UNIVERSITY OF THE WESTERN CAPE
Faculty of Community and Health Sciences

# Acceptability of collectors of medicine parcels for non-communicable disease patients from a primary health care facility in the Western Cape

Jo-Ann Willoughby

A mini-thesis submitted in partial fulfilment of the requirements for the degree of Master of Public Health at the School of Public Health, University of the Western Cape

Supervisor: Dr Hazel Bradley
Co-Supervisor: Prof Richard Laing

Date: November 2019

# KEYWORDS

Acceptability

Access

Chronic Medication

Collectors

Chronic Dispensing Unit

Medicine Agents

Non-communicable Diseases

Primary Health Care Facilities

Repeat Prescriptions

Western Cape

# DECLARATION

I declare that this thesis entitled *"Acceptability of collectors of medicine parcels for non-communicable disease patients from a primary health care facility in the Western Cape"* is my own work. It has not been submitted for any degree or examination in any other university and all the sources that I have used or quoted has been duly acknowledged as references.

Full name: Jo-Ann Willoughby
Date: November 2019
Signed:

# ABSTRACT

**Background:** Since 2005 the Chronic Dispensing Unit (CDU) has been part of the Western Cape Government's strategy to address increasing demand for chronic medication for patients with non-communicable diseases. However, some patients are unable to collect their pre-packed chronic medication parcels from health care facilities on the due date. Recent research reported that some patients utilise collectors or medicine agents to collect their pre-packed chronic medication parcels. Currently little is known about this phenomenon of collectors.

**Aim and Objectives:** This study explored the acceptability of collectors of CDU chronic medication parcels to improve access to medicines for patients with non-communicable diseases at Lotus River Community Day Centre (LRCDC).

**Methodology:** An exploratory descriptive qualitative study using semi-structured interviews in English and Afrikaans was conducted with six purposively selected collectors, three patients who use collectors and three key informants who have intimate knowledge of the collectors and system at the health facility. Interviews were recorded, transcribed, translated into English (where applicable) and thematically coded to derive themes from the data. Ethical approval was provided by the University of the Western Cape Bio-Medical Research Ethics Committee and informed consent was obtained from all study participants.

**Results:** Patients reported that their collectors exhibited positive characteristics such as trust, patience and reliability, as well as, a passion for helping the community and organisational skills. All patients acknowledged the benefits of utilising a collector and found them to be highly acceptable. Key informants, however, had some reservations about the characteristics of collectors and their role in medication distribution and were sceptical as to whether collectors were suitably equipped to perform this function. Patients were grateful when their collector had some knowledge about their condition and were able to converse with them regarding their medication. Key informants suggested that with sufficient training and skills development, collectors could potentially improve access to chronic medication parcels and impart basic knowledge about chronic medication adherence to patients.

**Conclusion:** The collector system that has emerged at LRCDC is highly acceptable to patients, but health facility staff were more measured in their assessments. Health facility staff, however, acknowledged the potential of collectors to improve access to chronic medication parcels for patients with chronic conditions and the benefit of upskilling collectors to perform this function.

**Recommendations:** As a short-term measure, collectors should be formally accepted at facilities as medicine agents. They should receive basic education about safe medication distribution practices. Patients should screen collectors to ensure that they have the desired positive attributes. Furthermore, future research is necessary to comprehensively understand the current scope of practice of collectors within communities.

# GLOSSARY OF ACRONYMS AND ABBREVIATIONS

| | |
|---|---|
| ART | Antiretroviral Therapy |
| CCMDD | Centralised Chronic Medication Dispensing and Distribution |
| CDU | Chronic Dispensing Unit |
| CHV | Community Health Volunteers |
| CHW | Community Health Workers |
| EML | Essential Medicines List |
| GPP | Good Pharmacy Practice |
| HIV | Human Immunodeficiency Virus |
| HPO | Health Promotion Officer |
| LMIC | Low- and Middle-Income Countries |
| LRCDC | Lotus River Community Day Centre |
| MDHS | Metro District Health Services |
| NCD | Non-communicable Disease |
| NMP | National Medicines Policies |
| NDOH | National Department of Health |
| NGO | Non-Government Organisation |
| PBPA | Post Basic Pharmacist’s Assistant |
| PMP | Pre-Packed Medication Parcel |
| PuP | Pick-up-point |
| SAPC | South African Pharmacy Council |
| SDG | Sustainable Development Goal |
| SMS | Short Message Service |
| SOP | Standard Operating Procedure |

| | |
|---|---|
| STG | Standard Treatment Guidelines |
| TB | Tuberculosis |
| UHC | Universal Health Coverage |
| UWC | University of the Western Cape |
| WHO | World Health Organization |

# ACKNOWLEDGEMENTS

Glory to God! Firstly, I need to thank the Almighty Father for His kindness and mercy throughout this journey. I feel truly blessed to have had this opportunity for growth, development and enlightenment.

I would like to sincerely thank my supervisors, Dr Hazel Bradley and Prof Richard Laing, for their invaluable, unfailing input, guidance and support throughout the research process. A special thank you to Dr Lungi Tsolekile for her mentorship and support while I was scaling over the numerous technical hurdles encountered during the final days, prior to submission.

To my beautiful daughters, Caytlin and Jemma, and my loving husband Carl, thank you for your patience and kind words of encouragement during the past couple of years.

To my loving parents Percival and Sheila Meissenheimer, I thank you for your prayers and blessings and always believing in me and motivating me to “go for gold!”

To my sister Candice your support during the final stages of writing this thesis has been incredible. I am truly grateful.

Lastly, my sincere gratitude goes to all the study participants for opening up your lives and sharing your experiences with me, without you this would not have been possible.

# DEDICATION

This thesis is dedicated to my late uncle Paul Meissenheimer. You have truly been instrumental in both; my career choice and professional growth. Your passion for the pharmacy profession and towards improving the quality of life of every person that you meet, has been an inspiration to me.  May you rest in peace.

# TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

# CHAPTER ONE: INTRODUCTION

## 1.1 Background

Since 2005 the Chronic Dispensing Unit has been part of the Western Cape’s strategy to address increasing demand for chronic medication for patients with non-communicable diseases. However, some patients are unable to collect their pre-packed chronic medication parcels from health care facilities on the due date which poses a problem both for patients and the health facility. Recent research reported that some patients utilise collectors or medicine agents to collect their medication from community health centres, but limited information is available about this phenomenon.

## 1.2 Access to Medication

Access to essential medicines remains a global health concern. Improving access to medicine should ideally be part of every country’s development plan, in alignment with the Sustainable Development Goal (SDG) three to reach Universal Health Coverage (UHC) (Meyer et al., 2017; Wirtz, Hogerzeil, & Gray, 2017). More recently the World Health Organization (WHO) has identified the expansion of access to medicines as one of the 13 urgent global health challenges that require attention and funding for the next decade (WHO, 2020).

Initiatives to improve access to medicines are multi-faceted, influenced by rational selection, affordable pricing, sustainable financing and reliable health and supply systems (Bigdeli et al., 2013; Bradley & Laing, 2015). In South Africa great strides have been made to achieve a high standard of healthcare through National Medicines Policies (NMP), Standard Treatment Guidelines (STGs) and Essential Medicines List (EML) (Meyer et al., 2017; WHO, 2010). Alongside these initiatives, the implementation of an outsourced Chronic Dispensing programme has further catapulted South Africa as a frontrunner in innovative access initiatives for chronic patients. Furthermore, through initiatives such as these, the National Health Insurance for South Africa intends to improve access to pharmaceutical services and medicines for stable chronic non-communicable disease patients (Castle-Clarke, 2016).

Despite the development of these initiatives, they can only be successful if the medication reaches the patient. This research is placed within the paradigm of reliable health and supply systems that directly affect medicine access by patients (De Geest & Sabaté, 2003).

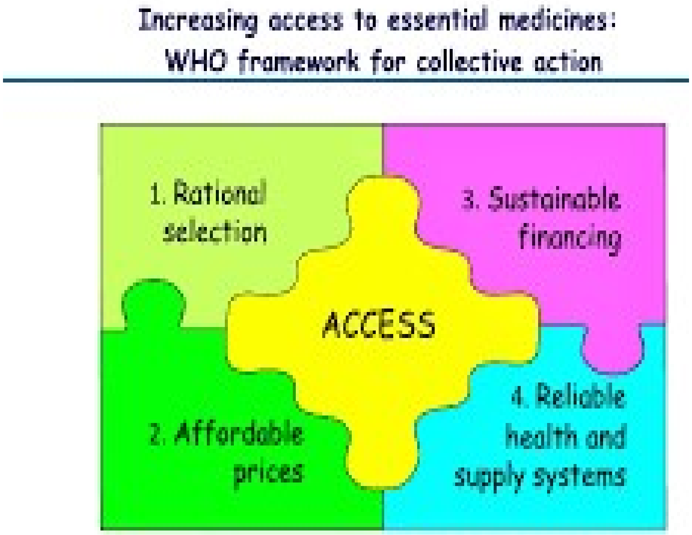


Figure 1: WHO framework for improvement of access to medicine

## 1.3 Non communicable diseases and the healthcare system

The World Health Organization (WHO) has reported that in 2016 “non-communicable diseases (NCDs) were estimated to account for 71% of the 57 million global deaths” (WHO, 2016: 188). According to the same report, in South Africa, NCDs such as hypertension, diabetes and chronic respiratory diseases were reported to account for 51% of deaths (Atun et al., 2013). Healthcare in South Africa is faced with major challenges arising from the quadruple burden of diseases including HIV/AIDS, TB, high maternal, neonatal, and child morbidity, high levels of trauma and violence and growing rates of NCDs (Mathers & Loncar, 2006; Pillay-van Wyk et al., 2016). The Western Cape mortality data indicated that NCDs accounted for 57% of deaths in 2009 and increased to 61% in 2013 (Groenewald et al., 2017; Pillay-van Wyk et al., 2016; World Health Organization, 2016). This increasing burden of disease, together with the shortage of health professionals threatens the ability of the public health sector to provide adequate care to patients with chronic conditions.

## 1.4 Western Cape Chronic Dispensing Unit

In 2005 the Western Cape Department of Health established the Chronic Dispensing Unit (CDU), an innovative intervention to address issues of poor retention in care and sub-optimal adherence to NCD medication by patients as well as issues at the health facility level (Bigdeli, Laing, Tomson, & Babar, 2015; Du Plessis, 2008; Magadzire, Mathys, & Ward, 2014). The CDU is an outsourced centralised dispensing pharmacy which collects prescriptions from public sector health facilities, dispenses and packs chronic medication parcels, also known as pre-packed medication parcels (PMPs), which are then delivered to the health facilities for patient collection (Magadzire, Marchal, & Ward, 2015; Toit, 2017).

The benefits for patients are reduced waiting times, improved access to medication and more recently the possibility of alternative collection points in the community closer to patients' residence or place of work (Bigdeli et al., 2015). Research on the CDU intervention has recommended that facility-specific challenges related to access and collection should be investigated (Magadzire et al., 2015). Another researcher found that some of the barriers experienced by patients are overcome by "patients using collectors to collect their CDU parcels on their behalf" (Hitchcock, 2016: 40). This study conducted in the Western Cape Province, was one of the first to formally document this phenomenon of collectors, who are lay volunteers who reside in the community and act as medication agents (Hitchcock, 2016).

Several years after the establishment of the CDU, the National Department of Health (NDOH) established the Centralised Chronic Medication Dispensing and Distribution system (CCMDD) in other provinces throughout South Africa. However the CDU operates independently of the NDOH-established CCMDD programme (Magadzire et al., 2015; Zeeman, 2015).

## 1.5 Medicine Collectors

The highly controlled pharmaceutical sector does not deviate from minimum standards of Good Pharmacy Practice principles, but as with most guidelines, they require updates and amendments according to service delivery needs. The rigidity of pharmaceutical control can be likened to the stringent controls and regulation of the aviation industry in which aircrafts and aviation personnel are required to abide by strict regulations with no deviation from the safety standards.

In 2017 the amendment of the Rules relating to Good Pharmacy Practice included the definition of a medicine agent, namely “a person nominated either formally or informally by the patient” to collect medication from a community pharmacy (Appendix 1). The rules state that a patient’s agent may only collect medicines for a patient who has provided written consent for such collection and there is a requirement that the agent must be sufficiently trained to adequately transport the pharmaceutical products and the pharmacist must furnish written instructions regarding the correct use of medicine.

Furthermore, the NDOH gazetted the minimum standards specifically related to the collection and the delivery of medicines to patients from a community pharmacy as stated in Appendix 1. A specific consideration is that “all efforts must be made to enable access to counselling of the patient by a pharmacist relevant to their healthcare needs” although, in practice, staff shortages and budgetary constraints present a major challenge to achieve this objective. The rules do not specifically differentiate between chronic repeat pre-packed medication parcels and other chronic medication. However, in the health facility the difference is clear and facility staff are able to differentiate between the folder-based chronic patients and the CDU patients based on the different processes for dispensing at facility level and the packaging of the chronic medication parcels.

Over the past few years, the phenomenon of collectors has emerged in primary health care facilities in the Western Cape, including in the Southern and Western Sub-Structure. Understanding this concept and phenomenon from the perspective of the patient, collector and health care providers could potentially shed light on these activities and their potential of improving access to chronic medication.

## 1.6 Research Setting

Lotus River Community Day Centre (LRCDC) is an eight hour per day primary health care facility situated within the Southern Sub-structure of the Western Cape Province. Lotus River is an urban residential area, with mostly formal housing and some back-yard dwellers and informal settlements (Isaacs et al., 2014). It is situated within ward 65 of Cape Town municipality and is surrounded by the communities of Parkwood, Wynberg, Grassy Park, Retreat and Lavender Hill. Census 2011 reported the population of Lotus River to be estimated at 38 143; 51.8% female and 48.2% male. The total households count was 8893, of which 53.73% were speaking English as first language and 44.04% speaking Afrikaans (Statistics South Africa, 2012). The community of Lotus River is an older community, with 67.4% between the ages of 15 and 64 (Statistics South Africa, 2012). According to the data obtained from Census 2011, the population of Lotus River comprised of 92.6 % coloureds, 3.67% African and 2.63% other (Statistics South Africa, 2012).

LRCDC provides primary level healthcare to the majority of this population since they are unable to afford private healthcare costs; approximately 75% are dependent on the public sector for healthcare (Gilson & Daire, 2011). The services provided by the facility to the community include comprehensive management of non-communicable diseases, pharmacy services, school health services, basic ante-natal care, comprehensive wound care, dental services, social work services, physiotherapy and x-ray services. At the commencement of this study, TB and HIV treatment was excluded from the package of care at LRCDC but screening for these communicable diseases was conducted at the facility and then referred appropriately. Treatment protocols for TB and HIV positive patients were initiated in December 2018. Previously these services were only provided by the City of Cape Town local government clinics and neighbouring health facilities.

LRCDC, like similar primary health care facilities within the district, are geographically located for ease of access by the community that they serve (Jon et al., 2008). Despite this structural organisation and location of health services; barriers to access, and hence adherence to treatment, remains a problem in the community. The WHO defines access to health facilities to be acceptable if it is within one-hour walking distance from the patients' residence. Despite the location of LRCDC meeting this standard, studies conducted in South Africa reported that participants stated that getting to and from a facility where health services and medication is received, is extremely problematic (Kagee, Le Roux, & Dick, 2007; Toit, 2017)

At the time of this study LRCDC pharmacy had an average of 5500 patients registered on the CDU system to receive monthly parcels of chronic medication. The data reports indicated that the facility dispenses an average of 5000 chronic medication pre-packed-medication-parcels (PMPs) were dispensed per month. Thus approximately 250 parcels were dispensed per day. During this period, the CDU PMP collection service was operational from 7am to 12pm, Monday to Friday, excluding public holidays. Distribution and issuing of CDU PMPs is separate and different from the folder-based patient medication systems. A post basic pharmacist's assistant (PBPA) and two community-health workers (CHWs) operate the CDU system under the supervision of the facility responsible pharmacist. Generally, the waiting time for collection is about 20 minutes and this is monitored quarterly.

Prescriptions are sent from the facility to the CDU via the delivery personnel. The medication parcels are prepared off-site at the CDU pharmacy and delivered to the facility daily, according to patient collection dates. The process for collection of the pre-packed medication parcels differs significantly from facility to facility depending on factors including, but not limited to, staff compliment, seating space in the relevant waiting areas and storage space. These factors also contribute directly to the waiting time of CDU patients at various facilities.

Lotus River management has stream-lined the CDU distribution process and provided a room known as, CDU Despatch, which is a temperature-controlled room where CDU parcels are stored and distributed from. By implication the folder-based patients and CDU patients are separated within the pharmacy waiting area, appropriately labelled. Upon implementation, the CDU collection service was available for patients to collect from 7.00 until 14:00, which was changed based on several factors including staff capacity and due to the nature and flow of patients from the various service points after 12:00. It is the responsibility of one post basic pharmacist's assistant with the support of community-based workers to ensure that issuing and dispensing of parcels occurs efficiently within the allocated operating hours.

Figure 2: Photograph of CDU Despatch waiting area

**Box 1: Ideal process of CDU parcel collection at Lotus River during data collection period**

- Cards are collected directly from the CDU patients queuing on the bench in the order of arrival.
- Once cards are collected patients move from the bench into the general pharmacy waiting area until called to the semi-private dispensing window at the CDU Despatch.
- The CDU Despatch staff then continue to retrieve each patients’ parcels from the relevant box
- Prior to dispensing the parcels, routine data is collected electronically for reporting and monitoring purposes.
- The contents of the parcel are checked by the PBPA and issued to the patient with the relevant information.
- Patients are all encouraged to verify that all their medication is correct before leaving the facility.
- CDU parcels are issued as per SOP.

## 1.7 Problem Statement

The Western Cape Department of Health has been utilizing the CDU system to distribute PMPs since 2005 (Magadzire et al., 2015). However, adherence to treatment guidelines and collection of NCD treatment is a complex and dynamic component of chronic disease management (Daar et al., 2007; Lee et al., 2013; Osterberg, Blaschke, & Koop, 2005; Tsiantou, Pantzou, Pavi, Koulierakis, & Kyriopoulos, 2010). Medication adherence is defined by the World Health Organization (WHO) as “the degree to which the person’s behaviour corresponds with the agreed recommendations from a health care provider”. This includes timeous collection of repeats of prescribed medication.

Despite innovative strategies to improve NCD outcomes in the Western Cape Province by increasing access and availability of chronic medication, patient adherence to timeously collect PMPs on the specified dates remains a problem. In 2014 the CDU reported that 8% to

12% of PMPs were returned to the CDU as a result of non-collection (Magadzire et al., 2015). This was reported to be an unexpected and undesirable outcome of the strategy. Routine data collected from primary health facilities in the Southern and Western Sub-structure of the Metro District Health Services reported an average non-collection rate of CDU PMPs of 15% for April 2017. The data collected from LRCDC during the period May to June 2017 indicated an average non-collection rate of 8.9%.

“Collectors” have emerged as a potential strategy initiated by patients to assist with regular collection of their chronic medication PMPs. Collectors could potentially be a new cadre of community health volunteers. This is an important consideration since the success of CDU to improve access to chronic medication largely depends on regular collections of PMPs.

## 1.8 Study Aim

This study explored the acceptability of collectors of Chronic Dispensing Unit medication parcels to improve access to medicines for patients with non-communicable diseases from a primary health care facility in the Western Cape. This included an exploration of how the collector system could potentially be formalised to support the public health system to improve adherence and promote positive health outcomes.

## 1.9 Study Objectives

- To describe the attributes of collectors and perceptions of their roles.
- To explore patients’ perceptions and experiences of collectors who collect CDU parcels on their behalf.
- To explore how healthcare workers, perceive and experience the phenomenon of collectors.
- To describe the barriers and enabling factors of medication collection.

## 1.10 Thesis structure

Chapter One introduces the research and describes the research setting, problem analysis and statement as well as the study aim and objectives.

Chapter Two reviews the literature pertinent to the topic.

Chapter Three describes the study design, methods used to conduct the study and methods used to analyse the data collected. Rigour and ethical considerations are also included.

Chapter Four presents the findings of the study.

Chapter Five discusses the findings of this study with reference to the literature that was reviewed.

Chapter Six draws conclusions about the study and provides recommendations based on the findings as well as recommendations for further research.

## 1.11 Summary

This chapter introduced the study by describing a health system approach to improve access to chronic medication, the rationale for the study and a detailed depiction of the research setting. The next chapter will review the literature related to access to chronic medication and associated factors that influence collection and specific strategies to address non-collection of medication.

# CHAPTER TWO: LITERATURE REVIEW

## 2.1 Introduction

This chapter commences by describing the importance of acceptability studies. It then introduces the critical concept of medication collection and describes the various factors influencing non-collection. It reviews lessons learnt from anti-retroviral treatment (ART) to improve adherence and finally it discusses interventions that have been introduced to improve medication collection, with particular relevance to the South African setting.

## 2.2 Acceptability studies

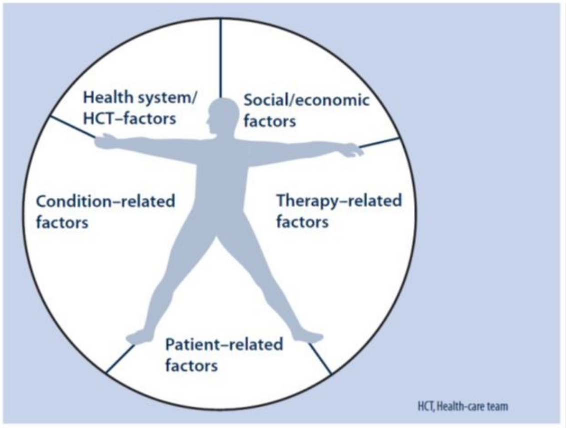
Healthcare interventions are often complex and multi-faceted. WHO recommends that when considering interventions for the management of NCDs, non-economic criteria for implementation should also be considered. These include health impact, acceptability, sustainability, scalability, equity, ethics, multi-sectoral actions, training needs and monitoring (De Geest & Sabaté, 2003; Wirtz, Kaplan, Kwan, & Laing, 2016). This study focused on acceptability, recognising it is an important, but not the only consideration, to determine the potential success of new interventions (Abegaz, Shehab, Gebreyohannes, Bhagavathula, & Elnour, 2017; Shaw, Larkin, & Flowers, 2014). For the purposes of this research, acceptability was defined as how people delivering and receiving the healthcare intervention consider it to be appropriate, based on expected or experienced cognitive and emotional responses to the intervention. Collectors, as a system may be considered a functional strategy for patients to access chronic medication regularly but with undetermined acceptability by stakeholders. A high degree of acceptability may not necessarily translate into the success of an intervention, feasibility, sustainability and other studies are used to determine whether an intervention would be implemented.

## 2.3 Concept of collection of medication

Collection of chronic medication involves the capability to collect medication at the appropriate time to ensure an adequate supply (Gadkari & McHorney, 2012). Non-collection leads to an insufficient supply of medication directly affecting patients’ ability to adhere to treatment regimens (Gadkari & McHorney, 2012; Tsiantou et al., 2010). The nature of chronic diseases is such that it renders it essential for patients to adhere to medication treatment regimens over an extended period. Implications of non-collection for patients are disease progression and a lower quality of life (Gadkari & McHorney, 2012; Horne et al., 2013). Further implications of non-collection for the health system are waste of medication and the increased use of medical resources such as hospital visits and hospital admissions (Coleman, Gill, & Wilkinson, 1998; Day et al., 2014; Iuga & McGuire, 2014).

## 2.4 Factors influencing non-collection of medication

Since non-collection is a function of adherence, similar factors that influence adherence to medication would likely influence non-collection of medication (Abegaz et al., 2017; Bosch-Lenders et al., 2016; Lin, Sklar, Oh, & Li, 2008; Magadzire et al., 2015; Osterberg et al., 2005; Scott, Gray, Martin, & Mitchell, 2012). It is widely accepted that factors influencing adherence may be classified within five dimensions as illustrated below (Figure 3) (De Geest & Sabaté, 2003; Osterberg et al., 2005). Non-collection of CDU parcels however can be categorised according to three dimensions, since the patients who are accepted into the CDU programme are considered as stable chronic patients and are expected to have received sufficient education regarding their condition. Thus, the factors affecting non-collection may be broadly categorised into, patient-related, socio-economic and health system related factors (Dalal et al., 2011; Lin et al., 2008; Mukumbang, Mwale, & Van Wyk, 2017; Tseng et al., 2016).



WHO: Adherence to long-term therapies: evidence for action. 2003

Figure 3: Diagrammatic representation of five dimensions of adherence

**Patient factors** influencing non-collection include age, race, culture, social class, demographics, forgetfulness, absentmindedness, physical difficulties and patient knowledge (Krska, Morecroft, Poole, & Rowe, 2013; Lin et al., 2008; Morrell, Park, Kidder, & Martin, 1997; Tseng et al., 2016). **Socio-economic factors** include the inability of patients to take time off work, household income, costs related to collection of repeat medication and social support (De Geest & Sabaté, 2003). The direct and indirect costs associated with medication collection may directly affect the patients' ability to collect and remain adherent. Although CDU patients are exempt from paying costs for medication, indirect costs, such as transport costs associated with medication collection influence their ability to collect medication refills (Alghurair, Hughes, Simpson, & Guirguis, 2012; Coleman et al., 1998; Monnickendam, Monnickendam, Katz, & Katan, 2007; WHO, 2008). **Health system factors** that influence non-collection are accessibility of health care services, long waiting times, difficulty in getting refill prescriptions and unhappy visits to health facilities (Dalal et al., 2011; Osterberg & Blaschke, 2005; Sastry et al., 2015; Travaglia et al., 2012). According to Duru (2010), medication delivery via mail resulted in an average of eight percent increase in adherence among chronic patients. While the traditional pharmacy system for distribution of chronic medication may still be acceptable by some, yet others may need more support, in terms of improved access and social support (Atun et al., 2013; Phul, Bessell, & Cantrill, 2004).

