The development of a tool to support the work of the rehabilitation care worker in documenting information about rehabilitation and health needs among persons with disability in home and community settings

by

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Declaration

I, Anthea Hansen, hereby declare that the work on which this research is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been submitted for any degree or examination in this or any other university.

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Abstract

The purpose of the study is to contribute to the development of a tool that can support the rehabilitation care worker towards intervention planning and the monitoring of their clients. The National Health Insurance and the Framework and Strategy for Disability and Rehabilitation of the South African Department of Health are strategies to work towards accessible, affordable, equitable and quality health care, which includes health promotion, disease prevention, curative, rehabilitation and palliative services for all South Africans. Both strategies emphasise the use of community health workers and mid-level workers as a key component of primary health care. In the Western Cape provincial Department of Health a new cadre, namely the rehabilitation care worker has been introduced as a member of the rehabilitation team. The introduction of the rehabilitation care worker is still in the pilot phase. The rehabilitation care workers face many barriers to providing effective care. One such challenge is the lack of a contextually relevant resource tool to collect information on the rehabilitation and health needs of persons with disabilities.

The aim of the study was to develop a contextually relevant resource tool that would support the rehabilitation care worker in understanding and documenting how the rehabilitation and related health needs of persons with disabilities are met in home- and community-based settings. Three specific objectives were defined: i) to develop the content and domains of the rehabilitation and health information tool; ii) to establish the validity (face and content) of the rehabilitation and health information tool; and, iii) to test the application of the rehabilitation and health information tool on a sample of persons with disabilities.

This study was an exploratory descriptive study adopting a sequential mixed methods design. There were two phases in this study. Phase 1 involved qualitative research methods in the development of the rehabilitation and health information tool through the use of document review and a focus group discussion with experts. Phase 2 of the study involved quantitative research methods in the field testing of the rehabilitation and health information tool by the rehabilitation care workers on a sample of persons with disabilities. The results of phase 1 included the development of the rehabilitation and health information tool, which was deemed by the experts to be a comprehensive, contextually relevant tool with face and content validity and could be easily administered by the rehabilitation care worker. The conceptual framework of the International Classification of Functioning, Disability and Health provided domains that could comprehensively document the multidimensional needs of persons with disabilities. The result was a draft rehabilitation and health information tool with 17 questions ranging across the domains of activities of daily living, sexual health, health behaviours, barriers and facilitators to good health, finance and understanding of disability. Changes were proposed to the wording, layout and flow of the tool and the persons with disabilities' goals were included as an element . The inclusion of the end users as experts in the development resulted in a richer understanding needed for the shaping of this tool. The results of phase 2 highlighted that the rehabilitation and health information tool was able to describe the rehabilitation and health needs of persons with disabilities. Additionally the tool was able to document the specific goals of the persons with disabilities which is useful to plan and monitor intervention. The rehabilitation care workers reported the tool to be useful, easy to use, and provided a structured manner to collect information. They also reported that it was useful in stimulating conversations on sensitive topics. However, it was indicated that it took too long to complete and there were components that were incomplete. The rehabilitation and health information tool requires further refinement, validation and further follow-up testing before it can be formally adopted and implemented as part of the rehabilitation care worker's standard practice.

Key words: Rehabilitation care workers, community health workers, community based rehabilitation, tool development, persons with disabilities.

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Glossary

Disability

"Persons with disabilities include those who have a long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (United Nations, 2006, p. 4)

Community- and home-based care

Community-based care is care that is given at the community level which is closest to the home and encompasses care at the level of the home. Home-based care includes health care services both informal and formal within the home. The purpose of community- and home-based care is to "promote, restore and maintain a person's maximum level of comfort, function and health including care towards a dignified death." In South Africa the various categories of community- and home-based care include preventive, promotive, therapeutic, rehabilitative and palliative care (Department of Health, 2001, p. 1).

Community health worker

A worker that has been appointed as a member of the primary health care team and is trained in: promoting health and wellness, identification of health concerns, providing support on an individual and community level to persons affected by ill-health, and importantly provides a connection between the various levels in the continuum of care i.e. the home, the community and the health facilities (Department of Health, 2018).

Rehabilitation care worker

A worker that is part of an inter-disciplinary primary health care team and who enhances access to rehabilitation services within the community- and home-based context (Western Cape Government Health, 2014).

Rehabilitation and health need

For this study the definition of need is derived from the concept of perceived needs which is "the need for rehabilitation and health services as experienced by the individual and which he or she is prepared to acknowledge; perceived need may or may not coincide with professionally defined or scientifically confirmed need" (World Health Organisation, 2011, p 8)

Patient

This refers to persons seen by, or referred to, medical- and health-related services as patients. This term is used across the literature and will be cited accordingly in this research project.

Client

This is the term used by RCW for any person who is using the services of the RCW and therefore is the term that will be used throughout this research project for such persons.

