Journey of Change exercise, I noticed two participants were more reserved than the others. I later accredited this to a language barrier after discovering that some community participants, who could converse in basic English, struggled to write and read the language. This consideration made it difficult for those participants to write out their feelings, thoughts, and opinions in English. I found myself confused and ashamed that I had not anticipated such occurrences during my planning.

In this section I reflected on my interactions with the primary stakeholder groups of our research. I described my observations, interpretations and feelings in a reflective manner. My intention with these narrations is to allow you a glimpse into my psyche whilst engaging with HEI, NGO, CHW and community research stakeholder/ participant groups. Recalling that more role-players were recruited as a result of these interactions, I reflect on my observations during the first and second Multi-stakeholder collaborative workshops (MSCWs) in the following section.

6.3 MULTI-STAKEHOLDER COLLABORATIVE WORKSHOPS (MSCWs)

The first and second MSCWs were both held on the university premises, in the seminar room of the School of Pharmacy and School of Public Health respectively. For both workshops, the venue set up was done the day before and participants arrived with everything set up. I arranged transport for participants coming from Delft that would pick-up and drop off participants at the NGO main offices. The large number of guests who attended both workshops (as previously explained) added significantly to my anxiety and fear that I would not manage facilitating such large groups on my own. I reflect on my observations and feelings from the first workshop in the following subsections. I incorporate my observations from the second MSCW under the lessons learnt and future recommendations sections.

6.3.1 Navigating new environments and group dynamics

As guests for the first MSCW arrived and settled into the venue, the HEI group offered the other participants refreshments, ensured they had signed the registers, directed them toward bathroom facilities and to some extent embraced a host role. Interestingly, other participants also showed a sense of familiarity with the new and unfamiliar venue. One CHW recognised a student who she had interacted with in the community and it was a wholesome moment to witness. As I walked around the room, I observed similar heartfelt moments, between participants who recognised each other from their previous engagements and other interactions and dived deep into inquisitive conversations.

It felt so comforting to observe how everyone seemed to know each other. As participants walked into the room, most smiled as they greeted me and shared how excited they were for the workshop. I remember slowly losing the fear and anxiety I had over facilitating such a large group of people as more and more people arrived.

6.3.2 Games and visual tools for enhanced communication

When I played the PBRG game with the participants, I asked each team to hold up their respective items all at once at the end of the game. This served as a powerful visual tool and almost everyone in the room gasped as they realized that each team had an item that they would need to win the game. Then a CHW excitedly announced; *"wawo, we each have what we need man*" as the rest of the group agreed with her as they nodded their heads and released "Hmm's" as echoes. After I linked the game to stakeholder relational dynamics, I looked around the room and a sense of excitement followed as I realised the power of games and visual tools to harness complexity. I also understood that at the core, even as adults we have a deep desire to converse and connect, and immersing in games allow such safe spaces to explore hidden potential and resources.

6.3.3 Trusting participants and letting go of control

During the Thoughts Pool- CMU revisited exercise, I walked around to each group several times, hovered over them and attempted to capture their discussion points. Warranted these efforts were almost impossible to maintain, and I stepped back after I remembered the importance of trusting participants and encouraging co-facilitation and co-creation within PAR.

After my reform, I walked around the room again, making sure to not interrupt the groups. Interestingly groups were doing well on their own and some went on to make new posters capturing their main discussions, others were in deep conversations about their own personal chronic disease experiences and managing family members with chronic diseases. The groups for some became a place of sharing commonalities of difficult realities that only others like them would understand. It was a wholesome feeling to stand at the front of the room and see how strangers who had not known each other before that morning were huddled together in a circle with some on the floor, sharing their stories with one another without my instruction.

6.3.4 Respecting and accommodating participant needs

During the first MSCW, a community participant brought along her young son (aged between 4-6 years old) to the workshop. Having learnt to deal with the unexpected from my previous workshops I embraced this unplanned turn of events. For most of the session, our young visitor seemed calm and distracted by his mother's mobile device. However, after sometime, he started to get fidgety and demanded his mother's attention. I quickly intervened and moved him toward the front of the room, and distracted him with crayons, blank flip-chart paper and sweets. I sat with him for some time and encouraged him to draw his favourite things while I also doodled on the same flip-chart paper. His mother and I took turns to check up on him as he continued drawing alone. I made sure he was in his mother's sight the entire duration of the workshop. I remember the mom coming to me after the session and expressing deep gratitude that I took care of him and that he had deeply enjoyed his time with us. I felt proud of myself for respecting and accommodating my research participants' needs.

In this section I reflected on my observations from the first MSCW. In the following section, I highlight key lessons that I learnt throughout my research journey before I end the Chapter with my recommendations for future research.

6.4 LESSONS LEARNT

We have learnt four main lessons throughout our research journey. I elaborate on these below.

6.4.1 Respecting cultural practices whilst working with communities

Working in communities requires that researchers respect and prioritise the cultural practices and ways of being within that community. In our research for instance, we worked with stakeholders and community members from Delft, which warranted upholding certain cultural practices and ways of being. It would be important to establish appropriate ways of referring to elders, phrases regarded as taboo, dress codes for different genders and culture around sharing food and conversational etiquette of the specific community you will be interacting with.

6.4.2 Literacy, language, and different ways of learning in PAR type of research.

PAR boasts its ability to be used within rural settings and requires minimal literacy levels. Within our research we discovered that to a certain extent some basic level of literacy and English language proficiency was necessary. When working with research participants whose home language is not English, it would be useful to appoint a translator during engagement sessions or training community representatives to co-facilitate sessions in a bilingual manner.

6.4.3 Flexibility, adaptability within stakeholder led research

The unstructured nature of PAR within contexts where research stakeholders led the project timelines require a well-developed ability to be flexible and adjust. For instance, in our project we had to postpone scheduled engagement sessions several times to meet the availability and needs of the participants. Additionally, during these engagements I often had to adapt the PAR tools on the spot and in some cases develop games and unplanned illustrations to communicate certain messages. PAR facilitation requires intentional efforts to work and understand people and a radical willingness to adjust research objectives and timelines so as to meet the needs of the people.

6.4.4 Evolving roles, loyalty and managing bias

In our project I wore many hats; researcher, facilitator, postgrad pharmacy student, and board secretary. At all times I ensured I kept the interests of the community participants. They were my constant and as such before any other role, I prioritised my role as a researcher and facilitator, and other roles served to supplement my understanding of the other stakeholders' contexts. In PAR and more particularly multi-stakeholder research, roles may evolve and researchers may find themselves crossing between different roles. This process is something that should be embraced and exploited to better understand the realities of the different stakeholders within contextualised settings.

Having narrated the lessons, we learned throughout our research journey, I outline my recommendations for ongoing and future research in the following and last section of this thesis.

6.5 RECOMMENDATIONS FOR FUTURE RESEARCH

We were not able to action stages 4 and 5 of our research approach, as such we would welcome opportunities for further exploration and collaboration.

Furthermore, I recommend that future community-based research that utilises our five stage PAR engagement approach divide the stages into three phases:

- The first phase would focus on understanding the research stakeholders' realities, community contexts and organisational functions.
- Thereafter the second stage could then focus on contextualising the chosen and prioritised health issue together with the identified primary stakeholders in both closed FGD and MSCWs.
- Thereafter the last stage could then attempt to collaboratively develop interventions to address the previously contextualised health issue.

These phases could be carried out over three separate and complete research projects and efforts made to maintain the same research participants. Consequently, the three research projects would occur over an extended time and would require a stable research grant stretching over a 5-7-year period. I believe this approach, if applied in the described manner, could offer credible interventions that could contribute to national policy and strategies targeting healthcare in the country.

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"Sane leadership is the unshakeable faith in people's capacity to be generous, creative and kind. It is the commitment to create the conditions for these capacities to blossom, protected from the external environment. It is the deep knowing that, even in the most dire circumstances, more becomes possible as people engage together with compassion and discernment, self-determining their way forward."