Several authors have suggested that interventions to improve access to medication are more likely to succeed if they address more than one factor from the above-mentioned categories (Atukunda et al., 2017a; Krousel-Wood, Hyre, Muntner, & Morisky, 2005; Mukumbang, Van Belle, Marchal, & Van Wyk, 2016; Olsson, Runnamo, & Engfeldt, 2012; Staden, 2013). A local study in the Cape Winelands district has proposed a range of solutions to the medicine wastage problem that arises from the non-collection of PMPs and non-adherence to chronic medication regimes (Staden, 2013). These solutions indicated that multiple interventions that address both patient and health system factors were required to address non-collection of CDU parcels. The National Health Insurance for South Africa also acknowledges that health services should be delivered in a manner that considers socio-cultural and socio-economic factors to prioritise vulnerable communities (Castle-Clarke, 2016).

## 2.5 Lessons from antiretroviral therapy to improve adherence

Antiretroviral therapy (ART) has several commonalities with NCD treatment, particularly the life-long nature of the treatment regimens, which provide an opportunity for sharing experiences and learning across disease morbidities. High levels of ART adherence are critical for HIV viral suppression and general health outcomes (Lalkhen & Mash, 2015; Maskew, Macphail, Menezes, & Rubel, 2007). However, ensuring long-term retention in care and treatment for HIV/AIDS has proved challenging in resource-scarce settings (Atukunda et al., 2017b; Mukumbang et al., 2016; Munro, Lewin, Swart, & Volmink, 2007). Social support, with multiple mechanisms, has been linked to improved medication adherence and quality of life among HIV-positive patients taking ART in many settings, including sub-Saharan Africa (Atukunda et al., 2017a; Mukumbang et al., 2016). Emotional and physical support related to refill of prescriptions and taking medication has been found to facilitate a positive state of mind and directly improves self-efficacy to adhere to treatment regimens (Atukunda et al., 2017a; Flämig, Decroo, van den Borne, & van de Pas, 2019; Knight, Mukumbang, & Schatz, 2018). In addition, lay mentoring and peer adherence support has proven to increase HIV/AIDS medication adherence and increased quality of life (Schneider, Hlophe, & Rensburg, 2008; Woldie et al., 2018). A systematic review conducted in 2018 reported that the ART Club Model provides a sustainable solution to address non-adherence, addressing multiple factors that influence adherence (Flämig et al., 2019).

## 2.6 Interventions to improve medication collection

Several interventions have been implemented and reviewed to improve collection of medication, which as discussed earlier is a critical component to adherence.

### 2.6.1 SMS reminders

Short message service (SMS) is a widely used global technology and may be used to improve adherence to medication collection dates. This intervention addresses the patient factors such as forgetfulness and absentmindedness and highlights that positive results can be achieved through active reminders (Bobrow et al., 2016). A randomized controlled trial involving real-time adherence monitoring found that individuals receiving scheduled daily and then weekly SMS reminders at ART initiation were found to have improved adherence compared to participants receiving no SMS reminders (Vervloet et al., 2012). Authors reported that SMS reminders promoted adherent behaviour among chronic patients and recommended that SMS notifications sent to pre-identified social supporters of patients may also be beneficial (Atukunda et al., 2017b; Vervloet et al., 2012). The CDU in the Western Cape implemented SMS reminders to patients but with little success in improvement of non-collection rate in the community of Lotus River, as evident by the fluctuating non-collection rate.

### 2.6.2 Alternative collection points

In developed countries such as United Kingdom and United States of America, the need for tailored pharmaceutical service delivery has been highly recognised and actioned (Phul et al., 2004). For this purpose, clients are provided the option of having their chronic medication delivered to an alternative address. These patients pay no additional fee for this service since they are already paying for their medication (Phul et al., 2004) .

The CCMDD in collaboration with NDOH, established 650 alternative pick up points (PuPs) for patients registered in their programme, known as external pick-up-points (Toit, 2017). In addition to this the NDOH awarded a private courier company a contract to distribute chronic medication parcels. The private company named Pharmacy Direct provides delivery of chronic medication parcels to patients at a variety of PuPs, including government health facilities, retail pharmacies, workplaces and churches (Chowles, 2018).

Similarly, in the Western Cape, as an initiative to ease the burden of patients waiting at health facilities for chronic medication parcel collection, alternative collection points were established for CDU patients (Gray, Riddin, & Jugathpal, 2016; Western Cape Department of Health, 2017). In addition to collection points at various health facilities; CDU collection points conveniently based within communities, such as church halls and community centres were identified by the department to improve access to chronic medication (Magadzire, Marchal, & Ward, 2016). The success of these alternative collection points has not been fully assessed but Hitchcock (2016) reported a lack of trust in the off-site collection system by patients in her study.

### 2.6.3 Smart Locker System

The smart locker system, also referred to as “Pelebox”, is a social innovative intervention in Gauteng province which harnesses technology to enable patients to easily access their chronic medication parcels (Smit, 2019). It functions by the Pelebox being loaded with the pre-packed medication parcel; the patient is notified via SMS. When the patient arrives at the smart locker, the patient is able to retrieve the medication parcel using the secret one-time-pin that was sent to the patient. The success of this intervention is largely determined by the ability of the patient to access the smart locker, timeously. Advantages to the health system are the decluttering of the health facility and offering a safe and convenient means of medication collection.

### 2.6.4 High technological advances for delivery

A very recent development in the United States of America has been the partnership between United Parcel Service (UPS) Flight Forward and Consumer Value Stores (CVS) pharmacy to explore the possibility of using drone delivery system to deliver prescription medication directly to patients in residential areas (Baertlein, 2019). Government approval was received for the operation of the drone, yet investigations are still in progress to assess the success of this type of intervention. Its relevance for delivery of regular chronic medication in a setting like South Africa would need to be evaluated.

### 2.6.5 Home delivery service

In 2013, Sizwe Nzima co-founded a business called Iyeza Health. It is a private delivery service structure which is Department of Health approved that delivers chronic medicines by bicycle to patients who are unable to wait in long queues at primary health care facilities in Khayelitsha, a low socio-economic suburb of Cape Town. This model is based on the collection of PMPs from the community health centre, by an authorised Iyeza employee who then delivers the parcel to patients' homes, at a cost of just R10 (Letsoalo, 2014). "The aim of Iyeza Health is to give everyone health access, people need good health access despite their income, despite where they live – it's a basic human right" said Nzima in an interview with a news reporter. Nzima said he first came up with idea after reading a newspaper article about how hospitals around the country could not cope with the number of patients on chronic medication. Nzima himself had to fetch chronic medication for his grandparents when he was a child and this too contributed to his decision to launch Iyeza Health. His business model is supported by pharmacist, Siraaj Adams. The official website provides more details about this model and how it has benefitted the community of Khayelitsha www.iyezahealth.co.za.

Major retail pharmacy franchises within South Africa offer a similar delivery service to their chronic clients at a negotiated fee. One of these retail pharmacies who offer the service free of charge is Clicks Pharmacy. For the convenience of the client, their medication is delivered to the address of their choice, either their home or work or even a holiday destination (Clicks Direct Medicine, 2008).

### 2.6.6 Lay health volunteers

Community health volunteers (CHVs) are lay health workers who receive brief health training on a specific health topic (Woldie et al., 2018). They differ to community health workers (CHWs) in that they provide services on a voluntary basis instead of employment capacity basis (Schneider et al., 2008; Tsolekile, Puoane, Schneider, Levitt, & Steyn, 2014). A recent review reported that CHVs may potentially supplement the public health system in the endeavour to reach Universal Health Coverage in LMICs (Woldie et al., 2018).

Several authors have reported that patients who receive social support from their family members and communities, have improved adherence which contributed to regular refill of repeat prescriptions (Dardano, Penno, Del Prato, & Miccoli, 2014; Kumar, Greenfield, & Raza, 2016; Petronio, Sargent, Andea, Reganis, & Cichocki, 2004). Since most elderly chronic patients have physical limitations, practical support is often needed to ensure that patients attend their health care appointments to keep prescriptions current, refill the prescription, and adhere to their medication regimen (Dardano et al., 2014; Lee et al., 2013; Patterson, Bradley, Kerse, Cardwell, & Hughes, 2013; Williams, Haskard-Zolnierek, & DiMatteo, 2016). The importance of social support for effective disease self-management has long been recognized in mental and physical health, and often naturally occurs within families and communities (Atukunda et al., 2017a; Gazmararian et al., 2006).

Community health volunteers (CHVs) who are trained lay volunteers and provide health services in their local communities, are an important part of a task shifting strategy and may help address health worker shortages (Sanjana, Torpey, Schwarzwalder, Simumba, Kasonde, Nyirenda, Kapanda, Kakungu-Simpungwe, et al., 2009). Several authors identified a close link between community members and CHVs as being one of the fundamental elements in generating positive health outcomes (Schneider et al., 2008). Trained CHVs can deliver crucial and culturally sensitive health messages, empower individuals to make informed decisions and increase access to life-saving chronic medication (Tsolekile et al., 2014). Few studies have examined the effects and acceptability of semi-skilled volunteers or mentors specifically engaging with patients about medication adherence.

CHVs generally reside within the communities that they serve and may have a close relationship and potentially an invested interest in the patients with whom they come into contact (Atun et al., 2013; Woldie et al., 2018). It is assumed that assistance provided by family, friends and neighbours in the low socio-economic community of Lotus River is based on experiential knowledge rather than formal training. Social support in a human resource deprived area such as Lotus River is important for patients to achieve better medication adherence and could lead to better outcomes (Williams et al., 2016). Collectors may possibly have developed in the community as social support to CDU patients and inadvertently are CHVs, who lack formal training, for CDU patients.

## 2.7 Conclusion

Upon review of the literature, it is evident that healthcare interventions to improve non-collection of chronic medication should ideally address more than one of the factors influencing adherence. Acceptability studies are an appropriate starting point to determine the extent to which a collector service is deemed satisfactory or agreeable to all stakeholders. The limited professional human resources available in low- and middle-income countries, including South Africa, creates an opportunity for re-thinking service delivery to empower the community in ways to minimise the risks associated with non-collection of NCD medication. The next chapter will describe the study methodology.

# CHAPTER THREE: METHODOLOGY

## 3.1 Introduction

This chapter is divided into several sections which describe the various components of the methodology used. First, the study design, study population, study sample and data collection procedure are described. The methods used to analyse the data are also described. Finally, rigour and ethical considerations are discussed.

## 3.2 Study design

An exploratory qualitative research study design was used to achieve the aim and objectives. This study design was useful to conduct an initial enquiry when limited information is available on a relatively new phenomenon, such as collectors. Qualitative research methodology allowed for a deep understanding of the individuals' beliefs, attitudes, motives, demands and obstacles involved in the collector system (Spencer, Ritchie, Lewis, & Dillon, 2003; Venables et al., 2016). The exploratory research design allowed the researcher to build an understanding of the establishment and acceptability of the phenomenon of collectors (Baum, 1995; Creswel, 2008; Patton, 2002). This research design was also useful to comprehensively report the accounts and findings accurately in everyday language, in a narrative format, as experienced by the participants (Golden-Biddle & Locke, 2007; Robson, Colin, McCartan, 2016). The flexibility of qualitative research methods allowed for the discovery of new findings that may have not been articulated in the research question, using an interview guide with open-ended questions and relevant probing questions (Baum, 1995; Nakkeeran & Zodpey, 2012). Another feature of qualitative study design is the ability to investigate how the collector system emerged and developed in the community of Lotus River (Spencer et al., 2003). These are both important features which are applicable to this research study.

## 3.3 Study population

The study population were those who have direct experience of the phenomenon of collectors at Lotus River Community Day Centre (LRCDC) (Mays & Pope, 2006; Silverman, 2013).

Three population categories were used for the study, namely, collectors, patients and key informants

The first group comprised the **collectors** who regularly present at LRCDC to collect CDU Pre-packed Medication Parcels (PMPs) on behalf of patients. The second group were **patients** who enlist the services of collectors. The third group comprised **key informants** who regularly experience this phenomenon of collector at the health facility. Key informants are a select group of individuals within a study setting, who are likely to provide ideas and insights on the subject of collectors (Mays & Pope, 2006; Robson, Colin, McCartan, 2016).

## 3.4 Study sample

The researcher purposively sampled six collectors, three patients and three key informants. Purposive sampling enabled the researcher to deliberately select participants who could provide an in-depth understanding of the research topic (MaxwellQ, 2009; Patton, 2002)

Collectors were identified by the researcher and the Post Basic Pharmacist's Assistants (PBPA) who issue the PMPs at LRCDC. During the period of January to February 2018, five collectors were identified based on the frequency with which they attended the facility. The sixth collector was identified based on the responses of key informants who personally knew and respected this collector. The inclusion criteria for collectors were those who collect chronic medication parcels for patients, weekly or more frequently for more than one patient at a time, from LRCDC. These collectors may or may not be patients at the health facility themselves. The researcher recruited collectors who utilised different means of transport to access the health facility. Facility staff who act as collectors were excluded from this group. Due to legislative regulations the age of collectors ranged from 14 years and above.

Patient participants were more challenging to recruit, due to the nature of the collector system. Patients who successfully enlist the services of a collector only physically present at LRCDC every six months to receive a medical evaluation and renewed prescription from a clinician and make use of the collectors the remainder of the time. For this reason, the pharmacy staff who dispense and provide counselling to the patient at the first issue of the new chronic prescription were best suited to identify the patient participants. The researcher recruited patients with diverse contextual features such as gender, age, culture, ethnicity and economic level. For this purpose, patients who are employed, unemployed and pensioners were included for variation of economic level. One male and two female patients aged between 60 and 61 years old were recruited. The researcher was not able to recruit patients from diverse ages since achieving diversity in socio-economic status, culture and ethnicity took precedence.

The researcher screened health facility staff to determine who had the most specialist information about the phenomenon of collectors based of their role in the setting (Marshall, 1996). The health facility staff who were in direct contact with the collectors on a daily basis and had information on the general characteristics of collectors were identified as key informants. The researcher recruited both health professional staff and non-health professional staff, namely Post Basic Pharmacist’s Assistant (PBPA), Health Promotion Officer (HPO) and an administrative clerk who were able to share their experiences of individual collectors and the general phenomenon of the collector system.

## 3.5 Data collection tools and procedure

Semi-structured interviews were used to collect data. Interviews were conducted individually to secure confidentiality of the discussion, as opposed to focus group discussions. The selected method of data collection allowed the researcher to create a rapport with the individual participants to facilitate an open discussion (Golden-Biddle & Locke, 2007; Robson, Colin, McCartan, 2016). Interviews allowed the researcher to understand the individual, cultural and social contexts through their own narrative and personal accounts. The one-on-one interaction allowed for rich descriptions of the emergence and extent to which the collector system is accepted by participants (Reeves, Albert, Kuper, & Hodges, 2008). It was important for the researcher to document each participants' individual experiences and furthermore, the face-to face interviews provide a platform to elicit non-verbal cues (Sandelowski & Barroso, 2003).

A semi-structured interview guide was utilized to facilitate the interviews (Appendix 2). The interview format provided a means for the researcher to explore, through probes, the reasons, feelings, opinions and beliefs that underpin the participants’ responses (Reeves et al., 2008). The interview guide was designed and developed to enable the researcher to use the introductory comments, topic headings, principal questions, prompts and closing comments to elicit meaning to the experiences as reported by participants (Robson, Colin, McCartan, 2016; Yin, 2013). Furthermore, the in-depth interview platform provided participants with an opportunity to follow thought processes that they were not previously aware of (Robson, Colin, McCartan, 2016)

The interviews were conducted between the period February 2018 and February 2019 in a private area on the premises of LRCDC at a pre-arranged date and time based on the availability of the participants.  All interviews were conducted by the researcher who is fluent in English and Afrikaans, and all interviews except one were conducted in English. The interviews were recorded with consent from the participants using a recording device and the researcher paid attention to the non-verbal cues of the participants and noted these observations during the interviews. After each interview the data from recordings were transferred to the researcher's laptop and then transcribed verbatim, and where necessary translated from Afrikaans to English. The data from the recording device was deleted but saved securely on the researcher's personal computer.

## 3.6 Data Analysis Approach

Analysis of data was carried out manually. A thematic analysis approach was used to analyse the data. Braun and Clarke (2006: 79) define thematic analysis as "a method of identifying, analysing and reporting patterns within data". Thematic analysis is a good approach when the enquiry revolves around participants' views, opinions, experience, knowledge and values. It allowed for rich, complex and detailed description of the concept of collectors as individuals and their role as a collective (Braun & Clarke, 2006; Marks & Yardley, 2011). This approach is subjective and relies heavily on the researcher's judgement. Careful reflexive thinking was applied by the researcher. Strategies employed to minimise bias to produce sufficiently valid data is reported in the rigour section. Furthermore, an inductive approach was used because the researcher did not have an established theoretical framework but planned to develop a framework based on the research data (Braun & Clarke, 2016; Kleiman, 2004; Marks & Yardley, 2011; Vaismoradi, Turunen, & Bondas, 2013). The researcher took a latent approach because the interest was not only in the semantic meaning of responses but the researcher was interested in what the responses reveal about assumptions and social context (Guest, MacQueen, & Namey, 2014; Kleiman, 2004).

### 3.6.1 Data Analysis Steps

Qualitative data analysis and collection is not mutually exclusive but rather a non-linear, cyclical process (Sandelowski & Barroso, 2003). Thematic analysis comprises an iterative six-step process, as described by Braun and Clarke (2006), where the researcher is constantly moving forward and backward between the data sets. The researcher followed these data analysis steps, familiarisation, coding, generating themes, reviewing themes, defining and naming themes and writing up (Braun & Clarke, 2016 ).

### Step 1: Familiarisation

After each interview, the recording was transcribed. Thereafter the researcher repeatedly read the transcripts and interview notes and listened diligently to the recordings, searching for meaning and patterns, jotting these ideas and trends down in a journal. This formed part of the familiarisation with the data. (Robson, Colin, McCartan, 2016).

### Step 2: Coding

Coding was data driven. The analytical process of coding provided meaning to the data (Williamson, Given, & Scifleet, 2017). The researcher had generated an initial list of ideas which indicated '*what is in the data'* and '*what was interesting about it'* (Braun & Clarke, 2006). Quotable quotes were highlighted on the transcripts, with relevant commentary in the margin. The researcher's supervisors also read the transcripts. The initial codes that were most prominent across all the interviews and of interest to answer the research were presented to the supervisors at the meeting, thereafter, the final codes were generated.

### Step 3: Generating themes

The researcher sorted all coded data into broader segments, namely themes. Using this data and notes from the interview, the researcher analysed the different codes, attempting to elicit re-curing themes related to the emergence of the phenomenon of collectors, the way in which participants experienced this phenomenon and the degree to which each category of participants deemed to agree with the concept of collectors. The researcher worked systematically through each data set to develop an understanding (Kleiman, 2004). A variety of A3-sized colour sheets were used to clearly identify the first set of themes.

Figure 4: Visual display of initial themes

### Step 4: Reviewing themes

The researcher visually represented potential themes related to the acceptability of collectors in a network to understand and display the relationship between themes related to this phenomenon. By creating a thematic network, it allowed the researcher to analyse by comparing and contrasting and noting relations between themes and variables.

### Step 5: Defining themes

Themes were clearly defined, and these definitions were explicitly explained to the supervisors to clarify what they entail and do not entail. At this phase, each theme was separated into sub-themes, for ease of understanding. This process generated meaning and identified what the data was telling the researcher and potential readers about the acceptability of collectors (Braun & Clarke, 2006).

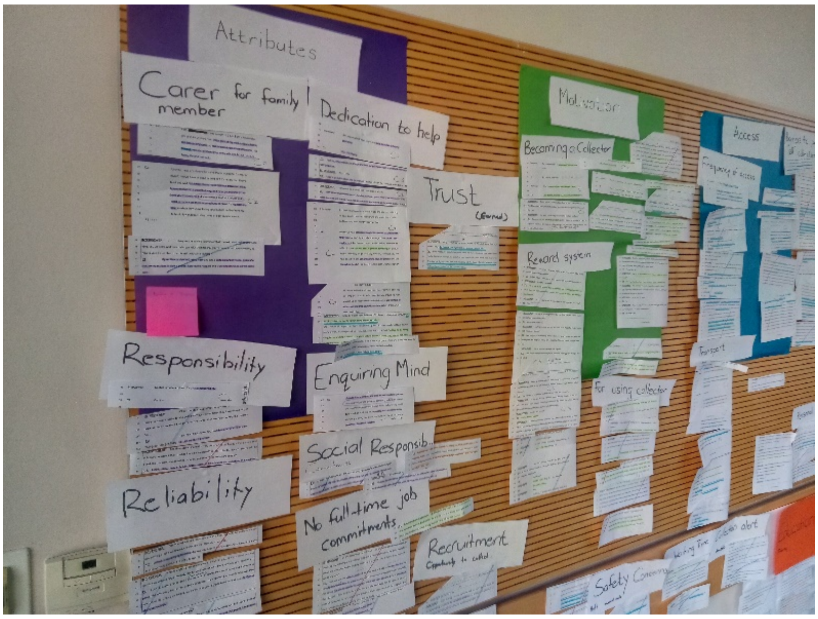


Figure 5: Visual display of defined themes and sub-themes

**Step 6: Write-up / Reporting**

At the reporting phase of the process, examples from each code were identified from the data and presented as quotations from the data (Guest et al., 2014). Trustworthiness was ensured by using participants' own words, demonstrating that the findings have emerged from the data and was not as a result of the researcher's own predispositions. Verbatim quotations are represented by indented italicised text between quotation marks followed by the descriptive identifier. Omissions from quotations are represented by ellipses. Square brackets represent addition of clarifying words by researcher. Three asterisks in parentheses represent omission of names reported by participants.

## 3.7 Rigour

Rigour is a crucial aspect of qualitative research. It is a pre-defined set of criteria used to ensure the quality of the research findings (Fullman et al., 2017; Kirk & Miller, 2012; Mays & Pope, 1995; Shenton, 2004). Rigour allows the reader to assess the researcher's actions and influences to determine the quality and validity of the findings (Jootun, McGhee, & Marland, 2009; Kirk & Miller, 2012; Spencer et al., 2003). In this study credibility, transferability and trustworthiness were used as criteria for rigour. The strategies employed to achieve these standards throughout the research process are described.

### 3.7.1 Credibility

Credibility in qualitative research is the means by which the reader can determine whether the study measured what it had intended (Mays & Pope, 1995; Shenton, 2004). Triangulation of data sources, member checking and reflexivity were strategies utilized to meet this validity standard.

**Triangulation of multiple data sources** was employed to ensure completeness of data by gathering and comparing responses from patients, collectors and key informants (Guba & Lincoln, 1994). Multiple sources of data were a means to provide a detailed and accurate description of who the collectors are and the degree of acceptability of the collector system by each participant group (Golafshani, 2003; Patton, 1999).

At the end of each section of the in-depth interviews, the researcher provided a summary of the participant's response. This allowed participants to confirm that the researcher's interpretation of their responses had been adequately and accurately captured and understood. This is known as **member checking** (Shenton, 2004; Tracy, 2010). It was a means to ensure that the researcher heard an honest and true account of the experiences of each study group; patients, collectors and key informants (Morrow, 2005).

To further ensure credibility of the study, the researcher maintained a **reflexive journal** recording personal views, assumptions and events during the research process steps and the researcher's responses to these events that would influence study design, data collection and interpretation (Guba & Lincoln, 1994). The researcher reported these to the supervisors for scrutiny and feedback. At the time of the data collection process, the researcher was formally employed in the capacity of Responsible Pharmacist at LRCDC. For this reason, through reflexivity the researcher attempted to show transparency and clarity about professional affiliations (Dodgson, 2019). The researcher's position within the study setting could have potentially influenced the selection of study participants. Demographics of potential study participants and their affiliation to the researcher was discussed with the supervisors to minimise bias selection of participants, and to ensure diversity among participants. Thus, the researcher's position and title did not influence the selection of study participants but was guided by the study aim and objectives.

Furthermore, to establish good rapport with each potential participant, the researcher approached potential participants carefully and in the capacity of researcher and not Responsible Pharmacist. It was made explicitly clear that participation in the study would be voluntary and that all possible measures will be followed to protect their confidentiality. Those who showed interest to partake in the research were briefed about the purpose of the research and allowed time to think about their decision to partake, prior to being enrolled.

### 3.7.2 Transferability

Transferability in qualitative research is creating an opportunity for the reader to discern whether the study findings would be applicable within another setting (Maxwell & Reybold, 2015; Tobin & Begley, 2004). Lincoln and Guba (1986) reported that qualitative research methods are not concerned with generalisability of results because of relatively small sample sizes. As a strategy to enable transferability, the provision of a **thick, rich contextual description** of the study setting and methods, and visual representation of these allow the researcher to assist the reader to determine if they can transfer the study to their own setting (Bowen, 2005). The researcher provided **contextual information** about the research problem in the introduction and literature review. The literature review provided **detailed description** of the concept of non-collection of chronic medication and established interventions situated within the dimensions of health system factors, individual and socio-economic factors to improve this. According to Shenton (2004) this will allow the reader to develop a full understanding of the research problem and compare it to their own setting. Furthermore, a detailed description of the study methodology was provided to enable the reader to discern the transferability of the research study (Braun & Clarke, 2016; Guba & Lincoln, 1994; Shenton, 2004).