Abbreviations

CBR:	Community-based rehabilitation
CHW:	Community health worker
FSDR:	Framework and Strategy for Disability and Rehabilitation
ICF:	International Classification of Functioning, Disability and Health
NHI:	National Health Insurance
PWD:	Persons with disability
RCW:	Rehabilitation care worker
RHIT:	Rehabilitation and health information tool
UNCRPD:	United Nations Convention on Rights for Persons with Disabilities
WHODAS 2.0:	World Health Organisation Disability Assessment Schedule 2.0
WHOQOL-BREF:	World Health Organisation quality of life short form

Chapter 1: Introduction

This chapter provides an introduction to the research study as well as the rationale and the context in which the study occurred. The following sections are presented: 1.1. The focus of the study: 1.2. The rationale for the study: and 1.3. Community health care context in South Africa.

1.1 Focus of the study

This research study aimed to develop a contextually relevant resource tool that could support rehabilitation care workers (RCWs) in their practice within community-based rehabilitation (CBR) service delivery. The purpose of the tool was to systematically collect information related to the rehabilitation and health needs of persons with disability (PWD) within the home and community settings, that would assist the RCW in intervention planning and monitoring of their clients' progress.

The aim of the research study was to develop a resource tool that would support the RCW to understand and document how the rehabilitation and related health needs of PWD are met in home- and community-based settings. The resource tool was named the rehabilitation and health needs information tool (RHIT).

In order to achieve this aim the objectives were:

- To develop the content and domains of the RHIT.
- To establish validity (face and content) of the RHIT.
- To test the application of the RHIT on a sample of PWD

In order to achieve the objectives of the research project the researcher adopted a sequential exploratory mixed methods study design (Creswell, 2009). The qualitative methods of a focus group with experts in the field and the feedback received on the proposed tool played a role in shaping the RHIT (the first two objectives). The quantitative methods involved field-testing the application of RHIT by the RCWs on a group of PWD (the third objective).

1.2 Rationale for the study

South Africa is a developing country (World Bank, 2015) with a diverse population and a history of a fragmented health system that was racially biased and fraught with health inequalities (Naidoo, 2012; World Bank, 2015). Despite South Africa becoming a democracy in 1994, the significant health inequalities which are based on socio-economic circumstances remain. The private health sector caters for individuals who can afford to pay for a medical scheme or pay for medical expenses, whereas the public health sector serves mainly those who are unable to afford private health services. Although expenditure in the public and private health sectors is similar, the public sector serves approximately 81% of the South Africa population and the private sector serves the small remainder (Republic of South Africa, 2015). The inequalities in the health sector are further exacerbated by challenges such as a quadruple burden disease, poor leadership and insufficient resources (human, funding, infrastructure) (Mayosi & Benatar, 2014; Naidoo, 2012). These inequalities are particularly evident within the most vulnerable sectors of the population, namely women, children and PWD. To address these inequalities the South African government has committed to achieving accessible, appropriate, affordable, efficient and quality universal health coverage for all through the National Health insurance (NHI).

The national Department of Health's 2015 White paper on the NHI calls for a required shift in the current health system (public and private) to create a unified health system through improving the financing system and thus making health care more affordable and accessible to the South African population (Department of Health, 2015b). The implementation of the NHI is envisioned to take place in phases over a period of 14 years. The first phase involves strengthening the public health sector through improving the service delivery platform. The public health system is divided into three areas of service delivery, namely: 1. Primary Health care services; 2. Hospital and specialized services; and 3. Emergency medical services. Primary health care is seen to be the "heartbeat" of NHI and "includes health promotion, disease prevention, curative services, rehabilitation and palliative services" (Department of Health, 2015b). South Africa has specific policies and guidelines that address rehabilitation and disability.

South Africa has been progressive in establishing policies and guidelines for the inclusion of PWD. The ratification of the United Nations Convention on Rights of Persons with Disabilities (UNCRPD) by South Africa in 2007, and the release of the White paper on the Rights of PWD in 2015 have displayed South Africa's commitment to realising the rights of PWD, including the right to the highest attainable standard of health care. "PWD include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others"(United Nations, 2006, p.4).

The World Health Organisation (2011b) report on disability reports that South Africa has an estimated disability prevalence of 24.2% when using data from the world health survey (2002-2004) as the source. Statistics South Africa reports a national disability prevalence of 7.5% when using the South African Census 2011 data as a source (Statistics South Africa, 2014).. The World report on disability cautions that these figures cannot be compared due to different approaches in terms of methodologies and definitions used. Although these estimates are incomparable, both estimates reflect a significant disability prevalence (World Health Organisation, 2011b). Despite South Africa’s good intentions and policies, the needs of PWD and the implementation of health care and rehabilitation for PWD remain overlooked (Sherry, 2014).

