

UNIVERSITY OF THE WESTERN CAPE

**Factors influencing the implementation of a Community Based
Information System and data use by Community Health Workers for the
planning and management of HIV/AIDS Programmes in Chris Hani
District, Eastern Cape.**

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Mini thesis submitted in partial fulfilment of the requirement of the Degree of Master of
Public Health, in the School of Public Health, Faculty of Community and Health Sciences,


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Supervisor Dr Verona Mathews

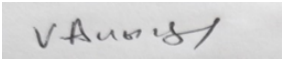
November 2022

DECLARATION

I declare that “Factors influencing the implementation of a Community Based Information System and data use by Community Health Workers for the planning and management of HIV/AIDS programmes in Chris Hani District, Eastern Cape” is my own work, which has not been submitted for any degree or examination in any other university. And that all the sources I have used or quoted have been acknowledged by complete references.

Vuyokazi August

Signature:



Date: November 2022



KEY TERMS

- Community health workers
- HIV/AIDS
- Community based information systems,
- South Africa
- Community based organisations
- Primary healthcare
- District health information system
- Data use
- Stakeholder collaborations
- Chris Hani District



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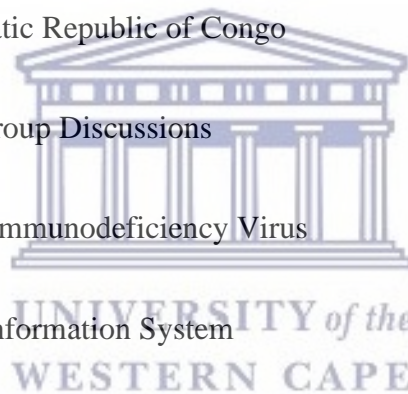
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ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
CBOs	Community Based Organisations
CBIS	Community Based Information System
CHDM	Chris Hani District Municipality
CHWs	Community Health Workers
DHIS	District Health Information System
DHMIS	District Health Management Information System
DRC	Democratic Republic of Congo
FGDs	Focus Group Discussions
HIV	Human Immunodeficiency Virus
HIS	Health Information System
KII	Key Informant Interview
MCSP	Maternal and Child Survival Program
NHIS	National Health Information System
POPIA	Protection of Personal Information Act
PHC	Primary Health Care
SDGs	Sustainable Development Goals
SOPs	Standard Operating Procedures



UN	United Nations
WBPHCOT	Ward-Based Primary Health Care Outreach Teams
WHO	World Health Organisation
YOLO	You Only Live Once



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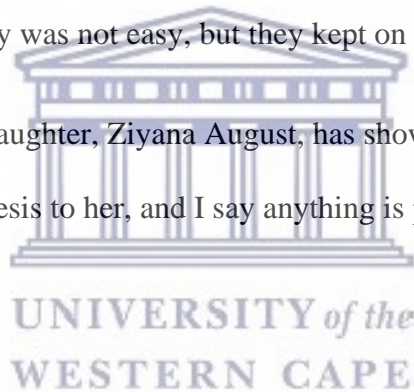
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ABSTRACT

Functional health information systems have been identified as one of the six building blocks of a successful health system by the World Health Organisation. Community health workers (CHWs) play a vital role in ensuring this goal is met through service delivery and implementation of community based information systems (CBIS). This cadre is faced with several challenges which influence and impact the successful implementation of their programmes. A functional community based information system is critical in ensuring that the data collected is assessed and analysed to inform decision-making.

This study aims to describe the factors that influence the implementation of CBIS and data use by CHWs for the planning and management of HIV/AIDS programmes. A qualitative descriptive study design with three data collection methods was used to collect data: document review, focus group discussions and semi-structured interviews. Four focus group discussions with CHWs and three semi-structured interviews with professional nurses and social workers were conducted. The data was analysed manually using a thematic analysis approach. Ethical standards and rigour were applied throughout the study.

The study findings revealed that CHWs are using an electronic Microsoft Excel depicting their CBIS to record and store their data. CHWs are identified as the main role players of the CBIS. The CBIS has no backup system, and it is not encrypted which puts risk of loss and easy access to clients' information. In addition, the CBIS has no standard operating procedures which have a negative impact on the correct use of tools. The CBOs have standardised tools. However, the lack of resources has affected the use of standardized tools and CHWs ended up using notebooks resulting in their credibility being questioned. Information is disseminated only to

the direct funder and the CBIS is not integrated with any health information system. Several factors influencing the use of data were identified including positive community feedback, stakeholder feedback, low literacy levels, CHWs turnover, lack of resources, and poor multi-sectoral collaboration.

In conclusion, poorly designed CBIS affects data use, the planning and management of HIV/AIDS programmes. Multi-sectoral collaboration in the design of CBIS is essential to ensure a functional and well-integrated CBIS.

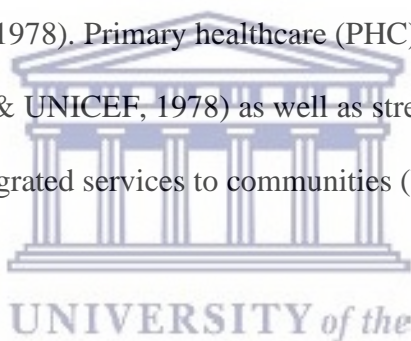


CHAPTER 1: INTRODUCTION

This chapter will provide a detailed background of the study. It further discusses the problem statement and the purpose of the study. In addition, it outlines the chapter layout and an overview of what to expect throughout the study.

1.1. Background

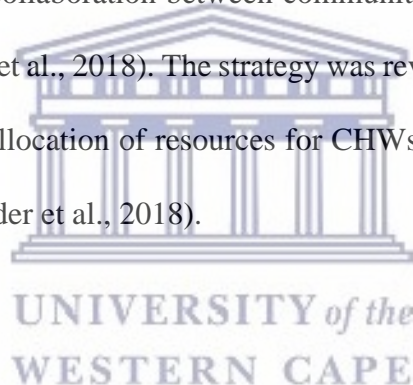
According to the Alma-Ata Declaration of 1978, access to quality health is a human right and the current inequality is unacceptable (WHO & UNICEF, 1978). As a result, all countries have the responsibility to ensure that their citizens receive quality healthcare by the year 2000 and it was further advised that this could be achieved through the implementation of primary healthcare (WHO & UNICEF, 1978). Primary healthcare (PHC) aims to address health issues at the community level (WHO & UNICEF, 1978) as well as strengthen collaboration between different sectors to provide integrated services to communities (WHO, 2017).



The notion of PHC has resulted in a global call for the recruitment of one million community health workers (CHWs) by the year 2015 (Singh & Sachs, 2013). The use of CHWs has played a significant role in meeting the United Nations Sustainable Development Goals (SDGs), as goal number three aims at ensuring healthy lives and promoting well-being for all ages (UN, 2015). Furthermore, this has increased health service provision and coverage, especially in hard-to-reach areas as CHWs are located mostly in the communities they service (Measure Evaluation, 2016).

CHWs play a pivotal role in addressing health issues, especially in the fight against HIV/AIDS (Busza et al., 2018). CHWs are defined as individuals that provide ‘health education, referral and follow-up, case management, basic preventive healthcare, and home visiting services to specific communities’ (International Labour Organization, 2012: 192). CHWs are also regarded as an extended hand of the government, and they have invaluable perspectives to improve the health outcomes of community members (Mlotshwa et al., 2015).

In South Africa, the National Department of Health took the call of PHC and introduced the ward based primary healthcare outreach teams (WBPHCOT) strategy which led to the recruitment of health facility based CHWs (Schneider et al., 2018). In addition, the strategy aimed at the establishment of collaboration between community based organisations (CBOs) and health facilities (Schneider et al., 2018). The strategy was revised to support the UN SDGs; however, it failed to state the allocation of resources for CHWs to achieve the goal of access to universal healthcare (Schneider et al., 2018).



As mentioned previously, HIV/AIDS is one of the critical programmes implemented by CHWs, funded by government and international donors in South Africa, (UNAIDS, cited in Avert, 2020). South Africa is one of the leading countries in the world with more than seven million cases of people infected by HIV/AIDS (WHO, 2020). While the global HIV/AIDS infection rate is standing at over 30 million cases (Avert, 2020). Due to the large funds spent on HIV/AIDS programmes the government and CBOs are under pressure to develop well-functioning information systems to monitor their work and plan for effective health programs (Measure Evaluation, 2016).

WHO (2017) states that in strengthening a health system there is a need to establish a well-functioning health information system. A health information system (HIS) involves data collection from health and other sectors which are analysed to produce information for decision-making (WHO, 2010). The HIS is guided by four key functions, namely, data generation, compilation, analysis and synthesis, communication, and use (WHO, 2010). In addition, the HIS plays a significant role in identifying health problems and needs, producing evidence-based decisions, and assisting with the allocation of resources (WHO, 2010).

Furthermore, the WHO (2010) has advised that HIS at the national level should be integrated with local health information systems including community based information systems (CBIS) (WHO, 2010). ‘A community based information system involves data collection, management, and analysis of health services that exist within a community outside of health facilities’ (Measure Evaluation, 2019: n.p.). However, integration of the CBIS with the national HIS is still a challenge across the globe (Shahmoradi & Habibi-Koolae, 2016). The challenges with the integration of CBIS with the national HIS identified in different countries include the lack of centralised databases, standardised processes, quality assurance procedures, fragmentation, and unresponsiveness to data users’ needs (Hodge, 2012).

In addition, CBIS across the globe faces several challenges such as a lack of CHW technical capacity, a lack of integration into the health system, poor coordination between stakeholders and a lack of resources (De Neve et al., 2017; Kaburu, 2016). Failure to address the above challenges will have dire implications for the health system as issues of duplicated data reporting will persist leading to wasteful expenditure (Mitsunaga et al., 2013) and the quality-of-service delivery by CHWs will continue to be questioned (Kaburu, 2016).

A functional CBIS plays a significant role in ensuring that the data collected is assessed and analysed to inform decision-making. Furthermore, the data collected from CBIS plays a key role in ensuring that CHWs do their jobs effectively, and it enables the management and government to track programme progress (Measure Evaluation, 2016). A CBIS is either paper-based or electronic (Walker, 2018). One of the main objectives of a CBIS is the sharing of data between community based service providers, health facilities, and the government to better serve the population in need. However, the development of electronic CBIS has been discovered to be still in the initiation stage in most countries (Walker, 2018).

1.2. Problem statement

There is a huge human resource and financial investment in the fight against HIV/AIDS (UNAIDS, cited in Avert, 2020). The success of HIV/AIDS programmes relies on accurate and reliable information. Emphasis has been placed on improving information systems to improve decision-making and planning (WHO, 2010). However, CHWs fail to use data as they lack knowledge, skills, and inadequate systems, which hinder progress in the fight against HIV/AIDS (Flora et al., 2017). In addition, internationally integration of CBIS is still a major challenge to the formal health management information system (Measure Evaluation, 2016).

In South Africa, community based information systems should be integrated with the national health information system (South African Government, 2012). However, Schneider et al. discovered that only 41% of CHWs were reporting to the District Health Information System (DHIS). On the other hand, there is a dearth of literature that describes the CBIS for the HIV programme and the factors that influence the implementation thereof.

1.3. Purpose of the study

The purpose of the study is to provide a description of CBIS and identify the factors that influence the implementation of CBIS. This will provide an opportunity for CBIS designers, users, and implementers to understand and identify the challenges that exist as well as develop strategies to address them.

1.4. Outline of the research

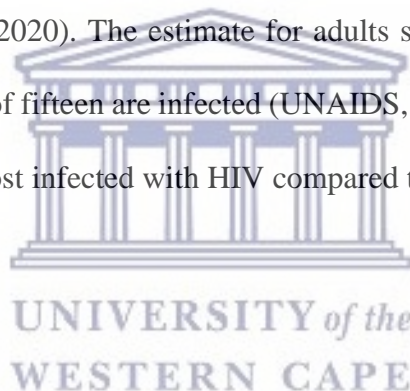
This mini thesis consists of six chapters. Chapter one provides the background of the study, the problem statement, and the purpose of the study. Chapter two is the review of literature relating to the global burden of HIV/AIDS and CHWs' programmes international. The chapter further provides an overview of CHWs programmes in South Africa and discusses the CBIS model as well as its challenges. Chapter three discusses the methodology used, the research aim and objectives, the study design, the study sample, data collection and analysis. In addition, it discusses the rigour and ethical processes followed throughout the study. The fourth chapter outlines the results, using verbatim quotes to support the findings. Chapter five discusses themes that emerged in the findings and how these relate to previous studies and the implications thereof. Chapter six as the last chapter concludes the study by relaying recommendations based on the study findings.