### 3.7.3 Trustworthiness

Trustworthiness in qualitative research refers to the processes where the researcher maintains sufficient objectivity and allow the reader to discern whether or not the results have been skewed by the researcher to fit a specific narrative (Dodgson, 2019). To ensure trustworthiness, the **supervisors analysed** sections of the data and compared it with the researcher’s analysis to confirm that the findings have been derived from the data (Shenton 2004). A detailed description of the research process is provided in the research report to allow the reader to determine the degree of acceptability of the findings (Bowen, 2005; Robson, Colin, McCartan, 2016; Tobin & Begley, 2004). The researcher kept an **audit trail** in the form of comprehensive notes, raw data and data analysis to provide context for the progress of the inquiry by providing descriptions of what was planned, what was done and evaluating effectiveness of the process (Morrow, 2005; Shenton, 2004). Being the responsible pharmacist in this research setting at LRCDC, the researcher has some pre-conceived ideas about the acceptability of this phenomenon. These were noted and through **peer debriefing sessions** with the supervisors, the researcher was able to minimise professional bias (Dodgson, 2019).

## 3.8 Ethical Considerations

Permission to conduct the research was obtained from the Biomedical Research Ethics Committee of University of the Western Cape (BMREC) (Appendix 3) and permission from the Western Cape Department of Health Research Committee and Lotus River facility management (Appendix 4).

Individual participation in the study was voluntary. All research participants were given an Information Sheet which explained the study and assured them of confidentiality. Potential risks and benefits associated with participation in the research were explained in the participant **Information Sheet**, in the language of their choice, English or Afrikaans (Appendix 5). No isi-Xhosa Information Sheets were prepared since the demographics of the Lotus River population indicated that predominant languages are English and Afrikaans. As stated in the Information Sheet and explicitly mentioned to the actual study participants, that they may not benefit from the research directly themselves, however it was explained that their contribution could be valuable to future decisions regarding chronic medication distribution systems.

**Written informed consent** was sought from all participants prior to the interviews (Appendix 6). Permission to record the interviews was also sought from participants. The process of informed consent allowed participants to make an informed and voluntary decision to participate in the research.

All human interactions and talking about self or others carry some form of risks. Due to the nature of the study and the role of the researcher at the facility there was a risk that participants may have experienced negative feelings regarding their participation in an unauthorised collector system. As a measure to ensure that participants do not feel judged, the researcher appraised the patient participants for their pro-active role in adherence to collection dates and collectors' participants were appraised for their support and service to the patients. Provision was made to refer participants to a counsellor, if needed. However, none of the participants requested this service. Participants were assured that they would not be penalised for partaking in the collector system at the time or at a future date. Participants were enrolled into the study after informed consent was provided. All participants were literate adults who were deemed legally competent to provide consent. The participants had the right to withdraw from the study at any time.

All participants remained anonymous and were allocated a unique identification code. Only the researcher knew the true identity of the participants and the key to the codes were kept separate from participant names. Confidentiality was further ensured by storing the identification key and all data collected in locked draws and in password protected computer files. Printed data was locked in a draw in the home office of the researcher and electronic data was stored in a password protected file on the laptop of the researcher. The identification key and interview notes were stored separately. Identifying information and files were only accessible to the researcher, who kept this information confidential.

The researcher intends to present the results of the research in the form of a PowerPoint presentation at the Southern-Western Sub-structure district primary health care meeting platform and at the CDU management platform. A less formal presentation of results will also be provided for the staff at LRCDC at an agreed upon date and time.

# CHAPTER FOUR: RESULTS

## 4.1 Introduction

This research study aimed to understand the perceptions and experiences of those involved in the collection of Chronic Dispensing Unit (CDU) parcels from Lotus River Community Day Centre (LRCDC) in the Western Cape. Furthermore, it was a means to determine whether collectors of CDU parcels could potentially be a new cadre of community health volunteers. A total of 12 participants were interviewed; six self-identified collectors, three patients and three key informants. Collectors were defined as those who regularly collect monthly CDU parcels from the health facility on behalf of patients. Table 1 depicts the key characteristics of the study participants.

### TABLE 1: Participant Demographics

<table>
<tr><th colspan="4">Collectors (6)</th></tr>
<tr><th>Gender</th><th>Age Range (years)</th><th>Period of time as collector</th><th>Ave no. of parcels per month</th></tr>
<tr><td>Female: 5<br>Male : 1</td><td>30-40 = 2<br>41-50 = 2<br>51-60 = 1<br>61-70 = 0<br>71-80 = 1</td><td>C1: 5 years<br>C2: 3 years<br>C3: 14 years<br>C4: 2 years<br>C5: 3 years<br>C6: 13 years</td><td>≤ 20 = 4<br>≥ 21 = 2</td></tr>
<tr><th colspan="4">Patients (3)</th></tr>
<tr><th>Gender</th><th>Age Range (years)</th><th>Chronic Condition</th><th>Length of time employing collector</th></tr>
<tr><td>Female: 2<br>Male : 1</td><td>60-70 = 3</td><td>P1: Hpt<br>P2: Hpt/DM/RA/ Psoriasis<br>P3: Hpt/DM/OA/</td><td>≤ 10 years =1<br>≥ 11 years =2</td></tr>
<tr><th colspan="4">Key Informants (3)</th></tr>
<tr><th>Gender</th><th>Age Range (years)</th><th>Employment Capacity</th><th>Number of years in employed capacity</th></tr>
<tr><td>Female: 2<br>Male : 1</td><td>30-40 = 2<br>41-50 = 0<br>51-60 = 1</td><td>KI 1: Post Basic Pharmacist’s Assistant<br>KI 2: Health Promotion Officer<br>KI 3: Administration Clerk</td><td>≤ 5 years = 2<br>≥ 6 years = 1</td></tr>
</table>

Hpt = Hypertension; DM = Diabetes Mellitus Type II; RA = Rheumatoid Arthritis;
OA = Osteoarthritis

The six collectors ranged in age from 34 to 79 years - the one male participant was the youngest, aged 34 years, and the eldest female, aged 79 years was the only participant with her own private vehicle. Collectors were classified by the average number of parcels collected per month. Those who collected more than 20 parcels per month were classified as high volume collectors whereas those collecting less than 20 parcels per month were classified as low volume collectors. Only one of the six collectors was formally employed at the time of the study.

One male and two female patients were interviewed.  The 60 year old male was unemployed, the 61 year old female was working full-time and the other 60 year old female was retired. All received chronic care for their various conditions at LRCDC and graduated onto the CDU system due to the stable nature of their conditions. The male patient was also receiving chronic care at a government tertiary hospital in Cape Town.

All key informants were permanently employed at the facility. The one male key informant was directly involved in the distribution of CDU parcels at the facility. The two female key informants were employed at the facility in health promotion and administrative roles, respectively.

Table 2 lists a range of classification criteria used as identifiers for the collector and patient participants. The identifiers used for the quotations are those which best described the key characteristics of the participants, relevant to the study objectives. Key informant identifiers are not included in Table 2 since their classification category is identified solely by their employment capacity.

## TABLE 2: Key depicting descriptive identifiers of collector and patient participants

| Participant group | Identification code; as per demographic table | Gender | Classification category | Employment status | Means of travel to LRCDC | Descriptive identification as reflected in results |
|---|---|---|---|---|---|---|
| | | | | | | |
| **Collector Participants** | C1 | Female | Low volume | Unemployed | Walk | Unemployed low volume female collector |
| | C2 | Female | Low volume | Previously employed | Public transport | Previously employed low volume female collector |
| | C3 | Female | Low volume | Retired | Private transport | Female collector with private transport |
| | C4 | Male | High volume | Unemployed | Walk | High volume, unemployed male collector |
| | C5 | Female | Low volume | NGO employed | Walk | NGO employed low volume female collector |
| | C6 | Female | High volume | Unemployed | Walk and public transport | Very well-known, high-volume female collector |
| | | | | | | |
| **Patient Participants** | | | **Employment status** | | | |
| | P1 | Female | Full-time employed | | Private transport | Full-time employed female patient |
| | P2 | Male | Unemployed | | Walk | Unemployed male patient |
| | P3 | Female | Retired | | Walk | Retired female patient |

Seven themes emerged from the study, which highlighted the complexity and challenges that patients experienced when collecting their monthly CDU medication parcels from the facility and how they enlisted the assistance of a collector. Furthermore, it revealed information about the collectors and their role in patient well-being, as well as the perspectives of health facility staff about collectors and future opportunities. Table 3 displays the themes and sub-themes that emerged from the data.

## TABLE 3: Themes that emerged from interviews

| Main Themes | Sub-themes |
|---|---|
| 1.Access barriers experienced by patients for medication collection | 1.1 Transport<br>1.2 Personal safety<br>1.3 Competing commitments |
| 2.Attributes of collectors | 2.1 Passion for helping community<br>2.2 Trust, patience and reliability<br>2.3 Organisational skills |
| 3.Motivation to become a collector | 3.1 No formal employment<br>3.2 Reward system |
| 4.Collector-patient relationship | 4.1 Recruitment of collector<br>4.2 Agreement with collector<br>4.3 Information sharing technique |
| 5.Processes of medication collection | 5.1 Differential process for collector<br>5.2 Alternative means of medication collection when no PMP |
| 6.In-facility relationships and communication | 6.1 Staff attitudes<br>6.2 In-facility communication techniques |
| 7.Education, training and suggestions from participants | 7.1 Acknowledgement of benefit<br>7.2 Suggested training course structure |

Patients reported that they had difficulty personally accessing the facility every month to collect their chronic medication parcel. Geographical access to the health facility was a major concern due to the lack of reliable public transport to the LRCDC, the threat to their personal safety when walking and competing commitments of work or to care for family members.

This prompted patients to seek a means to overcome these challenges and they reported that they achieved success by enlisting the services of a collector.

The collectors seemed to possess specific attributes which enabled them to perform this service for their community. These attributes included passion for helping others, trust, patience, reliability and a good level of organisational skills. These attributes appeared to motivate collectors to commence this type of service in their community. The fact that the majority were not formally employed, and the reward system was likely to contribute to the collectors' motivation to continue providing this service. The recruitment process and agreements that existed between collectors and patients revealed how the initial collection occurred and how the collector-patient relationship further developed over time.

The process of medication collection at LRCDC for patients and collectors is reported as the fifth theme. It highlights how some of the current processes present as obstacles to hinder third party collection and raise the issue of confidentiality and consent.

The relationship dynamics between collector and health facility staff emerged as an important theme in relation to communication and sharing knowledge of chronic disease management and medication use. Participants revealed the close connections and dynamic relationships that exist between collector, patient and facility staff.

Education, training and suggestions for taking this initiative forward emerged as the seventh theme.  Collectors, as caregivers to family members and the community reported having some knowledge about chronic disease management and medication. Their willingness to receive training was encouraging considering their minimal formal educational training. Finally, there were some suggestions relating to how further training of collectors could possibly be implemented. Collectors provided practical suggestions based on their preferred method of learning, technology available and other long-standing commitments to their family members.

## 4.2 Access barriers experienced by patients for medication collection

One facet of chronic disease management is the continual use of prescribed medication. Monthly collection of the prescribed medication can become a laborious task for many patients, even though they recognise the need to continually have a supply of medication. The CDU system operated by the Western Cape Department of Health provides a unique opportunity for simply collecting medication parcels from the health facility. However, patients reported challenges to personally collect CDU parcels from the facility. Several sub-themes emerged which were related to the barriers experienced by patients to collect their medication themselves. These were transport, personal safety and competing work or family commitments.

### 4.2.1 Transport

One of the structural barriers that hindered patients' access to LRCDC was that the facility is not situated on a public transport route in comparison to neighbouring facilities. Patients who do not have access to a private vehicle are required to walk the 15 minutes from the nearest bus or taxi stop to the facility. Generally, in low- and middle- income socio-economic areas such as Lotus River and surrounding areas, residents usually do not have their own private vehicles so patients attending the facility for chronic care need to make use of public transport, walking or rely on the transport of family members or neighbours.

Patients described how they usually access the facility and also the alternative when the first option is not feasible due to various circumstances.

> "*Well before I used to come and fetch it* [the medication] *myself, but then, you know things have changed over the years, I used to then come and fetch it because I had a car then… then that is when I asked my sister to fetch it, because I couldn't come.*" Full-time employed female patient

> *"I walk. It's not so far away, but if I can't walk… so if my legs are painful, then the neighbour takes me with his car."* Unemployed male patient

Collectors reported similar reasons why patients or family members who they serve are unable to collect CDU parcels from the facility.

> *"Mostly it's other family members, some* [patients] *can't make it, they work or like my aunt, she had a hip replacement so I'm helping her as well with meds and my mommy's sister has severe heart attack as well, due to cholesterol, so I go fetch her meds as well."* Unemployed low-volume female collector

> *"…the one that I know I mean she is a spinster and she's got problems with her legs to walk and all that, and she hasn't got a car so she must also get somebody to bring her…"* Female collector with private transport

> *"For the patients themselves, for mother-in-law there is nobody else to collect that is why I am here, like I said she has emphysema so she cannot collect, my aunt has foot problems and she cannot walk from Parkwood so when she gets here her feet are sore and tired and that is why I collect for her as well and for my aunt's uncle he is also an elderly person and he stays in Retreat with his daughter now so it's easier to collect their stuff as well, and I don't mind"* Previously employed low-volume female collector

Many patients and collectors rely on family members and those in the community with vehicles, to access the health facility when conditions are not suitable for walking the distance.

> "*we walk until here……more or less half an hour"* High volume, unemployed male collector
>
> "*But sometimes I take the bus…. yes only when it's winter*" Very well-known high volume female collector
>
> "*With my husband, he drops me off and sometimes when he is not too busy at work he would collect me or I would have to take a taxi back home. Yes, I have to take two taxis"* Previously employed low volume female collector

When health facility staff were asked for reasons why patients were unable to collect the CDU parcels themselves, they mainly reported that it was patients with work commitments who were unable to come to the facility themselves and subsequently engaged the services of collectors. They didn't mention frail patients or patients who have mobility problems, as was reported by collectors and patients.

> *"because there is certain people that just cannot make it for certain reasons, for example, work related, some supervisors, some bosses just don't understand that people need to fetch their medication at a certain time even though they have proof of a card or proof from pharmacy that they were here on a certain date they left here at a certain time but then they still maybe have to sign time which certain people just cannot afford to lose those hours, you know. I would say it is a good thing having a collector definitely."* Post Basic Pharmacist's Assistant

### 4.2.2 Personal Safety

Social ills that plague the community of Lotus River and surrounding areas posed a challenge for patients to access the facility monthly to collect their medication. Patients and health facility staff reported that fear for personal safety was a tangible concern when accessing the facility on foot and created a barrier to access.

> "*It's very dangerous - once they robbed me but that is why I asked* [a collector] *now to get it and then I give her taxi fare.*" Retired female patient

> *"I am sure that there is problems probably theft involved because they are walking with the medication and I know that there were times that people were robbing people for medication for drug purposes smoking it or whatever,…"* Post Basic Pharmacist's Assistant

Conversely, when collectors were asked about some of the challenges faced when having to come to the facility to collect medication, none reported personal safety issues as above.

### 4.2.3 Competing Commitments

Patients reported that even when travelling arrangements were secured for them to personally attend the health facility, commitments to family members still remained as a challenge. All patients reported having full time commitments to work or care for frail family members. Patients elaborated how the processes and limited collection period designed and implemented by the facility also acted as a barrier to CDU medication collection.

> "*I am looking after my mother-in-law… So I am sitting with this lady now she is 85 years old and I am looking after her.*" Retired female patient

> *"then that is when I asked my sister to fetch it, because I couldn't come because the times of the collecting was also changed because it like went from 1 o'clock I think or 2 o'clock, it went now to 12 o'clock, so I couldn't come then and, yes so this is why she's only been collecting it now for the last few months."* Full-time employed female patient

Many collectors were confronted with similar challenges but seemed to be more able to transfer their commitments to another family member. These actions taken by the collectors displayed their organizational skills which will be reported as one of their key attributes. The ability of collectors to overcome the access barriers reported by patient participants, is further reported as some of their defining attributes in the next theme.

## 4.3 Attributes of Collectors

The dynamic process of medication collection infers that certain characteristics are required for a person to be a collector. Collectors reported the following attributes; their passion to help the community, a high level of responsibility, patience, trustworthiness and some organisational skills. Patients similarly reported that their collectors displayed these characteristics.

### 4.3.1 Passionate about helping the community

Patients reported helpful and selfless actions of collectors. Some reported that even though collectors were not formally employed they were whole heartedly committed to caring for the elderly members of their family and the community.

> *"The thing that I am busy with is actually for the community, the work that I do is the passion that I have for the community people out that and as a collector me, myself, as a collector these patients that I had outside in the community after work I would just go pop in there and see how they are doing some of them trust me to bring their medication to them and ask me if I can bring their medication, and when I come there I would always have a talk about the medication and how they are doing,"* NGO employed low volume female collector

> *"I am a housewife going on for 2 years now, I take care of my mom-in law at home she has emphysema, so she is in bed right most of the time. So basically, my life revolves around my kids and household and family life and that is it"* Previously employed low volume female collector

When asked how they felt about helping others the overwhelming response was positive.

> *"Ja, I love helping"* Previously employed low volume female collector

> *"….I have a passion to work with patients out there, that is me"* NGO employed low volume female collector

However, health facility staff seemed to have a different perception assuming that collectors were only in it for monetary gain and did not actually care for the patients and the community.

### 4.3.2 Trust, patience and reliability

Patients and collectors described attributes of trust, patience and reliability to be inherent to become a collector at the facility. The patient needed to trust that the collector will perform the service as they agreed, the collector is required to have the patience to wait at the facility, and the patient needs to rely on the collector to ensure that their allocated medication parcel will be handed over to them as agreed.

> *"…my collector [***] is very reliable"* Retired female patient

When collectors were asked why they were the person their patients asked to collect their medication for them as opposed to someone else, they responded as follows;

> *"They trust me. I grew up with them...The only time when I wait long is when there's a lot of people and the hospital is busy, at its busiest then I wait long. I must say I must have patience. I must wait."* High volume, unemployed male collector
>
> *"…because you will have to sit here and you will have to have the patience and the respect for the staff"* Previously employed low volume female collector

> *"...and they will rely on me, trust me to bring it…some of them trust me to bring their medication to them"* NGO employed low volume female collector

However, health facility staff reported interactions with collectors that were contrary some complained about collectors who caused disruptions and others questioned the reliability of the collectors.

> *"If it's a busy day they* [collectors] *will always be impatient."* Administration Clerk
>
> *"…and they* [collector] *just not going to come because today I* [collector] *am not feeling well…."* Health Promotion Officer

Collectors acknowledged that collecting medication on behalf of a patient is a big responsibility. For this reason, a level of organisational skills is required by the collectors to ensure that they are able to ensure timely collection of CDU medication parcels.

### 4.3.3 Organisational skills

All collectors appeared to exhibit organisational skills. Health facility staff thought that one of the high volume collectors displayed exceptional organisational skills which allowed her to be more efficient. Tools used by this high-volume collector were a diary and ensuring a direct line of communication between collector and patient.

> *"I sort the cards out and I know who must get medication like the next day and I know the dates for the next day, my book is at home and I've got phone numbers from the people and I phone them and I tell them, I make appointments for them, I let them know earlier and so I do that and I sort the cards out."* Very well-known high volume female collector

Even the low volume collectors displayed some degree of organisational skills. In their case, due to their family commitments and duty they would need to make the appropriate arrangements at home prior to attending the health facility.

An important finding was that these attributes displayed by collectors namely; passion, patience, trustworthiness, reliability and organisational skills, were closely linked to the motivational capacity of the collectors to provide this service.

## 4.4 Motivation to become a Collector

As previously reported, patients' reasons to enlist the services of a collector stemmed from the requirements of the patients registered with the CDU system to collect their monthly medication on the allocated date and appointed time and their inability to meet this requirement. Most collectors were also patients at the facility or have family members who attended the facility. This attribute made them highly aware of the challenges that patients face to access chronic medication regularly. Their caring nature, coupled with other previously mentioned attributes, allowed collectors to make use of the opportunity to help others. Some collectors reported that it was purely out of kindness that collecting medication for those who experience challenges evolved. Other collectors explained that this was a temporary solution to being unemployed.

> *"This is my job because I'm still looking for work because I must work for my wife. I must put bread on the table."* High volume unemployed male collector

> "*Yes, they know it's my job, I like to do it, I like to help them out also.*" Very well-known high volume female collector

The choice to provide this service was viewed by all collectors as a rewarding one which provided feelings of fulfilment and purpose.

> *"To me because I'm doing them a favour I don't want anything I tell them I don't want anything."* Female collector with private transport

> "*Ja! because I was thinking first I want to do something for myself, for my life, ja, so I started to collect people's medication.*" Very well-known female high volume collector

Factors, such as, some of their patients having the same dates to collect their medication were viewed as a motivator to commence this service. Similarly, collectors viewed it as convenient when the household all had the same dates for medication collection.

> "*all the dates are the same… All of the dates are always the same that is wonderful for me… so it's easier to collect their stuff as well, and I don't mind*" Previously employed low volume female collector

> "*My mother is also in Grassy Park and she's quite old and my sister looks after her, so my mother is also a patient here at the hospital and lucky enough we're on the same day.*" Full-time employed female patient

Most collectors explained that the opportunity to help the elderly patients in the community by collecting their medication was a win-win situation in their opinion. Significantly, being remunerated was reported by collectors as a secondary motivator to helping the community. Others were primarily motivated by having a purpose for their life due to unemployment and then also as a form of income.

Two sub-themes emerged, namely the consequence of not being formally employed and the reward system that motivates them to remain committed to their service to their patients.

### 4.4.1 No formal employment

Most participants reported that collectors were not formally employed and hence were willing to assist their community by waiting for medication parcels to be issued. Patients and collectors were aware of the advantage that this group of people have, that is, the time and availability to physically present themselves at the facility during operating hours and the willingness to wait at the facility.

Having the time and willingness to spend time waiting at the facility to collect medication is a critical component of medication collection.  The process of CDU medication collection differs at various facilities in the Western Cape based on the staff compliment and also the operational hours of the facility.  This influences the waiting time for medication collection. Significantly, none of the collectors reported excessively long waiting times for CDU medication parcel collection.

> *"She*[the collector] *doesn't work yes"* Unemployed male patient
>
> *"so I can't actually work that's why I am helping the community, like elderly people, to go fetch their meds for them"* Unemployed low volume female collector
>
> *"I'm a house executive to put it that way, so I have got the time to be here you understand, but sometimes I can't sit too long…"* Previously employed low volume female collector
>
> *"I don't work. So I'm not worried about time. I can sit all day at the day hospital…"* High volume unemployed male collector

### 4.4.2 Reward System

The subject of rewards and, more specifically monetary compensation, revealed clear polarisation between participant groups. Patients were grateful for the collectors' efforts and most felt they wanted to reward them in some way. Collectors were similarly grateful for any type of reward. Some were simply satisfied with a "thank you", or a small gift at Christmas time whereas others expected a set fee.

> "*Just to get a thank you from the patient, from the elderly person, and do you know, the elderly persons, their blessings count more."* Unemployed low volume female collector
>
> "*…the Lord will bless you and I grab that blessing because one day I will need it on my path in the future and most of them are elderly seeing I am doing it out of love when they give me the money there are times when I would give it back and tell them there is no need to give, but then they would force it into my hand, or they will buy me*

> *a small gift at the end of year as a token of appreciation."* NGO employed low volume female collector

> *"To me because I'm doing them a favour I don't want anything I tell them I don't want anything. I mean like [***] will Easter or Christmas she will say [***] just come around I've got something for you she baked a Christmas cake and she will give me a Christmas cake. I tell them I don't want anything because I you know… I'm doing out of the goodness of my heart."* Female collector with private transport

> "*Yes, we give her R30 because I mean sometimes she walks she brings the tablets to our house, she comes and fetches it here it is quite a lot of work, she must come and sit here and spend her time."* Retired female patient

Those collectors who did not expect any compensation were appalled that some collectors would expect patients to pay for their own medication parcels.

> "*…but the next person would say I would collect the tablets for you, but you need to give me something"* Previously employed low volume female collector

> *"Like I can see for some collectors I would say that I feel that it all goes about the money the collectors don't just come to get the medication and do it with a passion, they would rather do it for the money."* NGO employed low volume female collector

> "*There are lots of people who collect peoples' medication and they [patients] must pay them to collect… I said no the Lord helps me."* Female collector with private transport

Some patients also reported that they were not able to continually provide their collector with monetary compensation but would provide alternative compensation, which was acceptable to the collector.

> *"And if not, I'll always give her something. Bread, food…."* Unemployed male patient

A surprising finding was that the health facility staff had very vague and prejudiced idea of how collectors were remunerated. They seemed to think that monetary remuneration was the only motivating factor involved and were under the impression that collectors easily earned income through commercialising the chronic medication collection process- mainly referring to the high volume collectors who present at the facility daily.

> *"…for them [collectors] it is just a packet and I'm going to get my R30 or my R20 and they just looking forward to that."* Health Promotion Officer

The requirement for patients to reward collectors for their services possibly stems from the relationship that had been built between them. This relationship and understanding seemed to be significant in the community of Lotus River for this type of service provision.

## 4.5 Collector-Patient Relationship

This theme comprised three sub-themes; namely recruitment process, agreement with collector and the communication or information sharing. No formal method of recruitment of collectors seemed to exist. Collectors were contacted by patients by word of mouth. The recruitment process reported by patient and collector participants demonstrates that it was usually the patient who sought out the collector, but that once a collector had a clientele, he or she then expanded by either volunteering to take on more clients or alternatively the satisfied clients promoted the services of the collector. As with most institutions, when sending a proxy, it is expected that written consent is provided. Most collectors were aware that written permission from the patient was a requirement from the facility to collect on a patient's behalf or alternatively the patient needed to complete an authorisation letter. All collectors reported that they shared relevant information with the patient, furthermore patients reported that their collector also supports in medication adherence by reminding them when the next repeat is due.

### 4.5.1 Recruitment of Collector

Recruitment or enlisting the services of a collector developed within the community by word of mouth.