To date, home-based care and community-based care (CBC) programmes have been fundamental in facilitating access to primary health care. The purpose of home-based care is to “promote, restore and maintain a person’s maximum level of comfort, function and health including care towards a dignified death.” (Department of Health, 2001, p.1) The various categories of home-based care and community-based care include preventive, promotive, therapeutic, rehabilitative and palliative care (Department of Health, 2001). The WHO definition of community-based care aims to be responsive to the needs of the people as well as empower people and communities to be active participants in health care (World Health Organisation, 2002). The re-engineering of a primary health care approach presents an opportunity for enhancing access to health care for PWD (Sherry, 2014). The policy Framework and Strategy for Disability and Rehabilitation (FSDR) services in South Africa 2015-2020 is aimed at creating comprehensive and integrated disability and rehabilitation services within the health care system (Department of Health, 2015a). The approach of the FSDR is underpinned by the community-based rehabilitation (CBR) philosophy. The World Health Organisation has advocated CBR to promote the inclusion and enhance the quality of life for PWD (World Health Organisation, 2010). Programmes of home-based care and community-based care, as well as CBR, play a crucial role in equitable health care provision which should include rehabilitation and the prevention of disability.

In South Africa the provision of rehabilitation and addressing the health care needs of PWD remains a challenge due to barriers such as inaccessible health care facilities because of a lack of transport, distance from patients and a lack of resources at the health care facilities (e.g. assistive devices and equipment). Additional barriers include negative attitudes towards PWD and lack of knowledge of health care workers (Sherry, 2014). There still remains a scarcity of rehabilitation personnel within various South African communities (Binken, Miller, & Concha, 2009). There are a variety of personnel within the health care system at a primary health care level; the ward-based outreach team consists of specialists such as allied health therapists (e.g. speech therapist or physiotherapist) as well as other cadres of workers such as CHWs. Sherry (2014) argues that within the Western Cape Province there still remain many unmet needs of PWD in relation to health. The literature extensively documents the role of community- and home-based care for people living with HIV/AIDS in Africa, particularly Botswana, Zimbabwe, Malawi and Uganda (Ncama, 2005; Russel & Schneider, 2000). Although CHWs enhance access to health care, the quality of the healthcare is still questionable as many healthcare professionals are ill-equipped to deal with the needs of PWD, are not supervised appropriately and healthcare still remains inaccessible (Sherry, 2014). Despite these documented challenges the literature reflects that CBR still remains an effective strategy for meeting health and rehabilitation needs of PWD (Binken et al., 2009).

In South Africa the FSDR is the national Department of Health's strategy for addressing the rehabilitation needs of PWD, and this approach is grounded in the values and philosophy of community-based rehabilitation. The FSDR approach within the home and community setting covers a wide range of areas including engagement with key stakeholders, community mapping and referrals, advocacy, health promotion, screening, assessment, treatment, referrals and follow-up, home visits and training of CHWs. The FSDR specifies that mid-level health workers would do follow-up visits to clients within their homes and that the CHW should be trained on disability to facilitate early detection of disability and appropriate referrals (Department of Health, 2015a). Literature supports the use of mid-level workers in service delivery and argues that mid-level workers make a significant contribution and are effective in low and middle income countries. The FSDR does not specify clearly who these mid-level workers are and what the training needs are for the development and efficacy of these workers. Additionally the supervision of the mid-level worker and regulation by a professional body is an issue that still needs to be clarified across the different types of mid-level workers (such as community-based rehabilitation workers, occupational therapy technicians and assistants).

CHWs are members of a community who respond to the health needs of the community and enhance access to primary health care for community members. The CHW is largely involved with health promotion and disease prevention activities (Health Systems Trust, 2011). In South Africa CHWs focus largely on HIV/AIDS and TB; the type and amount of training and supervision varies across different CHWs. In relation to supervision some CHWs report and account to primary health care facility staff, whereas others report to non-governmental organisations. There remains no standardised training or supervision model for this cadre and therefore different organisations train and supervise these CHWs according to the organisations' needs and mandate (Health Systems Trust, 2011). A new policy called the framework and strategy for Ward-Based Primary Healthcare Outreach Teams 2018/19-2023/24 has been published by the Department of Health to provide guidance on the use of CHWs (Department of Health, 2018). However, additional input and guidance would be required to ensure that disability and rehabilitation are appropriately addressed. In order to facilitate the achievement of the goals of the re-engineered primary health care model of the alternative cadres of workers such as mid-level workers and CHWs, adequate training and resources are needed for them to be better prepared to meet the needs of their clients (Setswe et al., 2009).

Within the context of trying to improve primary health care services and as part of their strategy of strengthening community-based services, the Western Cape Department of Health introduced a new cadre of worker in the continuum of care between hospitalised and specialised services and primary health care services. This strategy is outlined in the Healthcare 2030: Road to wellness document (Western Cape Government Health, 2014) that is specific to the Western Cape Department of Health and is guided by the national Department of Health policies.