CHAPTER 2: LITERATURE REVIEW

This chapter starts by providing an overview of the global and national burden of HIV/AIDS. It continues with an overview of the CHWs programmes internationally and nationally. It further outlines a review of the literature on the CBIS model, the use of CBIS and its integration into national and district health information systems. Lastly, it also reviews the global challenges of the CBIS.

2.1. Global burden of HIV/AIDS

Globally, HIV/AIDS is one of the gravest pandemics that presents an immense challenge to the public health system (HIV.org, 2020). Worldwide there are more than 38 million people infected with HIV (UNAIDS, 2020). The estimate for adults stands at 36.2 million, and 1.8 million children under the age of fifteen are infected (UNAIDS, 2020). UNAIDS further states that women globally are the most infected with HIV compared to their male counterparts with an estimated 53 per cent.



Targets for addressing HIV/AIDS were set during the United Nations General Assembly for the year 2020 and include the 90-90-90 strategy, to have less than 500 000 new HIV infections and AIDS-related deaths (UNAIDS, 2020). However, several of these targets were missed because of several issues, such as a decrease in funding, poor infrastructure, and gender inequalities (UNAIDS, 2020). Even though these targets were missed, significant progress has been made that could be attributed to the work of health workers, including CHWs (WHO, 2020). As mentioned previously, a funding gap has been identified as funding was reduced by seven per cent between the year 2017–2019 and imposing a disruptive impact on the progress

made, as 3.5 million new HIV infections and 820 000 AIDS-related deaths were reported globally (UNAIDS, 2020).

2.2. HIV/AIDS in South Africa

South Africa has been greatly affected by HIV/AIDS, with over 7.5 million people infected and making it one of the leading countries in the world with HIV/AIDS infections and deaths (UNAIDS, 2020). In addressing the spread of the virus, the government has committed itself by increasing its spending on HIV/AIDS programmes and sharing responsibility with international donors, as this call was influenced by UNAIDS during the United Nations General Assembly conference in 2011 (Resch, Ryckman & Hecht, 2015). This has played a significant role in the fight against HIV/AIDS as the country was able to meet the first 90 per cent (94%) of the United Nations' HIV/AIDS strategy which is about ensuring that 90 per cent of people that are HIV positive know their HIV status, from those that know their HIV status 74 per cent were on treatment (second 90 per cent) and 67 per cent were virally suppressed (the last 90 per cent) (UNAIDS, 2022). This is remarkable progress for the country as it is steering in a promising direction. However, South Africa is not yet out of the woods as in 2019 it reported over 200 000 new HIV cases (Avert, 2020). As the above report indicates, much needs to be done even though millions of dollars are spent on the HIV/AIDS programme.

2.3. CHWs' programmes international

Globally, CHWs are receiving attention and recognition based on the vital role they play in primary healthcare, especially in the HIV/AIDS pandemic (Busza et al., 2018; Shelley et al., 2019; Lorente et al., 2020). The CHWs fulfil various roles like counsellors, mobilisers, advocates, and liaisons (Busza et al., 2018; Cataldo et al., 2015; Ahmed et al., 2017). In a

qualitative study conducted by Callaghan (2019) in rural and urban America, it was discovered that CHWs served as a link between the community and primary healthcare. Whereas in another qualitative study conducted by Smith et al. (2014) in Malawi, CHWs played a role in health promotion, and prevention and then expanded to curative.

However, Cataldo et al. (2015) found that most of the time CHWs' contributions or services are motivated by altruism and this at times poses a great challenge to the quality of HIV programmes as CHWs lack the proper knowledge and skills. This requires various stakeholders to play their part, especially the health and welfare sector to provide training to these individuals as suggested by the WHO (2010). Progress has been observed against this cadre as some CHWs are now getting paid stipends to meet their personal demands (Cataldo, 2015). However, the sustainability of CHWs is still threatened due to a lack of funds and lack of recognition from the government (Cataldo et al., 2015; Shelley et al., 2019). This is supported by a qualitative study conducted by Mottiar and Lodge (2018) in three provinces in South Africa, as they discovered the lack of integration of CHWs from CBOs into the government policies may affect the sustainability of this cadre.

Some countries have recognized CHWs and integrated the cadre into their health workforce. In Brazil, community health service delivery was improved by the introduction of CHWs to reach hard-to-reach areas (Marten et al., 2014). The Indian government is committed to meeting the goal of Universal Health Care by funding CHWs to extend healthcare services at a community level and make services more accessible to the people (Marten et al., 2014). The availability of CHWs in the Bangladesh health system saw an increase in health outcomes such as improved TB treatment success rate and case detection (Ullah et al., 2006).

In addition, a qualitative study using descriptive case studies by De Neve et al. (2017) in Southern Africa, discovered that the government has failed to ensure alignment and harmonization of CHW programs. The authors further argue that this creates duplication of services and confusion as community based and health facility based CHWs are competing for the same clients. This challenge is further fueled by the different expectations from different funders like international donors, the private sector, and the government (De Neve et al., 2017). Around the globe, the coordination of the CHWs cadre is still lacking, and this affects their utilization, compensation, and retention (Mwai et al., 2013).

2.4. Overview of the CHWs program in South Africa

CHWs have a long history in South Africa as their existence can be traced back to the apartheid era; they were formed to address challenges of unmet health needs and inequality (van Ginneken et al., 2010). The authors further state that due to several challenges the CHW cadre collapsed in the middle of the 1990s, and this could be attributed to a lack of funds as well as resources. The rise of HIV/AIDS cases led to the re-emergence of CHW programs and an urgent need for intervention (Friedman, 2005). Even though the lack of funding was still eminent in the early 2000s the Department of Health during a national Lekgotla, committed to paying a stipend of R500-R1000 as a motivation for their services (Friedman, 2005). Furthermore, in 2004 a National CHW Policy Framework was developed to guide how CHW stipends would be paid (Friedman, 2005).

The framework highlighted that CBOs were responsible for providing training and supervision support to CHWs (Tsolekile, Schneider & Puaone, 2014). Schneider et al. (2018) highlighted several challenges that were identified such as literacy levels, poor coordination, and lack of

integration of CHWs programs into the primary health system. The government introduced the PHC re-engineering strategy in 2011 which was implemented through the ward-based primary healthcare outreach team (WBPHCOT) led by a professional nurse and includes a data capturer (National Department of Health, 2011). This call was a plan to formalize this cadre, however, they are not fully integrated as they still receive stipends from CBOs' third-party payment services (Schneider et al., 2018). Even though the introduction of WBPHCOT has been noted, there are still challenges that have been identified such as the inadequate provision of resources, the lack of supervision, the heavy workload for outreach teams, and the inadequate and irregular payments (Nelson & Madiba, 2020).

The introduction of the WBPHCOT strategy also aimed at ensuring that community based work is reported and integrated into the district health information system (DHIS) (Schneider et al., 2018). The teams are expected to submit monthly reports and in 2017 a total of 3275 out of 7800 WBPHCOTs submitted reports to the national DHIS (South African National Department of Health, 2017). The lack of reporting is traced to the heavy workload experienced by the teams (Nelson & Madiba, 2020). In addition, the WBPHCOTs faced a high burden of data collection and reporting which resulted in a lack of information use (Murphy et al., 2020).

However, there are CHWs that are not part of the Department of Health system and who have received little to no formal training (Daniels, Clarke & Ringsberg, 2012). This group of CHWs are either working with no funding or funded by international donors or the Department of Social Development (Daniel et al., 2012; Schneider, Hlophe & van Rensburg, 2008). CHWs experience additional challenges such as poor linkages with health facilities, lack of acknowledgement by health facilities and negative attitudes which also result in their data not

being integrated into the health system (Morley & Cashell, 2017; Tshitangano & Olaniyi, 2018).

2.5. The Community based Information System Model

CBIS has been described as involving data management of health services at the community level and involves information sharing among communities and government entities (Walker, 2019). Jeremie et al. (2014) support this when they discovered that CBIS promotes the engagement of community members with the system and access to services. This CBIS Model is proposed as a starting point and is designed to address several of the challenges associated with CBIS and provide a sense of structure for community based organisations Walker (2019).

The CBIS Model proposed by Walker (2019) consists of eight components: leadership and governance, system design, system management, data sources, data management, information products and dissemination, data quality, and data use (presented in the inner circle). These eight components can be categorized under three broader dimensions: enabling environment, system performance, and information generation (presented in the middle circle). The outer circle represents different stakeholders that should interact with the CBIS.

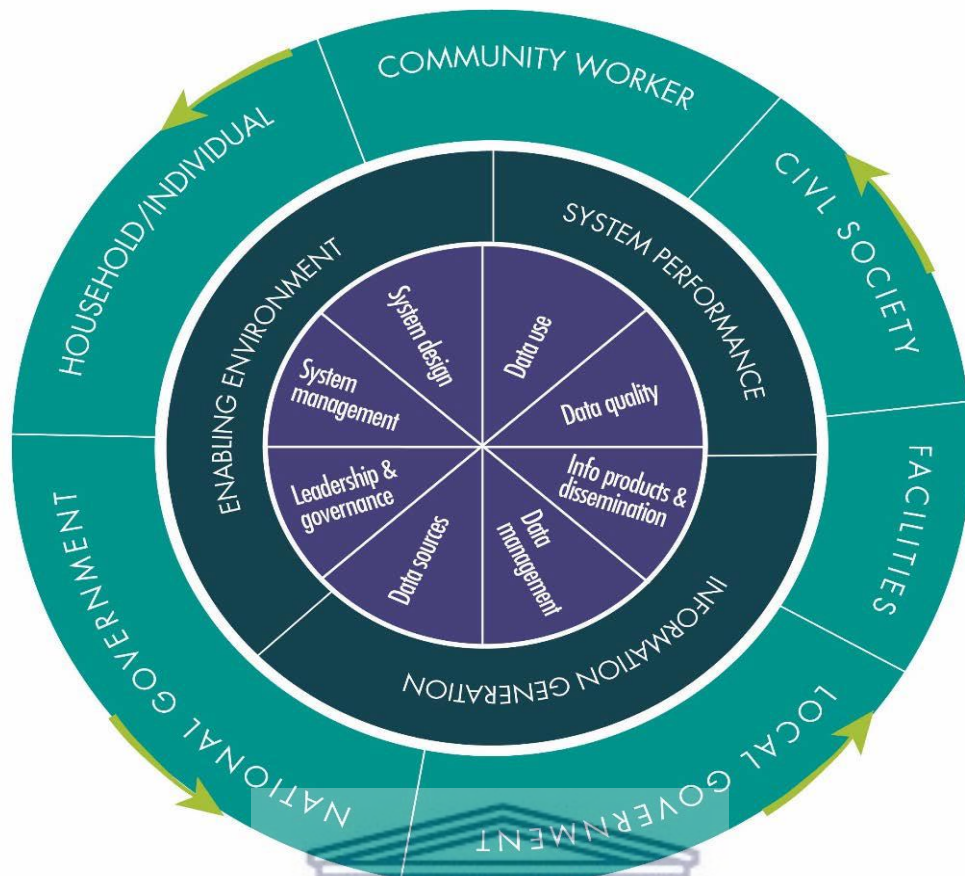


Figure 1: CBIS Model (Walker, 2019):

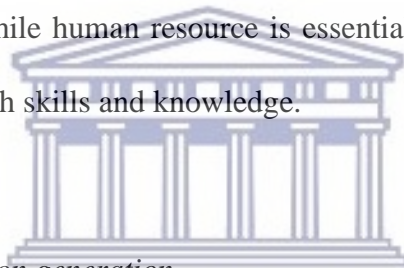
The eight components of the CBIS Model will now be described in detail:

2.5.1. Dimension A: Enabling environment

- a) **System design:** This is crucial for the development of CBIS as poorly designed CBIS have a negative impact on producing quality information for reporting and decision-making. The design of the system should be clear about its purpose, the type of data to be collected, the data workflow, the role of different stakeholders in the system, and integration with other management information systems. In addition, the design of the system should consider the resources that will be required and the literacy levels of the users.

b) Leadership and governance: These are essential for CBIS to provide a clear role to different stakeholders and ensure that data is used. Furthermore, it plays a huge role in reducing redundancy and the excessive burden of data collection by ensuring the harmonisation of data collection tools. Leadership plays a role in ensuring data collected at the community level is used for budget allocations, programmes, and policy formulations.

c) System management: A functional CBIS is influenced by the availability of management functions such as financial and human resources. This is crucial from the design stages of the system to ensure financial and human resources are available to guide the management and use of the system. Financial resources are needed to maintain the system, while human resource is essential in ensuring people using the system are equipped with skills and knowledge.



2.5.2. *Dimension B: Information generation*

a) Data sources: CBIS focuses on collecting routine sources of information using different tools such as household registration forms, case management tools, referral forms and others. At times, the routine data is triangulated with non-routine data to identify trends and assure the accuracy of data.

b) Data management: A functional CBIS is guided by clear data management processes, as these influence data utilisation for decision-making. The system must have standard operating procedures that guide data collection, capturing, analysis processes, right to access and storing of data.