Margaret Wheatley, Who do you choose to be

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APPENDICES

Appendix A: Research stakeholder invitation letter

UNIVERSITY of the
WESTERN CAPE

School of
PHARMACY
FACULTY OF NATURAL SCIENCE
Private Bag X17 Bellville 7535
Cape Town
Telephone 021 959 2190
3459397@myuwc.ac.za

6 February 2019

Dear potential research partner

Thank you for taking the time to read this letter. This letter serves to invite you to be a research partner in the study tilted; *Exploring the Community Based Participatory Development approach to address chronic medicine use*. The study has been approved by the Biomedical Research Ethics Committee of the University of the Western Cape (Ethics number **BM18/7/15**. The researchers of this study are: Bonheur Nfurayase, Angeni Bheekie, Cornel Hart and Mea Van Huyssteen.

We are asking you to become a research partner, because you are either a community member, Community health worker, Non-governmental organization staff member or a student and have experiences, knowledge and information about the use of chronic medicine in the community and the ongoing issues.

The Community-based Participatory Action development approach is used to encourage research partners to talk about issues that affect them, and discuss ways to improve and potentially develop interventions together as a team. We would like to explore the potential factors that are involved in using Community-based Participatory Action Research development as an approach; when different research partners work together. The research process will involve attending focus group discussions and workshops. The proposed dates will be sent to you or your organization or contact in due time. However, all focus group discussions and workshops will be organized such that they are on dates and at times that are convenient for you.

The potential benefit of participating in this study is the opportunity to be involved in the community-based Participatory Action development process. The process allows partners to influence and share control over development initiatives and over the decisions and resources that affect them, this allows them to develop a sense of ownership for the development efforts of a project or intervention; which increases the projects' sustainability and self-reliance. Also the process will allow you to partake in activities that promote social justice; through improving the quality of people's participation and could later be used as a reference towards influencing policy which governs the health services development in Western Cape communities. There are no foreseen risks or discomforts that are anticipated from your participation in the study.

Significantly, we will not reveal your name. To help protect your confidentiality, the results will be anonymous and will not contain information that will personally identify you. All the information collected in this study will be kept completely confidential. The information gathered during this study will remain in a secure place during the course of this project. Only the researchers will have access to the study data and information. If the results of this research are published in the form of a research paper for a professional journal you will receive a copy of any work published.

You are welcome to ask the researcher any questions that occur to you during the study. If you have further questions once the study has been completed, you are encouraged to contact the researcher; Bonny at Cell 066 224 1652 or via email on bnfurayase@uwc.ac.za

Sincerely,

Miss BP Nfurayase
Cell: 066 224 1652

Appendix B: Recruitment email sent to the NGO group

Bonheur Nfurayase <bnfurayase@uwc.ac.za>

Bonny's research_ Invitation to act as research partner
1 message

Bor :43 PM
To:
Cc:
<m

Details ommited for confidentiality

D.

I hope this email finds you well. This email is a follow up on the telephonic conversation I had with i on Wednesday, as well as the talk I had with (k after the board meeting on the same day. Once again thank you for accepting to be research partners within our study.

Attached to this email is the official invitation letter with brief details about the research and what it will entail for you as research partners.

In accordance with what i and I discussed on the phone, I remember us both agreeing that two focus group sessions on separate days for the NGO group and the CHW group would be heavy to manage for those involved. Hence an extended workshop on a Saturday; where maybe the content of the two focus group discussions could be combined, would work best for the NGO and CHW group(These groups are further elaborated on later in this email.

Hence what I would be most grateful to have from aunt Wini is the passing on of this invitation letter to the CHW group, as well as the NGO group after recruiting representatives that will form part of the two groups. As well as the confirmation of the dates for which Saturdays (/9/23/30 March 2019) would work well for the NGO group and subsequently the CHW group?

Now to further elaborate on the NGO and CHW group

NGO group: (6-8 people) - **9 March 2019**
To make up a cosmopolitan of the organization, hence would attempt to have executive, Human resources, operational and administrative staff represented. Ideally, perhaps:

1.
2. X1 HR or Admin staff member
3. A supervisor or Coordinator staff member from HAST project
4. A supervisor or Coordinator staff member from CBS project
5. A counselor staff member from HAST project
6. A community-based carer staff member from CBS project
7. Nurse staff member
8. Dietitian staff member

CHW group: (6-8 people) - **23 March 2019**
To represent the Community-based health care workers working for Ideally perhaps:

1. X3-4 Community-based care workers from HAST project
2. X3-4 Community-based care workers from CBS project

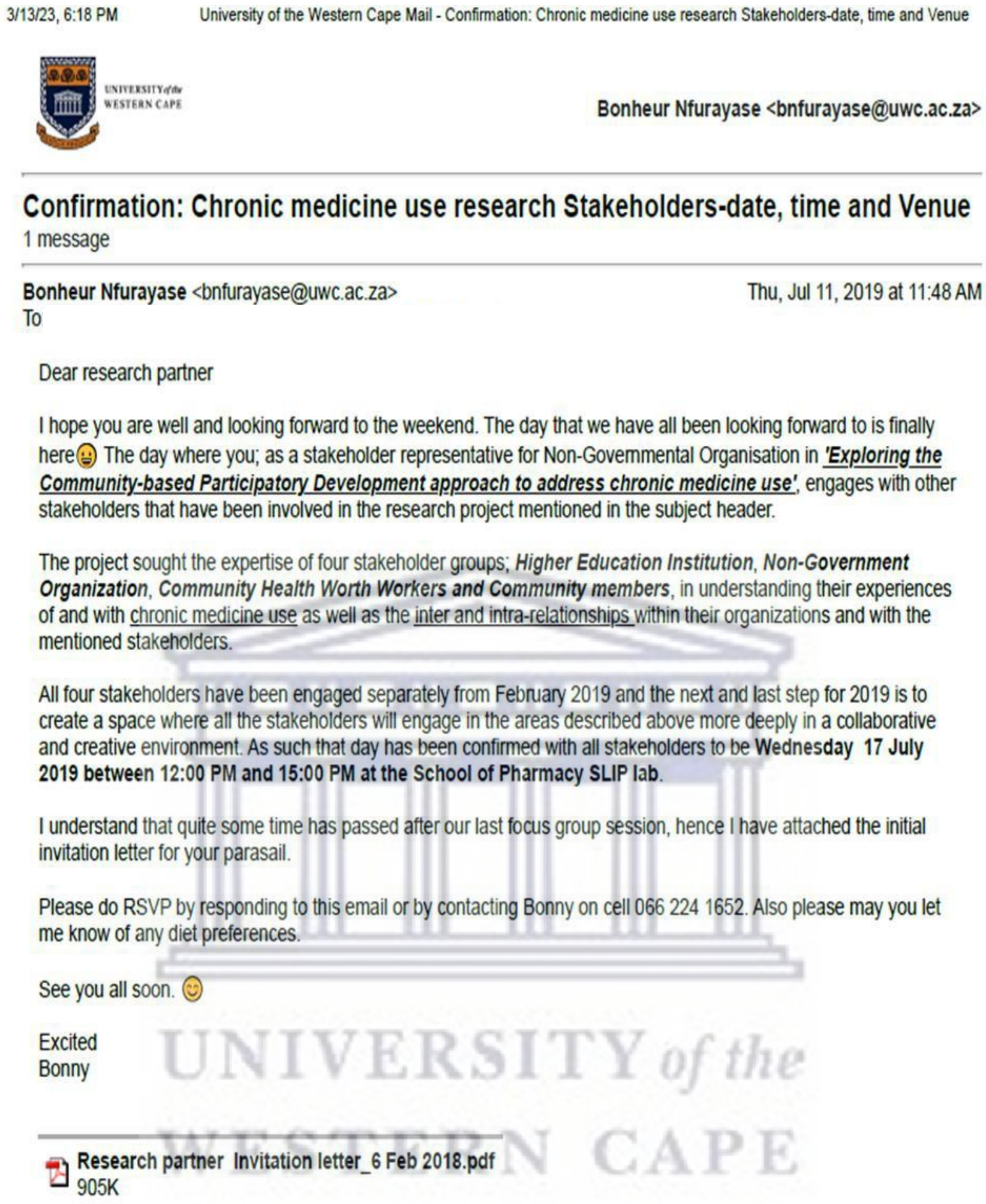
The CHW group will serve a vital role in assisting in the selection of the community members who will form the Community group research partner. Hence the Carers or community-based workers selected to form part of this group would need to be working with community members and be willing to invite 3-4 community members each to participate in the study as research partners. However, this process of recruitment will be discussed with the CHW group closer or during their workshop.