> "*My mommy let that person know I collect her medication, that person let that person know, and that person let that person know."* High volume unemployed male collector

Most health facility staff reported that when a patient explained that they have challenges with physically getting to the facility to collect their CDU medication parcel on the correct date and within the time frame allocated, they would refer the patient to one of the high volume collectors who live in their vicinity. This referral happens at the facility, either by the collector physically meeting the patient or the key informant would provide the name and contact details of the collector. Some collectors are well known in the community and recognised when in public places and would even be approached by patients as they are simply going about their everyday business.

> "*In the facility if they know me here then some of them would ask me if I can come and see them or as I walk down the road to my mom in Lotus River then some of the patients recognizes me and they call me and they ask if I can do a favor for them because they can't make it that day or there is no one to go for them and I would say yes! I would see if I can assist you, but we will take it one step at a time.*" NGO employed low volume female collector

> "*I just speak to my friends and they ask me,*[***] *can you take my number and my…and I take their number, then they ask me to collect medication, because they stay mos in Mitchell's Plain.*" Very well-known high volume female collector

Alternatively, some collectors would volunteer their services to those patients who they know. This is different to the abovementioned pathway since there is already an established relationship between the patient and the collector in this instance.

> "*And she is cutting the dogs hair and stuff like that wash the dog and one day she brought* [***] *with her and* [***] *said to me* [***] *if you want someone to go and fetch your tablets I am doing that and she is doing that for quite a few years now for me.*" Retired female patient

As a consequence of this, the patient would only physically present at the facility when routine tests are required and when a consultation with a clinician is scheduled.

### 4.5.2 Agreements with collector

The agreements between collector and patient seemed to vary, possibly due to the personal resources available to the collector. Most collectors would agree to deliver the CDU medication parcel to the patients home, but one of the high volume collectors had an agreement that the patients collect the medication parcel from her home.

> “*I phone them, then they come fetch it by me.*” Very well-known high volume female collector
>
> “*Yes, I collect it from her, but it’s…we see each other often, so it’s not a problem.*” Full-time employed female patient
>
> “*Well I will make arrangements through patients. If the patient ask me if I can collect the packet for them, then I will see how my schedule is then I would tell them that if I don't bring it this afternoon at this time or that time you can expect me night or the day after to bring the medication.*” NGO employed low volume female collector
>
> “*I know the gates* [whether they live]. *I got their cards at home. Then I just come and fetch their medication, then I drop it by them. Then I keep their hospital card.*” High volume unemployed male collector

Most collectors indicated that no discussion about a fee or remuneration takes place prior to them collecting, except for the high-volume collectors who have a set fee and they inform the patients prior to collection.

Neither parties appeared aware of patient folder confidentiality issues. The collector would only become aware of this at the point when no medication parcel had arrived at the facility and authorisation was required for the collector to handle the folder. Health facility staff reported that when a patient hands over confidential details such as an appointment card and a copy of the ID  (with or without an authorisation letter) that it is an informal agreement or indication that the patient is providing permission for the collector to be issued with the patients’ medication.  Matters are complicated when the CDU parcel does not arrive from the service provider with no fault of the patient nor collector.  Rejection of a prescription from CDU would lead to no medication parcel being delivered for that specific collection date. Since the collector has made a commitment to collect/deliver, the collector then faces numerous challenges. This are reported in the following main theme.

### 4.5.3 Information sharing

The information sharing process between the person issuing the parcel to the collector and then collector to patient is one that appeared to be insufficiently recognized by health facility staff.  However, patients reported receiving sufficient information from their collector.

> “*Well ja! I mean she will…I will ask her questions like, what did they…how did…did they give you another appointment, you know, to make for the medication, there are such things I need to know.”* Full-time employed female patient

For the collectors who deliver and have direct contact with the patient at the point of hand-over, it presents an opportunity to engage in conversation regarding the medication use and any other relevant health information. This is an important consideration related to pre-requisites for integrating collectors into the health system, discussed in the next chapter.

One of the collectors was purposively selected because of her previous experience within the facility as support staff at CDU Despatch. The participant reported having learnt about the medication names, indications for use, frequency of dosing and general chronic disease management from the Post Basic Pharmacist’s Assistant and clinical team. This participant was already conveying relevant messages about medication to the patients at their homes. Her strategy included engaging with the patient and the medication in the comfort of their own homes. The participant was furthermore able to identify when a patient needed to return to the facility for further extended information or care.

> “*and when I come there, I would always have a talk about the medication and how they are doing, if they are taking their medication properly and how does it work for them and stuff like that.”* NGO employed low volume female collector

Her unique experience and exposure to support chronic disease patients will be reported in the final result theme. Other collectors also reported they had learned about chronic conditions so they could answer simple questions regarding correct medicine use. This theme develops further with the Education, Training and Suggestions; theme seven.

## 4.6 Process of Medication Collection

Two sub-themes are reported, namely the perceptions of the differential process for a collector and lastly the process for medication collection when a parcel is expected but is not delivered to the facility. It was in July 2018, during the researcher’s data collection period, that the LRCDC management team introduced a clear distinction between collectors and patients performing an *ad hoc* additional collection for a family member. A key informant reported the ideal process that a collector would be expected to follow.

> "*So the collectors will then have the patient's card with the date, there is a form that we have at the facility issues the collector if we don't give it to the collector we give it to the person themselves, they then fill, person who the collector is fetching for they fill the form in for the collector, so they fill their details in, the collector's details and a copy of the patient's ID that accompanies this form every time the collector fetches the medication on behalf of the patient*" Post Basic Pharmacist's Assistant

As described in the study setting, the processes of medication collection of CDU parcels were developed to accommodate the large volume of patients that are served at the facility. Generally, the waiting time for CDU parcels was reported to be 20 minutes.

All collectors have reported the difficulty they experience when a medication parcel has not arrived for a patient. Generally, the reasons for no CDU parcel may either be an error on the part of the facility, or it may be an error by the CDU service provider. This creates a challenge for the collector. Some patients are unaware of these challenges that the collectors face. As mentioned previously, this scenario then raises the issue of confidentiality and consent due to the regulations regarding access to confidential medical records.

### 4.6.1 Differential Process for Collector

For the purpose of better service delivery and to minimise collectors' waiting time; the facility management in collaboration with the multi-disciplinary team created an opportunity for the collectors to be assisted during an allocated timeslot. The notice provided a brief definition of a collector and their allocated time slot (Appendix 7).

Health facility staff and collectors have reported the impact and increased satisfaction that this made.

> "*And also now with the set time it's less complaints from the collectors because they know when they can come and when it is their time and when the batches will go down because to run down with one, two folders is not working.*" Administration Clerk

### 4.6.2 Alternative means of medication collection, when no PMP

Matters are complicated when no medication parcel for a patient arrives from the CDU and medication collection can become tedious with very long waiting times. In order for the pharmacy to provide medication for these patients, the folder is required at the pharmacy for the prescription to be processed. Authorisation issued to the collector allows for medication collection but not for handling of the patients' folder due to confidentiality. For this reason, the folders for these patients are drawn and sent directly to the pharmacy in a batch. This is an additional duty for the reception clerks since there are no porters employed for this function as reported by this key informant.

> "*when meds didn't come from CDU and then I have to issue a folder and that is where the problem where I cannot just issue the folder to whoever is standing in front of me, it can only be the person the actual patient for confidentiality reasons. We have a set time when we draw those folders and then we send them down in bulk so we don't have to run up and down because we take it down physically because of the collectors that is standing in front of me it is not their folder they can take the medication, but not the folder.*" Administration Clerk

This increased waiting time and additional workload causes frustration for all parties involved. As a result, the high-volume collectors are perceived as a problem at reception when more than two of their clients are due to receive a medication parcel but did not arrive.

> "*Okay. The last time I was here I had to hand in four cards. So, two patients' names weren't on the board, so I had to go and fetch the folder.*" High volume unemployed male collector

Collectors responded that this is a tedious and unfair process, when it is not their fault, but seemed to be punishment for them. Health facility staff however labelled these collectors as difficult when they repeatedly enquire whether the folders had been sent to main pharmacy.

Health facility management have recognised the need for collectors but due to the fact that they are not formally employed they are not deemed as a priority. In fact, health facility staff reported that they prioritise a patient over a collector at the service point.

> *"Yes. Because they have the time to do that, that is their job we put them on a side so I service the client over them and they must just wait."* Administration Clerk

Potentially educating patients and collectors with regards to issues of consent, confidentiality and discretion may improve the relationship and understanding of collectors at a facility such as Lotus River CDC.

## 4.7 In-Facility Relationships and Communication

The nature of the study setting, namely a health facility, is such that patients and collectors are continually in contact with the staff. As a natural progression, the interactions between them become significant and more personal which positively influences their attendance at the health facility. The familiarity and relationships that have developed over time between staff and collectors seemed to be valued by all parties. Most collectors pride themselves on the fact that facility staff know that they are collectors.

> "*…but I kind of know all the collectors who are coming here on a monthly basis because you see them on a monthly basis they come like more than once a month to fetch certain people's medication so you kind of like know who they are.*" Post Basic Pharmacist's Assistant

Staff attitudes and in-facility communication techniques are the two sub-themes that emerged.

### 4.7.1 Staff attitudes

When collectors and patients were asked to describe the general experience of coming to the facility and the interactions with staff, the overall responses were positive. Whilst collectors reported several negative incidents, in several, there was great appreciation for the pressure that the staff have to deal with.

> "*The people are friendly.*" High volume, unemployed male collector

> *I feel good because I'm well known as [***] knows, I'm well known at the hospital,*" Unemployed low volume female collector

> "*It is always nice, but sometimes the next person is abrupt, I do understand you need to work and the nurses and staff work they do get a little agitated with the patients but that is only when patients are rude with them and that is why they are like that. So I am well received, yes, sometimes you have to be patient in a place like this and sometimes they are short staff also so you cannot rush the next person*" Previously employed low volume female collector

The positive relationships were accentuated by one collector who was able to name all the permanent and rotational staff. This is an indication of the familiarity that develops at a health facility over a period of time.

> "*When I come in here, it is always the security guard [***], then It's [***] (reception clerk) in front or [***] (reception clerk) or [***](reception clerk) and I'm always talkative to Sr [***] and Sr [***] (nurses), and the one who gave us the folder and [***] (Post Basic Pharmacist's Assistant) and [***] (medical officer)when he was here*" Previously employed low volume female collector

The development of these types of relationships may be key to improving communication with other collectors. Some key informants seemed to have a different perception of the collectors. One reported that they are simply messengers and used the following analogy to elaborate how she thinks that collectors are perceived by patients

> "*…that's normally when you send a child to the shop to go and buy bread and you will give him a R2 or R1 and you don't worry whether the child knows what is the difference between Dunes and Sasko or whatever as long as you get the bread on your table.*" Health Promotion Officer

and some facility staff perceived the collectors to be a nuisance, as reported by one collector…

> "*I like to do my job now this one girl there, oh it's you again, why are you here every second day!*" Very well-known high volume female collector

### 4.7.2 In-Facility Communication Techniques

One of the health facility staff who was passionate about ensuring that patients understand their chronic condition and had a greater insight into the importance of correct medicine use reported that she had identified this as a need in the community. For this reason, she provides general health talks to patients in the main waiting areas of the health facility. These messages reach the collectors at the same time, and so hopefully they communicate the information to their patients.

> "*So I do educate a little bit in the morning but it's like very minimal and for me I should have at least two, three hours to speak throughout the whole hospital and get everybody.*" Health Promotion Officer

## 4.8 Education, training and suggestions from participants

Participants were asked about the feasibility of collectors becoming a type of informal health educator about chronic diseases and for suggestions with regards to the structure of a course, frequency of training sessions, duration of sessions, venue and whether using technological devices would be useful.

### 4.8.1 Acknowledgement of Benefit

Generally, the collectors expressed enthusiasm at the prospect of receiving some form of education or training. They seemed even more excited at the prospect of sharing this knowledge with their patients.

> "*Of course! I'm always up for that… Like I said to you I'm a person that likes to ask questions and before me being the carer for my mother-in-law, my sister-in-law used to take her to hospital and so forth. They're not people that asks questions, that's why my mother-in-law likes me to be with her because I understand more and I ask the questions so that I can liaise with them what the doctor said, what she needs and what they need to do and so on. Then you get people who think they know better than the doctor or sister instead of following what they're told to do. So I'm always up for it."* Previously employed low volume female collector

> "*Yes! yes. I would like to learn to help other people. It will make me a better person because I'm helping my fellow human being…I actually learn ... how can I say, I'm learning something from it. At the end of the day I can now do that thing that you have taught me now, then I can do that, and teach the next person again."* High volume unemployed male collector

> *"…like a course, just to find out about the illnesses and how the meds work on the illness. To see more people getting involved in the community to help the elderly with their meds."* Unemployed low volume female collector

One collector was of the opinion that the providing training opportunity would not easily be accepted by all collectors. Key informants responded that collectors would all be able to acknowledge the benefit of such training and furthermore how it would enable them as collector to be valued and respected by the community.

> *"Yes, it would but not for all of them. For some of them that would maybe it will give a change of mind to them and actually go about okay I will do this as a passion or to care for the next patient out there because it could be my mom, my grandma, family member or myself so just to get that mindset and not for the money reason."* NGO employed low volume female collector

> "*I think so. I think they will feel wow… somebody pays attention to us also and don't just see us as somebody's messenger or whatever and they would feel I know how to relate to other people or how to tell the person that I'm maybe collecting for the importance of drinking your medication."* Health Promotion Officer

Two patients responded positively to potentially having their collector educated and trained to deliver health and medicine related information in the comfort of their homes. Significantly patients who showed interest in receiving this information from their collector were currently caring for elderly and frail members of their family.

> *"Yes, it will work it is possible."* Retired female patient

> *"It will be yes. It will help."* Unemployed male patient

However, one patient felt that she had sufficient knowledge about her medication and didn't necessarily need this type of service from her collector at this time.

> "*Well I don't really need any other information because I've been getting the same medication for quite a while, I know how to use it."* Full-time employed female patient

Most collectors were not in possession of a matric qualification which decreased their chances of being employed. All collectors, however, portrayed a willingness to learn and extend any information gained to those who need it.

> "*I'm busy with my matric at the moment for a better future. I'm working at the facility at the day hospital working for* [an NGO] *that is linked to the day hospital the facility where I am working at. Actually, I am a community home based Carer, CCW. The thing that I am busy with is actually for the community the work that I do is the pas-*

> *sion that I have for the community people"* NGO employed low volume female collector

The attribute of collectors who acknowledge the benefit of education and training may potentially be a criterion for inclusion into a training programme to improving access to medication.

### 4.8.2 Suggested training course structure

Once the participants had taken a stance as to whether training collectors was a feasible idea, they were asked to recommend a training course structure that would be suitable and viable for all stakeholders. Some of the collectors were willing to offer up more time than others. Some mentioning their willingness to participate irrespective of how long it takes. Some preferred face-to face contact with the trainer and training material that is printed whereas others preferred electronic means of learning and distributing this information.

Key informants were of the opinion that it would be beneficial for collectors to be educated and trained in this regard. They had already identified a need for the collectors to receive information about the value and use of medication. Some participants explained that it would allow collectors to be recognized as medication carriers and also to be actively involved in the patients' well-being. They expressed it as a need for the collectors to be informed, not so much as to impart the knowledge to every patient but only when the need arose.

> *"I think really, really truly all collectors need to be educated on medication on the process there needs to be some sort of a workshop for them. They need to know the importance of collecting on time, collecting and even the storage because sometimes they will go home and they will only see the person the next day and in that also things can go wrong because if it is somebody that doesn't… for them it is just a packet and I'm going to get my R30 or my R20 and they just looking forward to that but in the process I mean so many things are not considered that should be so. I feel really that collectors there should be some sort of workshop some kind of training for them."* Health Promotion Officer

One of the key informants who had a very polarised view of the collectors who attended LRCDC and expressed concern that they would not have the capacity to learn and perform such a function, never-the-less, agreed that the programme may be successful.

> “*I honestly think it won’t work because of the criteria of the collectors that we have I’m not going to say their state, but we are already struggling to get them here sober, understanding medication they won’t.”* Administration Clerk
>
> *“I do see a way forward in that way and then I do also think that maybe with the help of a professional nurse or even a registered nurse a staff nurse and a health promoter work together and run workshops maybe twice a year or something like that and give these people more insight into how valuable how precious the little packet is that they actually… also the cost involved and just that people see it in a different light.”* Health Promotion Officer

Health facility staff suggested which category of staff should be involved in this training. It was proposed that the training, should focus on health education and not too much detail about chronic conditions. Further suggestions were that general training about chronic condition management should be provided.

> “ *I think in a case like that if we should go I don't think that we should go into too much depth in explaining exactly what certain medications are used for maybe get the HPO (health promotion officer) involved, maybe trying to do some more health talks on certain types of medication you know just like in general while the collectors are sitting here and maybe try and bring the point across but maybe just in a different way not directly saying that Metformin is used for diabetes , Hydrochlorothiazide is used for hypertension you know, just like the importance of or maybe educating on a level on how important it is for a patient to use the medication on a regular basis, drink lots of water, ja in that sense”* Post Basic Pharmacist’s Assistant

Most participants provided suggestions with regards to logistical considerations. Some reported that training should be easily accessible to collectors. One participant took a firm stance that direct contact with patients was the best method of interaction with patients. Most collectors displayed willingness to partake in a course and was willing to make provisions to attend based on requirements.

> *"At University? the University is a little far and out of the reach, there would be a lot of expenses involved, like travelling fare, so a Facility and maybe for 4 hours, 2 to 3 days a week… I'd say for a month"* NGO employed low volume female collector

> "*Because I'm helping elderly people so I've lost it* (cellphone)*, I'd rather prefer to see them face to face than chat or talk over the phone, it's better to have a chat with them face to face, then you can see more or less what their reactions is towards what you're telling them."* Unemployed low volume female collector

Some collectors also recognized that they would benefit from having direct contact with a pharmacy professional.

> "*If I've got the time. Like I said I must make sure that there's somebody with her and with my kids that are coming home from school. So I'd have to make arrangements for them. But if it's something that I can do while at home then yes, it's fine. Maybe via email or Whatsapp because I have Wi-Fi at home. Yes, that's why I love (***). I asked her permission to call whenever something is wrong at home and she said yes because she knows my mother-in-law's situation. It takes nothing to ask, it's either a yes or a no from the next person. There was once a question that I had regarding a tablet so I asked her over the phone and she gave me the information and said that if there's anything else I should come in and she'll explain. So yes something like that would work."* Previously employed low volume female collector

When asked whether minimum criteria should be established to engage in training, the response was as follows.

> "*I would say we should have it open to anyone who is interested, cause if your heart is not with something that you want to do then, it not gonna work, it's best to do something that you put your heart on."* NGO employed low volume female collector

As a potential implementation best practice strategy, one collector had implemented what she has learned at the facility. She said that she has a specific way of engaging with her patient to ensure that they understand how to use their medication. She reported that it would take her roughly 30 minutes per session.

> “*I would go to the patient and ask the patient to go fetch the bag of medication for me but the experience that I got in the facility where I am working at I exactly know what tablet is for what so I ask the patient first ask the patient if the patient knows what medication this is… the purpose it is, so if the patient can’t tell me, then I would explain to the patient and what I do or a patient I see is a little forgetful or so, I would write on the box for the patient and that is a water tablet, that is your high blood pressure tablet or that is your sugar tablet.*” NGO employed low volume female collector

The suggestions from participants as reported were practical and implementable. The benefit for patients, collectors and the health system were acknowledged by all.

## 4.9 Conclusion

As with qualitative research, the unique perceptions and experiences of the participants may reform this novel idea of a collector system. The following chapter discusses the pertinent issues that arose and how literature supports or juxtaposes these.

# CHAPTER FIVE: DISCUSSION

## 5.1 Introduction

This chapter discusses the results of the study which sought to establish the acceptability of the collection of medication parcels by “collectors”. Collectors are a patient-driven phenomenon that has emerged organically as a proactive initiative by patients. This under-researched phenomenon of collectors has developed from the Western Cape Chronic Dispensing Unit (CDU) system which has existed for more than 10 years in the community of Lotus River. The CDU system facilitates predictable delivery and retrieval of monthly medication parcels without direct patient contact being necessary. It is an innovative and unique health system approach that improves access to chronic medication parcels and is thereby likely to improve adherence to medication with positive patient outcomes. It is important to determine the acceptability of this novel concept of collectors because access to, and regular collection of, medication is an important element of chronic non-communicable disease (NCD) management. Acceptability studies, as recognized by the WHO, is a starting point to determine feasibility and sustainability of a healthcare intervention (Shaw et al., 2014).

Whilst the concept of collectors as a system was a relatively familiar concept to patients, health facility staff appeared to have paid little attention to the fact that it may be an innovative concept to allow patients to overcome access barriers. For the purposes of this discussion, “collector” is the term coined by the patient to describe the individual person who they enlist as their proxy; whereas the term “collectors” refers to the collective system as experienced by stakeholders. The findings of this study could contribute to our understanding of collectors, the degree to which collectors are accepted by patients and facility based health workers and integrated into the community, as well as future opportunities for formalising the system.

In this study the researcher identified collectors as the focal point and two distinct relationships dynamics that depicted the acceptability levels by each category of participants. The researcher has included a diagrammatic representation of the current situational positioning of collectors within the health system as an intermediary between health facility staff and patients in the community. They seem to operate on the outskirts of this highly controlled health system with minimal training or formal education.

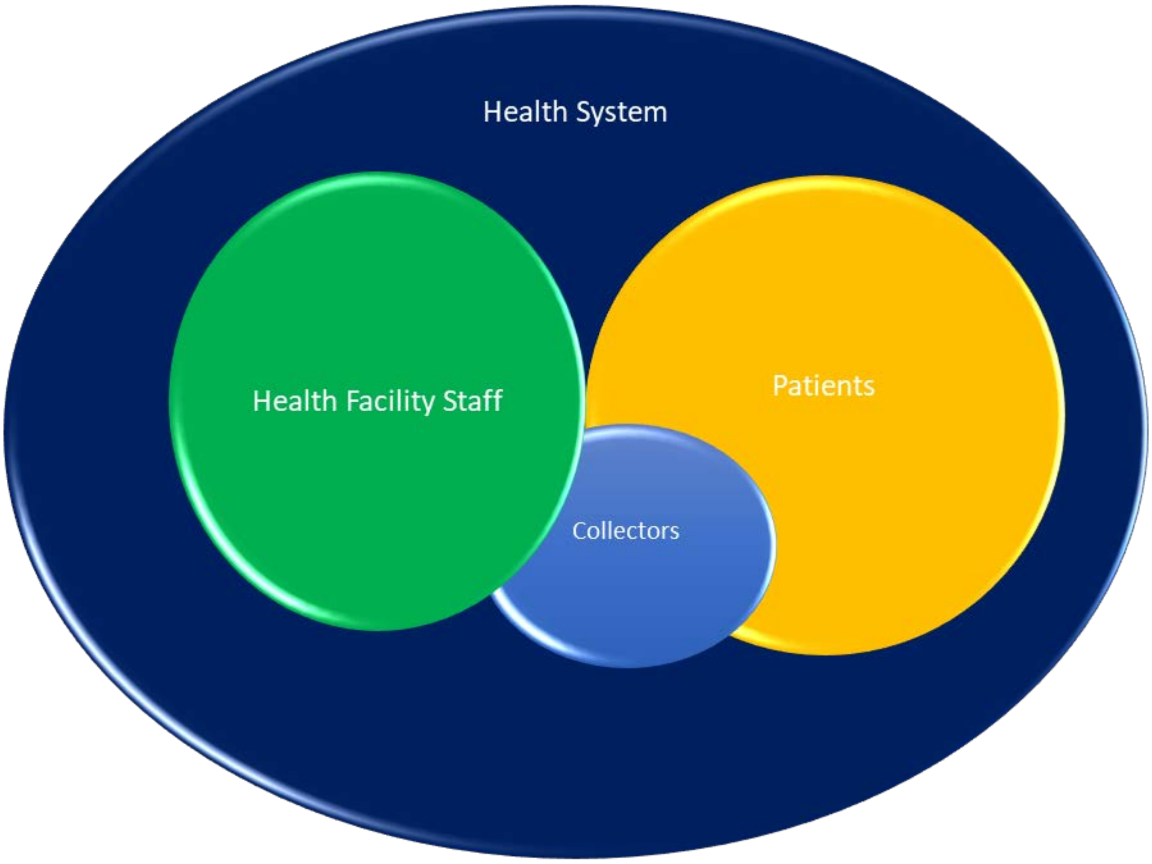


Figure 6: Diagrammatic representation of current position of collectors within the health system

This discussion will first focus on acceptability of collectors by patients and then it will discuss the perceptions that health facility staff have of the collectors and the perceived benefit to the larger public health system. Lastly, the discussion will consider the pre-requisites for formally and successfully integrating collectors into the health system to improve equity and access to chronic medication parcels.

## 5.2 Acceptability of collectors by patients

All patients found collectors to be highly acceptable and acknowledged the benefits of the services of a collector. In this this study, patients initiated the services of collectors as a means to overcome barriers such as transport, personal safety and competing commitments which hindered their ability to collect their routine monthly chronic medication parcel timeously. Several other studies have identified individual factors as barriers to collecting medication, however, very few have reported how patients have developed means to overcome these (Bigdeli et al., 2013; Kumar et al., 2016; Lin et al., 2008).

This study found that most collectors originated as family members and neighbours who assisted patients to overcome access barriers. Some collectors have developed from extended family support to more income-generating schemes, but all acknowledged the need to support their family members and local community. Despite the differences between the collectors, one commonality was their innate social responsibility towards their patients and community. The value that both patients and collectors placed on their relationship was noteworthy. We may speculate that if this concept is scaled-up then it may become a more competitive, business-orientated model compared to the current, patient-support model.