- c) **Information product and data dissemination:** A variety of information products such as reports, presentations, and others can be developed and distributed to different stakeholders. This ensures that the data collected is used for decision-making to inform programme and policy formulations. The type of data to be distributed to stakeholders lies with the requirements of each stakeholder. Dissemination of data is important to ensure communities and stakeholders are informed, as well as encourage reciprocal feedback.

2.5.3. *Dimension C: System performance*

- a) **Data quality:** High-quality data is determined by the effective functionality of the above-mentioned components, if any component is compromised, so is the quality. The quality of the data is also influenced by the skill set of CHWs, literacy levels, lack of data verification at the household level, the complexity of forms, lack of supervision, and data quality checks.
- b) **Data use:** This is the end result of having a functional CBIS. The aim is to produce data that is usable and influences decision-making at all levels. All users involved in the system must be able to interpret the data and understand how it can bring about change in communities. It is important that data must not be used to collect stats or reporting purposes only but must be used for informed decision-making in program implementation and policy formulation. Data use allows community members to hold stakeholders accountable for the services they deliver.

In conclusion, it is important for stakeholders to engage with the development of the system to ensure that the information needs are being met (Penn et al, 2019). Also, to ensure that there is

a harmonization of tools whilst the data quality challenges are addressed (Flora et al., 2017; MCSP, 2019; Otieno et al., 2012).

2.6. Utilisation of community based information systems globally

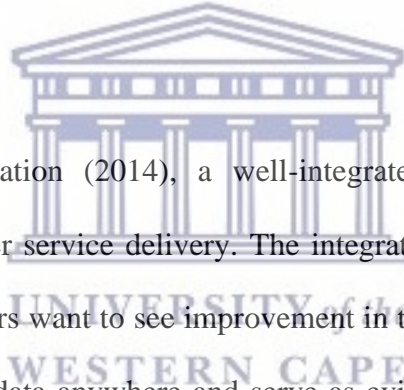
A recent mixed-method study conducted in 17 countries in west and east Africa discovered that CBIS is still in the early stages of development (Russpatrick, 2019). In addition, in western Kenya, it was discovered that data from CBIS is unused as the CHWs lacked the ability to quantify and analyse data collected for programme planning and implementation Flora et al. (2017).

In a Maternal and Child Survival Program (2019), it discovered the following regarding the use of CBIS:

- In the Democratic Republic of Congo (DRC), data usage has been identified as weak, especially in organisations that do not have partner support.
- In Egypt, data is utilised for reporting at the health facility level and not reliably analysed for programme planning.
- In Namibia, a formal CBIS was developed by the government with guidelines and standard operating procedures. However, the lack of data usage and decision-making is still a challenge, even though CHWs participate in data review meetings.
- In Uganda, CHWs have shown minimal data usage. This is more evident in CHWs who are linked to health facilities and receiving supervision.

2.7. Integration of community based information systems to national and district health information systems

Integrating health information systems has been identified as making a significant contribution to health performance as it provides quality data (Shahmoradi & Habibi-Koolae, 2016). The lack of data on the integration of CBIS poses a challenge in understanding progress on the establishment of a well-functioning health information system around the world. This causes redundancy and an additional workload to health workers due to the inability to access data timely (Sahay et al., 2000 cited in Dlodlo & Hamunyela, 2017). The authors further state that a huge amount of data is not usable as it is too fragmented for decision-making. Furthermore, this has a negative impact on implementing the WHO's six building blocks of a health system as the problem starts at the community level due to inadequate data flow (Shahmoradi & Habibi-Koolae, 2016).



According to Measure Evaluation (2014), a well-integrated CBIS would provide the government with data for better service delivery. The integration of CBIS is important and needs to be accelerated if leaders want to see improvement in the healthcare system as it will allow accessibility to updated data anywhere and serve as evidence for policy development (Dlodlo & Hamunyela, 2017).

In four countries on the Maternal and Child Survival Program (2019), the following was discovered regarding the integration of CBIS:

- In DRC and Egypt, the CBIS has been integrated with national and district health information systems. However, reporting is one-sided as there are no feedback mechanisms reporting back to community based organisations from the district or national level, and this is only possible at the health facility level.

- In Namibia, the CBIS is comprehensively integrated into the district and national health information system. In addition, it has some positive functions such as a feedback mechanism to CHWs, even though it needs strengthening.
- In Uganda, the CBIS is unintegrated with the district and national information system. However, the government is in the process of integrating data at the district level.

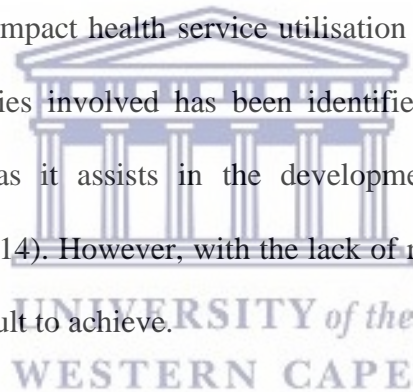
In South Africa, the expectation is that the CBIS should be integrated with national health information systems (NHIS) (South African Government, 2012). However, NHIS is not yet available in the country (National Department of Health, 2011). The Department of Health envisions that the NHIS would consist of at least five components namely, population-based information; health services based information; health resources records; vital registration data; and transversal (government-wide) support systems (National Department of Health, 2011). The author alludes that the country is currently using a district health management information system (DHMIS), where the district health information system forms part of. “DHMIS is a system for deriving a combination of health statistics from various sources, mainly from routine information system used in the public sector to track health service delivery in sub-districts, districts, provinces and nationally (National Department of Health, 2011)”. The National Department of Health introduced the WBPHCOT strategy to address the call of integrating CBIS with DHIS (Schneider et al., 2018). However, the authors discovered that this is still a challenge as only 41% of CHWs were reporting to the DHIS (Schneider et al., 2018).

2.8. Challenges of community based information systems globally

The CBIS has the following challenges: lack of coordination by management, poor linkages, lack of resources, and a lack of knowledge and skills in respect of the use of data for programme planning (Flora et al., 2017). The challenges are discussed further below.

2.8.1. Lack of coordination and poor linkages between CHWs and health facilities

UNICEF and WHO (1978) have emphasised the need for an inter-sectoral collaboration through the Alma Ata declaration. However, even this is still a challenge. The lack of coordination among various stakeholders has led the HIV/AIDS programmes to be managed and implemented in parallel (De Neve et al., 2017). They further argue that this has caused confusion and duplication of services. In addition, poor linkages between the community based CHWs and the health facility impact health service utilisation (Flora et al., 2017). Having a functional CBIS with all parties involved has been identified to play a vital role in the management of information as it assists in the development of strategies to improve programmes (Jeremie et al., 2014). However, with the lack of resources and skills on how to utilise data, this could be difficult to achieve.



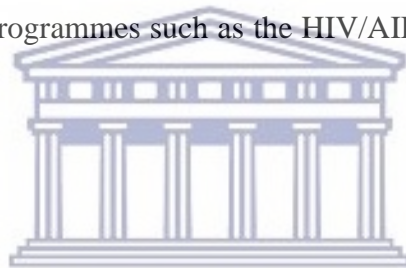
2.8.2. Lack of resources

The lack of resources has been identified as having a negative impact on the implementation of healthcare services (Naidoo et al., 2018). The authors add that the lack of resources is not only based on tangible goods but could include human resources; as the ward based PHC outreach teams in South Africa are made up of four to five CHWs and are expected to service clients on a 1:76 ratio. In Kenya, it was discovered that a lack of reporting tools and lack of funds affected the functionality of CBIS (Kaburu et al., 2016). This is a setback to the CHWs

programmes that need to be addressed, as this could reduce the workload and pressure experienced by facility based CHWs.

2.8.3. *Lack of knowledge and skills*

CHWs have been identified as lacking skills in data analysis; this has a major impact on information usage as data collected is passed to the district and national levels without engagement (Kaburu et al., 2016). According to Flora et al. (2017), emphasis has been placed on data collection rather than data use. This means that a lot of data is available but is not effectively managed. This has caused tensions not only at the community level as communities do not trust CHWs even at a facility level, especially if the CHWs are unsupported by health facilities (Flora et al., 2017). Training interventions are pivotal to ensure the quality implementation of healthcare programmes such as the HIV/AIDS programme (Cataldo et al., 2015).



2.8.4. *Lack of dialogue*

The lack of dialogue amongst CHWs has an impact on programme implementation as these platforms allow CHWs to engage with the data collected and plan accordingly (Kaburu et al. 2016). Community dialogues were found to be essential as they allow role players to assess information analysed to effectively plan healthcare programmes and this has an influence on the integration of services with other stakeholders like the healthcare system (Jeremie et al., 2014).

The review of the literature has shown that CHWs have played a significant role in improving the primary healthcare system. In addition, the literature has also shown that CBIS has made little progress around the globe and several challenges still exist. Consequently, if these

challenges are left unaddressed, this will hinder the progress of the primary healthcare system.

This study is significant as it contributes to the limited CBIS body of knowledge both in South Africa and globally.



CHAPTER 3: METHODOLOGY

The following chapter will describe the aim, objectives, and design of the study. It will further discuss the study setting, processes followed to identify the population, sampling, data collection, and analysis. In addition, it will describe the processes applied to ensure rigour in this qualitative study.

3.1. Research aim

This study aims to describe the factors that influence the implementation of a community based information system and data use by CHWs for the planning and management of HIV/AIDS programmes in Chris Hani District, Eastern Cape.

3.2. Objectives

The **objectives** of the study are:

- To describe the community based information system in the district.
- To explore factors that influence the implementation of community based information systems by CHWs.
- To explore factors that promote the use of data by CHWs.
- To explore factors that hinder the use of data by CHWs.

3.3. Study design

A descriptive study design employing qualitative research methodology was used. This methodology is appropriate as the phenomenon will be investigated, and the information will be described from the views of the participants (Robson & McCartan, 2016).

3.4. Research setting

The Chris Hani District Municipality (CMDM) covers a surface area of 36,756 km² and is in the northern region of the Eastern Cape Province (Chris Hani District Municipality, 2020). The district is divided into six sub-districts, namely, Enoch Mgijima, Intsika Yethu, Engcobo, Sakhisizwe, Inxuba Yethemba and Emalahleni (Chris Hani District Municipality, 2020). The author further states that only 35.2 per cent of the district population lives in areas classified as urban, while 63.8% live in rural areas. Below is the CHDM map.

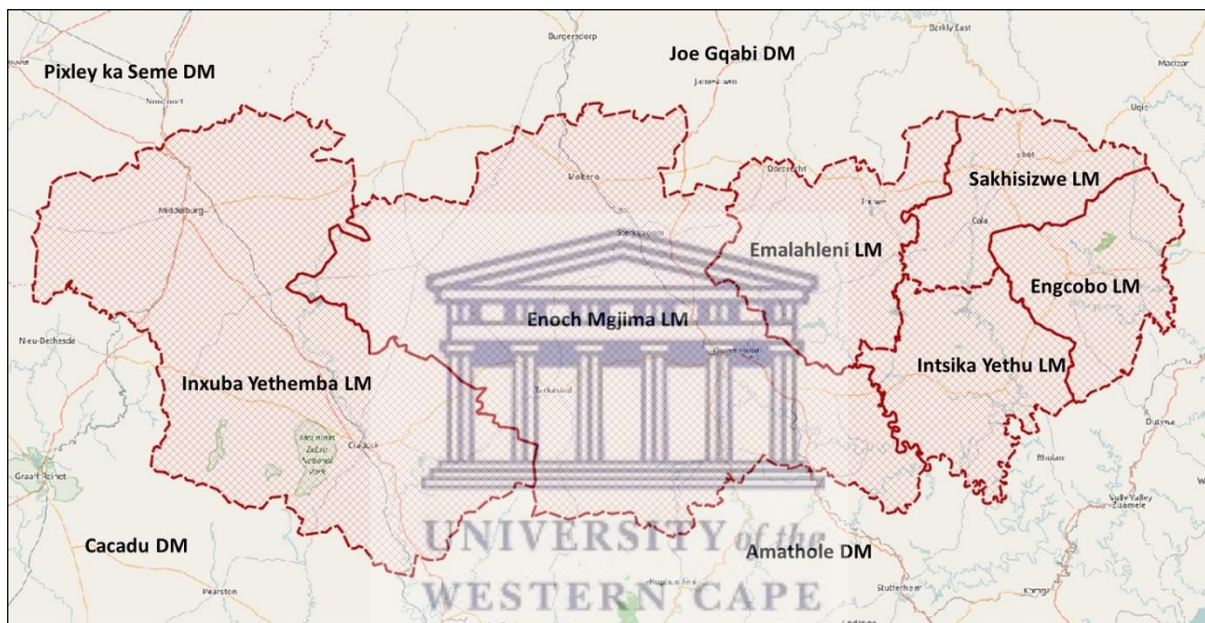


Figure 2: CHDM map (Chris Hani District Municipality, 2020)

The district has a total population of 849 000, which accounts for 12 per cent of the total population in the province (Chris Hani District Municipality, 2020). In addition, the gender distribution within the district is 51.69% for females while their male counterparts are at 48.31% (Chris Hani District Municipality, 2020). The report further states that the district is faced with many challenges such as high rates of unemployment, poverty, and poor infrastructure. The district is mostly rural which has a negative effect on health service due to the distance between and sparseness of the locations.