Please feel free to contact me for further clarity or more information or even just for a chat on cell: 066 224 1652 or via this email.

Kind regards
Bonny

Research partner Invitation letter_6 Feb 2018.pdf
905K

Appendix C: First MSCW email invite



3/13/23, 6:18 PM University of the Western Cape Mail - Confirmation: Chronic medicine use research Stakeholders-date, time and Venue

UNIVERSITY of the WESTERN CAPE

Bonheur Nfurayase <bnfurayase@uwc.ac.za>

Confirmation: Chronic medicine use research Stakeholders-date, time and Venue
1 message

Bonheur Nfurayase <bnfurayase@uwc.ac.za> Thu, Jul 11, 2019 at 11:48 AM
To

Dear research partner

I hope you are well and looking forward to the weekend. The day that we have all been looking forward to is finally here😀 The day where you; as a stakeholder representative for Non-Governmental Organisation in ***'Exploring the Community-based Participatory Development approach to address chronic medicine use'***, engages with other stakeholders that have been involved in the research project mentioned in the subject header.

The project sought the expertise of four stakeholder groups; ***Higher Education Institution***, ***Non-Government Organization***, ***Community Health Worth Workers and Community members***, in understanding their experiences of and with chronic medicine use as well as the inter and intra-relationships within their organizations and with the mentioned stakeholders.

All four stakeholders have been engaged separately from February 2019 and the next and last step for 2019 is to create a space where all the stakeholders will engage in the areas described above more deeply in a collaborative and creative environment. As such that day has been confirmed with all stakeholders to be **Wednesday 17 July 2019 between 12:00 PM and 15:00 PM at the School of Pharmacy SLIP lab**.

I understand that quite some time has passed after our last focus group session, hence I have attached the initial invitation letter for your parasail.

Please do RSVP by responding to this email or by contacting Bonny on cell 066 224 1652. Also please may you let me know of any diet preferences.

See you all soon. 😊

Excited
Bonny

Research partner Invitation letter_6 Feb 2018.pdf
905K

Appendix D: Second MSCW email invite

3/13/23, 6:10 PM University of the Western Cape Mail - Chronic medicine use workshop_ Sat 21 September 2019- UWC School of Pharmacy

Bonheur Nfurayase <bnfurayase@uwc.ac.za>

Chronic medicine use workshop_ Sat 21 September 2019- UWC School of Pharmacy

1 message

Bonheur Nfurayase <bnfurayase@uwc.ac.za> Thu, Sep 19, 2019 at 1:35 PM
Bcc:

Dear specially invited guest

It is with great excitement that we send this email reminder of the upcoming Multistakeholder Chronic medicine use workshop, taking place this **Saturday 21st September 2019** at the **University of the Western Cape, School of Pharmacy between 09:00 AM and 14:00 PM.**

As previously communicated in the initial invite, the workshop seeks to bring together different stakeholders in and or who have an interest in Delft. Where a safe space will be provided to explore Chronic medicines and its pathways in Delft; with the focus on how all stakeholders can work together to identify opportunities to address issues surrounding communication channels, inherent resources and improving access in Delft.

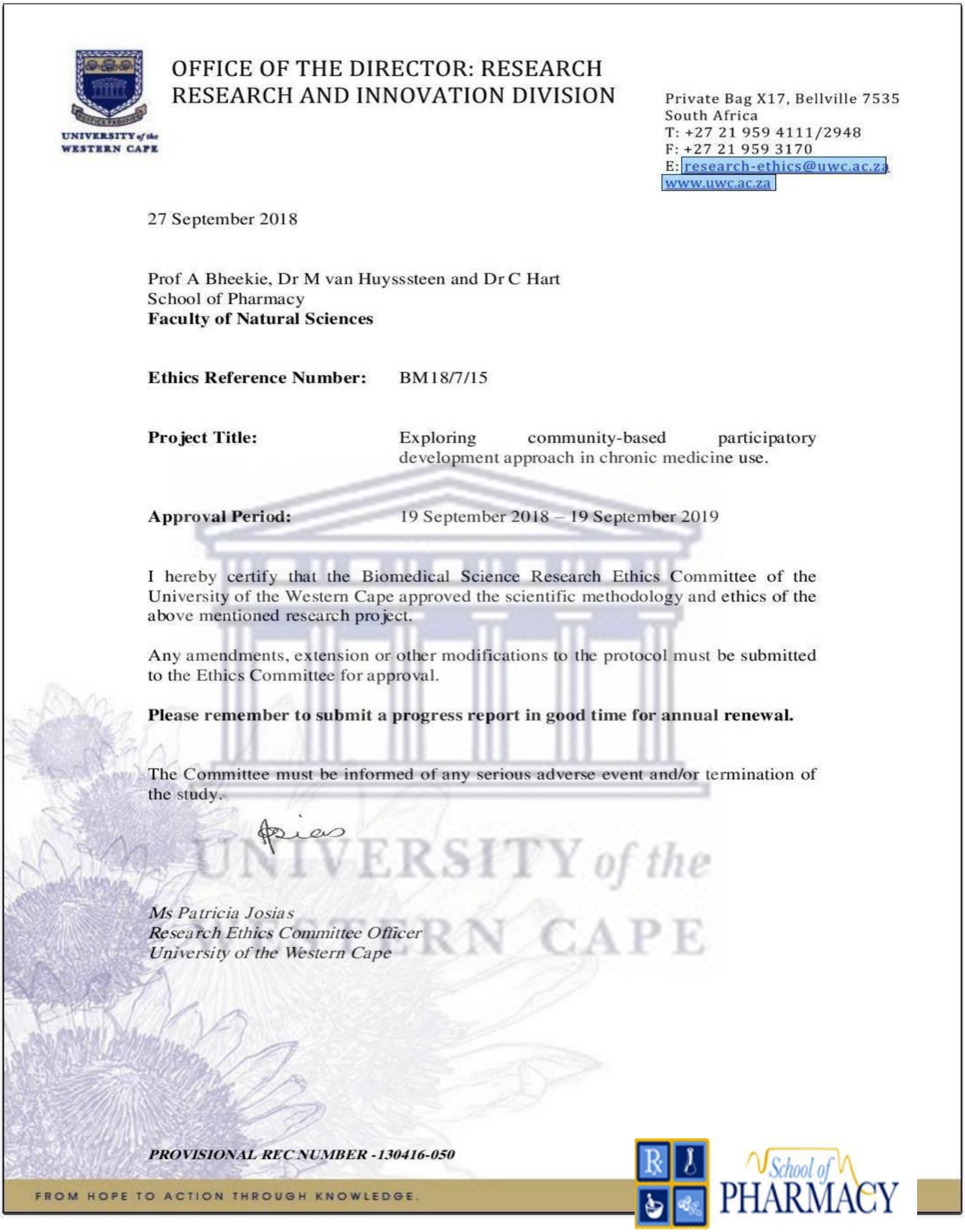
You are specially invited to this very unique collaborative, participatory and interactive event, because of the expertise that you have in working with Delft or communities and as such, your presence will be highly valuable.

The program for the day will be sent out shortly, but please do **RSVP** by responding to this email or giving the workshop facilitator (Bonny) a call or message.

Highly excited

Bonheur(Bonny) Nfurayase
Mpharm Candidate (Community Engagement), School of Pharmacy
University of the Western Cape, Robert Sobukwe Road, Bellville, 7535
Tel: 021 959 3686
Cell. 066 224 1652

Appendix E: Research ethics clearance certificate



UNIVERSITY of the
WESTERN CAPE

OFFICE OF THE DIRECTOR: RESEARCH
RESEARCH AND INNOVATION DIVISION

Private Bag X17, Bellville 7535
South Africa
T: +27 21 959 4111/2948
F: +27 21 959 3170
E: research-ethics@uwc.ac.za
www.uwc.ac.za

27 September 2018

Prof A Bheekie, Dr M van Huysssteen and Dr C Hart
School of Pharmacy
Faculty of Natural Sciences

Ethics Reference Number: BM18/7/15

Project Title: Exploring community-based participatory development approach in chronic medicine use.