The phenomenon of collectors is not unique to Lotus River Community Day Centre (LRCDC) but has emerged at similar health facilities in the Western Cape. Significantly, patients from Lotus River recruited collectors with a specific set of positive attributes. This is contrary to other reports where patients had adverse experiences. For example, Hitchcock (2016) discovered that collectors in the Elsies River area were not sufficiently reliable to ensure that their patient received their CDU parcel timeously. It may be necessary for patients to be advised to screen collectors prior to recruitment to ensure that they have the desired qualities.

Noteworthy was the level of satisfaction of patients with collectors sharing of information and their unique communication techniques. This satisfaction may be due to the nature in which the collector transfers messages to the patient. This aspect of engaging with patients presents the role of collectors similar to that of established lay health workers for HIV adherence programmes in LMICs (Baiden et al., 2014; Franco, Bennett, & Kanfer, 2002; Sanjana, Torpey, Schwarzwalder, Simumba, Kasonde, Nyirenda, Kapanda, Kakungu-Simpungwe, et al., 2009; Schneider & Lehmann, 2010). This is augmented by literature on lay health workers that they are able to provide counselling and support and convey culturally sensitive messages to HIV patients (Atukunda et al., 2017a; Sanjana, Torpey, Schwarzwalder, Simumba, Kasonde, Nyirenda, Kapanda, Kakungu-, et al., 2009; Schneider & Lehmann, 2010; Tsolekile et al., 2014; Woldie et al., 2018). Similarly, collectors may be able to improve adherence to NCD medication regimes and promote positive healthy lifestyles of NCD patients.

Patients expressed enthusiasm at the thought that their collector may be up skilled, and they acknowledged the benefit of collectors to their personal health and subsequent improvement to their quality of life. This could potentially directly and positively affect the health system by alleviating strain on our precious health resources.

Despite one of the key features of collectors being home delivery of medication parcels, one high volume collector was highly acceptable to patients even though the patients were expected to collect their parcel from her home. This may be due to the convenience of closer proximity to patients' homes and the flexibility of after-hours collection from the collector's home. In contrast, a low volume collector who was found to be highly acceptable and in demand by patients chose to restrict the number of patients. Despite having an opportunity to become a high-volume collector, this collector focussed on informal consultations with patients regarding their general health and medication adherence in the comfort of their home. This collector retained a low volume of patients, explaining that it would take approximately 30 minutes to engage with a patient.  The reliability and organisational skills displayed by these two different types of collectors allowed them to both be highly acceptable by the community.

## 5.3 Acceptability of collectors to health facility staff

It was not surprising that, health facility staff had varied opinions regarding the acceptability of collectors. The reservation of health facility staff was three-fold. They were critical of the capability of collectors to render the collection and delivery service in a reliable manner and being accountable and responsible for the medication parcels. Secondly, not all health facility staff were convinced that the collectors who presented at LRCDC possessed the positive attributes as reported by patients, especially the organisational skills required to deliver medication parcels to multiple patients. Thirdly, they tended to be more sceptical about the motives of collectors as opposed to focussing on the potential benefit to the patients of the health system. It is plausible that most health professionals have not thought of how the collector service was personally benefiting patients and the public health system.

It is understandable that health facility staff working under professional mandates, regulatory frameworks and health department policies would have some apprehensions about collectors. Whilst working according to regulations is important, the community solution that emerged may require professionals and health facility staff to be flexible in order to meet the needs of the patients. The study found cognitive dissonance between the ability of facility staff to marry the community needs with the collectors' capabilities and in recognition of this to develop their competencies appropriately.

It is promising to note, that in recognition of moving forward and the need to modify the way health services are rendered, the Republic of South Africa has already amended Rule 2.7.5 to read "MINIMIUM STANDARDS SPECIFICALLY RELATING TO THE COLLECTION AND THE DELIVERY OF MEDICINES TO PATIENTS FROM A COMMUNITY OR INSTITUTIONAL PHARMACY". The Department of Health Notice 431 of 2017, dated 6 June 2017, Number 40892, clearly outlines the standards as general considerations, collection and delivery of medicines and transportation for the delivery of medicines (Appendix 1). Available electronically at www.gpwonline.co.za

Prior to the release of the notice, in November 2016, the pharmacy regulatory body, the South African Pharmacy Council had developed the first requirements and conditions for the evaluation of alternative models for delivery of chronic medication to patients (South African Pharmacy Council, 2016). The Western Cape Health Department have also acknowledged this movement towards medicine agents or collectors and has furthermore informed the public with regards to the importance of collection of chronic medication parcels, in saying that it is acceptable to send a proxy. An official public notification was printed and distributed as communication to patients attending health facilities in the Western Cape (Appendix 8).

Contrary to expectations all health facility staff lauded the one well-known high-volume female collector who displayed exceptional organisational skills. This may be perceived as a good notion in that if the collector system is formalised and structured with supervision of trained collectors then it may be more acceptable to health facility staff. Similarly, since the advent of CHWs and lay health workers, there has been reluctance from facility based staff

(Magadzire et al., 2016) Currently there is a plethora of studies as their role and function and acceptability into the health system has developed (Flämig et al., 2019; Sanjana, Torpey, Schwarzwalder, Simumba, Kasonde, Nyirenda, Kapanda, Kakungu-Simpungwe, et al., 2009; Schneider et al., 2008; Tsolekile et al., 2014; Woldie et al., 2018).

Furthermore, health facility staff acknowledged that after the appropriate training and up-skilling of collectors could be advantageous to the health system. We may speculate that health facility staff may be more supportive of collectors once an official collector programme with clearly defined principles and functions has been established. Tsolekile (2018) has reported the importance of formalising roles of CHWs and lay health workers since competency levels and training needs would differ depending on whether they are general or specialised.

## 5.4 Pre-requisites for integrating collectors into the public health system

Two major pre-requisites for integrating a collector programme into the public health system were reported by participants. Health professionals indicated that collectors would need to be up skilled if they were to play a greater role in medication collection and delivery. The finding that collectors having minimal formal education but are eager to embark on a training programme indicates the potential success of such a development programme. Another pre-requisite would be the formal inclusion of collectors into the public health system. Significantly, collectors have the ability to appeal to patients on an individual level, a client-centred approach which underscores the core values of the Department of Health (Western Cape Department of Health, 2018).

Lay health workers have successfully been used in HIV adherence in different forms within the health system (Woldie et al., 2018). Collectors could potentially be the informal counterpart of lay health workers for patients with NCDs. The growing number of patients requiring NCD treatment coupled with the high demands on facility based health professionals to convey critical continual education regarding safe medication use and health messages present an opportunity to the health system to evolve to meet the needs of all patients (Bigdeli et al., 2015). This however does not negate the fact that health professionals are an essential and valued part of the healthcare system; and cannot be replaced (Sanjana, Torpey, Schwarzwalder, Simumba, Kasonde, Nyirenda, Kapanda, Kakungu-Simpungwe, et al., 2009). From a pharmaceutical professionals and health system point of view it may be the time for modification of service delivery. The WHO supports the notion that in LMIC, lay health workers provide an opportunity for task shifting (Coleman et al., 1998). The concept of collectors as lay health workers presents a unique opportunity for task shifting to improve equity in access to chronic medication and develop their role at the interface between formal health services and civil society. In light of the growing NCD burden, the collector's system creates an opportunity to train and develop their competency as medication lay counsellors.

If collectors were to become a more integral part of the health system, their role and function would need to be clearly defined based on their competency and clear division of responsibility. Previous studies have determined the use of lay workers in HIV adherence club as quite acceptable and feasible in LMIC, despite initially there being reservations and challenges (Baiden et al., 2014; Sanjana, Torpey, Schwarzwalder, Simumba, Kasonde, Nyirenda, Kapanda, Kakungu-Simpungwe, et al., 2009). The unique characteristics, values, competency and understanding rendered them suitable to support HIV patients. It may be speculated that the concept would be similar for elderly and frail NCD patients who require added support, but the concept may not necessarily suit all CDU patients in the community.

Medication in combination with continual support and education are the requirements for better health outcomes (Atun et al., 2013; Woldie et al., 2018). A growing body of evidence exists which displays effectiveness of community health volunteers for diabetic patients. Authors have reported that the continual social support and education allow diabetic patients to achieve optimal blood sugar levels (Harries, Jahn, Zachariah, & Enarson, 2008).

An opinion paper published by the School of Pharmacy at the University of the Western Cape described the possibility of extending the opportunity for collecting and delivery of CDU parcels to patients by currently employed CHW's (Boswell, Conradie, Keshave, Khan, & Mngadi, 2018). A collaborative effort between the University of Western Cape School of Pharmacy is currently in progress, harnessing the current CHWs as an approach to integrate them as medicine runners into the health system. Currently the debate continues as to whether CHWs role should be specialised or generalised.  Some may argue that specialised CHWs allow patients to receive better quality of care, as opposed to a generalised CHW who would be able to provide a more holistic approach. For medication collection and delivery, it would be imperative that the collector has specific knowledge and understanding to appropriately handle medication.

Home delivery and various other models that allow patients to overcome barriers are emerging to allow better access to chronic medication. Iyeza Health is one emerging model. In an interview, the founder remarked that he hires people that shares the vision, core values and passion to learn and help the community as opposed to wanting the monetary gain (Mykhalevych, 2019). This aligns to the results of this study which indicated that similarly patients recruit collectors who have a specific set of values, altruism and understanding. These systems of delivery have been established external to the health system but are now more integrated into the public health system. This is evidence that this formalised model is feasible and acceptable to patients willing to pay a small fee for this service.

Pharmacy Direct is a courier service to both public and private health facilities in other provinces in South Africa, including KwaZulu-Natal. As at June 2019, they commenced a bicycle courier model which allows delivery directly to patients' homes (Chowles, 2018). Similarly, private medical aids and franchised retail pharmacies provide the option to patients, at a minimal fee, to have their chronic medication delivered to the address of their choice.

Both these models employ lay workers who make contact with the patients. However this model is not a one size fits all. Participants of this study presented that they would prefer the person who they make contact with to have some knowledge of their chronic condition, medication regime and have an invested interest in their health.  Most business models for home delivery, do not offer this type of support to patients.

## 5.5 Limitations of the study

This study had two major limitations. Due to the limited time and resources available for a mini-thesis the researcher was not able to reach data saturation, which is a desired goal of qualitative research.

The researcher was employed at LRCDC, in the capacity of Responsible Pharmacist, during the data collection period. To avoid participant courtesy bias, the researcher employed the following strategies:

- Each participant was assured that data was being collected for the research project, as described in the participant information sheet.
- After enrolment into the study each participant was informed that there are no right or wrong responses but and that their honest accounts are valued by the researcher.

## 5.6 Summary

The study found that collectors are a patient driven phenomenon with established acceptability by patients. Health facility staff recognize the need for collectors but found it difficult to navigate the notion of collectors within the context of strict regulations and work guidelines. Significantly, recent South African Pharmacy Council regulations related to Good Pharmacy Practice have been reviewed and updated to include the minimum standards related to collecting and delivering medication which appears to pave the way for innovations such as medicine collectors. Lay health workers are deemed capable to supplement some aspects of services provided by facility based health professionals, particularly in the fields of HIV and TB care and treatment. Similarly, collectors could provide a home delivery service for patients with chronic NCDs with the potential to impart knowledge about adherence to chronic medication. This is an important consideration that has the potential to be embedded as an initiative related to the CDU and CCMDD programmes, as part of both the South Africa's National Health Insurance and WHO's objective towards strengthening access to medicines.

# CHAPTER SIX: CONCLUSION & RECOMMENDATIONS

## 6.1 Conclusion

Collectors as individuals were deemed highly acceptable to their patients. To a lesser degree, the health facility staff also found the individual collectors to be acceptable. As a system which operates both within the facility and in the community, collectors act as intermediary between patients, larger community and the health facility. The collector system is an intervention which addresses patient factors, socio-economic factors and health system factors that influences non-collection of chronic medication parcels. For this reason, the collector system has the potential to become a critical component in the improvement of chronic disease management programmes.

Similar to lay health workers for HIV adherence programmes, an advantage of collectors is that they are from the same community with similar backgrounds and language to the patients that they serve. Health facility staff recognise that collectors as lay health volunteers with appropriate training could potentially offer a service which aligns with the health goals of the Department of Health. Patients appeared more excited at the possibility of receiving medication and health advice and support from someone who understands them. Apprehensions from health facility staff regarding the current role and function of collectors clearly indicate the lower extent to which they agree with the system. There is thus a challenge to successfully up-skill collectors as lay medicine carriers with caution to safeguard against infringement on the duties of professional health staff.

The newly developed Rules relating to Good Pharmacy Practice are based on the assumption that the person who is collecting and delivering medication has some knowledge of medicine handling, since the expectation is for the collector or medicine agent to comply with the prescribed minimum standards. (South African Pharmacy Council, 2016). However, it does not explicitly mention that this “training” or knowledge should be provided to the “medicine agent”. Medicine agents or collectors who receive the adequate coaching and have requisite skills may provide the educational and social support required to overcome some of the barriers of medicine access and minimise the harmful consequences related to non-collection.

## 6.2 Recommendations based on findings

The following short-term measures should be implemented at facility level for more effective management of the current collector system to comply with regulations.

- The facility should formally accept the collectors as supporters of better health outcomes for the community through an internal voluntary formal registration process.
- The facility should keep a record of collectors contact details.
- With the appropriate consent from collectors their contact details could be made available to patients on their request.
- Patients who employ the services of a collector should be encouraged to screen collectors prior to an agreement to ensure that they have the positive attributes required to perform the service. Furthermore, patients should refrain from employing multiple collectors.
- The establishment of a designated time slot for collectors would provide an opportunity for pharmacy staff to provide basic instructions to collectors with regards to medicine control and safety during transport.
- The CDU service provider should provide an option for patients who employ a collector to also receive a SMS reminder.
- Collectors should be encouraged to always carry a copy of the authorisation letters and valid copies of both their identification document and the patients' identification document at every visit to the facility.

As a long-term measure, collectors should be equipped to safely distribute medication parcels through a standardised training programme designed for them to become a new or complimentary cadre of community health volunteers. Upon successful completion of such programme, collectors may be awarded a competency certificate and identification badges.

## 6.3 Recommendations for further research

- Since the collector system is active in government health facilities in the Western Cape, further quantitative analysis of the magnitude of the system would inform future development of a formalised collector system to support CDU patients.
- An analysis of the different internal processes for collectors operational at the various health facilities, should be investigated. Best practices should be presented as shared learning and their role and responsibilities should be clearly defined.
- A study should be performed to establish the current knowledge and competency of collectors. This would inform the development of an evidence-based, structured training programme for collectors, to adequately perform their function.

# REFERENCES

Abegaz, T. M., Shehab, A., Gebreyohannes, E. A., Bhagavathula, A. S., & Elnour, A. A. (2017). Nonadherence to antihypertensive drugs a systematic review and meta-analysis. *Medicine*, Vol. 96. https://doi.org/10.1097/MD.0000000000005641

Alghurair, S. A., Hughes, C. A., Simpson, S. H., & Guirguis, L. M. (2012). A systematic review of patient self-reported barriers of adherence to antihypertensive medications using the world health organization multidimensional adherence model. *Journal of Clinical Hypertension*, Vol. 14, pp. 877–886.

Atukunda, E. C., Musiimenta, A., Musinguzi, N., Wyatt, M. A., Ashaba, J., Ware, N. C., & Haberer, J. E. (2017a). Understanding Patterns of Social Support and Their Relationship to an ART Adherence Intervention Among Adults in Rural Southwestern Uganda. *AIDS and Behavior, 21*(2), 428–440. https://doi.org/10.1007/s10461-016-1559-7

Atukunda, E. C., Musiimenta, A., Musinguzi, N., Wyatt, M. A., Ashaba, J., Ware, N. C., & Haberer, J. E. (2017b). Understanding Patterns of Social Support and Their Relationship to an ART Adherence Intervention Among Adults in Rural Southwestern Uganda. *AIDS and Behavior*. https://doi.org/10.1007/s10461-016-1559-7

Atun, R., Jaffar, S., Nishtar, S., Knaul, F. M., Barreto, M. L., Nyirenda, M., … Piot, P. (2013). Improving responsiveness of health systems to non-communicable diseases. *The Lancet*. https://doi.org/10.1016/S0140-6736(13)60063-X

Baertlein, L. (2019). UPS Drone Makes First Home Prescription Deliveries for CVS. Retrieved from IOL Business Report website: www.iol.co.za/business-report/international/ups-drone-makes-first-home-prescription-deliveries-for-cvs-36748570.

Baiden, F., Akweongo, P., Debpuur, C., Health, N., Binka, F., & Sciences, A. (2014). *Using lay counsellors to promote community-based voluntary counselling and HIV testing in rural northern Ghana : A baseline survey on community acceptance and sti .... USING LAY COUNSELLORS TO PROMOTE COMMUNITY-BASED VOLUNTARY COUNSELLING AND HIV TESTING* . (May). https://doi.org/10.1017/S0021932006001829

Baum, F. (1995). Researching Public Health: Behind the Qualitative-Quantitative Methodological Debate*. *Social Science and Medicine Med*, *4068*(4), 277–9536.

Bigdeli, M., Jacobs, B., Tomson, G., Laing, R., Ghaffar, A., & Dujardin, B. (2013). *Access to medicines from a health system perspective*. (November 2012), 692–704. https://doi.org/10.1093/heapol/czs108

Bigdeli, M., Laing, R., Tomson, G., & Babar, Z. U. D. (2015). Medicines and universal health coverage:Challenges and opportunities. *Journal of Pharmaceutical Policy and Practice*. https://doi.org/10.1186/s40545-015-0028-4

Bobrow, K., Farmer, A. J., Springer, D., Shanyinde, M., Yu, L. M., Brennan, T., … Levitt, N. (2016). Mobile Phone Text Messages to Support Treatment Adherence in Adults with High Blood Pressure (SMS-Text Adherence Support [StAR]): A Single-Blind, Randomized Trial. *Circulation*, *133*(6), 592–600. https://doi.org/10.1161/CIRCULATIONAHA.115.017530

Bosch-Lenders, D., Maessen, D. W. H. A., Jelle Stoffers, H. E. J. H., André Knottnerus, J., Winkens, B., & Van Den Akker, M. (2016). Factors associated with appropriate knowledge of the indications for prescribed drugs among Community-Dwelling older patients with polypharmacy. *Age and Ageing*, *45*(3), 353–359. https://doi.org/10.1093/ageing/afw045

Boswell, D., Conradie, S., Keshave, B., Khan, T., & Mngadi, S. (2018). *Medicine Runners : A community-initiated solution to chronic medicine access in underserved communities*. *85*(4), 64–67.

Bowen, G. a. (2005). Preparing a qualitative research-based dissertation: Lessons learned. *The Qualitative Report*. https://doi.org/no doi on file

Bradley, H., & Laing, R. (2015). Access to medicines – Overcoming the barriers. *Eastern Mediterranean Health Journal*. https://doi.org/10.26719/2015.21.8.553

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101.

Braun, V., & Clarke, V. (2016). (Mis)conceptualising themes, thematic analysis, and other problems with Fugard and Potts' (2015) sample-size tool for thematic analysis. *International Journal of Social Research Methodology*, *19*(6), 739–743. https://doi.org/10.1080/13645579.2016.1195588

Castle-Clarke, S. (2016). NHI Whitepaper. South Africa Department of Planning Monitoring and Evaluation, *Government Gazette*, *633*(1), 1. https://doi.org/10.1080/00293652.1976.9965235

Chowles, T. (2018). NDoH Partners with New Chronic Medication Distributor. Retrieved from EHealth News ZA website: ehealthnews.co.za/ndoh-partners-new-chronic-medication-distributor/.

Clicks Direct Medicine. (2008). South Africa's Courier Pharmacy of Choice. Retrieved from www.clicksdirectmedicine.co.za/index.php/about-us

Coleman, R., Gill, G., & Wilkinson, D. (1998). Noncommunicable disease management in resource-poor settings: A primary care model from rural South Africa. *Bulletin of the World Health Organization*, *76*(6), 633–640.

Creswel, J. W. (2008). The Selection of a Research Approach. *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*, 3–22. https://doi.org/45593:01

Daar, A. S., Singer, P. A., Persad, D. L., Pramming, S. K., Matthews, D. R., Beaglehole, R., … Bell, J. (2007, November 21). Grand challenges in chronic non-communicable diseases. *Nature*, Vol. 450, pp. 494–496. https://doi.org/10.1038/450494a

Dalal, S., Beunza, J. J., Volmink, J., Adebamowo, C., Bajunirwe, F., Njelekela, M., … Holmes, M. D. (2011). Non-communicable diseases in sub-Saharan Africa: What we know now. *International Journal of Epidemiology*, *40*(4), 885–901. https://doi.org/10.1093/ije/dyr050

Dardano, A., Penno, G., Del Prato, S., & Miccoli, R. (2014). Optimal therapy of type 2 diabetes: A controversial challenge. *Aging*, *6*(3), 187–206. https://doi.org/10.18632/aging.100646

Day, C., Groenewald, P., Laubscher, R., Chaudhry, S., van Schaik, N., & Bradshaw, D. (2014). Monitoring of non-communicable diseases such as hypertension in South Africa: Challenges for the post-2015 global development agenda. *South African Medical Journal*. https://doi.org/10.7196/SAMJ.7868

De Geest, S., & Sabaté, E. (2003). Adherence to long-term therapies: Evidence for action. *European Journal of Cardiovascular Nursing*, *2*(4), 323. https://doi.org/10.1016/S1474-5151(03)00091-4

Dodgson, J. E. (2019). Reflexivity in Qualitative Research. *Journal of Human Lactation*, *35*(2), 220–222. https://doi.org/10.1177/0890334419830990

Du Plessis, J. (2008). The Chronic Dispensing Unit. *South African Pharmaceutical Journal*.

Flämig, K., Decroo, T., van den Borne, B., & van de Pas, R. (2019). ART adherence clubs in the Western Cape of South Africa: what does the sustainability framework tell us? A scoping literature review. *Journal of the International AIDS Society*, Vol. 22, pp. 1–15. https://doi.org/10.1002/jia2.25235

Franco, L. M., Bennett, S., & Kanfer, R. (2002). Health sector reform and public sector health worker motivation: a conceptual framework. *Social Science & Medicine*, *54*(8), 1255–1266. https://doi.org/10.1016/S0277-9536(01)00094-6

Fullman, N., Barber, R. M., Abajobir, A. A., Abate, K. H., Abbafati, C., Abbas, K. M., … Murray, C. J. L. (2017). Erratum: Measuring progress and projecting attainment on the basis of past trends of the health-related Sustainable Development Goals in 188 countries: an analysis from the Global Burden of Disease Study 2016 (The Lancet (2017) 390(10100) (1423–1459) (S01. *The Lancet*. https://doi.org/10.1016/S0140-6736(17)32650-8

Gadkari, A. S., & McHorney, C. a. (2012). Unintentional non-adherence to chronic prescription medications: How unintentional is it really? *BMC Health Services Research*, *12*(1), 98. https://doi.org/10.1186/1472-6963-12-98

Gazmararian, J. A., Kripalani, S., Miller, M. J., Echt, K. V., Ren, J., & Rask, K. (2006). Factors associated with medication refill adherence in cardiovascular- related diseases: A focus on health literacy. *Journal of General Internal Medicine*, *21*(12), 1215–1221. https://doi.org/10.1111/j.1525-1497.2006.00591.x

Gilson, L., & Daire, J. (2011). Leadership and governance within the South African health system. *South African Health Review*, 69–80. Retrieved from http://reference.sabinet.co.za/sa_epublication_article/healthr_2011_a8

Golafshani, N. (2003). Understanding reliability and validity in qualitative research. *The Qualitative Report*, *8*(4), 597–607. https://doi.org/10.3367/UFNr.0180.201012c.1305

Golden-Biddle, K., & Locke, K. L. (2007). *Qualitative Composing Second Edition*. Sage.

Gray, A., Riddin, J., & Jugathpal, J. (2016). Health care and pharmacy practice in South Africa. *Canadian Journal of Hospital Pharmacy*, *69*(1), 36–41. https://doi.org/10.4212/cjhp.v69i1.1521

Groenewald, P., Neethling, I., Evans, J., Azevedo, V., Naledi, T., Matzopoulos, R., … Bradshaw, D. (2017). Mortality trends in the city of Cape Town between 2001 and 2013: Reducing inequities in health. *South African Medical Journal*, *107*(12), 1091–1098. https://doi.org/10.7196/SAMJ.2017.v107i12.12458

Guba, E. G. E., & Lincoln, Y. S. Y. (1994). Competing Paradigms in Qualitative Research. *Handbook of Qualitative Research*, pp. 105–117. https://doi.org/http://www.uncg.edu/hdf/facultystaff/Tudge/Guba%20&%20Lincoln%20 1994.pdf

Guest, G., MacQueen, K., & Namey, E. (2014). Writing Up Thematic Analyses. In *Applied Thematic Analysis*. https://doi.org/10.4135/9781483384436.n10

Harries, A. D., Jahn, A., Zachariah, R., & Enarson, D. (2008). Adapting the DOTS Framework for Tuberculosis Control to the Management of Non-Communicable Diseases in Sub-Saharan Africa. *PLoS Medicine*, *5*(6), e124. https://doi.org/10.1371/journal.pmed.0050124

Hitchcock, H. (2016). *Factors that influence the collection of chronic medication parcels by patients with Type 2 diabetes from a primary health care facility in the Western Cape Province Henriette Hitchcock*. (November).