As a pilot project commencing in 2012 the Western Cape Department of Health embarked on the initiative to train 33 CHWs from the Mitchells Plain/Klipfontein substructure in rehabilitation and disability support skills through the Higher Certificate in Disability Practice (NQF level5) at the University of Cape Town, which included theoretical and practical components. The profile of the CHWs varied in terms of age, the type of CHW training and their experience as CHWs. These chosen CHWs were already providing services to PWD and their families and had some knowledge and skills that were required for home -based care. On successful completion of the Higher Certificate in Disability Practice the CHWs were referred to as rehabilitation care workers (RCW) by the Western Cape Department of Health. The outcome of the training was to equip the RCWs with the knowledge, skills and attitudes to provide support for PWD and to address their rehabilitation and related health needs in communities. The RCWs would work together with qualified therapists to render basic rehabilitation services in the community and refer for any health concerns. The roles and skills set of the RCWs are emerging as part of this pilot within Western Cape Department of Health where a possible additional role is that the RCWs could also provide support for the CHWs within the community. This would enhance community-based services and improve the participation of PWD in the areas of living, learning, working and socialising. This pilot initiative aims to strengthen the primary health care platform and to tailor services to place the individual at the centre of care (Western Cape Government Health, 2014). The pilot initiative was not without critique. There remains concerns about the governing regulatory bodies for this cadre of worker to mitigate against any risks that may emerge. There was also anxiety around the role and scope of the RCW, as many health and rehabilitation services had not engaged with the training curriculum as well as qualified RCW and therefore had limited knowledge on the potential of the RCW.

Research in South Africa has found that that many CHWs and community rehabilitation workers play a vital role in the physical and social rehabilitation of PWD (Binken et al., 2009; Chappell & Johannsmeier, 2009; Lorenzo, Motau, van der Merwe, Janse van Rensburg, & Cramm, 2014). In addition, disability awareness, health promotion and supporting the fight for the rights of PWD are equally important roles that these cadres of workers undertake (Chappell & Johannsmeier, 2009; Lorenzo et al., 2014).

The Department of Health (2001) guidelines for home-based care specify that community-based service providers have the responsibility to identify the priorities and needs of their community. It is vital that the needs of the patients be documented to inform the service delivery (Tousignant, Dubuc, Hebert, & Coulombe, 2007). Patients and health professionals have different perspectives and expectations in relation to health. Therefore, in order for health services to be adequate and tailored to meet the individual PWD needs it is essential to understand their perspective and priorities (Grut, Braathen, Mji, & Ingstad, 2012). Furthermore accurate data of this nature would inform resource allocation to community-based services to ensure that this is adequate to meet the needs of the community (Tousignant et al., 2007). It is desirable and in line with the principles of the UNCRPD that health services which encompass rehabilitation services be contextually relevant and person-centred. Therefore, it is important to include the perspective of the PWD when tailoring these services.

It has been argued that the success of health intervention is built on positive trust relationships at the levels of the patient, health service provider and the health system. CHWs and the positive trust relationship and rapport built with patients can enhance rehabilitation and health outcomes and the uptake of rehabilitation and health interventions (Grant et al., 2017). The community health workers often have insight and understand the norms, values and socio-cultural context of their clients, which facilitates access to and trust with the client. Key elements of enhancing RCWs' and CHWs' efficacy in establishing trust and rapport with PWDs include support structures, training and supervision (Grant et al., 2017).

The FSDR includes goals to develop an effective referral system and enhance monitoring and evaluation of rehabilitation services (Department of Health, 2015a). With the introduction of the RCW within the Western Cape Department of Health rehabilitation community-based service delivery, there is a need to create effective support structures for the RCW. Rehabilitation and health are intricately linked and rehabilitation is relevant to the needs of people with disability as well as other health conditions across a person's lifetime. Therefore, rehabilitation should be an integral component of the health system. A comprehensive and efficient resource tool for use within a community- and home-based care context, could be useful in supporting the RCWs in the field. This proposed RHIT will assist in providing a structured means of identifying, understanding, documenting and monitoring rehabilitation and health needs and treatment priorities from the perspective of the PWD. This resource tool would support the RCWs in understanding the PWD concern, ultimately facilitating the quality of care and improved health outcomes.