Approval Period: 19 September 2018 – 19 September 2019

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report in good time for annual renewal.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

PROVISIONAL REC NUMBER - 130416-050

FROM HOPE TO ACTION THROUGH KNOWLEDGE.

School of PHARMACY

Appendix F: Research stakeholder information sheet

UNIVERSITY of the
WESTERN CAPE

FACULTY OF NATURAL
SCIENCE Private Bag X17
Bellville 7535 Telephone +27
21 959 2190
Angeni: 021 959 2977
Bonny: 066 224 1652

Study Title: ***Exploring the Community-Based Participatory Development approach in chronic medicine use***

Researchers: Bonheur Parfaite Nfurayase, Angeni Bheekie, Mea Van Huyssteen and Cornel Hart

Dear research partner

Before agreeing to participate in this study, we strongly encourage you to read the following information regarding the study. This study has been approved by the Biomedical Research Ethics Committee of the University of the Western Cape.

We are inviting you to participate in a research project to explore the use of The Community-Based Participatory development approach to address chronic medicine use issues within the community. The Community-based Participatory development approach is one that is based on providing a space for research partners to talk about issues, of a particular topic of great interest, that affects them, and discuss ways to improve and potentially solve the issues together.

We would like to explore the potential factors that are involved in using Community-based Participatory development as an approach, when different research partners work together to come up with the solutions to addressing chronic medicine use problems that they identified themselves. You are being asked to participate because you are community member, Community health worker, Non-governmental staff member or a student and you have experiences, knowledge and information about the use of chronic medicine in the community and the issues surrounding the matter. The research process will involve attending workshops and focus groups, participating in group discussions and activities; however, all at a time and date that is suitable to you. These activities will allow for an intervention or solution to an issue concerning the use of chronic medicine use in the community being identified, carried out and eventually analysed by all the involved research partners. It is our hope that through your participation, we will be able to identify the factors that affect the community-based Participatory development approach when used in resolving health disparities. The long-term goal or hoped impact of this study is that it will allow the developed solution to continue even when the research has stopped and will be used as a reference to start the process of influencing policy that govern health services development in the communities of the Western Cape.

We will not reveal your name. To help protect your confidentiality, the results will be anonymous and will not contain information that will personally identify you. All the information collected in this study will be kept completely confidential. The information gathered during this study will remain in a secure place during course of this project. Only the researchers will have access to the study data and information. If the results of this research are published in the form of a research paper for a professional journal, you will receive a copy of any work published.

The foreseen benefit of participating in this study is the opportunity to be involved in the community-based participatory development process. The process allows partners to influence and share control over development initiatives and over the decisions and resources that affect them, this allows them to develop a sense of ownership for the development efforts of a project or intervention; which increases projects' sustainability and self-reliance. Also, the process will allow you to partake in activities that promote social justice; through improving the quality of people's participation. There are no foreseen risks or discomforts that are anticipated from your participation in the study.

Participation in the study is voluntary; refusal to participate will involve no penalty. You are free to withdraw consent and discontinue participation in this project at any time without prejudice or penalty.

You are welcome to ask the researcher any questions that occur to you during the study. If you have further questions once the study is completed, you are encouraged to contact the researcher; Bonny at Cell 066 224 1652 or via email on bnfurayase@uwc.ac.za

By signing the attached consent form you are indicating that you have read this document and voluntarily agree to take part in this research study.

Sincerely,

BP Nfurayase
University of the Western Cape

……

Biomedical Research Ethics Committee (BMREC)
Research Development

Room 28 C Block New Arts Building
University of the Western Cape
Robert Sobukwe Road
Bellville
Cape Town
7535

Tel: +2721 9592988
research-ethics@uwc.ac.za

Appendix G: Informed consent form template

UNIVERSITY of the
WESTERN CAPE

School of
PHARMACY

FACULTY OF NATURAL
SCIENCE Private Bag X17
Bellville 7535 Telephone +27
21 959 2190
Angeni: 021 959 2977
Bonny: 066 224 1652

I have read the information given above and I have had the opportunity to ask questions about the reason for the workshop/ focus group discussion. I consent voluntarily to be a participant in this study.

By signing this consent form I agree that;

1. I am voluntarily taking part in this research project and I understand that I do not have to take part, and I can stop my participation at any time;
2. I have read the attached information sheet;
3. I do not expect to receive any incentives for my participation;
4. I have been able to ask any questions I might have, and I understand that I am free to contact the researcher with any questions I may have in the future.

Name of Participant: ____________________ Name of person taking consent: _______________

Research partner group:

Signature: ________________

☐ Community member

Date: ___________________

☐ NGO representative

☐ CHW

☐ UWC

Signature: ____________________

Date: ____________

………
…

Biomedical Research Ethics Committee (BMREC)
Research Development

Room 28 C Block New Arts Building
University of the Western Cape
Robert Sobukwe Road
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Cape Town
7535

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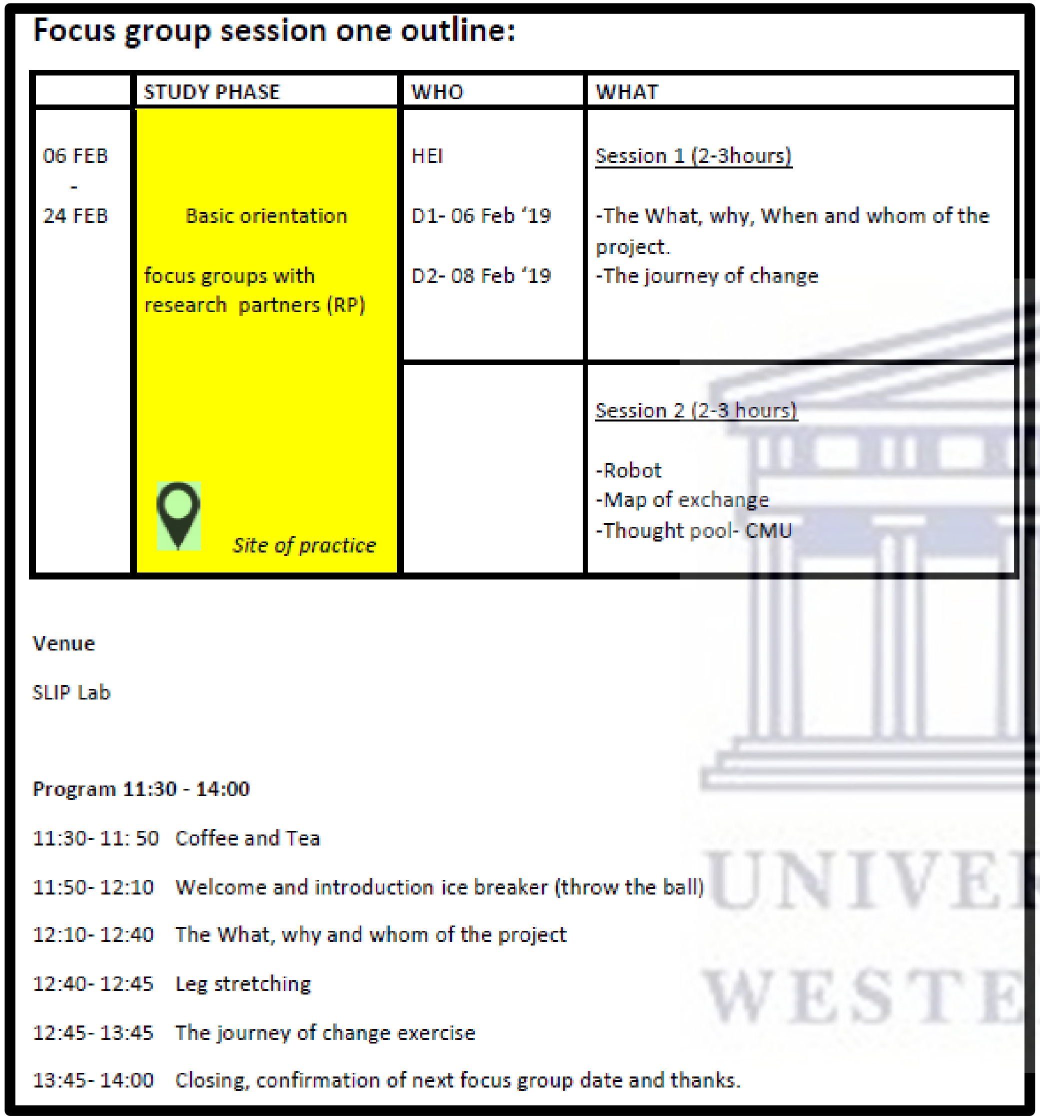
Appendix H: HEI engagement session outline