Horne, R., Chapman, S. C. E., Parham, R., Freemantle, N., Forbes, A., & Cooper, V. (2013). Understanding Patients' Adherence-Related Beliefs about Medicines Prescribed for Long-Term Conditions: A Meta-Analytic Review of the Necessity-Concerns Framework. *PLoS ONE*, *8*(12), e80633. https://doi.org/10.1371/journal.pone.0080633

Isaacs, A., Manga, N., Le Grange, C., Hellenberg, D., Titus, V., & Sayed, R. (2014). A snapshot of noncommunicable disease profiles and their prescription costs at ten primary healthcare facilities in the in the western half of the Cape Town Metropole. *South African Family Practice*, *56*(1), 43–49. https://doi.org/10.1080/20786204.2014.10844582

Iuga, A. O., & McGuire, M. J. (2014). Adherence and health care costs. *Risk Management and Healthcare Policy*, *7*, 35–44. https://doi.org/10.2147/RMHP.S19801

Jon, R. E., Vincent, S., Calle, H., Narah, S., Sonja, V., Kobie, V., & Langa, M. (2008). Information for Primary Health Care. *South African Health Review*, 195–210.

Jootun, D., McGhee, G., & Marland, G. R. (2009). Reflexivity: promoting rigour in qualitative research. *Nursing Standard (Royal College of Nursing (Great Britain) : 1987)*. https://doi.org/10.7748/ns2009.02.23.23.42.c6800

Kagee, A., Le Roux, M., & Dick, J. (2007). Treatment adherence among primary care patients in a historically disadvantaged community in South Africa: a qualitative study. *Journal of Health Psychology*, *12*(3), 444–460. https://doi.org/10.1177/1359105307076232

Kirk, J., & Miller, M. (2012). Reliability and Validity in Qualitative Research. In *Reliability and Validity in Qualitative Research*. https://doi.org/10.4135/9781412985659

Kleiman, S. (2004). Phenomenology: to wonder and search for meanings. *Nurse Researcher*, *11*(4), 7–19. https://doi.org/10.7748/nr2004.07.11.4.7.c6211

Knight, L., Mukumbang, F. C., & Schatz, E. (2018). Behavioral and cognitive interventions to improve treatment adherence and access to HIV care among older adults in sub-Saharan Africa: An updated systematic review. *Systematic Reviews*. https://doi.org/10.1186/s13643-018-0759-9

Krousel-Wood, M., Hyre, A., Muntner, P., & Morisky, D. (2005). Methods to improve medication adherence in patients with hypertension: Current status and future directions.

*Current Opinion in Cardiology*. https://doi.org/10.1097/01.hco.0000166597.52335.23

Krska, J., Morecroft, C. W., Poole, H., & Rowe, P. H. (2013). Issues potentially affecting quality of life arising from long-term medicines use: A qualitative study. *International Journal of Clinical Pharmacy*, *35*(6), 1161–1169. https://doi.org/10.1007/s11096-013-9841-5

Kumar, K., Greenfield, S., & Raza, K. (2016). Understanding adherence-related beliefs about medicine amongst patients of South Asian origin with diabetes and cardiovascular disease patients: a. *Bmc*, 1–11. https://doi.org/10.1186/s12902-016-0103-0

Lalkhen, H., & Mash, R. (2015). Multimorbidity in non-communicable diseases in South African primary healthcare. *South African Medical Journal*. https://doi.org/10.7196/SAMJ.8696

Lee, V. W., Pang, K. K., Hui, K. C., Kwok, J. C., Leung, S. L., Yu, D. S. F., & Lee, D. T. F. (2013). Medication adherence: Is it a hidden drug-related problem in hidden elderly? *Geriatrics and Gerontology International*, *13*(4), 978–985. https://doi.org/10.1111/ggi.12042

Letsoalo, T. (2014). Sizwe Nzima’s Iyeza Express: Medicine on Wheels. Retrieved from Cape Town Magazine website: www.capetownmagazine.com/social/iyeza-express-medicine-on-wheels/118_22_19021.

Lin, J., Sklar, G. E., Oh, V. M. Sen, & Li, S. C. (2008). Factors affecting therapeutic compliance: A review from the patient’s perspective. *Therapeutics and Clinical Risk Management*, *4*(1), 269–286. https://doi.org/https://dx.doi.org/10.2147/TCRM.S1458

Magadzire, B. P., Marchal, B., & Ward, K. (2015). Improving access to medicines through centralised dispensing in the public sector: A case study of the Chronic Dispensing Unit in the Western Cape Province, South Africa. *BMC Health Services Research*, *15*(1), 1–8. https://doi.org/10.1186/s12913-015-1164-x

Magadzire, B. P., Marchal, B., & Ward, K. (2016). Novel models to improve access to medicines for chronic diseases in South Africa: An analysis of stakeholder perspectives on community-based distribution models. *Journal of Pharmaceutical Policy and Practice*, *9*(1), 1–12. https://doi.org/10.1186/s40545-016-0082-6

Magadzire PhD Candidate, B. P., Mathys, T., & Ward, K. (2014). Improving medicine supply chain efficiency through centralised dispensing of ART and other chronic medicines: a South African model. *20th International AIDS Conference, July 20-25, 2014, Melbourne, Australia*.

Marks, D., & Yardley, L. (2011). Content and Thematic Analysis. In *Research Methods for Clinical and Health Psychology*. https://doi.org/10.4135/9781849209793.n4

Marrero, S., & Adashi, E. Y. (2015). Noncommunicable diseases. *Seminars in Reproductive Medicine*, *33*(1), 35–40. https://doi.org/10.1055/s-0034-1395277

Marshall, M. N. (1996). Sampling for qualitative research. *Family Practice*, *13*(6), 522–526. https://doi.org/10.1093/fampra/13.6.522

Maskew, M., Macphail, P., Menezes, C., & Rubel, D. (2007). Lost to follow up - contributing factors and challenges in South African patients on antiretroviral therapy. *Samj*, *97*(9), 853–857.

Mathers, C. D., & Loncar, D. (2006). Projections of global mortality and burden of disease from 2002 to 2030. *PLoS Medicine*. https://doi.org/10.1371/journal.pmed.0030442

Maxwell, J. A., & Reybold, L. E. (2015). Qualitative Research. In *International Encyclopedia of the Social & Behavioral Sciences: Second Edition*. https://doi.org/10.1016/B978-0-08-097086-8.10558-6

MaxwellQ, J. A. (2009). Designing a qualitative study. *Applied Social Research Methods*, 214–253.

Mays, N., & Pope, C. (1995). Rigour and qualitative research. *British Medical Journal*. https://doi.org/10.1136/bmj.311.6997.109

Mays, N., & Pope, C. (2006). Qualitative research in health care: Assessing quality in qualitative research. *British Medical Journal*, *2000*(320), 50–52. https://doi.org/10.1136/bmj.320.7226.50

Meyer, J. C., Schellack, N., Stokes, J., Lancaster, R., Zeeman, H., Defty, D., … Steel, G. (2017). Ongoing initiatives to improve the quality and efficiency of medicine use within the public healthcare system in South Africa; A preliminary study. *Frontiers in Pharmacology*, *8*(NOV), 1–16. https://doi.org/10.3389/fphar.2017.00751

Monnickendam, M., Monnickendam, S. M., Katz, C., & Katan, J. (2007). Health care for the poor—An exploration of primary-care physicians’ perceptions of poor patients and of their helping behaviors. *Social Science & Medicine*, *64*(7), 1463–1474. https://doi.org/10.1016/J.SOCSCIMED.2006.11.033

Morrell, R. W., Park, D. C., Kidder, D. P., & Martin, M. (1997). Adherence to antihypertensive medications across the life span. *The Gerontologist*, *37*(5), 609–619. https://doi.org/10.1093/geront/37.5.609

Morrow, S. L. (2005). Quality and Trustworthiness in Qualitative Research in Counseling Psychology. *Journal of Counseling Psychology*, *52*(2), 250–260. https://doi.org/10.1037/0022-0167.52.2.250

Mukumbang, F. C., Mwale, J. C., & Van Wyk, B. (2017). Conceptualising the Factors Affecting Retention in Care of Patients on Antiretroviral Treatment in Kabwe District, Zambia, Using the Ecological Framework. *AIDS Research and Treatment*. https://doi.org/10.1155/2017/7356362

Mukumbang, F. C., Van Belle, S., Marchal, B., & Van Wyk, B. (2016). Realist evaluation of the antiretroviral treatment adherence club programme in selected primary healthcare facilities in the metropolitan area of Western Cape Province, South Africa: A study protocol. *BMJ Open*, *6*(4). https://doi.org/10.1136/bmjopen-2015-009977

Munro, S., Lewin, S., Swart, T., & Volmink, J. (2007). A review of health behaviour theories: How useful are these for developing interventions to promote long-term medication adherence for TB and HIV/AIDS? *BMC Public Health*. https://doi.org/10.1186/1471-2458-7-104

Mykhalevych, N. (2019). Iyeza Health: Beyond Delivering Medication in South Africa. Retrieved from Seedstars website: www.seedstars.com/magazine/iyeza-health-beyond-delivering-medication-south-africa/.

Nakkeeran, N., & Zodpey, S. (2012). Qualitative research in applied situations: Strategies to ensure rigor and validity. *Indian Journal of Public Health*, *56*(1), 4.

https://doi.org/10.4103/0019-557X.96949

*No Title*. (2012). (Intd 670), 64–81.

Olsson, I. N., Runnamo, R., & Engfeldt, P. (2012). Drug treatment in the elderly: an intervention in primary care to enhance prescription quality and quality of life. *Scandinavian Journal of Primary Health Care*, *30*(1), 3–9. https://doi.org/10.3109/02813432.2011.629149

Osterberg, L., & Blaschke, T. (2005). Drug Therapy: Adherence to Medication. *The New England Journal of Medicine*. https://doi.org/10.1056/NEJMra050100

Osterberg, L., Blaschke, T., & Koop, — C Everett. (2005). Adherence to Medication. *N Engl J Med*, *353*, 487–497. https://doi.org/10.1056/NEJMra050100

Patterson, S. M., Bradley, M. C., Kerse, N., Cardwell, C. R., & Hughes, C. M. (2013). Interventions to improve the appropriate use of polypharmacy for older people: A cochrane systematic review. *Pharmacoepidemiology and Drug Safety*, *Conference*(5), and-686. https://doi.org/http://dx.doi.org/10.1111/j.2042-7174.2011.00102.x

Patton, M Q. (1999). Enhancing the quality and credibility of qualitative analysis. *Health Services Research*.

Patton, Michael Quinn. (2002). Patton 2002.pdf. *Qualitative Research and Evaluation Methods*.

Petronio, S., Sargent, J., Andea, L., Reganis, P., & Cichocki, D. (2004). Family and friends as healthcare advocates: Dilemmas of confidentiality and privacy. *Journal of Social and Personal Relationships*, *21*(1), 33–52. https://doi.org/10.1177/0265407504039838

Phul, S., Bessell, T., & Cantrill, J. A. (2004). Alternative delivery methods for pharmacy services. *International Journal of Pharmacy Practice*, *12*(2), 53–63. https://doi.org/10.1211/0022357023709

Pillay-van Wyk, V., Msemburi, W., Laubscher, R., Dorrington, R. E., Groenewald, P., Glass, T., … Bradshaw, D. (2016). Mortality trends and differentials in South Africa from 1997 to 2012: second National Burden of Disease Study. *The Lancet Global Health*. https://doi.org/10.1016/S2214-109X(16)30113-9

Reeves, S., Albert, M., Kuper, A., & Hodges, B. D. (2008). Qualitative research: Why use theories in qualitative research? *BMJ*, *337*. https://doi.org/10.1136/bmj.a949Sandelowski, M., & Barroso, J. (2003). Classifying the findings in qualitative studies. Qual Health Res, 13(7), 905–923. https://doi.org/10.1177/1049732303253488

Robson, Colin, McCartan, K. (2016a). Real World Research: A Resource for Users oof Social Research Methods in Applied Settings. In *Wiley*. Wiley.

Robson, Colin, McCartan, K. (2016b). Real World Research: A Resource for Users oof Social Research Methods in Applied Settings. In *Wiley*.

Sandelowski, M., & Barroso, J. (2003). Classifying the findings in qualitative studies. *Qualitative Health Research*, *13*(7), 905–923. https://doi.org/10.1177/1049732303253488

Sanjana, P., Torpey, K., Schwarzwalder, A., Simumba, C., Kasonde, P., Nyirenda, L., …

Thompson, C. (2009). *Human Resources for Health Task-shifting HIV counselling and testing services in Zambia : the role of lay counsellors*. *7*, 1–7. https://doi.org/10.1186/1478-4491-7-44

Sanjana, P., Torpey, K., Schwarzwalder, A., Simumba, C., Kasonde, P., Nyirenda, L., … Thompson, C. (2009). Task-shifting HIV counselling and testing services in Zambia: The role of lay counsellors. *Human Resources for Health*, *7*. https://doi.org/10.1186/1478-4491-7-44

Sastry, A., Long, K. N. G., de Sa, A., Salie, H., Topp, S., Sanghvi, S., & van Niekerk, L. (2015). Collaborative action research to reduce persistently long patient wait times in two public clinics in Western Cape, South Africa. *The Lancet Global Health*. https://doi.org/10.1016/s2214-109x(15)70137-3

Schneider, H, & Lehmann, U. (2010). *Lay health workers and HIV programmes : implications for health systems*. *0121*. https://doi.org/10.1080/09540120903483042

Schneider, Helen, Hlophe, H., & Rensburg, D. Van. (2008). *Community health workers and the response to HIV / AIDS in South Africa : tensions and prospects*. (April), 179–187. https://doi.org/10.1093/heapol/czn006

Scott, I. A., Gray, L. C., Martin, J. H., & Mitchell, C. A. (2012). Minimizing inappropriate medications in older populations: A 10-step conceptual framework. *American Journal of Medicine*, *125*(6), 529-537.e4. https://doi.org/10.1016/j.amjmed.2011.09.021

Shaw, R. L., Larkin, M., & Flowers, P. (2014, December 1). Expanding the evidence within evidence-based healthcare: Thinking about the context, acceptability and feasibility of interventions. *Evidence-Based Medicine*, Vol. 19, pp. 201–203. https://doi.org/10.1136/eb-2014-101791

Shenton, A. K. (2004a). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, *22*, 63–75. https://doi.org/10.1111/j.1744-618X.2000.tb00391.x

Shenton, A. K. (2004b). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*. https://doi.org/10.3233/EFI-2004-22201

Silverman, D. (2013). Doing Qualitative Research: A Practical Handbook. In *Sage Publications* (Fourth). London: Sage.

Smit, S. (2019). Pelebox: A Cure for Clinic Queues. Retrieved from The M&G Online, website: mg.co.za/article/2019-06-07-00-pelebox-a-cure-for-clinic-queues.

Spencer, L., Ritchie, J., Lewis, J., & Dillon, L. (2003). Quality in Qualitative Evaluation : A framework for assessing research evidence A Quality Framework. *Social Research*, *108*(21/08/05), 170. https://doi.org/10.1093/eurpub/ckv219

Staden, S. van. (2013). Alternative Distribution of Chrinic Medication to Clients in the Winelands. *ANOVA Cape Winelands Health Systems Strengthening Workshop*.

Statistics South Africa. (2012). Census 2011 - Census in brief. In *Stats SA Library Cataloguing-in-Publication*. https://doi.org/ISBN 978-0-621-41388-5

Tobin, G. A., & Begley, C. M. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing*, *48*(4), 388–396. https://doi.org/10.1111/j.1365-2648.2004.03207.x

Toit, J. (2017). *Alternative models for delivery of medication to stable patients on long term therapy*. *84*(3), 56–57.

Tracy, S. J. (2010). Qualitative quality: Eight a"big-tent" criteria for excellent qualitative research. *Qualitative Inquiry*. https://doi.org/10.1177/1077800410383121

Travaglia, J., Westbrook, J., Foxwell, A. R., Westbrook, M., Nugus, P., Boyce, R. A., … Devinney, T. (2012). Continuing differences between health professions' attitudes: the saga of accomplishing systems-wide interprofessionalism. *International Journal for Quality in Health Care*, *25*(1), 8–15. https://doi.org/10.1093/intqhc/mzs071

Tseng, H. M., Lee, C. H., Chen, Y. J., Hsu, H. H., Huang, L. Y., & Huang, J. L. (2016). Developing a measure of medication-related quality of life for people with polypharmacy. *Quality of Life Research*, *25*(5), 1295–1302. https://doi.org/10.1007/s11136-015-1177-2

Tsiantou, V., Pantzou, P., Pavi, E., Koulierakis, G., & Kyriopoulos, J. (2010). Factors affecting adherence to antihypertensive medication in Greece: results from a qualitative study. *Patient Preference and Adherence, 4,* 335–343. https://doi.org/10.2147/PPA.S12326

Tsolekile, L. P., Puoane, T., Schneider, H., Levitt, N. S., & Steyn, K. (2014). The roles of community health workers in management of non-communicable diseases in an urban township. *African Journal of Primary Health Care and Family Medicine*, *6*(1). https://doi.org/10.4102/phcfm.v6i1.693

Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing and Health Sciences*. https://doi.org/10.1111/nhs.12048

Venables, E., Edwards, J. K., Baert, S., Etienne, W., Khabala, K., & Bygrave, H. (2016). "They just come, pick and go." the acceptability of integrated medication adherence clubs for HIV and Non Communicable Disease (NCD) Patients in Kibera, Kenya. *PLoS ONE*, *11*(10), 1–12. https://doi.org/10.1371/journal.pone.0164634

Vervloet, M., Linn, A. J., van Weert, J. C., de Bakker, D. H., Bouvy, M. L., & van Dijk, L. (2012). The effectiveness of interventions using electronic reminders to improve adherence to chronic medication: a systematic review of the literature. *J Am Med Inform Assoc*, *19*(5), 696–704. https://doi.org/10.1136/amiajnl-2011-000748

WHO. (2008). Action Plan for the Global Strategy for the Prevention and Control of Noncommunicable Diseases 2008-2013. *Geneva: World Health Organization*.

WHO. (2010). Health - United Nations Sustainable Development. *Who*, 1–92. https://doi.org/10.1146/annurev.ecolsys.35.021103.105711

WHO. (2020). Urgent health challenges for the next decade.

Retrieved from https://www.who.int/news-room/photo-story/photo-story-detail/urgent-health-challenges-for-the-next-decade

Williams, S. L., Haskard-Zolnierek, K., & DiMatteo, M. R. (2016). Improving adherence to health regimens. In *APA handbook of clinical psychology: Psychopathology and health*. https://doi.org/10.1037/14862-026

Williamson, K., Given, L. M., & Scifleet, P. (2017). Qualitative data analysis. In *Research Methods: Information, Systems, and Contexts: Second Edition*. https://doi.org/10.1016/B978-0-08-102220-7.00019-4

Wirtz, V. J., Hogerzeil, H. V., & Gray, A. L. (2017). Essential medicines for universal health coverage – Authors' reply. *The Lancet*, *389*(10082), 1881–1882. https://doi.org/10.1016/S0140-6736(17)31209-6

Wirtz, V. J., Kaplan, W. A., Kwan, G. F., & Laing, R. O. (2016). Access to medications for cardiovascular diseases in low- and middle-income countries. *Circulation*, *133*(21), 2076–2085. https://doi.org/10.1161/CIRCULATIONAHA.115.008722

Woldie, M., Feyissa, G. T., Admasu, B., Hassen, K., Mitchell, K., Mayhew, S., … Balabanova, D. (2018). Community health volunteers could help improve access to and use of essential health services by communities in LMICs: An umbrella review. *Health Policy and Planning*, *33*(10), 1128–1143. https://doi.org/10.1093/heapol/czy094

Woodrum, E. (1984). "Mainstreaming" content analysis in social science: Methodological advantages, obstacles, and solutions. *Social Science Research*. https://doi.org/10.1016/0049-089X(84)90001-2

World Health Organization. (2016). Proportional mortality (% of total deaths, all ages). *World Health Organization*, 1. Retrieved from https://www.who.int/diabetes/country-profiles/bra_en.pdf

World Health Organization (WHO). (2020). Urgent health challenges for the next decade.

Yin, R. K. (2013). Applications of case study research. *Applied Social Research Methods Series*. https://doi.org/10.1097/FCH.0b013e31822dda9e

Zeeman, H. (2015). Central Chronic Medicine Dispensing and Distribution Programme (CCMDD ). *Health Systems Trust*, (May). Retrieved from http://www.hst.org.za/projects/central-chronic-medicine-dispensing-and-distribution-programme-ccmdd

# APPENDIX 1: DEPARTMENT OF HEALTH NOTICE 431 OF 2017

No. 40892 GOVERNMENT GAZETTE, 6 JUNE 2017

General notices • alGemene KennisGewinGs

---

## DEPARTMENT OF HEALTH

## NOTICE 431 OF 2017

## THE SOUTH AFRICAN PHARMACY COUNCIL

## RULES RELATING TO GOOD PHARMACY PRACTICE

The South African Pharmacy Council herewith publishes amendments for implementation to the minimum standards as contained in Annexure A of the *Rules relating to good pharmacy practice* which was published on 17 December 2004 Government Gazette No: 27112, in Board Notice 129 of 2004 (as amended) in terms of Section 35A(b)(ii) of the Pharmacy Act, 53 of 1974.

**SCHEDULE Rules relating to what constitutes good pharmacy practice**

1. In these rules "the Act" shall mean the Pharmacy Act, 53 of 1974, as amended, and any expression to which a meaning has been assigned in the Act shall bear such meaning.

2. The following rules to Annexure A of the *Rules relating to good pharmacy practice* in are hereby amended –

   (a) Rule 2.7.5

**TA MASANGO**
**REGISTRAR**

## AMENDMENT TO RULE 2.7.5

The title of Rule 2.7.5 is hereby amended to read:

## MINIMUM STANDARDS SPECIFICALLY RELATING TO THE COLLECTION AND THE DELIVERY OF MEDICINES TO PATIENTS FROM A COMMUNITY OR INSTITUTIONAL PHARMACY

Rule 2.7.5 is hereby withdrawn and substituted as follow:

### 2.7.5.1 Purpose

The purpose of this standard is to regulate activities relating to the collection by and the delivery of medicines to patients from a community or institutional pharmacy.

### 2.7.5.2 General considerations

(a) All efforts must be made to enable access to counselling of the patient by a pharmacist relevant to their healthcare needs;

(b) When a person other than a pharmacist delivers medicines to a patient or a patient’s caregiver, the pharmacist must furnish written instructions, that shall include the patient’s details and information regarding the correct use of medicine, and a patient information leaflet (where applicable);

(c) All medicines should, whenever possible, be delivered to patients at an agreed time or date; and

(d) In the absence of an adult (i.e. a person above 14 years old as defined by the Medicines Act) or another person entitled by law to receive the medicine, it must be retained and stored under appropriate conditions until delivery can be affected or be returned to the pharmacy.

### 2.7.5.3 Collection of medicines from the pharmacy

Definition: **Agent** – a person nominated, either formally or informally, by the patient

**Caregiver:** a person who has accepted responsibility for looking after a patient

The caregiver or agent may not practice the scope of practice of a pharmacist

(a) A patient’s agent or caregiver may collect medicines and accept information pertaining to a particular patient provided that the pharmacist is satisfied that patient safety, confidentiality and medicine quality is maintained and the patient has~~,~~ provided written consent;

(b) The patient’s caregiver may only collect medicines for a patient or patients who are under their direct care, a patient’s agent may only collect medicines for a patient or patients who have given written consent for such collection, and in the case of multiple patients the pharmacist must satisfy themselves that the patient’s agent or caregiver is the appropriate person to give the medicines to.

### 2.7.5.4 Transportation for the delivery of medicines

(a) Transportation of medicines must be in such a way that it is secure and limits access to medicines by persons allowed to have access to medicine in law only, prevents any contamination and ensures integrity to the manufacturers product specifications;

(b) The vehicle should allow orderly storage to ensure safety, quality and efficacy of pharmaceutical products during transportation;

(c) Where relevant and to the extent that it is applicable, cold chain management must be observed, and delivery must prove compliance with the minimum standards for thermolabile pharmaceutical products;

(d) Personnel transporting pharmaceutical products must be appropriately trained and shall provide the suitable documentation as proof, for this function and they must ensure that the correct procedures are followed to maintain the cold chain within the manufacturer’s specification;

(e) At any stage of transportation, a delivery document must show evidence that the transport requirements, inter alia temperature control have been met;

(f) Damage to containers or any other event or problem which occurs during transit must be reported to and recorded by the responsible pharmacist of the pharmacy from which the pharmaceutical products were sent;

(g) Upon arrival the person responsible for the transportation of the pharmaceutical products must inform the patient or patient’s caregiver, that the package contains pharmaceutical products and provide information about specific storage requirements (as applicable); and

(h) Proof of delivery (signed by the patient or the patient’s caregiver) must be presented to the pharmacy to ensure that the medicines have been received.

# APPENDIX 2: PARTICIPANT INTERVIEW GUIDES

## **Semi-structured Interview Guide** (Collector) **DATE:**

Welcome and thank participant.

Provide participant information sheet in relevant language.

Complete Informed Consent form.

There are no right or wrong answers to the questions being discussed so all your ideas, experiences and opinions are valuable.