The study was conducted in four CBOs, Department of Social Development offices and two public health facilities (Department of Health). This setting was chosen due to the prominent levels of HIV/AIDS, as it has been identified as the leading cause of death in the district, especially among youth (Chris Hani District Health Plan, 2018-2019). In addition, this setting was considered suitable as CBOs are being funded by the Department of Social Development.

3.5. Study population

The study population is CHWs from community based organisations registered and funded in the Chris Hani District by the Department of Social Development to implement the HIV/AIDS programme. The study population will additionally include key informants that work with CHWs and have insights into the work being provided by CHWs. Furthermore, their experiences and engagement with CHWs will provide a deeper meaning to the study. The study consists of three study populations:

- Community health workers: the primary population and implementers of the HIV/AIDS programme at the community level. There are more than 120 CHWs in the district that are being funded by the Department of Social Development.
- Social workers: the secondary population and the key informants employed by the Department of Social Development to provide support to the CHWs.
- Professional nurses: the secondary population and key informants employed by the Department of Health.

3.6. Sampling

Purposive sampling was used to select participants to provide in-depth descriptions of the use of HIV information to plan and manage HIV/AIDS programmes. According to Creswell

(2012), purposive sampling is when a researcher deliberately selects participants to explain the phenomenon better. Below are the five stages followed to select participants:

3.6.1. Stage 1: Selection of the district

Chris Hani District Municipality was selected, as the district has several CBOs implementing HIV/AIDS programmes. In addition, the researcher used to work at one of the sub-districts under the CHDM and is familiar with the district.

3.6.2. Stage 2: Selection of CBOs

CBOs were selected, based on being registered and funded by the Department of Social Development to implement the HIV/AIDS programme. In addition, the selection involved CBOs that are easily accessible in terms of transport as CHDM is mostly deep rural with poor infrastructure. The department is funding twelve community based organisations which are two per sub-district within the CHDM.

3.6.3. Stage 3: Selection of CHWs

Forty CHWs were selected from the CHDM area and were divided into four groups (ten per group). During the data collection process, 36 CHWs were interviewed, and the remainder were on leave.

Inclusion criteria:

- A maximum of ten CHWs per CBO.
- CHWs registered and received funding from the Department of Social Development.
- CHWs with a minimum of two years of experience implementing the HIV/AIDS programme.
- CHWs linked to a local health facility.

Exclusion criteria:

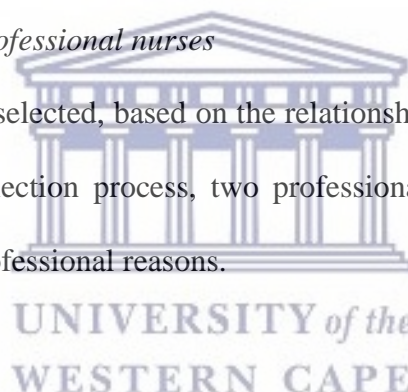
- CHWs not receiving funding from the Department of Social Development
- CHWs with less than two years of experience implementing the HIV/AIDS programme.
- CHWs not serving in the CHDM area.

3.6.4. Stage 4: Selection of social workers

Three social workers were selected based on the role they play in providing support to CHWs. However, during the data collection process, one social worker withdrew from the process due to personal reasons.

3.6.5. Stage 5: Selection of professional nurses

Four professional nurses were selected, based on the relationship they have with the CHWs. However, during the data collection process, two professional nurses withdrew from the process due to personal and professional reasons.



The graph below illustrates the total number of study participants.

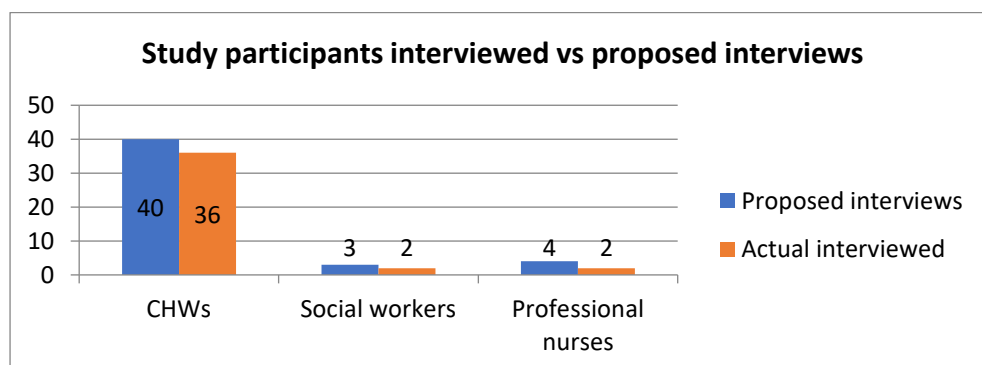
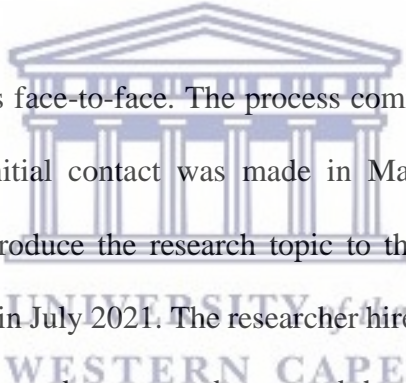


Figure 3: Study participants interviewed vs proposed interviews

3.7. Data collection

Three methods were used to collect data, namely, document review, semi-structured interviews, and focus group discussions. A document review was used to identify data collection tools used by CBOs and to determine their purpose and frequency of use. Focus group discussions were used to collect data with CHWs while semi-structured interviews were conducted with key informants. However, during two interviews with key informants, the process was adjusted as the social workers wanted to be interviewed as a pair to save time, and a nurse extended the invite to a facility based CHW so that they can be interviewed together; her reasoning was that the CHW was more involved with the CBO CHWs. This adjustment proved to be beneficial for the study as rich information was collected and participants took turns answering the questions.

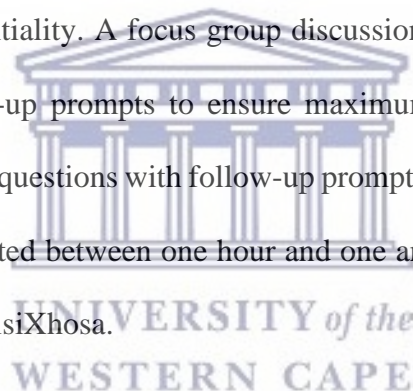


The data collection process was face-to-face. The process commenced in July 2021 and was completed in August 2021. Initial contact was made in May 2021 when the researcher submitted request letters to introduce the research topic to the departments. Permission to conduct research was approved in July 2021. The researcher hired a research assistant to assist with data collection. An audio recorder was used to record the sessions with permission from the participants to enable the researcher to transcribe and provide a verbatim account of the interview. COVID-19 protocols were observed by the research assistant throughout the data collection process. The research assistant maintained a safe distance during the interviews, wore a face mask, a protective shield and ensured all participants wore face masks. The research assistant and participants made use of hand sanitiser before and after the sessions. Field notes and reflections were documented to note critical views and record non-verbal cues. The interviews were transcribed and then shared with the supervisor for review.

3.7.1. Focus group discussions

A focus group discussion has been described as an interview of a group grouped together due to a common topic (Robson and McCartan, 2016). Four focus group discussions were conducted with participants ranging from seven to ten participants per group. Two CBOs had ten CHWs each, while the other two CBOs had seven and nine CHWs, respectively. The research assistant scheduled appointments with the project managers of the CBOs to conduct the focus group discussions. Appointments were scheduled a week before, and reminders were sent a day before the sessions. The research assistant ensured that the audio recorder was charged before the appointments to limit technical problems during the sessions.

An information sheet and consent forms were shared with the participants before the start of the sessions to ensure confidentiality. A focus group discussion interview guide was used to guide the session with follow-up prompts to ensure maximum participation. The guide is comprised of three open-ended questions with follow-up prompts to enable deeper discussions. The focus group discussion lasted between one hour and one and half-hour. The focus group discussions were conducted in isiXhosa.



3.7.2. Semi-structured interviews

The semi-structured interview is a flexible interview method which allows the researcher to use an interview guide to structure the data collection process and use unplanned follow-up questions to get more clarity on the topic (Robson & McCartan, 2016). Four semi-structured interviews were conducted with key informants: two social workers and two professional nurses. Appointments were scheduled weeks prior to the interviews by the research assistant and on the day before the interviews she called the participants to remind them about the interviews. These were conducted in venues the participants preferred.

Three potential participants refused to participate for personal and professional reasons. An information sheet and consent forms were shared and signed by participants before the interviews. The research assistant used a key informant interview guide during the process and open-ended questions were used to gather broad and rich information. According to Robson and McCartan (2016), open-ended questions are significant as they are flexible, not restrictive on the topic and allow participants to share more information. The interviews were recorded and then transcribed. The interviews lasted between 30 and 60 minutes. As mentioned before, two social workers requested to be interviewed together to save time; they took turns responding to questions. A nurse requested a facility based CHW to join the interview process as she works better with CBO CHWs.

3.7.3. Document review

Document review is about understanding the purpose of the document and its validity (Robson & McCartan, 2016). The research assistant conducted a document review in four CBOs and worked under the supervision of the project manager to review available documents. The research assistant explained that the contents of the documents would not be used, and everything would be kept confidential. The research assistant reviewed the following documents: notebooks, client forms, reports, registers, and electronic information systems. The research assistant assessed the purpose of the documents, their use and frequency.

3.8. Data analysis

‘Data analysis is the process of bringing order, structure and meaning to the mass of collected data’ (de Vos et al., 2011: 397). Thematic analysis was used to analyse the data collected and was guided by five phases, namely, familiarisation, coding, identifying themes, defining, and naming themes, integration, and interpretation (Robson and McCartan, 2016).

3.8.1. *Familiarisation*

The research assistant made notes of the focus group discussions and interviews. She then made verbatim transcriptions as data collection was done in isiXhosa, and then translated into English. The researcher then listened to the audio recordings to ensure the accuracy and quality of the data collected. She familiarised herself with the transcripts to gain an understanding of the data collected (Gibbs, 2012). The transcripts were then organised into a folder. Through reading the transcripts repeatedly, the researcher wrote her initial understanding of the data collected using track changes.

3.8.2. *Coding*

The researcher made sense of the text and views shared (Robson & McCartan, 2016). The researcher coded specific sections of text that highlighted ideas and feelings by using track changes (Gibbs, 2012). Various codes emerged from the transcript and were then transferred into a table for further analysis. A master copy of the transcripts and code identification were stored to ensure data accuracy. The codes were shared with the research supervisor for review and guidance.

3.8.3. *Identifying themes*

A table was used for the third phase to sort and categorise the codes (Gibbs, 2012). The researcher studied and identified patterns from codes (Robson & McCartan, 2016). The codes were then translated into possible themes. Throughout this process, a table was used to categorise potential themes as per transcript, then compared to identify similarities and differences. This led to the final identification of themes and sub-themes.

3.8.4. Defining and naming themes

After a thorough examination of the themes, the researcher grouped similar themes and sub-themes to draw links. Final themes were named and defined using a table to indicate their relationship (Robson & McCartan, 2016). The naming of themes was accurate as it ensured each theme was backed up by data.

3.8.5. Integration and interpretation

The definition of final themes enabled the integration of themes to note trends and patterns (Robson & McCartan, 2016). The use of a table ensured the interpretation of clear networks of the themes from the data. This produced a clear meaning and the conclusion of the data to support the research aim. The themes will be discussed further in the Results Chapter and the conceptual model will be applied to Results Chapter to construct the Discussion Chapter.



3.9. Rigour

Rigour was ensured throughout the study by establishing trustworthiness, credibility, conformability, dependability, transferability, and reflexivity (Malterud, 2001). According to Robson and McCartan (2016), rigour plays a significant role in a study as it adds scientific value to the study method and findings.

3.9.1. Trustworthiness

Trustworthiness of the study was achieved using various methods during the data collection phase such as the document review, focus group discussion and semi-structured interviews (Polit & Beck, 2014). Trustworthiness was further achieved by using the Lincon and Guba (1985) model to assess credibility, conformability, transferability, and dependability.