Focus group session one outline:

	STUDY PHASE	WHO	WHAT
06 FEB - 24 FEB	Basic orientation focus groups with research partners (RP) *Site of practice*	HEI D1- 06 Feb '19 D2- 08 Feb '19	Session 1 (2-3hours) -The What, why, When and whom of the project. -The journey of change
			Session 2 (2-3 hours) -Robot -Map of exchange -Thought pool- CMU

Venue

SLIP Lab

Program 11:30 - 14:00

11:30- 11: 50 Coffee and Tea

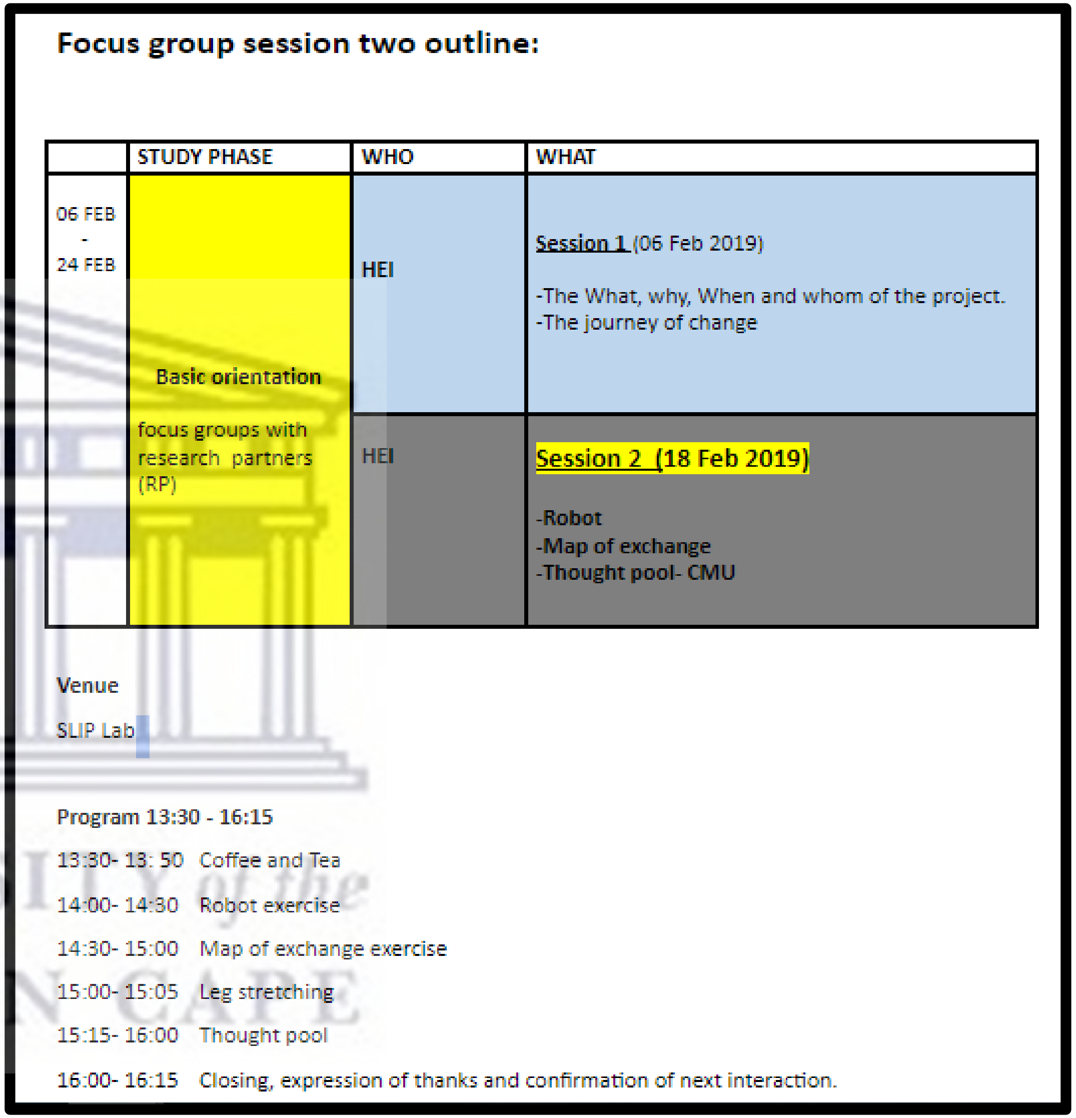
11:50- 12:10 Welcome and introduction ice breaker (throw the ball)

12:10- 12:40 The What, why and whom of the project

12:40- 12:45 Leg stretching

12:45- 13:45 The journey of change exercise

13:45- 14:00 Closing, confirmation of next focus group date and thanks.



Focus group session two outline:

	STUDY PHASE	WHO	WHAT
06 FEB - 24 FEB	**Basic orientation** focus groups with research partners (RP)	**HEI**	**Session 1** (06 Feb 2019) -The What, why, When and whom of the project. -The journey of change
		HEI	**Session 2 (18 Feb 2019)** -Robot -Map of exchange -Thought pool- CMU