When developing a resource tool for the RCWs it was important to consider accepted measurement and resource tools in current use. The International Classification of Functioning, Disability and Health (ICF) (Üstün, Chatterji, Bickenbach, Kostanjsek, & Schneider, 2003); the World Health Organisation Disability Assessment Schedule 2 (WHODAS-2) (World Health Organisation, 2000) and the World Health Organisation Quality of life Assessment-Brief version (WHOQOL-BREF) (WHOQOL Group, 1998) are valid, reliable measures of disability, function and quality of life. A more detailed description of these tools is in the Literature Review in Chapter 2. These tools are generic measures and the premise was that a resource tool which was guided and derived from these measures would be able to assist in providing information on the perceived rehabilitation and health need, who is meeting the perceived need and what methods are being used to meet this need, as well as documenting the PWD priorities. There is a need for a contextually relevant and simple tool for the RCW, as a new cadre with an emerging role within the Western Cape Department of Health, to use in their engagement with their clients. The development of a valid resource tool that could support RCWs to systematically gather information and monitor rehabilitation and related health needs of PWD will strengthen and improve the quality of the data collected within the health care system as well as strengthen the link between the home, the community and the clinic. Furthermore, this information would support intervention and management outcomes.

1.3 Study context: Community health care context in South Africa

South African context and disability

The World Report on Disability estimates that 15.6% of the world population have a disability (when using data from the World Health survey) and of these PWD a greater proportion live in developing and low income countries. In addition, when considering families of PWD it is estimated that 25% of the world is directly affected by disability (World Health Organisation, 2011b). The context of South Africa is one plagued by inequality, and even in the post-apartheid era there still remain substantial social inequities which have a complex interaction with health and disability. The literature, both internationally and locally, reflects that there is a link between poverty, disability and ill-health. The absence of many essential requirements for health such as access to nutrition, access to clean water, effective sanitation and decent housing still remain a challenge for a large majority of the South African population (Mayosi & Benatar, 2014). The intersection of poverty and disability opens PWD up to multiple health risks which have an impact on them and their households (Sherry, 2014).

However, it is difficult to quantify the scale of the relationship between poverty and disability in developing countries due to inappropriate and insufficient data.

Social inequality, together with a high disease profile in impoverished communities, places a large demand on the available health resources. Thus the responsibility for care, especially for PWD, has been transferred to families and the community (Ncama, 2005). It has become a household challenge to meet the increasing needs of PWD, such as the need for food, health care and rehabilitation, assistance with activities of daily living, palliative care and assistance with accessing financial grants (Naidoo, 2012; Setswe et al., 2009). This situation highlights the need for effective community-based health care.

The World Health Organisation states that community-based programmes should facilitate the achievement of the highest attainable level of health for people with disabilities. Working towards this goal involves many stakeholders and sectors and can only be achieved in close collaboration with the health sector (World Health Organisation, 2010). The Department of Health policy on the quality of health care in South Africa (2007) clearly specified that the vulnerable sectors of society namely women, children, older people and PWD need to be prioritized (Mseleku, 2007).

The Western Cape Department of Health *Healthcare 2030: The Road to Wellness* document re-envisioned a transition from health care service delivery towards patient-centred care. The vision included four conceptual pillars of patient-centred care, namely: a person-centred approach, integrated provision of care, continuity of care and a life course perspective (Western Cape Government Health, 2014). The Healthcare 2030 document highlights a continued commitment to strengthening community-based services and primary health care. Community-based services are geared at “prevention and health promotion with a complementary capacity for curative, rehabilitative and palliative care” (Western Cape Government Health, 2014, p. xi). Community-based services have two service elements which included home- and community- based care and intermediate care services. As defined by Western Cape Department of Health

> Intermediate care refers to inpatient transitional care enabling patients to regain skills and abilities in daily living, with the ultimate discharge destination being home or an alternate supported living environment. Intermediate care involves post-acute-, rehabilitative- and end-of-life care. It allows for a seamless transition between acute care and the living environment, particularly where the person’s ability to self-care is significantly compromised. (Western Cape Government Health, 2014, p. xi)

As part of the continuum of care the intermediate care teams are envisioned to work closely with the RCWs who will enhance access to health and rehabilitation services. This would facilitate integrated provision of care by ensuring rehabilitation services are accessible at all levels of care. Figure 1 depicts the interrelated health service delivery platform where the RCWs would support the continuum of care from facility-based services to community-based services within primary health care services.