3.9.2. *Credibility*

While the study was being conducted, an audit trail was used to keep track of all activities to eliminate biases and improve rigour (Robson & McCartan, 2016). In addition, transcripts were reviewed by the researcher and research supervisor before being analysed.

3.9.3. *Conformability*

Data triangulation was achieved using three data collection methods such as focus group discussion, semi-structured interviews, and document review to eliminate threats to validity (Robson & McCartan, 2016). Triangulation was also achieved through the identification of common themes and confirming them through comparison with the available data (Creswell and Miller, 2000). Different data collection techniques and data sources were also used to provide rich information.



3.9.4. *Dependability*

An interview guide was used to guide the semi-structured interviews and focus group discussions. The data obtained were reviewed and analysed by the researcher and then submitted to the study supervisor for final review. This was to ensure findings, interpretations and recommendations are examined to prove they are supported by the data.

3.9.5. *Transferability*

Transferability ensures that the research aim will have shareable results and can be used in other settings (Malterud, 2001). The purposive sampling of CHWs and key informants increased trustworthiness of the study as research findings were able to answer the research aim. In addition, research findings during data analysis process revealed that the findings could be beneficial to similar settings to plan and manage HIV/AIDS programmes.

3.9.6. Reflexivity

A diary was used throughout the process to keep track of and monitor the thoughts of the researcher and the research assistant during the data collection process. Reflexivity involves the process of the researcher being aware of her own preconceptions and opinions on a phenomenon (Malterud, 2001). The researcher acknowledges potential biases as she has previously worked in the environment, although her insight has contributed to a more in-depth understanding of the phenomena. The CHWs shared invaluable information, even though during the interview process they lacked understanding of the questions although they were thoroughly explained. The key informants played a significant role in supporting the study especially because their years of experience and their views confirmed the CHWs' views.

3.10. Ethical considerations

Ethical consideration was first sought from the University of the Western Cape's Community and Health Sciences Faculty, the Senate Higher Degrees Committee, and the Biomedical Ethics and Research Committee. Approval was granted for the period of 09 June 2022 to 09 June 2025 with ethics reference number: BM21/3/10. Secondly, permission to conduct research was granted by the Department of Social Development via email which led to the recruitment of the key informants. Thirdly, permission was requested online from the Eastern Cape Department of Health National Health Research Database via their link: <http://nhrd.hst.org.za>. The Eastern Cape Health Research Committee granted the permission in July 2021 with reference number EC_202106_026. Lastly, permission was requested from CBO project managers after referral by the Department of Social Development.

“Research ethics are guided by four principles namely, autonomy and respect for the dignity of persons, non-maleficence, beneficence and justice” (de Vos et al., 2011: 397). Information

sessions were conducted with all focus group discussions participants and participant information sheets were shared with participants for further reference. Key informants were contacted via cellphone and in person, and participant information sheets were shared to outline the research topic and aim. Participation was explained as being voluntary and that participants may withdraw at any stage if they no longer wish to participate, and there would be no penalties. Consent forms to ensure voluntary participation and focus group confidentiality binding forms were signed by all participants and stored in a lockable cabinet. The meaning of confidentiality was explained to both groups. and pseudonyms were used to hide the identities of participants.

In the case of a traumatic event during data collection, the participants were informed they would be referred to a local social worker from the Department of Social Development, Chris Hani District. The ethics forms offered were in two languages (IsiXhosa and English) for a better understanding of participants. During the document review, the research assistant explained that the contents of the documents would not be used, and that all information would be kept confidential.

All the focus group discussions and interviews were audio recorded, and recordings were immediately transferred to a computer and Google drive for safekeeping. The recordings are stored on a computer that is password protected and will be kept for five years before being destroyed. Recordings were transcribed and pseudonyms were used to withhold the identities of participants. The transcriptions and analysed data are kept in a password protected computer. The final report of the findings and recommendations will be shared with the various

stakeholders such as the Department of Health, the Department of Social Development, and CBO project managers.



CHAPTER 4: RESEARCH FINDINGS

This chapter outlines the research findings of the focus group discussions with CHWs, semi-structured interviews with key informants and a document review. A socio-demographic description of the participants is provided and a summary analysis of the document review. Furthermore, the following themes were identified: participants' routine roles, description of CBIS, data use, factors promoting and prohibiting data use are described. Lastly, a description of findings on CBIS functionality and monitoring and evaluation of programme impact is given.

4.1. Socio-demographics profile of research participants

The table below illustrates the socio-demographic profile of the research participants during the data collection process and their distribution by gender and age.

Table 1: Socio-demographics of research participants segregated by gender and age.

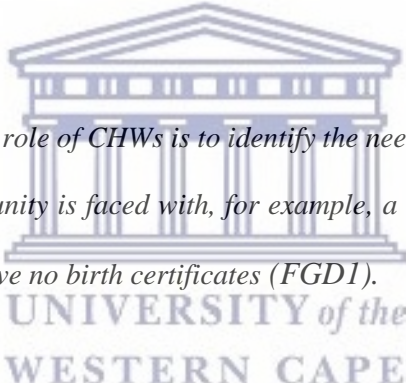
Demographics	Total number	
CHWs	36	
Social workers	02	
Professional nurses	02	
Overall total	40	
	Females	Males
Total participants	36	04
Ages 25 – 40	12	03
Ages 40 – above	24	01

4.2. Routine roles of participants of the study

To provide context and demonstrate the relationships and linkages between the different participants their routine roles will be described providing perspectives into their potential roles in a community based information system for an HIV/AIDS programme.

4.2.1. CHWs' roles

CHWs play various roles in addressing the HIV/AIDS pandemic within their communities and this is no exception in the Chris Hani District as several of these roles were reported. CHWs reported that some of their roles are to conduct home visits, do assessments and address any challenges identified.



I was going to say that the role of CHWs is to identify the needs of the community and the challenges that the community is faced with, for example, a child that is born with HIV, orphans and those who have no birth certificates (FGD1).

The CHWs explained that their role includes being an advocate for their clients, as some would default on their treatment and be afraid to go back to health facilities. This ensures treatment adherence and reduces defaulter rates.

We explain how we work and what we do as well as identify challenges in that home. For example, we explain that if we find a treatment defaulter, we escort them to the clinic, as a way of allaying their fears. This is most common in areas that are far from the health facility (FGD2).

The nurse confirmed their claim as she mentioned that on some occasions, they would ask the CHWs to trace defaulters for them.

Our relationship is exceptionally good and strong with the CBO because we have the outreach team here at the clinic, they work together looking for sick people and trace defaulters and bring them to the clinic (KI3).

The CHWs further reported that they play a role as an educator in which they educate clients and community members on several issues such as condom use, health hygiene and HIV/AIDS.

Before the lockdown, we had awareness campaigns where we educated the community about HIV, to protect those who do not have HIV from getting infected and those who have it, to treat it (FGD3).



The nurse concurred that CHWs play the role of being educators to their clients, as clients will visit the health facility after being visited by CHWs.

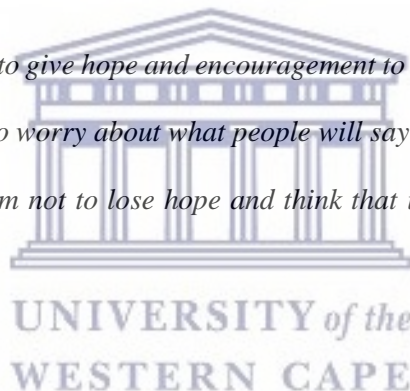
We see it in the clients' compliance because when some clients have been visited by CHWs from the community based organization. The CHWs get there and educate the client, the client had some questions that they needed clarity on, or it is a client that we have been looking for in the clinic, for a long time. After CHWs' home visit, the client will come to the clinic (KI4).

In addition, the CHWs play the role of being liaisons between the community and different stakeholders, during the household visit CHWs encounter different challenges that require attention and would link clients with different departments so that they can get assistance.

I make referrals as needed. If the case needs to be referred to the clinic, I refer it to the clinic. If it needs referral to Social Workers, I refer to them (FGD1).

Lastly, CHWs also reported that they play the role of an advisor as they advise their clients to look after their health, reduce the HIV/AIDS stigma and start food gardens for good nutrition.

Our role as CHWs is also to give hope and encouragement to clients who are on ARVs. You encourage them not to worry about what people will say but rather focus on their health. We encourage them not to lose hope and think that it is the end of the world (FGD2).



4.2.2. Social workers' role (Department of Social Development)

CHWs receive support and funding from different stakeholders to address the HIV/AIDS pandemic in their communities. Social workers as key informants shared their roles in relation to CHWs in Chris Hani District:

Social workers provide guidance to CHWs to ensure quality implementation of their programmes and understanding of the department's processes.

We give them guidance as to how to work with the Department of Social Development. We explain to them what is expected of them (KI1).

The social workers reported that they also play the role of monitoring and evaluation, to ensure funds are used for intended activities and programmes that have an impact on communities.

Our other role is, once they get funding, we monitor if they are using the money for what it is intended for (KI2).

Another role reported by social workers is that of being an educator in which they train CHWs on various aspects such as project management and programme implementation.

There are a lot of ways in which we empower them. For example, how they should be working as organisations in terms of administration, conducting door-to-door visits as one of the activities is to conduct home visits (KI 1).



Furthermore, social workers reported that they provide CHWs with resources such as forms and information so that they can apply for more funding.

There are also other funders like the National Lottery. We assist them to apply to these funders. We provide them with application forms (KI1).

Lastly, social workers play the role of consultants in which they consult CHWs whenever they need information related to their clients or services.

We consult them whenever we need them in terms of departmental developments (KI1).

4.2.3. Professional nurses' role (Department of Health)

CHWs from CBOs are expected to work with health facilities within their areas according to the National Department of Health (2011). Professional nurses as key informants shared some of their roles in supporting CHWs from CBOs and below are some of the roles:

The professional nurse reported that she and her colleagues provide material support to CHWs to help them with their health education services.

If they want to do health education, we provide them with IEC material that assists them in their health education (KI4).



The professional nurse added that they also provide CHWs with assistance on issues with which they are overwhelmed.

If they have a client that presents with a challenge that they do not understand, they come and request assistance from the clinic (KI4).

4.3. Review of the community based information system

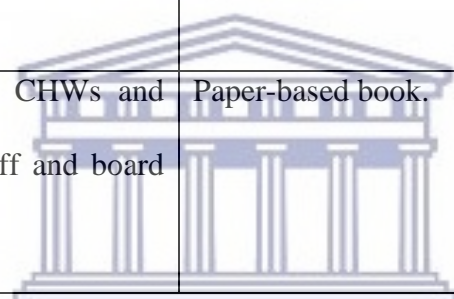
The document review highlighted the data sources (name and type), the information collected, and the completeness of the data collection process in the community information system in the four CBOs.

Table 2: Description of the community information systems' data sources

Document name	Purpose	Type of document	Standard operating procedure: Yes/ No	Completeness of tool
CO1 or household registration form	The document is used by CHWs during the first visit to register clients and assess their needs as well as their challenges.	Paper-based form	No	The document is completely filled in only in one CBO. It mostly lacks answers to the assessment questions.
CO2	The document is used by CHWs and is used to record service provisions for adult clients.	Paper-based book.	No	The document is completely filled in and is only available in one CBO.

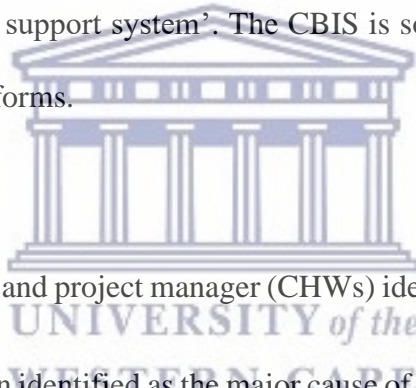
CO3	The document is used by CHWs and is used to record service provisions for children.	Paper-based book.	No	The document is completely filled in and is only available in one CBO.
SO3	The document is a monthly reporting tool, which is used by the organisation's supervisor and then sent to social workers to provide the progress of the programmes.	Electronic-based form.	No	All the reports are filled in by all CBOs.
CHW daily attendance register	All the registers are used by CHWs and record the daily attendance of CHWs.	Paper-based form.	No	The documents are filled in by all CBOs.
Client attendance register	The attendance register is signed by clients when attending events such as awareness campaigns or group sessions.	Paper-based form.	No	The forms are filled in by all the CBOs.
Microsoft Excel Electronic database	The database is used by data capturers or secretaries in some organisations. It is used to record clients and services provided.	Electronic register.	No	The database is somewhat completed. Minor gaps are due to the lack of information from the

				CO1 form which is used by all CBOs.
Notebooks or home-based care service provision forms.	The notebooks are used by CHWs and are used to record daily services provided to clients.	Paper-based book.	No	The document is not filled in. Gaps included missing dates and clear descriptions of services provided. It is used by three CBOs.
Minute books	The documents are used by CHWs and board members to record staff and board minutes.	Paper-based book.	No	In some minute books, there are gaps such as missing signatures to prove attendance.