Venue

SLIP Lab

Program 13:30 - 16:15

13:30- 13: 50 Coffee and Tea

14:00- 14:30 Robot exercise

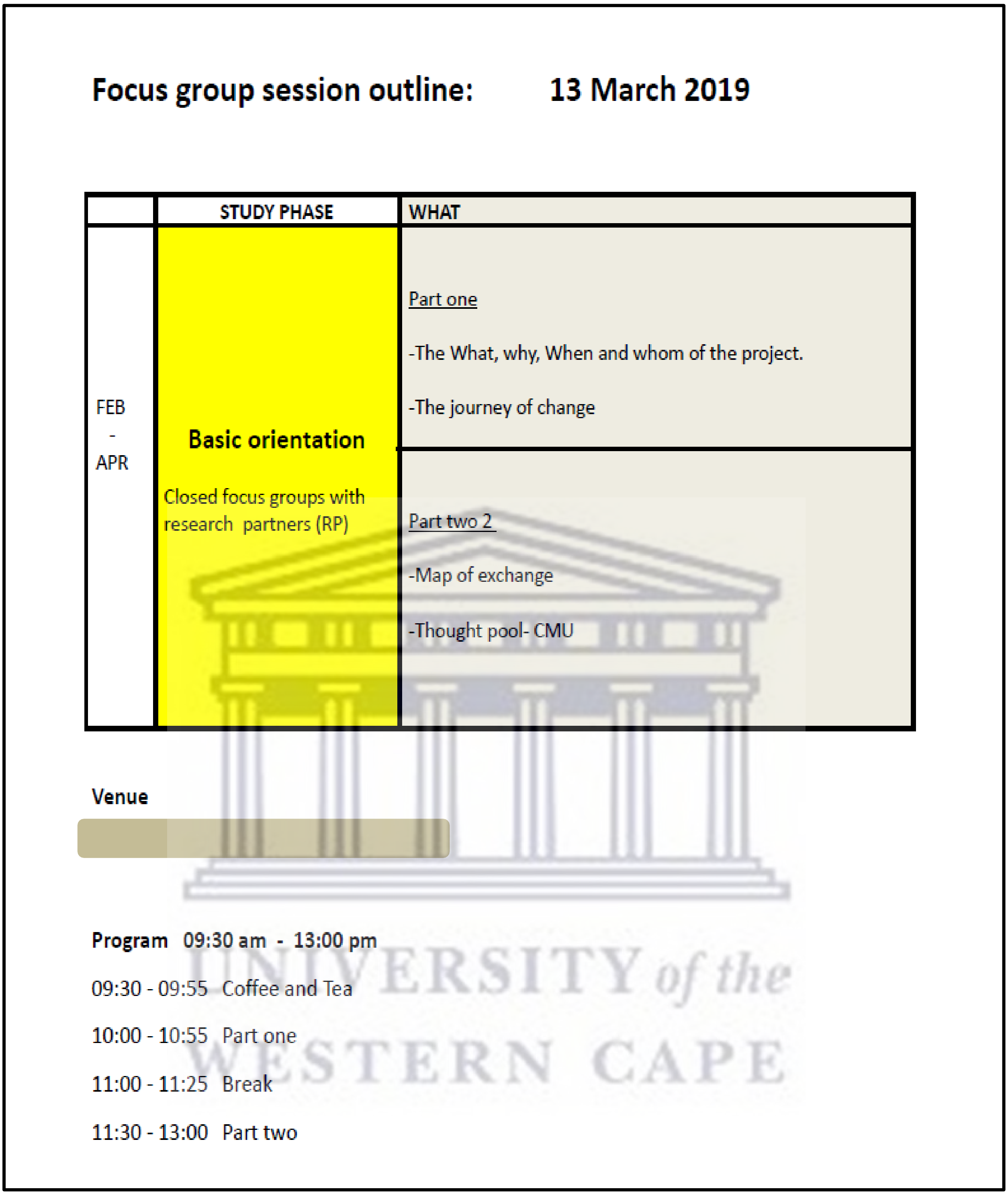
14:30- 15:00 Map of exchange exercise

15:00- 15:05 Leg stretching

15:15- 16:00 Thought pool

16:00- 16:15 Closing, expression of thanks and confirmation of next interaction.

Appendix I: NGO engagement session outline



Focus group session outline: 13 March 2019

	STUDY PHASE	WHAT
FEB - APR	**Basic orientation** Closed focus groups with research partners (RP)	Part one -The What, why, When and whom of the project. -The journey of change
		Part two 2 -Map of exchange -Thought pool- CMU

Venue

Program 09:30 am - 13:00 pm

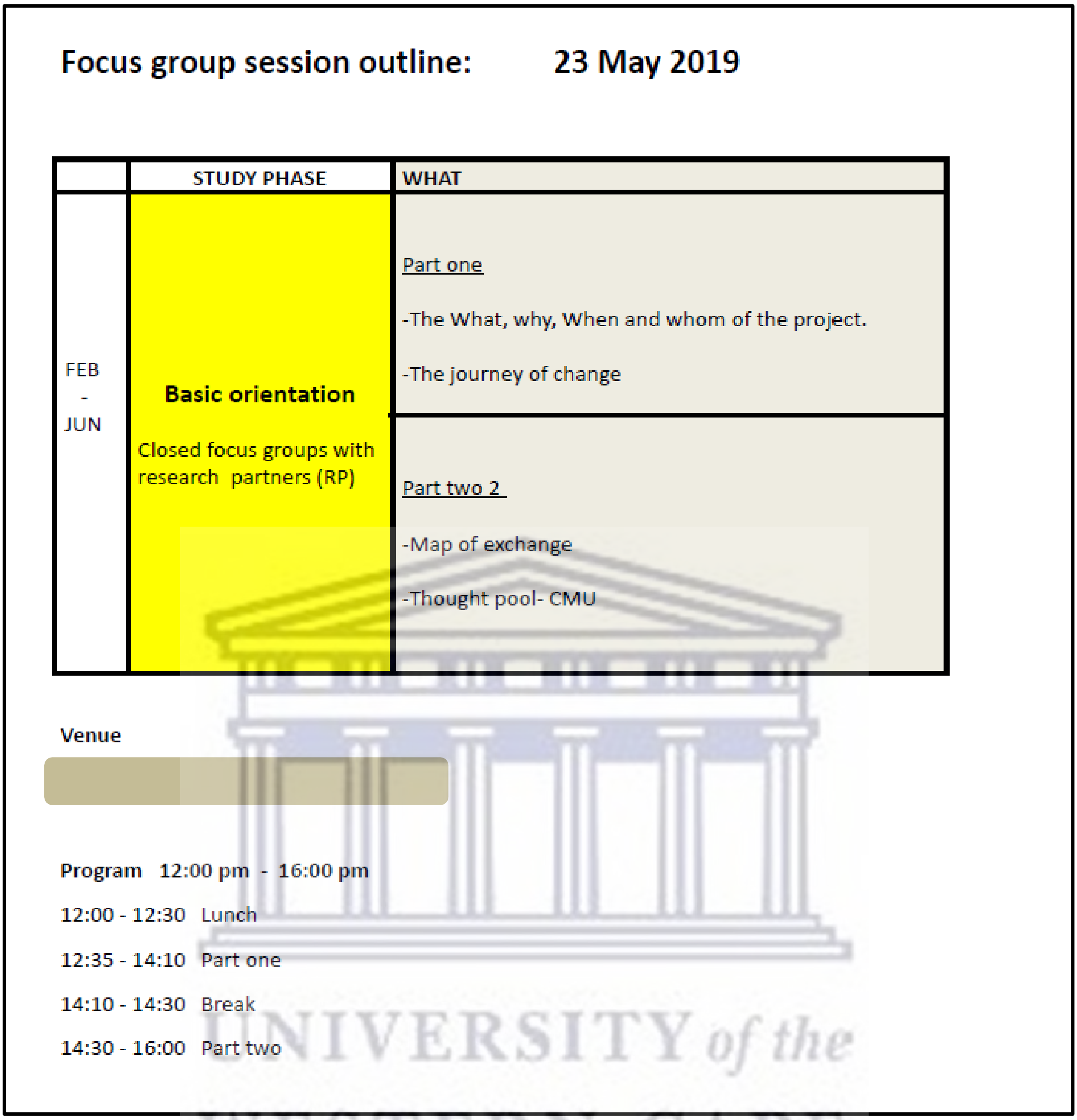
09:30 - 09:55 Coffee and Tea

10:00 - 10:55 Part one

11:00 - 11:25 Break

11:30 - 13:00 Part two

Appendix J: CHW engagement session outline



Focus group session outline: 23 May 2019

	STUDY PHASE	WHAT
FEB - JUN	**Basic orientation** Closed focus groups with research partners (RP)	Part one -The What, why, When and whom of the project. -The journey of change
		Part two 2 -Map of exchange -Thought pool- CMU