**Participant number ______________________________________**

**Participant contact number________________________________**

### Demographic/context questions

1. Can you tell me briefly about yourself and where you live?

   *Please describe the activities of a typical day in your life?*

2. Can you tell me how often you come to this health facility, as a collector?

   *For how long have you been doing this?*

3. How do you get from where you stay to the facility?

   *How long does it take you?*

### Collector's experience

(Now that you have told me about yourself, now we can start focusing on some of your experience when you come to the day hospital as a collector)

4. What are the processes that you follow once you arrive at the day hospital?

   *How did you know what to do?*

   *Who explained this process to you?*

5. Can you tell me about your experiences when coming to this day hospital?

   *Do you have any bad experiences? Can you describe any of these experiences?*

   *Do you have any good experiences? Can you describe any of these experiences?*

   *Can you give me an example of your own experience/s?*

*Can you tell me more on that?*

6. Who do you have contact with when you are here?

   *How do they make you feel?*

   *Why do they make you feel like that?*

   *Do you receive any form of information?*

   *What kind of information/ from who/ give me an example?*

**Roles as collectors**

7. So why do you think you are asked to collect for patients?

8. Why do you think you were asked to be a collector versus anyone else?

**Challenges faced as collector**

9. Is there anything that makes it difficult for you to collect / perform this duty on behalf of the patient?

   *Why does X make it difficult for you to collect? (After they state their reason)*
   *Can you give me some examples of why that makes it hard for you to collect?*
   *Do you think this reason is the same for other collectors?*
   *How do patients feel/react when you are not able to collect for them?*
   *What do you think will make it easier for you to be a collector/reduce the challenges you face?*

**Attitudes and behaviours of collectors**

10. People are motivated by various reasons to become a collector, let us start this discussion by talking about some of the reasons why you decided to become a collector?

11. If you could describe your experience of working as a collector, what would you say? Is it fulfilling? Why?

We are nearing the end of the interview, are there any further comments that you would like to add? What could the staff at the day hospital do to help you be a better collector? Would you be interested in learning about the diseases that the medicines you collect treat? How do you think, we should go about implementing your recommendations?

Thank the participant.

## Semi-Gestruktueerde Onderhoud Gids (Kollekteerder) Datum:____

---

Verwelkom en bedank deelnemer.

Voorsien deelnemer inligting vorm in relevante taal.

Voltooi “Ingeligte” toestemmings vorm.

Daar is geen regte of verkeerde antwoord op die vrae wat bespreek word nie; alle idees, ervaringe en opinies word waardeer.

**Deelnemer nommer:_____________**

**Deelnemer kontaknommer:________________________________**

### Demografie/konteksvrae

1. Kan u my kortliks omtrent uself vertel en waar u woon?
   Beskryf asseblief die aktiwiteite van ‘n tipiese dag in u lewe.

2. Kan u my vertel hoe gereeld u na hierdie gesondheid fasiliteit kom, as kollekteerder?
   Waarom kom u hierheen?

   Hoe lank doen u dit al?

3. Hoe kom u van waar u bly tot by die fasiliteit?
   Hoe lank neem dit u?

### Kollekteerder se ervaring

(Noudat u my omtrent uself vertel het, kan ons begin fokus op sommige van u ervaringe wanneer u na die Daghospitaal kom as kollekteerder.)

4. Wat is die proses wat u volg sodra u by die Daghospitaal opdaag?
   Hoe weet u wat om te doen?

   Wie het die proses aan u verduidelik?

5. Kan u my vertel van u ervaringe wanneer u na die Daghospitaal kom?
   Het u enige slegte ervaringe gehad?

   Kan u enige van hierdie ervaringe beskryf?

   Het u enige goeie ervaringe gehad?

Kan u enige van hierdie ervaringe beskryf?

Kan u my enige voorbeelde van u ervaring/e gee?

Kan u my meer omtrent u ervaring vertel?

6. Met wie het u kontak wanneer u hier is?
   Hoe laat hulle u voel?

   Waarom laat hulle u so voel?

   Ontvang u enige vorm van kommunikasie?

   Watter tipe kommunikasie/ vanaf wie? Gee my ‘n voorbeeld.

   **<u>Rolle as kollekteerders</u>**

7. Waarom dink u word u gevra om namens pasiënte te kollekteer?
8. Waarom dink u was u gevra om ‘n kollekteerder te word teenoor enige ander persoon?
   **Uitdagings wat kollekteerders ervaar:**

9. Is daar enigiets anders wat dit bemoeilik om te kollekteer/ u plig teenoor die pasiënt na te kom?
   Waarom maak dit vir u moeilik om te kollekteer? (Nadat hulle redes noem)

   Kan u my enige voorbeelde noem wat dinge bemoeilik om te kollekteer?

   Dink u dat ander kollekteerders dieselfde dinge ervaar?

   Hoe voel pasiënte/reageer hulle wanneer u ‘n onvermoë het om hul kroniese medikasie namens hulle af te haal/kollekteer?

   Wat dink u sal dinge vergemaklik vir u as kollekteerder om uitdagings wat u in die gesig staar te verminder?

10. Mense word om verskillende redes gemotiveer om kollekteerders te word; Laat ons hierdie gesprek begin deur te gesels oor van die redes waarom u besluit het om ‘n kollekteerder te word.
11. Indien u u ervaring van werk as ‘n kollekteerder kan beskryf, wat sou u sệ?
    Verskaf dit aan u tevredenheid? Waarom?

Ons kom aan die einde van ons onderhoud. Is daar enige verdere kommentaar wat u sou wou byvoeg. Wat kan die personeel by die dag hospital doen om vir jou te ondersteun as kollekteerder? Sal jy bereid wees om te leer oor die siektes en medikasie wat jy kollek vir pasiente? Hoe dink jy, kan ons jou aanbeveling implementeer?

Bedank die deelnemer.

## **Semi-structured Interview Guide** (Patient) **DATE:**

Welcome and thank participant.

Provide participant information sheet in relevant language.

Complete Informed Consent form.

There are no right or wrong answers to the questions being discussed so all your ideas, experiences and opinions are valuable.

**Participant number** ______________________________________

**Participant contact number**________________________________

### Demographic/context questions

1. Can you tell me briefly about yourself and where you live?

   *Please describe the activities of a typical day in your life?*

2. *Can you tell me about your illness?*

   *How long have you been living with it?*

   *Can you tell me how many times do you need to come to this day hospital in a year?*

   *How long have you been a patient coming to this day hospital?*

   *What are the reasons that you come here/ What service do you make use of?*

3. How do you get from where you stay to the facility?

   *How long does it take you?*

### Patient's experience

(Now that you have told me about yourself, now we can start focusing on some of your experience when you collect your chronic medication from the day hospital)

4. What are challenges that you experience when you need to collect your monthly chronic medication?

   *What are the things that make it hard for you to collect your own chronic medication?*

5. *On the occasions that you need to be at the day hospital, what you do when you need to get from home or work to the facility?*

*What arrangement or preparations do you make when you know that you need to come here?*

*How many hours do you need to avail to do this?*

6. What are the processes that you follow once you arrive at the day hospital?
*How did you know what to do?*
*Who explained this process to you?*
*Can you tell me about the procedure that you need to follow when you arrive at the facility?*
*What do you normally have to do once you arrive at the facility? What are the things that makes this hard?*

**Patients reasons for employing collectors / Patients experience with collector**

*7. How do you remember that you need to collect your chronic medication?*

*Is there anyone who helps you remember?*

*How do these people/person alert you?*

8. People are motivated by various reasons to ask someone else to collect their chronic medication, let us start this discussion by talking about some of the reasons why you decided ask a collector?

*What motivated you to ask someone else to collect your medication?*

*How frequently / often does the collector provide this service?*

*What is your arrangement / What procedure does the collector follow when you are due to collect your chronic medication?*

*How does this help you?*

*What do you expect from the collector?*

*What are your responsibilities in this process?*

*Can you explain what happens when the collects brings it to you?*

*Are you required to remunerate the collector?*

*Does the collector ask you to sign that you have received the medicines?*

9. If you could describe your experience of employing a collector, what would you say? Is it an advantage? Why?

**Challenges faced with collector**

*10.* Is there anything that makes this arrangement difficult for you?
*Why does X make it difficult for you to collect? (After they state their reason)*
*Can you give me some examples of why that makes it hard for you to collect?*
*Do you think this reason is the same for other patients who use collectors?*

*What do you think will make it easier for you as a patient and your collector to collect your chronic medication/reduce the challenges you face?*

*What do you think can be done to support you to always have sufficient supply of medication?*

*Do you think the collectors would benefit from being taught about the medicines they collect and deliver? Would they be interested? How do you think, we should go about implementing your recommendations?*

We are nearing the end of the interview, are there any further comments that you would like to add?

Thank the participant.

## Semi-gestruktueerde Onderhoud Gids (Pasiënt) Datum: _____

---

Verwelkom en bedank deelnemer.

Voorsien deelnemer inligting vorm in relevante taal.

Voltooi ingeligte toestemmings vorm.

Daar is geen regte of verkeerde antwoorde op die vrae onder bespreking; daarom is al u idees, ervaringe en opinies waardevol.

**Deelnemer nommer** _________________

**Deelnemer kontaknommer:** __________________

**<u>Demografie/ Konteksvrae</u>**

1. Kan u my kortliks van uself vertel en waar u bly?

   Beskryf asseblief die aktiwiteite van u tipiese dag in u lewe.

2. Kan u my van u siekte vertel?
   Hoelank leef u al daarmee?

   Kan u my vertel hoeveel maal u per jaar na hierdie Daghospitaal moet kom?

   Om watter redes kom u hierheen?

   Van watter dienste maak u gebruik?

3. Hoe kom u van u blyplek tot by hierdie fasiliteit?
   Hoe lank neem dit u?

   **<u>Pasiënt se ervaring</u>.**

   (Noudat u my omtrent uself vertel het, kan ons begin fokus op sommige van u ervaringe wanneer u u kroniese medikasie by die Daghospitaal afhaal.)

4. Watter uitdagings ervaar u wanneer u u maandelikse kroniese medikasie kom afhaal?
   Wat is die dinge wat dit moeilik maak om u kroniese medikasie af te haal/

5. Die tye wanneer dit vir u nodig is om by die Daghospitaal te wees, watter reëlings tref u om vanaf u woning of werk by die fasiliteit uit te kom?
   Watter reëling of voorbereidings moet u tref wanneer u weet dat u hierheen moet kom?

Hoeveel ure moet u insit om dit te doen?

6. Wat is die proses wat u volg sodra u by die Daghospitaal opdaag?
   Hoe het u geweet wat om te doen?

   Wie het die prosedure aan u verduidelik?

   Wat kan u my omtrent die prosedure vertel wat u behoort te volg sodra u by die fasiliteit opdaag? (Wat moet u normaalweg doen sodra u by die fasiliteit opdaag?)

   Wat is die dinge wat dit moeilik maak?

**<u>Pasiënt se redes om kollekteerders aan te stel/Pasiënt se ervaringe met kollekteerders.</u>**

7. Hoe onthou u dat dit nodig is om u kroniese medikasie te kollekteer?
   Is daar enigiemand wat u herinner?

   Hoe herinner hierdie persoon/e u?

8. Mense word om verskeie redes gemotiveer om iemand anders te vra om hul kroniese medikasie af te haal. Laat ons hierdie gesprek begin deur sommige redes te noem waarom u besluit het om ‘n kollekteerder te vra.
   Wat het u motiveer om iemand anders te vra om u medikasie te kollekteer?

   Hoe gereeld lewer die kollekteerder hierdie diens?

   Wat is u reëling? Watter prosedure volg die kollekteerder wanneer dit tyd is om u kroniese medikasie te kollekteer?

   Hoe help dit u?

   Wat is u verwagtinge van die kollekteerder?

   Wat is u verantwoordelikhede in hierdie proses?

   Kan u verduidelik wat gebeur wanneer die kollekteerder dit vir u bring?

   Word dit van u verwag om die kollekteerder te betaal?

   *Vra die kollekteerder ooit dat jy enige papier teken om te bewys dat jy die medikasie ontvang?*

9. Kan u u ervaringe met die gebruik van ‘n kollekteerder beskryf; wat sou u sệ?
   Is dit voordelig vir u? Waarom?

**<u>Uitdagings wat u ervaar met kollekteerders.</u>**

10. Is daar enigiets wat hierdie reëlings vir u bemoeilik?
    Waarom maak die reëlings dit moeilik vir u om te kollekteer? (Nadat hul die redes verskaf het)

Kan u my voorbeelde verskaf waarom dit vir u moeilik is om self te kollekteer?

Dink u dat hierdie rede ook geld vir ander pasiënte wat kollekteerders gebruik?

Wat dink u sal dit makliker maak vir die pasiënt en sy kollekteerder om u kroniese medikasie te kollekteer/die uitdagings te verminder?

Wat dink u kan gedoen word om u te ondersteun sodat u altyd genoeg voorraad medikasie het?

Dink jy dat die kollekteerders sal nut vind uit opvoeding oor die medikasie wat hulle kollekteer and aflewer? Sal hulle belangstel? Hoe dink jy, kan ons jou aanbeveling implementeer?

Ons kom nou by die einde van die onderhoud; is daar enige verdere kommentaar wat u wil byvoeg?

Bedank die deelnemer.

## **Semi-structured Interview Guide** (Key Informant) **DATE:**

Welcome and thank participant.

Provide participant information sheet in relevant language.

Complete Informed Consent form.

There are no right or wrong answers to the questions being discussed so all your ideas, experiences and opinions are valuable.

**Participant number** ______________________________________

**Participant contact number**________________________________

1. What is your involvement in the CDU process?

   What is your specific role? Do you enjoy it?
2. Who are the people that you serve?

   Are the processes different for different people?

3. What do you think about the collectors programme?
4. What do you feel about the programme? Why?
   How does it work?
   What kind of arrangements are currently there?

5. What process do you follow when you assist a collector?

6. Can you explain your experience of interacting with a collector?

Could you give me an example?
How did that make you feel?
Do you think others in management have the same experience? Why

7. What are some of the challenges that you face?

8. Are you aware of any of the challenges that patients face to collect their packs on time?

9. Are you aware of any of the challenges that collectors face?

Do you think the collectors would be interested in learning about the medicines they collect? Or the diseases that the medicines are used to treat? Could you see the collectors becoming informal health educators about NCDs? Do you have any suggestions in this regard? How do you think, we should go about implementing your recommendations?

We are nearing the end of the interview, are there any further comments that you would like to add?

Thank the participant.

## APPENDIX 3: BIOMEDICAL RESEARCH ETHICS COMMITTEE APPROVAL

UNIVERSITY of the WESTERN CAPE

OFFICE OF THE DIRECTOR: RESEARCH
RESEARCH AND INNOVATION DIVISION

Private Bag X 17, Bellville 7535
South Africa
T: +27 21 959 2988/2948
F: +27 21 959 3170
E: research-ethics@uwc.ac.za
www.uwc.ac.za

07 December 2017

Ms J Willoughby
School of Public Health
**Faculty of Community and Health Sciences**

**Ethics Reference Number:** BM17/10/16

**Project Title:** Acceptability of collectors of medicine parcels for non-communicable disease patients from a primary health care facility in the Western Cape

**Approval Period:** 07 December 2017 – 07 December 2018

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 permission from the facilities/health department must be submitted for record keeping purposes*

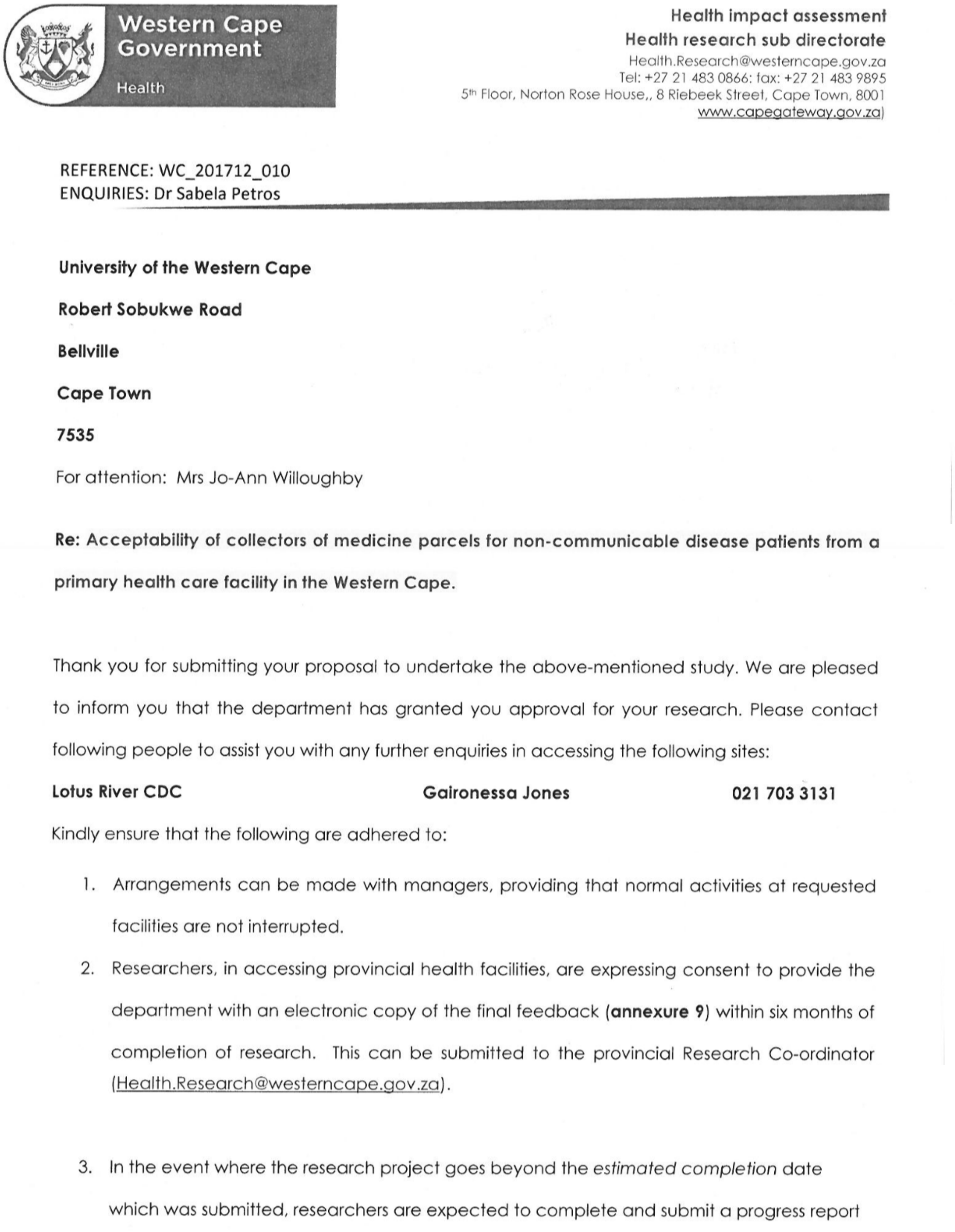
The Committee must be informed of any serious adverse event and/or termination of the study.

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

***PROVISIONAL REC NUMBER -130416-050***

FROM HOPE TO ACTION THROUGH KNOWLEDGE.

# APPENDIX 4: WESTERN CAPE DEPARTMENT OF HEALTH APPROVAL



**Western Cape Government**
Health

**Health impact assessment**
**Health research sub directorate**
Health.Research@westerncape.gov.za
Tel: +27 21 483 0866: fax: +27 21 483 9895
5th Floor, Norton Rose House,, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za)

REFERENCE: WC_201712_010
ENQUIRIES: Dr Sabela Petros

**University of the Western Cape**

**Robert Sobukwe Road**

**Bellville**

**Cape Town**

**7535**

For attention: Mrs Jo-Ann Willoughby

**Re: Acceptability of collectors of medicine parcels for non-communicable disease patients from a primary health care facility in the Western Cape.**

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact following people to assist you with any further enquiries in accessing the following sites:

| | | |
|---|---|---|
| **Lotus River CDC** | **Gaironessa Jones** | **021 703 3131** |

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

3. In the event where the research project goes beyond the *estimated completion* date which was submitted, researchers are expected to complete and submit a progress report

(**Annexure 8**) to the provincial Research Co-ordinator

(Health.Research@westerncape.gov.za).

4. The reference number above should be quoted in all future correspondence.

Yours sincerely

AO HAWKRIDGE.

**DR A HAWKRIDGE**

**DIRECTOR: HEALTH IMPACT ASSESSMENT**

**DATE:** 6/2/2018.

**CC:** **K GRAMMER** **DIRECTOR: SOUTHERN/ WESTERN**

# APPENDIX 5: PARTICIPANT INFORMATION SHEETS

## PARTCIPANT INFORMATION SHEET: COLLECTOR

**Project Title:** **Acceptability of collectors of medicine parcels for non- communicable disease patients from a primary health care facility in the Western Cape.**

### What is this study about?

This is a research project being conducted by Jo-Ann Willoughby. The research is being conducted for a mini-thesis for a Master of Public Health at the University of the Western Cape. You are invited to participate in this research project because I value your knowledge and experience. The purpose of this research project is to find out about the acceptability of collectors of Chronic Dispensing Unit (CDU) parcels. Your participation will help me to understand how and why collectors, such as yourself, make it possible for patients to receive their chronic medication.

### What will I be asked to do if I agree to participate?

You will be given a participant information sheet which explains what the project is about. If you agree to participate, you will be asked to sign a consent form. By signing the consent form, you indicate that you understand what you have read or what has been read to you and you agree to take part in the research project. You will be given a copy of the participant information sheet and consent form to keep for your records.

You will be asked to participate in a face-to-face interview with the researcher. The interview will be approximately one hour long and will be conducted at Lotus River Community Day Centre at a time and date that is convenient for you. You will be asked questions about how you have experienced collecting medication parcels on behalf of patients. The interview will be recorded using a voice recorder. The interview will be recorded to ensure that I capture all the information you provide.

### Would my participation in this study be kept confidential?

The information that you share will be confidential. To ensure your anonymity, your name will not be used on any information source and cannot be used to identify you. A code, that will be developed using an identification key, will be used to link your information to your identity. Only I will have access to this identification key. To ensure your confidentiality, all collected data will be stored using password-protected computer files. Only I will have access to these files. If a report or article about this research project is written, your identity will be protected.

### What are the risks of this research?

There may be some risks from participating in this research study. All human interactions and talking about self or others carry some amount of risks. I will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study.

Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

**What are the benefits of this research?**
This research is not designed to help you personally, but the results may help the investigator learn more about the acceptability of collectors. We hope that, in the future, other people might benefit from this study through improved understanding of collectors and access to chronic medication parcels.

**Do I have to be in this research and may I stop participating at any time?**
Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

**What if I have questions?**
This research is being conducted by Jo-Ann Willoughby from the School of Public Health at the University of the Western Cape. If you have any questions about the research study itself, please contact Jo-Ann at: 2101955@myuwc.ac.za.

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Prof Uta Lehmann
Director, School of Public Health
University of the Western Cape
Private Bag X17
Bellville 7535
soph-comm@uwc.ac.za

Prof Anthea Rhoda
Acting Dean, Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17
Bellville 7535
chs-deansoffice@uwc.ac.za

Ethics Reference Number : BM17/10/16

**BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**

**Research Office**

**New Arts Building,**

**C-Block, Top Floor, Room 28**

**University of the Western Cape**

**Private Bag X17, Bellville 7535**

## INFORMASIE BLAD: KOLLEKTEERDER

**Titel van Navorsings Projek: Aanvaarbaarheid van kollekteerders van medikasie pakkies vir pasiente met nie-oordraagbare siektes van n Primere gesondheidsdiens fasiliteit in die Wes Kaap.**

### Waaroor handel die projek?

Die navorsings projek word gedoen deur Jo-Ann Willoughby vir n kort tesis vir Meesters in Publieke Gesondheid by die Universiteit van die Weskaapland. Ek nooi u uit om deel te neem aan heirdie projek omdat ek u kennis and ervaring waardevol sal vind. U deelname sal my instaat stel om n beter oorsig te skep aangaande die redes, waarom en hoekom, kollekteerders, soos u, dit moontlik maak om kroniese medikasie te ontvang.Die doel van die navorsing projek is om vas te stel die aanvaarbaarheid van kollekteerders van Chronic Dispensing Unit (CDU) pakkies. Ek hoop dat hierdie navorsing sal die toegang verbeter van kroniese medikasie.

### Wat sal van my verwag word as ek instem om deel te neem?

As deelnemer sal u n informasie bladsy ontvang wat n oorsig sal gee van die navorsing projek. Indien toestemming verskaf word sal daar verwag word dat u n toestemming form voltooi. Die voltooing van die toestemming form sal n duidelike indikasie wees dat u verstaan waaroor die navorsings projek handel en dat u toestemming verleen om deelname aan die projek te verleen. U sal n afskrif ontvang van u informasie bladsy en toestemings form tydens die projek en u kan dit vir veilige bewaring behou.

Jy sal gevra word om deel te neem aan n onderhoud waar jy informasie sal deel. Die onderhoud sal by die Lotus Rivier Gemeenskap Gesondheid Sentrum gedoen word op n dag en tyd wat gerieflik is vir jou. Die onderhoud sal vir ongeveer 1 uur lank duur. Vrae sal fokus op u as kollekteerder van kroniese medikasie. Die onderhoud sal deurgans opgeneem word met n band opname. Die onderhoud word opgeneem ten einde te verseker dat alle informasie akkuraat op gevang word.

### Sal my deelname aan die projek vetroulik gehou word?

Die informasie wat jy deel sal vertroulik wees. Om anonimiteit te verseker sal jou naam nie
op enige informasie bron gebruik word nie en kan nie gebruik word om jou te identifiseer. 'n
Kode wat ontwikkel sal word met behulp van 'n identifikasie sleutel sal gebruik word om jou
informasie aan jou identiteit te koppel. Slegs ek sal toegang het tot die indentifikasie sleutel. Om vertroulikheid te verseker sal alle informasie in rekenaar leers met n wagwoord gestoor word. Slegs ek sal toegang he tot die leers. Indien daar n verslag of artikel geskryf
word, sal jou identiteit beskerm word.

**Wat is die risiko van hierdie projek?**

Daar mag risiekos verbonde wees aan deelmane in hierdie navorsings projek. Alle menslike interaksie en praat oor self of ander, dra n risiko. Ek sal nogtans die risiko verminder en vinnig reageer indien jy enige ongemak, sielkundig of andersins ervaar tydens jou deelname in die projek. 'n Verwysing na n geskikte profesionele persoon sal gemaak word vir verdere hulp en ingryping, indien nodig.