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The researcher discovered that CHWs are using almost similar documents which were provided by social workers from the Department of Social Development. In total, the CBOs use four to six tools for their programmes. However, due to a lack of funds and resources, CHWs have shifted to using notebooks instead of forms such as the CO2 and CO3 tools. The tools in all CBOs are somewhat completed. The CO1 or household registration tool is the major tool that was not fully completed, and the project managers attributed this to low literacy levels as the forms are written in English. In addition, this could be a lack of data quality appraisals as these are not conducted at all to ensure the completeness of forms. Some documents are kept in lockable cabinets to ensure clients' information is kept confidential, while notebooks are kept in backpacks. The CBOs have an electronic database (Microsoft Excel) and in three CBOs the database has no title while in one CBO it is called a 'psychosocial support system'. The CBIS is somewhat completed, and this is due to the poor completeness of forms.



In addition, the document review and project manager (CHWs) identified the following challenges

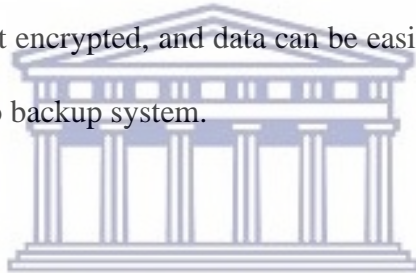
- Low literacy levels have been identified as the major cause of forms not being fully completed by CHWs.
- The CBOs have no standard operating procedures in place, and this has resulted in CHWs using their own discretion to fill out forms.
- The CBOs are in deep rural areas with poor infrastructure, this affects the availability of electricity which then has implications for data capturing to the electronic database.

- Lack of funds has been identified to affect the printing of forms which resulted in the use of notebooks.

4.4. Description of the community based information system

4.4.1. CBIS Description

The document review revealed that CHWs are using an electronic CBIS. The electronic database being used is a Microsoft Excel spreadsheet. The CBOs have clients whose numbers range from 300 and the database can register up to 5000 clients. It is used to record clients, their challenges, and the services provided. A data capturer or secretary oversees the system and data is received from the CHWs. The CBIS is not encrypted, and data can be easily accessible when the laptop is lost. In addition, the CBIS has no backup system.



4.4.2. Data collection process and data sources

The document reviewed revealed that the CO1 form is used to register clients to the database, while CO2, CO3, notebooks, and clients' registers are used to record service provision to the database. Also, SO3 is used by a data capturer, working with the CBO supervisor to transfer data from the database to the tool for monthly reporting which is then sent to the Department of Social Development using a USB flash drive.

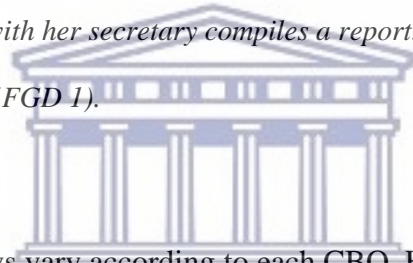
4.4.3. Data management

Data is collected, collated, and analysed by CHWs on a weekly basis, submitted to a data capturer or secretary and then gets captured to the database.

When we do the door-to-door visits, we record all the information in notebooks. Then we come with the notebooks to the office so that the information is captured on the laptop (FGD 2).

The organisation's supervisor then works with the data capturer or secretary to make referrals.

The Chairperson together with her secretary compiles a report. Then as the chairperson, I make referrals as needed (FGD 1).



Data collection and reporting days vary according to each CBO. For example,

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We do door-to-door visits on Monday, then on Tuesday we come to capture at the office, we do field work again on Wednesday then come to report on Thursday. The data is then sent to the Social Worker every 20th of the month (FGD 2).

Another CBO reported:

They conduct visits daily and on Wednesday they come and report to the office. Then I capture the data and send it. Reports are submitted every Wednesday. Then they do home visits again on Thursday and Friday (FGD 4).

4.4.4. Data dissemination

CHWs reported that they share monthly reports or data with the Department of Social Development and the Department of Health. Reports are shared with the social workers and nurses they work with. However, only one CBO mentioned that they report to the health facility.

When we do the home visits, we record the number of people who are HIV positive and send the data to Social Development and the clinic (FGD 2).

The key informant has confirmed that they receive monthly reports from CHWs, the reports provide information on their monthly performance, and they also train them on how to compile the reports.



The monthly reports are for providing feedback on how they performed each month. We empower them on how to do the report (KII).

The key informant has reported that they hold monthly meetings with CHWs to share feedback and monitor if they work according to their work plans.

There are also meetings; the monthly meetings we schedule for them as part of the data review and to ensure they work according to their plans (KII)

4.4.5. Data flow process

Based on the review and the description of the community based information system the following diagram was developed to illustrate the data flow process of the community based information system of the four CBO's.

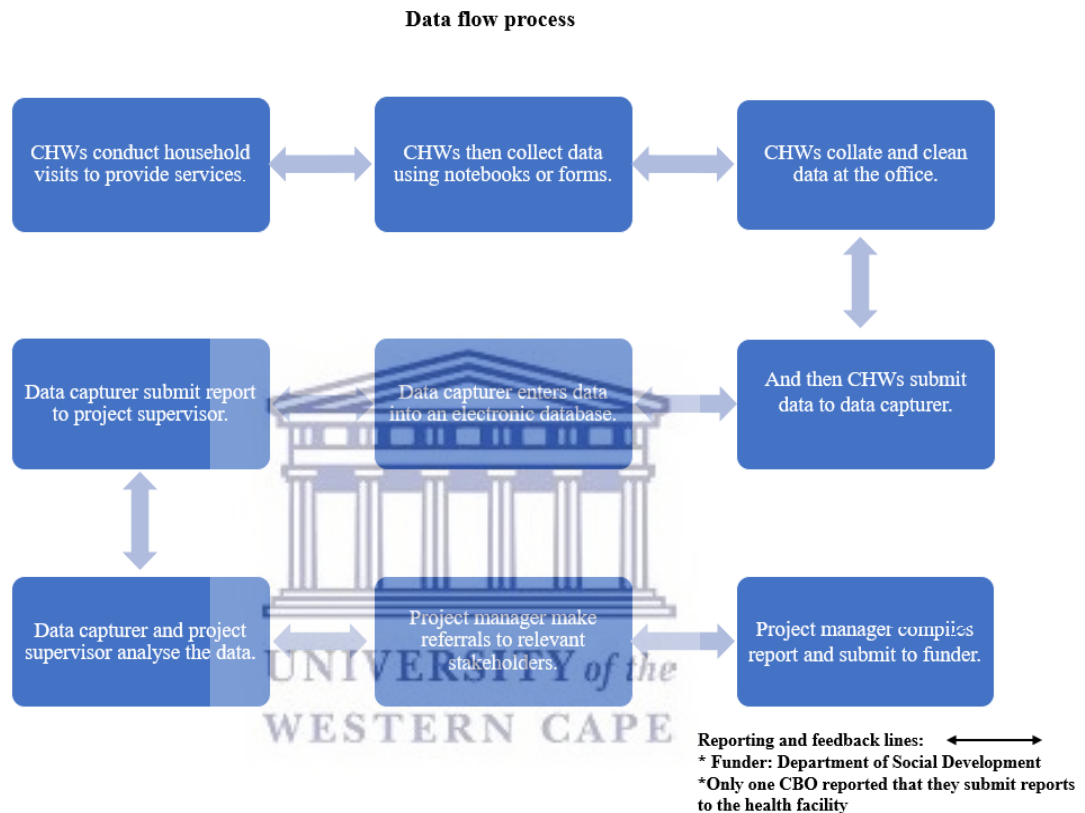


Figure 4: Data flow process

The data flow process revealed that only one CBO is reporting to the health facility. In addition, it revealed that CHWs receive programme feedback from social workers as a way of monitoring their work.

4.4.6. Data use

The CHWs reported three data uses such as conducting follow-up visits to address clients' problems, secondly, they escalate some problems to the supervisor for external referrals, thirdly they plan collective activities to address mass challenges (community dialogues).

After we have gathered the information, we then make follow-ups on Mondays and Wednesdays. Say you came across a child who is on ARVs; you make a follow-up to see if the child is indeed taking their treatment (FGD1).

CHWs mentioned that during their door-to-door visits, they identify challenges and share the information with the supervisor, and then she makes referrals to different stakeholders.

Then as the chairperson, I make referrals as needed. If the case needs to be referred to the clinic, I refer it to the clinic. If it needs referral to social workers, I refer to them (FGD1).

Furthermore, CHWs reported that they used data collected to plan different activities to address identified challenges.

As he already mentioned, we do home visits to gather data about our clients. That assists us in doing follow-ups. For example, if we identify that in a certain area there are many defaulters, we will then plan a community dialogue as a way of making the community aware of such challenges and finding ways of intervening (FGD3).

The social worker reported that CHWs' data is integrated into the district level for the monitoring of the programme and the allocation of funds.

We then consolidate their reports and send them to the district coordinator for programme tracking, planning, and allocation of funds (KI2).

While professional nurses mentioned that they use data from CHWs to address problems.

The CBO's community health workers came to me as the person in charge of the clinic and explained the lady's situation. We visited the household together, that is, me and the CHWs. I interviewed the lady and we intervened. As we speak the lady has her ID and her kids have their birth certificates. She is now in the process of getting a social grant for the kids (KI3).



4.5. Factors promoting data use

Several factors have been identified that promote the use of data such as data review meetings, positive community feedback, stakeholder feedback, positive change in clients' welfare, and receiving recognition and acknowledgement.

CHWs have reported that data review meetings session within the organisation promotes data use, as CHWs would advise and support each other on how to deal with identified challenges.

During data review meetings we would then encourage and advise each other on how to address the problems identified as it is our duty to help the community (FGD 4).

We use the meetings to discuss among ourselves how to deal with difficult situations and then sometimes we send a different caregiver to attend to the household (FGD2).

CHWs have reported that receiving positive feedback from clients and noticing clients' progress promotes the use of data.

What encourages us is the positive feedback that we get from clients. They report that since our visit, their situation has improved (FGD 2).



In addition, to receiving feedback from the community; it is the feedback received from stakeholders such as clinics that promote the use of data.

I was going to say the feedback we get from stakeholders encourages us, for example, the clinic (FGD 3).

Furthermore, the CHWs have mentioned that observing change and witnessing clients taking responsibility for their health encourages them to use data.

Also seeing the effect our work has on the community, is also encouraging. Once we visit, even those who were not willing to come to the clinic get encouraged to come (FGD 2).

CHWs reported that data use is promoted by receiving recognition and acknowledgement of their work from community members.

Also, the love and appreciation we receive from the households. Being welcomed in the households and acknowledgement of the job we do by the people we serve (FGD 1).

4.6. Factors prohibiting data use

Various issues have been identified to affect data use and quality implementation of programmes such as literacy levels, lack of ownership from CHWs, staff retention, lack of resources, lack of collaboration and lack of trust.



Literacy levels have been reported by key informants as one of the issues that prohibit CHWs to use data proficiently.

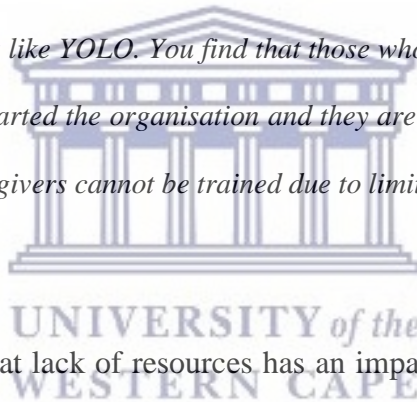
The caregivers do use data but due to their low levels of literacy, you find that one month they do everything correctly, and then the next month they have not done well in terms of planning and service delivery (KI 1).

The key informant has reported that lack of ownership from some CHWs affects data use, as some lack ownership of the programme.

The caregivers tend to undermine themselves because they have the mentality that they are not educated they think that the programme belongs to so and so (KI 1).

In addition, staff retention has been identified as another factor that affects the use of data, as staff that were trained on certain programmes resign and leave a gap which affects programme implementation.

There are HIV programmes like YOLO. You find that those who were trained are the first caregivers, the ones who started the organisation and they are no longer working for the organisation. The new caregivers cannot be trained due to limited resources (KI 1).



The key informant mentioned that lack of resources has an impact on data use as CHWs would need training at times to improve their skills but due to low budgets, they would not meet this need.

One of them is limited resources. You will find that they want and need training, but their budget is extremely limited. It has been cut (KI 1).