Venue

Program 12:00 pm - 16:00 pm

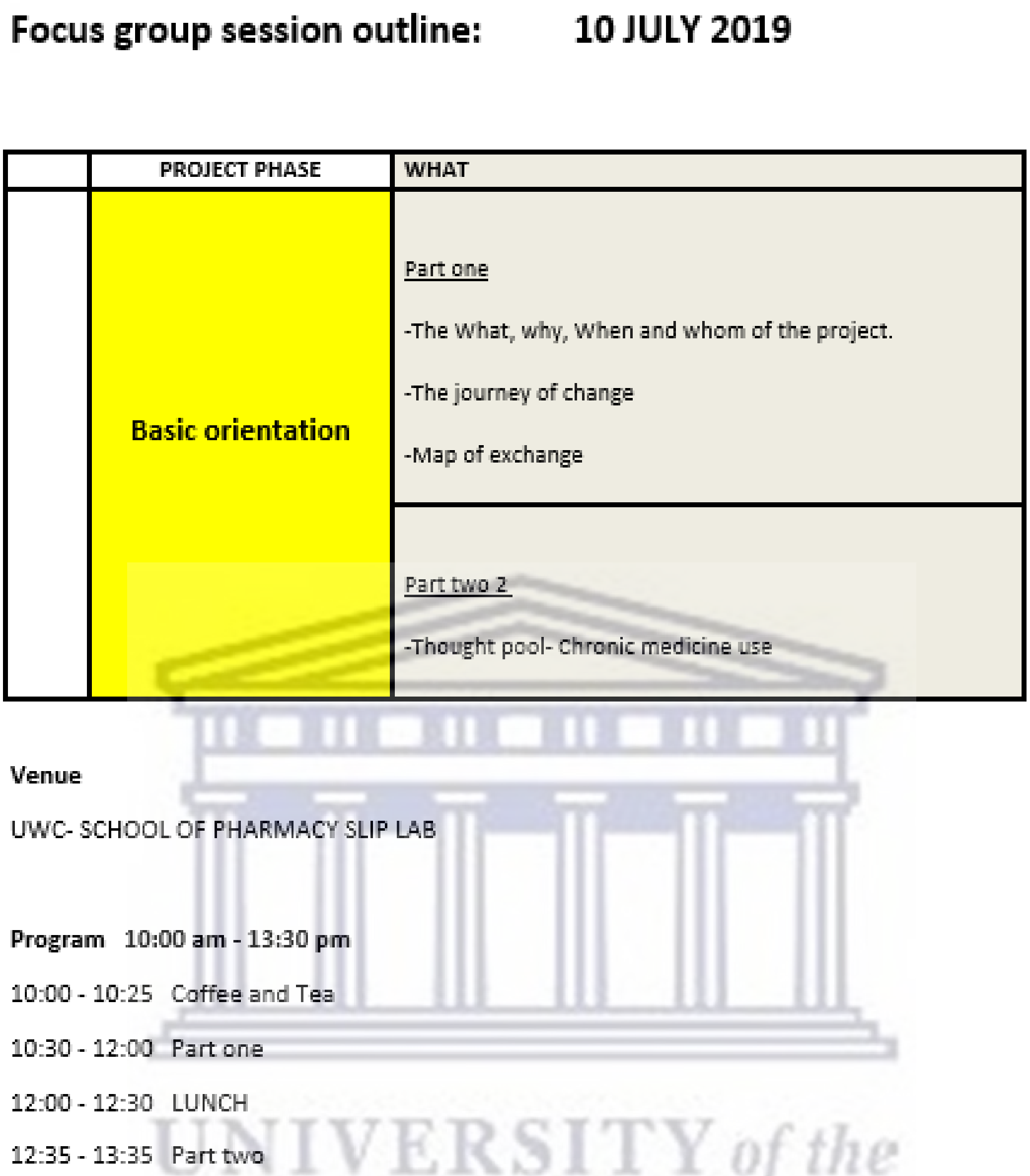
12:00 - 12:30 Lunch

12:35 - 14:10 Part one

14:10 - 14:30 Break

14:30 - 16:00 Part two

Appendix K: Community engagement session outline



Focus group session outline: 10 JULY 2019

	PROJECT PHASE	WHAT
	Basic orientation	<u>Part one</u> -The What, why, When and whom of the project. -The journey of change -Map of exchange
		<u>Part two 2</u> -Thought pool- Chronic medicine use

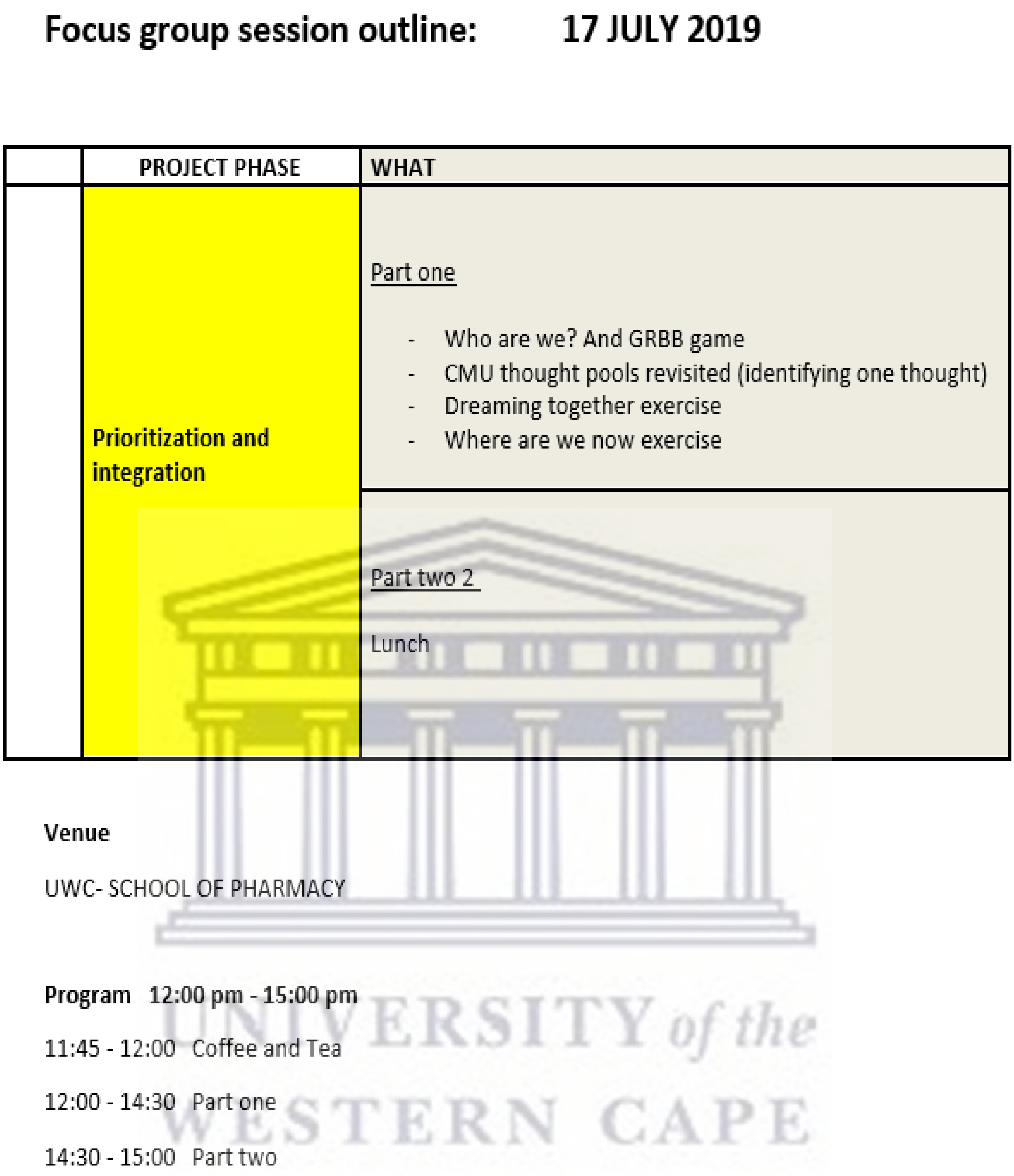
Venue

UWC- SCHOOL OF PHARMACY SLIP LAB

Program 10:00 am - 13:30 pm

10:00 - 10:25	Coffee and Tea
10:30 - 12:00	Part one
12:00 - 12:30	LUNCH
12:35 - 13:35	Part two

Appendix L: First MSCW engagement session outline



Focus group session outline: 17 JULY 2019

	PROJECT PHASE	WHAT
	Prioritization and integration	Part one - Who are we? And GRBB game - CMU thought pools revisited (identifying one thought) - Dreaming together exercise - Where are we now exercise
		Part two 2 Lunch