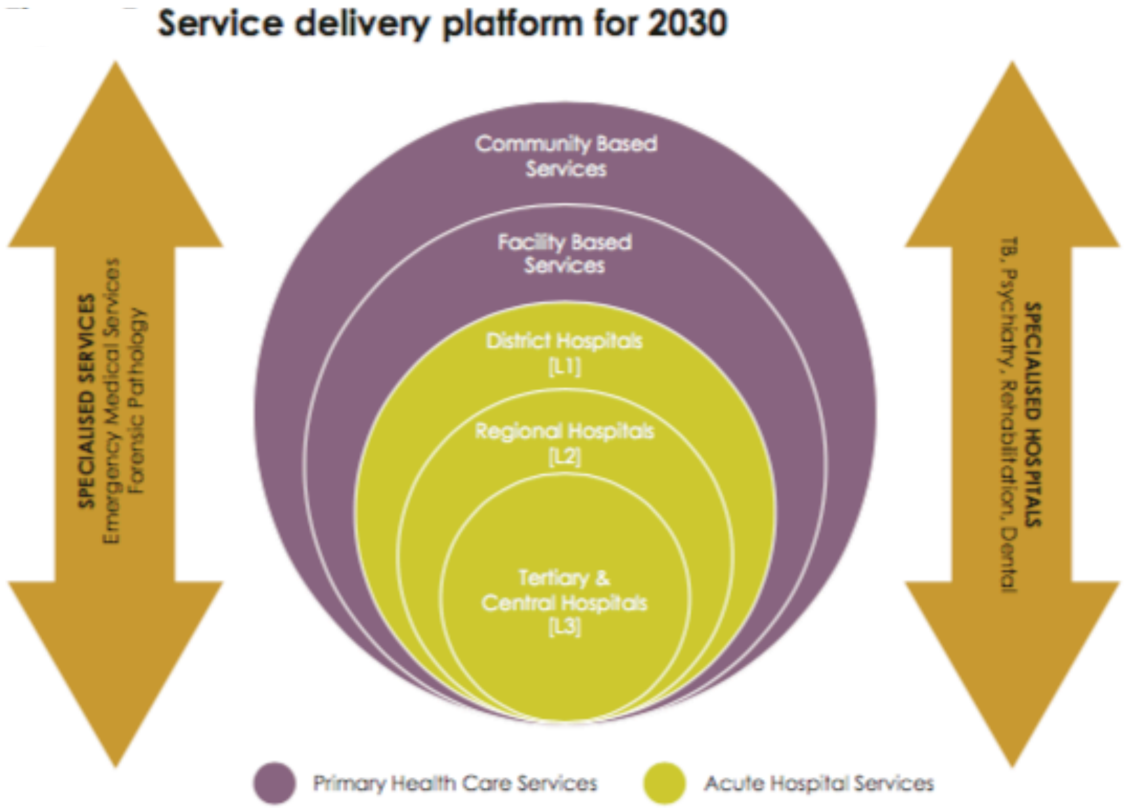

Figure 1: Service Delivery platform for 2030 (Western Cape Department of Health Care, 2014, p.37.)

Study Context

This study was based on one substructure in the Western Cape, namely the Mitchells Plain / Klipfontein area. The reason is that the RCWs that were part of the Western Cape Department of Health pilot training project have been deployed in this substructure. The Mitchells Plain / Klipfontein area is an historically disadvantaged area in the Western Cape and is still plagued by a lower socio-economic status and impoverished conditions. The socio-economic profiling of urban renewal nodes: Khayelitsha and Mitchells Plain report described Mitchells Plain as an Afrikaans- and English-speaking community with a high unemployment rate which may be linked to the low levels of education and training. This report further indicated that the Mitchells Plain district has a significant crime rate and that alcohol, drug abuse and gang-related activities are high (City of Cape Town, 2006). These contextual socio-economic factors add to the complexity facing the RCW when engaging in community-based service delivery for PWD due to the impact on the clients and personally on the RCWs (e.g. heightened risks for the RCWs when visiting the homes of their clients due to crime).

A contextually relevant RHIT that is appropriate for use by a cadre of workers such as the RCWs would be an asset to the practice of RCWs. Such a tool would contribute to working towards a specific inter-professional care planning process in the patient's journey of care, which is part of the aim of the Western Cape Department of Health (Western Cape Government Health, 2014). The development process of the RHIT considered relevant frameworks and measurement tools that are in use by the health care team such as the ICF and WHODAS-2 and WHOQOL-BREF, as well as any other record systems that that RCWs are currently using in their practice. This will be described in more detail in the literature review.

1.4. Problem statement

Currently the RCWs are new to the Western Cape community based services. Their role and scope of practice is still emerging. The RCWs do not have contextually relevant resources to assist them in documenting the rehabilitation and health needs of PWD. No study has yet been done with the RCWs in the Western Cape that examines this aspect and proposes a contextually relevant resource for this cadre of worker to enhance the interprofessional and collaborative care of PWD. The literature cited in the rationale for the study highlights that CHWs are ill-equipped to deal with the needs of PWD, therefore a resource to support the RCW in understanding and documenting the needs of PWDs will be a start at addressing this gap.

1.5 Summary

This chapter has described the focus of the study, the rationale for the study and the community health care context in South. The chapter has highlighted that the RCW is an essential member of the community-based services' team that is directly linked to the Western Cape Department of Health Healthcare 2030 vision. The RCWs require a tool to support them in a systematic process of documenting what and how the rehabilitation and related health needs of PWD are met in a community- and home-based context. This RHIT would also facilitate building a positive relationship and good rapport with clients which is fundamental to effective health care delivery. The next chapter will look at the literature relevant to this study in more detail.