**Wat is die voordele van hierdie projek?**

Die navorsing is nie ontwerp om jou persoonlik te help nie maar die uitslag van die navorsing mag die navorser help om meer te leer oor die aanvaarbaarheid van kollekteerders van kroniese medikasie pakkies. Ons hoop dat ander pasiente in die toekoms nut sal vind uit die navorsing deur verbeterde begrip van toegang na kroniese medikasie.

**Moet ek in die projek deelneem en mag ek enige tyd onttrek?**

Jou deelname aan die projek is heeltemal vrywillig. Jy mag besluit om glad nie deel te neem nie. As jy wel besluit om deel te neem, mag jy enige tyd onttrek. As jy besluit om nie deel te neem nie of om te onttrek, sal jy nie gepenaliseer word or enige voordeel waarvoor jy andersins sou kwalifiseer, verloor nie. Jou behandeling en sorg by Lotus Rivier Gemeenskap Gesondheid Sentrum sal nie op enige manier geaffekteer word nie.

**Wat as ek vrae het?**

Die navorsings projek word gedoen deur Jo-Ann Willoughby van die Skool vir Publieke Gesongheid by die Universiteit van die Wes-Kaap. Indien jy enige vrae in verband met die navorsings projek het, kontak asseblief vir Jo-Ann by 2101955@myuwc.ac.za.

Indien jy enige vrae in verband met die navorsings projek of jou regte as n deelnemer of as jy enige probleem met die navorsigns projek ondervind, kontak asseblief:

Prof Uta Lehmann
Director, School of Public Health
University of the Western Cape
Private Bag X17
Bellville 7535
soph-comm@uwc.ac.za

Prof Anthea Rhoda
Acting Dean, Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17

Bellville 7535
chs-deansoffice@uwc.ac.za
Ethics Reference Number : BM17/10/16

# PARTCIPANT INFORMATION SHEET: PATIENT

**Project Title:** **Acceptability of collectors of medicine parcels for non- communicable disease patients from a primary health care facility in the Western Cape.**

## What is this study about?

This is a research project being conducted by Jo-Ann Willoughby. The research is being conducted for a mini-thesis for a Master of Public Health at the University of the Western Cape. You are invited to participate in this research project because I value your knowledge and experience. The purpose of this research project is to find out about the acceptability of collectors of Chronic Dispensing Unit (CDU) parcels. Your participation will help me to understand how and why collectors make it possible for patients, such as yourself, to receive their chronic medication.

## What will I be asked to do if I agree to participate?

You will be given a participant information sheet which explains what the project is about. If you agree to participate, you will be asked to sign a consent form. By signing the consent form, you indicate that you understand what you have read or what has been read to you and you agree to take part in the research project. You will be given a copy of the participant information and consent form to keep for your records.

You will be asked to participate in a face-to-face interview with the researcher. The interview be approximately one hour long and will be conducted at Lotus River Community Day Centre at a time and date that is convenient for you. You will be asked questions about your experience with collectors of CDU parcels. The interview will be recorded using a voice recorder. The interview will be recorded to ensure that I capture all the information you provide.

## Would my participation in this study be kept confidential?

The information that you share will be confidential. To ensure your anonymity, your name will not be used on any information source and cannot be used to identify you. A code, that will be developed using an identification key, will be used to link your information to your identity. Only I will have access to this identification key. To ensure your confidentiality, all collected data will be stored using password-protected computer files. Only I will have access to these files. If a report or article about this research project is written, your identity will be protected.

## What are the risks of this research?

There may be some risks from participating in this research study. All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

**What are the benefits of this research?**

This research is not designed to help you personally, but the results may help the investigator learn more about the acceptability of collectors. We hope that, in the future, other people might benefit from this study through improved understanding of collectors and access to chronic medication parcels.

**Do I have to be in this research and may I stop participating at any time?**

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

**What if I have questions?**

This research is being conducted by Jo-Ann Willoughby from the School of Public Health at the University of the Western Cape. If you have any questions about the research study itself, please contact Jo-Ann at: 2101955@myuwc.ac.za.

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Prof Uta Lehmann
Director, School of Public Health
University of the Western Cape
Private Bag X17
Bellville 7535
soph-comm@uwc.ac.za

Prof Anthea Rhoda
Acting Dean, Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17
Bellville 7535
chs-deansoffice@uwc.ac.za

Ethics Reference Number : BM17/10/16
**BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**

**Research Office**

**New Arts Building,**

**C-Block, Top Floor, Room 28**

**University of the Western Cape**
**Private Bag X17**
**Bellville 7535**

# INFORMASIE BLAD: PASIENT

**Titel van Navorsings Projek: Aanvaarbaarheid van kollekteerders van medikasie pakkies vir pasiente met nie-oordraagbare siektes van n Primere gesondheidsdiens fasiliteit in die Wes Kaap.**

### Waaroor handel die projek?

Die navorsings projek word gedoen deur Jo-Ann Willoughby vir n kort tesis vir Meesters in Publieke Gesondheid by die Universiteit van die Weskaapland.Ek nooi u uit om deel te neem aan heirdie projek omdat ek u kennis and ervaring waardevol sal vind. U deelname sal my instaat stel om n beter oorsig te skep aangaande die redes, waarom en hoekom, kollekteerders, soos u, dit moontlik maak om kroniese medikasie te ontvang.Die doel van die navorsing projek is om vas te stel die aanvaarbaarheid van kollekteerders van Chronic Dispensing Unit (CDU) pakkies. Ek hoop dat hierdie navorsing sal die toegang verbeter van kroniese medikasie.

### Wat sal van my verwag word as ek in stem om deel te neem?

As deelnemer sal u n informasie bladsy ontvang wat n oorsig sal gee van die navorsing projek. Indien toestemming verskaf word sal daar verwag word dat u n toestemming form voltooi. Die voltooing van die toestemming form sal n duidelike indikasie wees dat u verstaan waaroor die navorsings projek handel en dat u toestemming verleen om deelname aan die projek te verleen. U sal n afskrif ontvang van u informasie bladsy en toestemings form tydens die projek en u kan dit vir veilige bewaring behou.

Jy sal gevra word om deel te neem aan n onderhoud waar jy informasie sal deel. Die onderhoud sal by die Lotus Rivier Gemeenskap Gesondheid Sentrum gedoen word op n dag en tyd wat gerieflik is vir jou. Die onderhoud sal vir ongeveer 1 uur lank duur. Vrae sal fokus op u interaksies met kollekteerders. Die onderhoud sal deurgans opgeneem word met n band opname. Die onderhoud word opgeneem ten einde te verseker dat alle informasie akkuraat op gevang word.

### Sal my deelname aan die projek vetroulik gehou word?

Die informasie wat jy deel sal vertroulik wees. Om anonimiteit te verseker sal jou naam nie op enige informasie bron gebruik word nie en kan nie gebruik word om jou te identifiseer. 'n Kode wat ontwikkel sal word met behulp van 'n identifikasie sleutel sal gebruik word om jou informasie aan jou identiteit te koppel. Slegs ek sal toegang he tot die indentifikasie sleutel.Om vertroulikheid te verseker sal alle informasie in rekenaar leers met n wagwoord gestoorword. Slegs ek sal toegang he tot die leers. Indien daar n verslag of artikel geskryf word, sal jou identiteit beskerm word.

### Wat is die risiko van hierdie projek?

Daar mag risiekos verbonde aan deelmane in hierdie navorsings projek. Alle menslike interaksie en praat oor self of ander, dra n risiko. Ons sal nogtans die risiko verminder en vinnig reageer indien jy enige ongemak, sielkundig of andersins ervaar tydens jou deelname in die projek. 'n Verwysing na n geskikte profesionele persoon sal gemaak
word vir verdere hulp en ingryping, indien nodig.

### Wat is die voordele van hierdie projek?

Die navorsing is nie ontwerp om jou persoonlik te help nie maar die uitslag van die navorsing mag die navorser help om meer te leer oor die aanvaarbaarheid van kollekteerders van kroniese medikasie pakkies. Ons hoop dat ander pasiente in die toekoms nut sal vind uit die navorsing deur verbeterde begrip van toegang na kroniese medikasie.

### Moet ek in die projek deelneem en mag ek enige tyd onttrek?

Jou deelname aan die projek is heeltemal vrywillig. Jy mag besluit om glad nie deel te neem nie. As jy wel besluit om deel te neem, mag jy enige tyd onttrek. As jy besluit om nie deel te neem nie of om te onttrek, sal jy nie gepenaliseer word or enige voordeel waarvoor jy andersins sou kwalifiseer, verloor nie. Jou behandeling en sorg by Lotus Rivier Gemeenskap Gesondheid Sentrum sal nie op enige manier geaffekteer word nie.

### Wat as ek vrae het?

Die navorsings projek word gedoen deur Jo-Ann Willoughby van die Skool vir Publieke Gesongheid by die Universiteit van die Wes-Kaap. Indien jy enige vrae in verband met die navorsings projek het, kontak asseblief vir Jo-Ann by 2101955@myuwc.ac.za.

Indien jy enige vrae in verband met die navorsings projek of jou regte as n deelnemer of as jy enige probleem met die navorsigns projek ondervind, kontak asseblief:

Prof Uta Lehmann
Director, School of Public Health
University of the Western Cape
Private Bag X17
Bellville 7535
soph-comm@uwc.ac.za

Prof Anthea Rhoda
Acting Dean, Faculty of Community and Health Sciences

University of the Western Cape
Private Bag X17
Bellville 7535 chs-deansoffice@uwc.ac.za

Ethics Reference Number : BM17/10/16

# PARTCIPANT INFORMATION SHEET: KEY INFORMANT

**Project Title:** **Acceptability of collectors of medicine parcels for non- communicable disease patients from a primary health care facility in the Western Cape.**

## What is this study about?

This is a research project being conducted by Jo-Ann Willoughby. The research is being conducted for a mini-thesis for a Master of Public Health at the University of the Western Cape. You are invited to participate in this research project because I value your knowledge and experience.

The purpose of this research project is to understand the acceptability of collectors of Chronic Dispensing Unit (CDU) parcels. Your participation will help me to understand how and why collectors make it possible for patients to receive their chronic medication.

## What will I be asked to do if I agree to participate?

You will be given a participant information sheet which explains what the project is about. If you agree to participate, you will be asked to sign a consent form. By signing the consent form, you indicate that you understand what you have read or what has been read to you and you agree to take part in the research project. You will be given a copy of the participant information and consent form to keep for your records.

You will be asked to participate in a face-to-face interview with the researcher. The interview will be approximately one hour long and will be conducted at Lotus River Community Day Centre at a time and date that is convenient for you. You will be asked questions about your interaction and experience with collectors. The interview will be recorded using a voice recorder. The interview will be recorded to ensure that I capture all the information you provide.

## Would my participation in this study be kept confidential?

The information that you share will be confidential. To ensure your anonymity, your name will not be used on any information source and cannot be used to identify you. A code, that will be developed using an identification key, will be used to link your information to your identity. Only I will have access to this identification key. To ensure your confidentiality, all collected data will be stored using password-protected computer files. Only I will have access to these files. If a report or article about this research project is written, your identity will be protected.

## What are the risks of this research?

There may be some risks from participating in this research study. All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

**What are the benefits of this research?**
This research is not designed to help you personally, but the results may help the investigator learn more about the acceptability of collectors. We hope that, in the future, other people might benefit from this study through improved understanding of collectors and access to chronic medication parcels.

**Do I have to be in this research and may I stop participating at any time?**
Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

**What if I have questions?**
This research is being conducted by Jo-Ann Willoughby from the School of Public Health at the University of the Western Cape. If you have any questions about the research study itself, please contact Jo-Ann at: 2101955@myuwc.ac.za.

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Prof Uta Lehmann
Director, School of Public Health
University of the Western Cape
Private Bag X17
Bellville 7535
soph-comm@uwc.ac.za

Prof Anthea Rhoda
Acting Dean, Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17
Bellville 7535
chs-deansoffice@uwc.ac.za

Ethics Reference Number : BM17/10/16
**BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**

**Research Office**

**New Arts Building,**

**C-Block, Top Floor, Room 28**

**University of the Western Cape**

**Private Bag X17, Bellville 7535**

# APPENDIX 6: PARTICIPANT CONSENT FORMS

## PARTICIPANT CONSENT FORM: COLLECTOR

**Title of Research Project:** **Acceptability of collectors of medicine parcels for non- communicable disease patients from a primary health care facility in the Western Cape.**

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

___ I agree to be audiotaped during my participation in this study.

___ I do not agree to be audiotaped during my participation in this study.

Participant's name……………………….

Participant's signature……………………………..

Date……………………..

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Prof Uta Lehmann
Director, School of Public Health
University of the Western Cape
Private Bag X17
Bellville 7535
soph-comm@uwc.ac.za

Prof Anthea Rhoda
Acting Dean, Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17
Bellville 7535
chs-deansoffice@uwc.ac.za

Ethics Reference Number : BM17/10/16

# TOESTEMMING FORM: KOLLETEERDER

**Titel van Navorsings Projek:** **Aanvaarbaarheid van kollekteerders van medikasie pakkies vir pasiente met nie-oordraagbare siektes van n Primere gesondheidsdiens fasiliteit in die Wes Kaap.**

Die navorsing is aan my verduidelik in a taal wat ek verstaan. My vrae oor die navorsing is beantwoord. Ek verstaan wat my deelname betrek en ek is bereid om vrywillig deel te neem. Ek verstaan dat my identiteit nie aan enige persoon openbaar gaan word nie. Ek verstaan dat ek enige tyd kan onttrek sonder om n rede te verskaf en sonder vrees van negatiewe gevolge of verlies van voordele.

___ Ek gee toestemming dat n oudio-opname kan plaasvind gedeurende my deelname tydens hierdie studie.

___ Geen toestemmimg word verleen vir n oudio-opneeming tydens my deelname in hierdie studie.

**Naam van deelnemer………………………..**
**Handtekening van deelnemer……………………………….**

**Datum………………………**

Indien jy enige vrae in verband met die navorsings projek of jou regte as n deelnemer of as jy enige probleem met die navorsing projek ondervind, kontak asseblief:

Prof Uta Lehmann
Director, School of Public Health
University of the Western Cape
Private Bag X17
Bellville 7535
soph-comm@uwc.ac.za

Prof Anthea Rhoda
Acting Dean, Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17
Bellville 7535
chs-deansoffice@uwc.ac.za

Ethics Reference Number : BM17/10/16

# PARTICPANT CONSENT FORM: PATIENT

**Title of Research Project: Acceptability of collectors of medicine parcels for non- communicable disease patients from a primary health care facility in the Western Cape.**

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

___ I agree to be audiotaped during my participation in this study.

___ I do not agree to be audiotaped during my participation in this study.

Participant's name………………………..

Participant's signature……………………………….

Date………………………

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Prof Uta Lehmann
Director, School of Public Health
University of the Western Cape
Private Bag X17
Bellville 7535
soph-comm@uwc.ac.za

Prof Anthea Rhoda
Acting Dean, Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17
Bellville 7535
chs-deansoffice@uwc.ac.za

Ethics Reference Number : BM17/10/16

# TOESTEMMING FORM: PATIENT

**Titel van Navorsings Projek:** **Aanvaarbaarheid van kollekteerders van medikasie pakkies vir pasiente met nie-oordraagbare siektes van n Primere gesondheidsdiens fasiliteit in die Wes Kaap.**

Die navorsing is aan my verduidelik in a taal wat ek verstaan. My vrae oor die navorsing is beantwoord. Ek verstaan wat my deelname betrek en ek is bereid om vrywillig deel te neem. Ek verstaan dat my identiteit nie aan enige persoon openbaar gaan word nie. Ek verstaan dat ek enige tyd kan onttrek sonder om n rede te verskaf en sonder vrees van negatiewe gevolge of verlies van voordele.

___ Ek gee toestemming dat n oudio-opname kan plaasvind gedeurende my deelname tydens hierdie studie.

___ Geen toestemmimg word verleen vir n oudio-opneeming tydens my deelname in hierdie studie.

**Naam van deelnemer………………………..**
**Handtekening van deelnemer……………………………….**

**Datum………………………**

Indien jy enige vrae in verband met die navorsings projek of jou regte as n deelnemer of as jy enige probleem met die navorsing projek ondervind, kontak asseblief:

Prof Uta Lehmann
Director, School of Public Health
University of the Western Cape
Private Bag X17
Bellville 7535
soph-comm@uwc.ac.za

Prof Anthea Rhoda
Acting Dean, Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17
Bellville 7535
chs-deansoffice@uwc.ac.za

Ethics Reference Number : BM17/10/16

# PARTICPANT CONSENT FORM: KEY INFORMANT

**Title of Research Project:** **Acceptability of collectors of medicine parcels for non- communicable disease patients from a primary health care facility in the Western Cape.**

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

___ I agree to be audiotaped during my participation in this study.

___ I do not agree to be audiotaped during my participation in this study.

Participant's name………………………

Participant's signature………………………………

Date……………………..

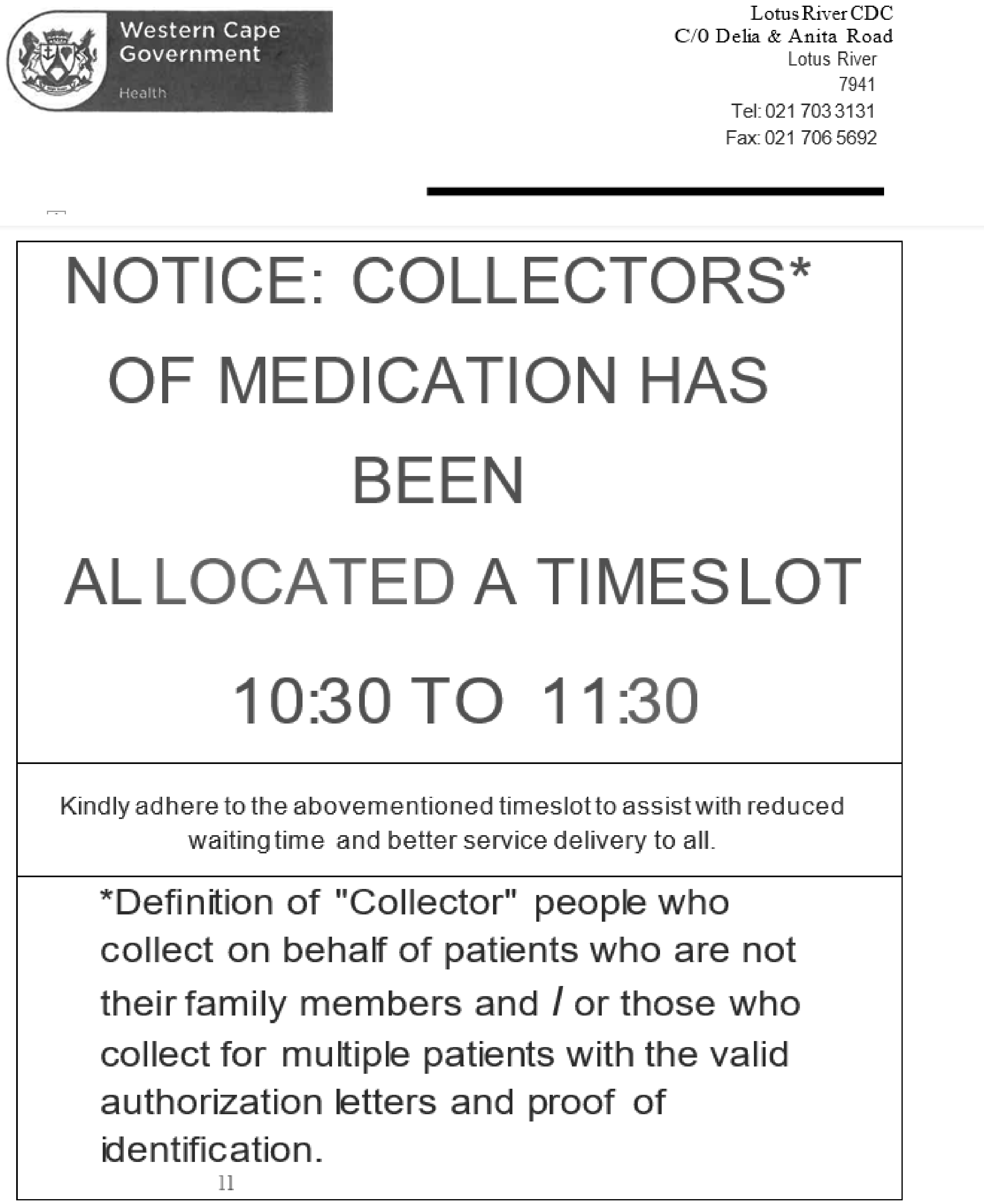
Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Prof Uta Lehmann
Director, School of Public Health
University of the Western Cape
Private Bag X17
Bellville 7535
soph-comm@uwc.ac.za

Prof Anthea Rhoda
Acting Dean, Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17
Bellville 7535
chs-deansoffice@uwc.ac.za

Ethics Reference Number : BM17/10/16

## APPENDIX 7: LOTUS RIVER OFFICIAL NOTICE TO COLLECTORS



Western Cape Government
Health

Lotus River CDC
C/0 Delia & Anita Road
Lotus River
7941
Tel: 021 703 3131
Fax: 021 706 5692

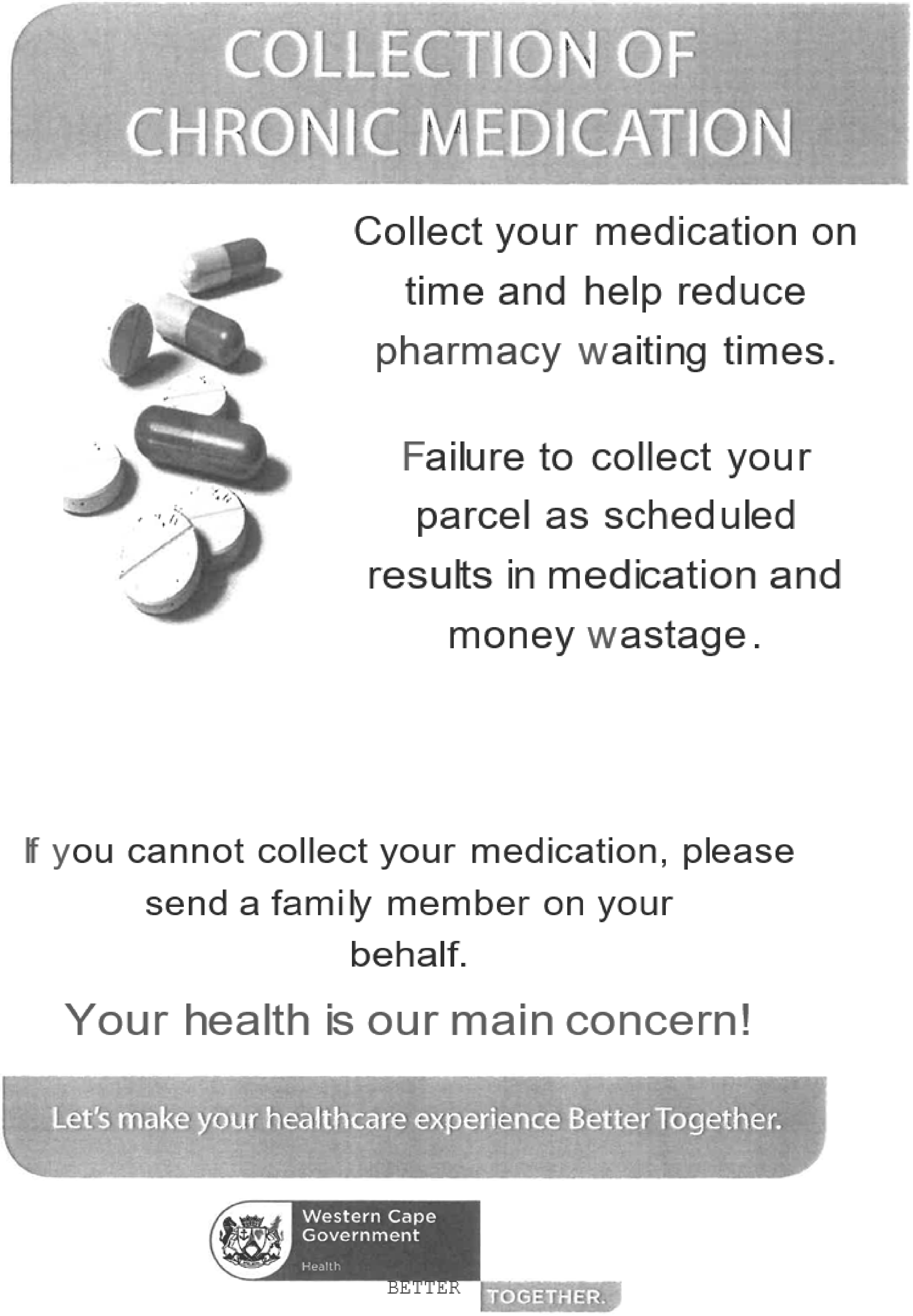
NOTICE: COLLECTORS*
OF MEDICATION HAS
BEEN
ALLOCATED A TIMESLOT
10:30 TO 11:30

Kindly adhere to the abovementioned timeslot to assist with reduced waiting time and better service delivery to all.

*Definition of "Collector" people who collect on behalf of patients who are not their family members and / or those who collect for multiple patients with the valid authorization letters and proof of identification.

11

## APPENDIX 8: WESTERN CAPE DEPARTMENT OF HEALTH NOTICE FOR COLLECTION OF CHRONIC MEDICATION



# COLLECTION OF CHRONIC MEDICATION

Collect your medication on time and help reduce pharmacy waiting times.

Failure to collect your parcel as scheduled results in medication and money wastage.

If you cannot collect your medication, please send a family member on your behalf.

Your health is our main concern!

Let's make your healthcare experience Better Together.

Western Cape Government
Health

BETTER TOGETHER.