Venue

UWC- SCHOOL OF PHARMACY

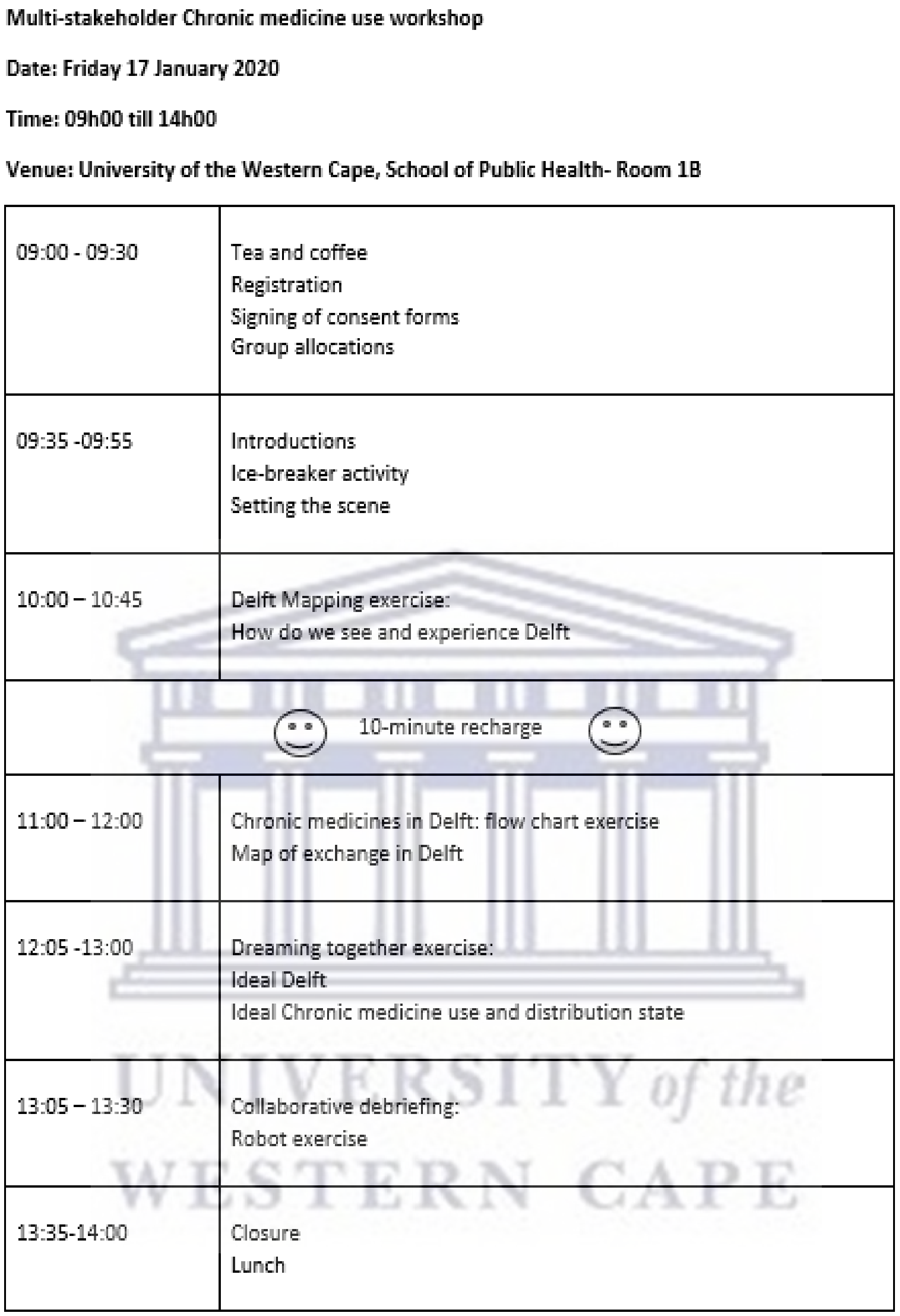
Program 12:00 pm - 15:00 pm

11:45 - 12:00 Coffee and Tea

12:00 - 14:30 Part one

14:30 - 15:00 Part two

Appendix M: Second MSCW engagement session outline



Multi-stakeholder Chronic medicine use workshop

Date: Friday 17 January 2020

Time: 09h00 till 14h00

Venue: University of the Western Cape, School of Public Health- Room 1B

09:00 - 09:30	Tea and coffee Registration Signing of consent forms Group allocations
09:35 -09:55	Introductions Ice-breaker activity Setting the scene
10:00 – 10:45	Delft Mapping exercise: How do we see and experience Delft
☺ 10-minute recharge ☺	
11:00 – 12:00	Chronic medicines in Delft: flow chart exercise Map of exchange in Delft
12:05 -13:00	Dreaming together exercise: Ideal Delft Ideal Chronic medicine use and distribution state
13:05 – 13:30	Collaborative debriefing: Robot exercise
13:35-14:00	Closure Lunch

Appendix N: Research participant quoted in the findings

Participant identifier	**Role in research**	**Primary stakeholder group**	**Attended engagements and dates**
S1	*Fourth-year Pharmacy Student*	HEI	i. HEI focus group 1 -06 February 2019 ii. HEI focus group 2 – 17 February 20219 iii. MSCW I – 17 July 2019
S4	*Fourth-year Pharmacy Student*	HEI	i. HEI focus group 1 -06 February 2019 ii. HEI focus group 2 – 17 February 20219 iii. MSCW I – 17 July 2019
S5	*Fourth-year Pharmacy Student*	HEI	i. HEI focus group 1 -06 February 2019 ii. HEI focus group 2 – 17 February 20219 iii. MSCW I – 17 July 2019
L1	*Pharmacy Lecturer*	HEI	i. HEI focus group 1 -06 February 2019 ii. HEI focus group 2 – 17 February 20219 iii. MSCW I – 17 July 2019 iv. MSCW II – 17 January 2020
L2	*Pharmacy Lecturer*	HEI	i. HEI focus group 1 -06 February 2019

			ii. HEI focus group 2 – 17 February 20219 iii. MSCW I – 17 July 2019 iv. MSCW II – 17 January 2020
C1	*Delft Community member*	Community	i. Community workshop – 10 July 2019 ii. MSCW I – 17 July 2019
C2	*Delft Community member*	Community	i. Community workshop – 10 July 2019 ii. MSCW I – 17 July 2019 iii. MSCW II – 17 January 2020
C3	*Delft Community member*	Community	i. Community workshop – 10 July 2019 ii. MSCW I – 17 July 2019 iii. MSCW II – 17 January 2020
C4	*Delft Community member*	Community	i. Community workshop – 10 July 2019 ii. MSCW I – 17 July 2019 iii. MSCW II – 17 January 2020
C5	*Delft Community member*	Community	i. Community workshop – 10 July 2019 ii. MSCW I – 17 July 2019 iii. MSCW II – 17 January 2020

Ch1	*Community health worker*	NGO	i. NGO focus group 13 March 2019 ii. CHW focus group 23 May 2019 iii. MSCW I – 17 July 2019 iv. MSCW II – 17 January 2020
Ch2	*Community health worker*	NGO	i. NGO focus group 13 March 2019 ii. MSCW I – 17 July 2019 iii. MSCW II – 17 January 2020
Ch3	*Community health worker*	NGO	i. NGO focus group 13 March 2019 ii. MSCW I – 17 July 2019 iii. MSCW II – 17 January 2020
Ch4	*Community health worker*	CHW	i. CHW focus group 23 May 2019 ii. Community workshop – 10 July 2019 iii. MSCW I – 17 July 2019 iv. MSCW II – 17 January 2020
Ch5	*Community health worker*	CHW	i. NGO focus group 13 March 2019 ii. CHW focus group 23 May 2019 iii. MSCW I – 17 July 2019 iv. MSCW II – 17 January 2020

Ch6	*Community health worker*	CHW	i. CHW focus group 23 May 2019 ii. MSCW I – 17 July 2019 iii. MSCW II – 17 January 2020
Ch7	*Community health worker*	NGO	iv. NGO focus group 13 March 2019 v. MSCW I – 17 July 2019 vi. MSCW II – 17 January 2020
N1	*Nurse*	CHW	i. CHW focus group 23 May 2019 ii. MSCW I – 17 July 2019 iii. MSCW II – 17 January 2020
N2	*Nurse*	Community	i. Community workshop – 10 July 2019 ii. MSCW I – 17 July 2019 iii. MSCW II – 17 January 2020
P1	*Project manager*	NGO	i. NGO focus group 13 March 2019 ii. MSCW I – 17 July 2019 iii. MSCW II – 17 January 2020
Su1	*Supervisor*	NGO	i. NGO focus group 13 March 2019 ii. MSCW I – 17 July 2019

			iii. MSCW II – 17 January 2020
F1	*Facility manager*	None	i. MSCW II – 17 January 2020
Pa1	*Pharmacist's assistant*	None	i. MSCW II – 17 January 2020
Pa2	*Pharmacist's assistant*	None	i. MSCW II – 17 January 2020