Lack of collaboration has been reported as a factor that hinders data use. CHWs would identify challenges in a certain area and due to poor relations with other stakeholders, they would not be

able to address the problem comprehensively as at times such problems would require experts' assistance.

Lack of cooperation may hinder the effective use of data. If there is no cooperation between the organisation and stakeholders from whom they need assistance, for example, the Department of Health, who are experts when it comes to HIV, it will lead to all HIV programmes having challenges because of the non-cooperation and this might affect the sustainability of the programmes. (K11).

The CHWs reported lack of collaboration with stakeholders impacts programme and data use as the CHWs to know whether they refer clients for services they will not get assistance.

In this case, I make a referral to the clinic. The clinic may also say no we do not have pap or supplements. Then they will ask SASSA or Social Development, and even there you find that there is no solution (FGD4).

It is not getting enough support. We go to the households and make promises that they are going to get this or that then we refer the client to the relevant department for example SASSA for food parcels since they do not have anything to eat (FGD 4).

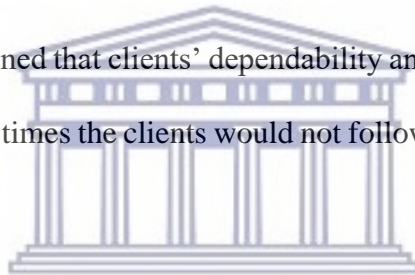
A key informant reported that CHWs need to ensure that they integrate their services with other stakeholders and ensure that local leaders are engaged.

What we also do is integrate our services with other stakeholders available in the communities they work in. There are also local authorities there so the CBO must be community based. It must not be an individual thing (KI2).

CHWs have reported that lack of interest from community members affects data use, as at times the community members would refuse CHWs' services.

It is to see that you are not welcome in the household. It happens that on your second visit, the people show disinterest, they do not even stop the dogs from attacking you (FGD 1).

Furthermore, CHWs have mentioned that clients' dependability and lack of accountability for their health hinder the use of data as at times the clients would not follow instructions as directed, unless in the presence of CHWs.



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The client's failure to take responsibility affects the use of information. Say there is a case you are following up on a regular basis at a certain household, then you advise them of the next step or action they should take, then it happens that you are unable to visit the home at the scheduled time when you visit, you find out they did not do what they were supposed to do (FGD 1).

A key informant has mentioned that a lack of trust from community members can prohibit the use of data by CHWs as communities will refuse services as they think CHWs have ulterior motives.

For example, the conflicts between neighbours or those who think that there is an ulterior motive behind the collection of the information, these things may negatively impact the work of community health workers (KI 3).

CHWs confirm that lack of trust and confidentiality affects the effective use of data, as confidentiality will be breached, and clients' information becomes public knowledge.

It is that, for example, let me talk about the support group. It is difficult to establish a support group. A client may trust me but not trust the other person. So, the client will not know who took their news outside the support group. Then that comes back to us because it is the CBO that started the support group. This gives us a bad image; rumour goes around that the CBO has no confidentiality (FGD 3).



4.8. Suggestions of factors for promoting data use

Several suggestions were provided to improve the CHWs programmes, and these are rotation of CHWs duties, evaluation of programmes, monitoring and evaluation of programmes, exchanging of clients, training, mentorship, networking, trauma debriefing counselling, and multi-stakeholder collaboration.

The key informant has suggested the need for CHWs' duties to be rotated within an organisation to ensure all CHWs take ownership of the programme and are accountable.

Duties must be rotated. It must not only be one person who knows the programme so that the others also see themselves as having responsibility. For example, if you will be going there, they should all be able to answer. There should be no one who says no, it is so and so who knows about that (KI 1).

Furthermore, the key informant has suggested the importance of evaluating programmes to ensure that the CHWs use data proficiently and it is in line with their expected activities.

As my colleague has already stated, evaluation is very important. We must establish whether the organisation's programme had an impact on the community, and on its sustainability, (KI 1).

The key informant has suggested the importance of providing support to CHWs to promote data use. This support could be empowerment with skills or materials.



One of them is the continuous monitoring and empowerment of our funded organisations (KI 1).

The CHWs have suggested that when dealing with a difficult client, it helps to exchange clients amongst CHWs, and this will promote data use as it will assist in resolving clients' problems.

We sometimes swap working areas with the hope that if the clients see a different face, they may behave differently. This usually yields better results, (FGD 1).

The key informant has reported the importance of monitoring and evaluating programme impact to ensure that service provision produces desired results.

What is important is monitoring and evaluation. We must identify what they did well and what they did not do well. We also need to look at the impact. We need to see if their programme had an impact (KII).

Furthermore, the key informant has reported that evaluating impact is important to ensure the sustainability of the organisation as this will ensure that they are providing services that are needed based on evidence of evaluation.

As my colleague has already mentioned, evaluation is important. We must establish whether the organisation's programme had an impact on the community, also for its sustainability" (KI 1).



CHWs also reported the importance of the programme's impact on the community as it motivates them to do more.

Also seeing the effect our work has on the community, is also encouraging. Once we visit, even those who were not willing to come to the clinic get encouraged to come (FGD 2).

The CHWs also mentioned the importance of trauma counselling, as they deal with traumatic cases. It has been suggested that it will promote data use as it will enable CHWs to heal and offload some of the burdens they carry.

The truth is, as caregivers we carry a lot of burdens. Sometimes we come across very painful situations in our households that cause us not to sleep at night. But you hold on by faith and hope (FGD 1).

Confidentiality is another factor that has been suggested to promote data use, as this will build trust and confidence in CHWs' work.

To add a little, here we work under confidentiality. So, we need to show confidentiality to the people so that they can trust us because our work entails tackling challenges (FGD 3).

Another suggestion by key informants to promote data use is mentorship. The key informant believes that if CHWs can receive mentorship from other stakeholders or other CHWs from other CBOs, this could enable them to learn new skills and ways of using data to improve their programmes.



Mentorship is also important. We wish that they do not always hear about these things from us. We should look around the Chris Hani District to see if there is no programme that can be used as a best practice so that they are either taken to the programme to benchmark or the programme taken to them to mentor, so they learn how things are done (K11).

In addition, the key informant suggested the importance of networking. This is to ensure their sustainability where they will need to apply for other funding using their data not only for programme implementation but for expanding their programmes.

Networking is also important so that they have an exit strategy. Not that we will dump them, but they must look for other donors and learn to be independent. There are some of our NPOs get funding from other donors (KI 1).

CHWs have confirmed the importance of collaboration with other CBOs or stakeholders when a client refuses assistance from them. This will ensure that a client will still receive assistance.

Sometimes we come across challenges that are beyond us. In such cases, we refer the situation to the clinic (FGD 2).



The key informant has suggested the importance of training for CHWs to strengthen their programmes.

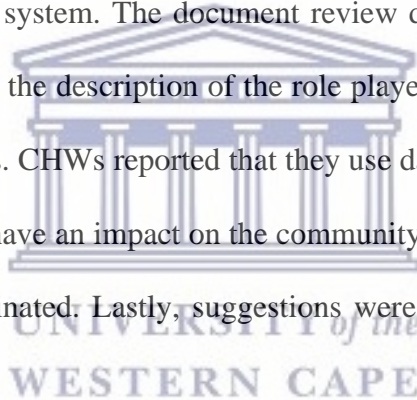
Maybe if the CBO's Community Health Workers would, we do not know how they are trained but the most important thing is for them to get health education sessions or training that keep them updated because at the facilities we work with evidence-based practice (KI4).

Lastly, the CHWs have suggested the importance of building strong relations with community members and clients to ensure problems are resolved.

What is needed is that we do not get discouraged because there are challenges. You must try and build a relationship with the person. Maybe it is their family that told you about the person's status and they did not disclose their status themselves (FGD 3).

4.9. Conclusion

The findings indicate that CHWs funded by the Department of Social Development are using both a paper-based and an electronic system. The document review demonstrated inconsistency and data quality issues. Furthermore, the description of the role players highlighted the collaboration between CHWs and stakeholders. CHWs reported that they use data for planning, managing, and ensuring that their programmes have an impact on the community. Several factors promoting and prohibiting data use were illuminated. Lastly, suggestions were identified with the purpose of promoting data use.

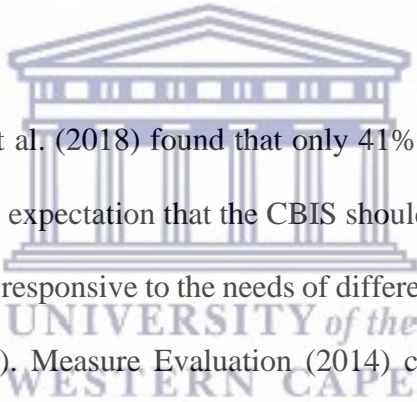


CHAPTER 5: DISCUSSION

This study aims to describe the factors that influence the implementation of community based information systems and data use by CHWs for the planning and management of HIV/AIDS programmes in Chris Hani District, Eastern Cape. This chapter will focus on interpreting the findings of the study. It discusses the description of the CBIS and the main role players. It further discusses data management and data use factors that influence the implementation of CBIS. Lastly, it discusses the limitations of the study.

The findings revealed that the main role player in a community based information system is the community health worker. CHWs were discovered to serve as links or liaisons between the community and other government departments, including primary healthcare by the study. This finding is similar to those of Callaghan (2019) and Busza et al. (2018) as they reported that CHWs serve as a link between community and primary health care. Furthermore, the findings revealed that the roles performed by the CHWs include being community advocates and ensuring that clients receive assistance from health facilities as some clients will default from their treatments and fear returning to healthcare due to stigmatisation. Rachlis et al. (2016) state that CHWs make health services more accessible to the community through referrals. In addition, this study revealed CHWs also perform the roles of default tracers and health educators as they provide education on health issues. Similarly, to what was found by Shelly et al. (2019) when they posited that CHWs provide health promotion and education to reduce HIV infections.

In terms of the information system, this study found that a Microsoft Excel electronic database is being used to record clients, and services provided on a weekly basis depicting a community based information system. The findings revealed that the CBIS was designed, maintained, and implemented by the Department of Social Development to cater for their own information needs. Penn et al. (2019) reported that when one stakeholder is involved in the design of a management information system, the aim is to control the reporting so that it meet its needs. Unfortunately, in this case, the CBIS is not integrated into any other health information system at the local, district or national level. Although, in 2011 the National Department of Health introduced the WBPHCOT strategy to promote the integration of community based CHWs' data with the district health information system (National Department of Health, 2011).



A previous study by Schneider et al. (2018) found that only 41% of CHWs' data was integrated into DHIS. This is contrary to the expectation that the CBIS should be integrated into the national health information system and be responsive to the needs of different stakeholders (Creswell et al., 2017, cited in Penn et al., 2019). Measure Evaluation (2014) conducted case studies in three countries (Tanzania, Zambia, and Kenya) and the study revealed that the CBOs are using electronic CBIS and out of the five sites selected only four were functional as their programs are at a mature stage. In contrast, Russpatrick et al. (2019) uncovered that the design and functioning of CBIS are still in the nascent stages in seventeen West and Central African countries.

The findings of the study revealed that the CBIS design has no backup system; data could be lost when the laptop is lost, or crashes and it also lacks privacy as the database is not encrypted. Penn

et al. (2017) posit that data security is a major issue that needs to be addressed as the databases contain clients' information. Furthermore, the Protection of Personal Information Act argues that CBO managers and data capturers have the responsibility to ensure that the personal information of clients is kept confidential and protected by putting in place measures that will prevent unauthorised people to access the information and if the breach does occur, clients should be notified (POPIA, 2019). This is also supported by MCSP (2019) as they argue that CBIS needs to be encrypted to keep client information confidential and not easily accessible.

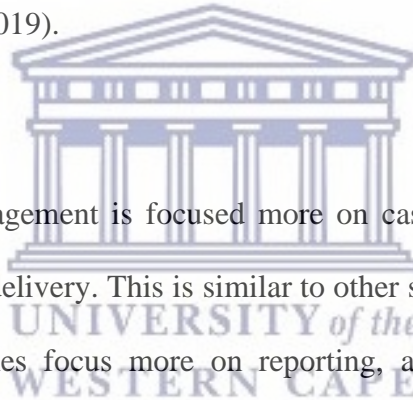
According to MCSP (2019) data management involves the process of data capturing, cleaning, verification, and analysis. The authors further add that data management ensures that data flow processes are well defined, and data is protected. The study findings revealed that the CBOs use standardised forms (CO1, CO2, CO3, SO3) to collect data and then the data get transferred to a standardised CBIS. However, the study further discovered that although the data collection tools are harmonized and standardized, they are not used because of a lack of resources (printing of forms) and CHWs end up using notebooks to record data. Measure Evaluation (2014) discovered that tools are not harmonized due to different donor expectations and in one country the funder was in the process of streamlining data collection tools to ensure similar indicator reporting. Harmonisation and standardisation of tools are lucrative for CHWs programmes to reduce redundancy and fragmentation of data collection tools (Russpatrick et al., 2019). Flora et al. (2017) concurred and argues that the lack of harmonisation of tools affects the utilisation of data.