Chapter 2: Literature Review

2.1 Introduction

This chapter presents the literature on the health and rehabilitation needs of people with moderate to severe disability requiring community- and home-based care. The chapter commences by looking at community-based rehabilitation (CBR) to provide the researcher with the understanding of disability, CBR and the needs of PWD within a community-based context. The role of CHWs and different mid-level workers is described in the context of CBR. Secondly, as this research aimed to develop a contextually relevant resource tool for use by RCWs in their practice to help them document and understand the rehabilitation and related health needs of PWD, the literature related to the current tools available to assess disability and health needs, as well as the process of tool development was reviewed.

For the present study a methodical literature search was conducted using EBSCO host, Cumulative Index of Nursing and Allied Health Literature (CINAHL), PUBMED and Google Scholar as relevant information sources.

2.2 Community-based rehabilitation and the needs of persons with disabilities

As highlighted in Chapter 1 the local and international literature argues that PWD are marginalised and have significantly less access to health care than people without disabilities (Sherry, 2014). The World Health Organisation Disability report (2011b) indicated that although PWD have the same health needs as able-bodied people, they may be at greater risk for developing chronic conditions because of environmental and behavioural factors such as increased physical inactivity. Despite South Africa having signed the UNCRPD, the inequalities between PWD and able-bodied persons in terms of health care and support still persists (Schneider, Schaay, Dudley, Goliath, & Qukula, 2015). The inequality is exacerbated by the lack of accurate, reliable and relevant disability data, which further perpetuates the discrepancy between well-intentioned policies and meeting the needs of PWD. In addition, discriminatory attitudes remain a challenge which contributes to social exclusion and further reduces access to health care for PWD (World Health Organisation, 2010).

In this study the researcher recognises that the concept of need is abstract and the literature agrees that the manner in which needs are satisfied is relational in nature (Max-Neef, 1991). There is no universally accepted definition of need. Many theories and concepts for need exist and it is further argued that the needs of PWD are defined differently by the various stakeholders involved such as the professionals and the PWD. However, this research project recognises that needs are complex in nature and that this complexity increases as needs as well as the manner in which they are satisfied, evolve over time (Max-Neef, 1991).

Health needs encompass physical, sensory, cognitive, mental health and rehabilitation needs (United Nations, 2006). Lorenzo, Motau & Chappell (2012) emphasise the importance of focusing not only on needs related to the person's impairment, but to look at the interaction of other factors such as biological, psychological, cultural, socio-economic and political, which is an argument that is grounded in the ICF philosophy.

This study recognises that the needs of PWD extend beyond the health domain and that other domains which are included in the CBR guidelines such as education, livelihoods and social needs as well as the family's needs are equally important (United Nations, 2006; World Health Organisation,2010). These needs influence health and the attainment of good health. However, the needs that extend beyond the health domain are not the focus of this study.

The World Health Organisation published CBR guidelines across five key domain areas, namely: health, education, livelihood, social and empowerment. CBR has been effective in promoting the inclusion of PWD and their families (World Health Organisation, 2010). CBR is housed within a community development framework and places importance on disability inclusion, equal opportunities for PWD and their families, partnerships across various sectors, communities and disabled peoples organisations (Chappell & Johannsmeier, 2009). As argued by the UN standard rules for equal opportunities for PWD, the notion of equal opportunities is achieved through a process that holds participation, access and partnership as core principles (United Nations General Assembly, 1993).

The health domain of CBR is a key component relevant to this study. According to the World Health Organisation, CBR

> supports people with disabilities in attaining their highest possible level of health, working across the following key areas: health promotion, prevention, medical care, rehabilitation and assistive devices. Importantly CBR works towards facilitating access to health care for PWD by advocating for health services to accommodate the rights of PWD and through a responsive participatory and community based approach (World Health Organisation, 2010, p.1).

As outlined by the CBR health component these three areas: firstly to be responsive, secondly community-based, and thirdly participatory, speaks to the approach that is needed when facilitating access to health and equal opportunities for PWD.

A study conducted by Grut et al. (2012) described the challenges faced in accessing community health by poor people with disabilities in the rural Eastern Cape. The study confirms the importance of a participatory and responsive approach to health. The study argued that numerous factors interplay to impact on access to health. The authors argued that health professionals and patients were presented with different priorities and obligations in terms of health. Therefore, the expectations and measures taken towards health are from different perspectives and are often contradictory and work against an optimal outcome. The authors highlighted that for effective health services to be rendered and truly meet the PWD needs an understanding of the reasons for the person's priorities and actions. The person needs to be understood within a holistic manner addressing aspects of the person's history, and the person in the context of the family and the community. This would facilitate a better understanding of how to adapt services to increase compliance and promote health (Grut et al., 2012).