Furthermore, this study discovered that there are no standard operating procedures (SOPs) which guide the use of tools. Russpatrick et al. (2019) discovered that SOPs are still lacking and countries that had them, only used the SOPs for reporting while others did not adhere to them. This is further supported by another study where they discovered that SOPs exist but are not used (MCSP, 2019).

The findings of this study revealed that data flow within the CBOs is very similar even with noted differences. This finding revealed that information sharing was limited to the Department of Social Development as they are the main funder of the CBOs and reports are disseminated monthly. In addition, the study findings have revealed that the funder provides regular feedback meetings to monitor their work plans. In contrast, CHWs mentioned that they have a good working relationship with health facilities, but the findings exposed that only one CBO is submitting reports to the health facilities. This further highlights the lack of integration of CBOs with health facilities. The lack of integration of CHWs with health facilities has been reported by other studies to create obstacles for CHWs' programmes such as duplication of services (De Neve et al., 2017; Mottiar & Lodge, 2018). Many calls to strengthen the integration of CHWs with the health system have been made but the challenge persists. According to MCSP (2019) and Walker (2018) professionally designed CBIS must have a well-defined guideline on information dissemination to ensure the broad use of information. Russpatrick et al. (2019) add that CBIS design should involve direct users to ensure its usability, and sustainability and this should be done at the onset.

The study findings discovered that data review meetings promote data use, and these meetings can be formal or informal. Also, data review meetings enable CHWs to analyse their data and discuss

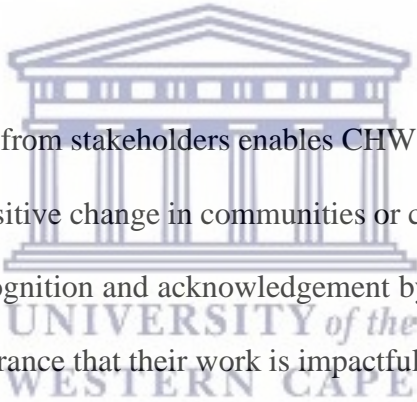
challenges they encounter during household visits. Furthermore, data review meetings play a key role in programme planning and management as CHWs compare their data against set targets, conduct referrals and follow-up activities. According to Data for Impact (2021) data review is the procedure of carefully analysing data to compare achievements against targets, assess the quality of data for use and decision-making. Unfortunately, the findings of this study suggest that these meetings only focus on comparing data against targets and not data quality, which is a crucial element of data management. Mutale et al. (2013) uncovered in five sub-Saharan African countries that data review meetings are significant in engaging health workers to use data for decision-making as well as demonstrate the value of data. Data review meetings should not mainly focus on programme reporting and monitoring but should encourage the engagement of all stakeholders and influence policies (MCSP, 2019).



The study found that data management is focused more on case management which includes reporting, referrals, and service delivery. This is similar to other studies where their findings also revealed that CHWs programmes focus more on reporting, and data completeness than on programme planning or measuring data quality (MCSP, 2019; Flora et al., 2017). It is also argued that a lack of monitoring and evaluation plans is a major setback to the measurement of data quality (MCSP, 2019). However, Walker (2018) noted that data management is essential for CBIS to ensure effective decision-making.

Several factors have been identified to influence data use and these are positive community feedback, stakeholder feedback, low literacy levels, CHW turnover, lack of resources and poor

multi-sectoral collaboration. Positive community feedback has been revealed by this study to promote data use, and it boosts CHWs' morale which results in improved service delivery. This is supported by Scott et al. (2018) in a systematic review study where they discovered that when CHWs receive positive feedback it improves programme performance and motivation. Furthermore, when CHWs feel accepted, supported, and respected by community members it leads to effective programme implementation (Jaskiewicz and Tulenko, 2012). In addition, CHWs reported that they get motivated to use data more when they observe clients' health or welfare status improving and becoming accountable for their lives. While a study by Flora et al. (2017) discovered that a lack of community members' receptiveness to advice and lack of attendance at community dialogues affects data use as this indicates a lack of ownership for their health.



The study revealed that feedback from stakeholders enables CHWs to use their data with the view that stakeholders will notice a positive change in communities or clients because of their services. Scott et al. (2018) noted that recognition and acknowledgement by other health workers promote the use of data as CHWs get assurance that their work is impactful in the communities they serve. In addition, MCSP (2019) discovered that the use of data received from CHWs by stakeholders creates a positive influence on CHWs and boosts their morale as well. Another study highlighted that the lack of recognition from other health workers or stakeholders can reduce CHWs' motivation (Baatiema et al., 2016 cited in Scott et al., 2018).

Low literacy levels have an impact on the use of data as this study found that some CHWs had no formal qualification or a school leaving certificate. This result in CHWs not understanding forms

written in a different language other than their home language. Similarly, Chewicha (2013) in Ethiopia discovered that CHWs have problems with data collection tools that are written in other languages and impact the quality and reliability of data being disseminated to different stakeholders. In contrast, van Pletzen and MacGregor (2013) study revealed that HIV/AIDS programmes are implemented by CHWs that have no formal qualifications and though they received training there was no prerequisite for literacy levels. However, some authors argue that low literacy impacts the quality of services being rendered by CHWs which has caused doubt about the reliability of their work (Otieno et al., 2012; Flora et al., 2017).

CHW turnover was identified as one of the challenges experienced due to the lack of funds in this study and Chewachi, 2013 found that CHW turnover has an impact on data use and implementation of community health information systems. This study found that CHWs would resign and leave for better remuneration which will then create a gap affecting programme implementation. In South Africa, the introduction of the WBPHCOTs by the NDOH aimed to address this challenge by providing CHWs with stipends and placing them within health facilities but there are still some challenges (Schneider, 2018).

Furthermore, the lack of resources has been identified by this study to affect the use of data as CHWs could not conduct some of their planned activities. This is a shared challenge in South Africa as CBOs funded by the Department of Social Development tend to have fewer resources which affect programme implementation (van Pletzen and MacGregor, 2013). In addition, the CBOs do not have a dedicated monitoring and evaluation system due to a lack of resources which

could play a huge role in the effective use of data for comprehensive program planning rather than case management only. Flora et al. (2017) argue that the lack of resources is a barrier to data use.

Poor multi-sectoral collaborations with different government departments were one of the main findings of the study where CHWs would identify problems but the clients would not receive assistance or access services to address their problems because there is no established linkage between CHWs and public services. Flora et al. (2017) found weak linkages between CHWs and health facilities as a barrier to data use and access to services. Similarly, Jeremie et al. (year) also found weak linkages between CHWs and other departments as a barrier to the use of information by CHWs. A potential impact is on the image of CHWs as the study identified that CHWs' reputations were compromised and led to communities' disinterest and rejection of their services.



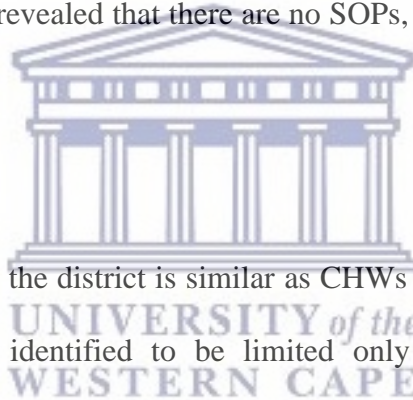
Limitations of the study

Participants from this study are drawn only from CBOs that are being funded by the Department of Social Development to implement the HIV/AIDS programme in the Chris Hani District, Eastern Cape. It must be noted that the aim of the study was to understand factors that influence the implementation of the CBIS and data use as a result issues of data quality were not studied due to the nature of the study.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

6.1. Conclusion

In conclusion, this qualitative study established that in CHDM an electronic CBIS is being used on a weekly basis to record, track data and the main role-players are CHWs. The significant contributions made by CHWs to address health and social issues have been noted and this corroborates multiple studies that have been conducted around the world. Several data management factors that influence the implementation of CBIS have been identified such as the standardisation of tools, SOPs, data flow, information dissemination, data reviews and data use. Even though, the forms have been standardized, CHWs are using notebooks due to a lack of resources. In addition, the study revealed that there are no SOPs, and this impacts the correct use of tools.



Data flow between CBOs within the district is similar as CHWs are using the same patterns and information dissemination was identified to be limited only to the Department of Social Development as they are the main funder. However, the CBIS is not integrated with the DHIS. The lack of integration is a setback to the National Development Plan 2030, as one of its objectives is to have a CBIS integrated up to the national level (National Development Plan 2030, 2012). Although the CBIS is available, it experiences several challenges which require urgent attention such as an online backup system and data protection. The data management process revealed that the focus for CHWs is case management rather than comprehensive program planning. Lastly, The CHWs' programme is faced with multiple challenges, and these have profound consequences for the progress of HIV/AIDS programmes and meeting United Nations SDGs.

6.1. Recommendations

- The Department of Social Development in partnership with other departments should avail a budget to update or redesign the CBIS using Walker's CBIS Model as a guide. This will ensure clients' data is protected by having two or three authentications. Secondly, the system should have an online backup system which will allow data to be retrieved if lost, accessible anytime and anywhere. Thirdly, the design should involve all relevant stakeholders and ensure it is integrated into the local, district, provincial and national health information systems. Lastly, the design should have elements that allow two-way reciprocal feedback systems from CBO to the national level.
- Data management process needs to be strengthened to ensure that quality data is produced by CHWs. This could be achieved through the project supervisor or board members conducting routine data quality appraisals on a quarterly basis to improve data quality and ensure the completeness of forms. Secondly, standard operating procedures need to be developed for all the tools being used by CHWs by the Department of Social Development. This is significant in ensuring that CHWs will complete forms according to the requirements.
- A monitoring and evaluation unit as a stand-alone is needed in all the CBOs which will have dedicated human resources such as the data capturer, monitoring and evaluation officer or manager who will focus specifically on comprehensive data analysis. Monitoring and evaluation are important to examine if CHWs use data meaningfully and

impactful. MCSP (2019) and Penn et al. (2019) also argue that programme monitoring and evaluation are necessary to ensure service provision provides value to the lives of community members. Flora et al. (2017) further argue that monitoring and evaluation of data collected increases confidence in data and its use.

- Key informants recommended that all CHWs should be trained on the data management system to avoid challenges such as lack of capturing or backlog when one CHW resigns.
- Quarterly refresher training should be provided to CHWs to accommodate literacy levels and the forms should also be written in accommodating language. The key informants have added that adequate training is significant to ensure CHWs are equipped with the necessary skills and knowledge to manage data and enable them to have confidence in their abilities to address problems. Allen et al. (2015) report that continuous training is important to ensure that CHWs provide quality services to their clients as well as collect accurate data (Jeremie et al., 2014). It is also recommended that the training sessions should include debriefing sessions as CHWs deal with traumatic events.
- The DoH at the district level need to realign the WBPHCOT strategy to strengthen linkages between CBOs and health facilities as they are still working in silos. In addition, these should encourage monthly or quarterly meetings as these will provide CHWs with an opportunity to share work plans, receive health education and updates on new health guidelines or policies. These will also combat confusion and duplication among health facilities and CBO CHWs.

- The Department of Social Development needs to strengthen CHWs' mentorship with social workers as it will provide an opportunity for external data review meetings which will not only focus on monitoring their work plans but improve data quality as well. Mentorship has been identified as imperative in keeping CHWs updated with changing information and policies. It also provides a great platform for CHWs to learn new skills, grow and improve their performance (MCSP, 2019; Routine Health Information Network, 2003 cited in Flora et al., 2017).
- Multi-sectoral collaboration needs to be strengthened and quarterly stakeholder forums established at the community level to discuss data, challenges and strengthen working relations. Multi-sectoral collaboration is identified as a significant factor that could promote data use as CHWs will refer clients and seek guidance when faced with difficult issues echoed by Flora et al. (2017) when positing that the improvement of linkages and collaboration would improve data use. Several studies have reported that the collaboration of CHWs with other stakeholders boosts programme growth and confidence of CHWs within communities (Glenton et al., 2013; Jaskiewicz & Tulenko, 2012; Scott et al., 2018).
- CHWs should be trained in fundraising skills to detach dependency syndrome. Financial freedom is a key to ensuring a functional organisation and programmes. van Pletzen and MacGregor (2013) state that adequate funding should be made available for CHWs to ensure they implement more comprehensive programmes. This will further address the challenges of lack of funds and resources.

- A CHW networking system should be established to promote networking among CHWs and CBOs. Networking has been suggested as being essential as it offers CHWs an opportunity to receive technical assistance and emotional support to deal with different cases (Allen et al., 2015).



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