A study conducted by (Booyens, van Pletzen, & Lorenzo, 2015) looked at the complexities of rural contexts as experienced by community disability worker in three countries, namely: South Africa, Malawi and Botswana. Across these African countries the participants reflected the challenges for PWD in accessing community resources such as education, transport and health, particularly in rural areas. The authors highlighted that there remains a wide gap between the ideals outlined in the CBR guidelines; the UNCRPD, and the practical realities of the contexts in which these workers practice. These community disability workers were encouraged to identify and create opportunities for inclusion and participation for PWD by removing barriers to participation. In so doing they facilitate and empower the PWD to satisfy and meet their fundamental human needs. The reality however is that many community disability workers are faced with challenges in meeting these ideals. Few studies have been conducted in Africa to understand these challenges. The challenges that emerged from the Booyens et al. (2015) study reflected a complex interaction between poverty, power relations, negative attitudes towards PWD on a family, community and service provider level which acted as barriers to the inclusion of PWD and barriers to the community disability worker effectively working towards inclusion. Despite this, Booyens et al. (2015) still argue that an understanding of these challenges and that the use of an approach that is participatory, community-based and responsive will allow the PWD to be empowered and enable the PWD to "do for themselves" as far as their capabilities permit in meeting their own needs. The inclusion of the family and community was argued as fundamental to breaking down discriminatory attitudes and cultivating an environment in which the PWD can have optimal outcomes.

The Western Cape Department of Health has committed to address the needs of PWD at a community level and this includes rehabilitation needs which remain underserved within the South

African context (Sherry, 2014; Western Cape Government Health, 2014). To do this will involve the decentralisation of health care service delivery and will include human resource cadres such as the RCW in the provision of rehabilitation and health care. The Western Cape Department of Health strives towards patient-centred health care which encompasses the perspective of the patient which are principles that are grounded in the UNCRPD (United Nations, 2006; Western Cape Government Health, 2014). A study conducted by Kahonde, Mlenzana, and Rhoda (2010) described the experiences of rehabilitation services at community health centres in Cape Town by persons with physical disabilities. PWD reported having both positive and negative experiences of the rehabilitation service. Positive experiences were linked to the service providers' attitude and interaction with the PWD and family. PWD reported that service providers supported their emotional needs and that they felt involved in the rehabilitation process. Negative experiences highlighted that accessibility to services, specifically transport, was still a major challenge as well as a lack of information around support services available once out of the hospital and back home in the community (Kahonde et al., 2010). These findings demonstrate that there still remains a breakdown in the continuum of care between in-patient and community-based care. Therefore, it is evident that mechanisms and structures that can facilitate the continuum of care should be encouraged.

The literature argues that cadres of workers trained in CBR can enhance health, education, social inclusion and empowerment of PWD. This is evident in the Binken et al. (2009) study that reviewed the value of the services offered by community rehabilitation workers to a community in the rural Limpopo province. Through the various roles and manner in which the community rehabilitation workers' operate the study concluded that they are indeed valued by their clients. It remains for the system to reflect value to the community rehabilitation worker through meaningful ways such as appropriate recognition by other members of the health team as well as adequate supervision and remuneration. Table 1 (Binken et al., 2009) reflects the tasks by which community rehabilitation workers define their value in the community. These tasks are offered by RCWs as well and this research anticipates that through the use of the RHIT these tasks can be strengthened.

Table 1: Tasks by which community rehabilitation workers define their value to the Community (Binken et al., 2009, p.15).

Activities ***Direct Client Contact***
➢ Carrying out rehabilitation in clients homes which overcomes the financial difficulties experienced e.g. getting to hospital
➢ Teaching disabled people and their families to make assistive devices for themselves
➢ Promoting independence in disabled people
➢ Encouraging disabled people to manage themselves better in the home and in the community
➢ Educating caregivers to understand the behaviour of their disabled family member
➢ Involving families in treatment, thereby teaching them skills
➢ Helping families to use the cheapest possible resources and those that are available in the community
➢ Encouraging disabled people to start self-help groups
➢ Sharing ideas and adopting a client centred approach on deciding on priorities in treatment
Community Education
➢ Integrating disabled people into the community to prevent discrimination

➢ Changing attitudes in the community
➢ Creating jobs and work for disabled people
➢ Including disabled people in community meetings
➢ Raising disability awareness and carrying out health promotion
➢ Encouraging disabled people to fight for their rights
➢ Identifying people in the community with disabilities.
➢ Influencing teachers to admit disabled children to their schools.
Intersectoral Collaboration
➢ Working hand in hand with Indunas and traditional healers
➢ Making referrals in cases where they are unsure of the diagnosis or unable to help
➢ Promoting networks with other health structures and working as a team
Other
➢ Understanding the community's beliefs and respecting their cultural norms

Achieving success in CBR and facilitating the continuum of care for PWD can be done through means of task shifting. The World Health Organisation defines task shifting as involving the redistribution of tasks where appropriate in the health team from highly qualified health workers to cadres of workers with limited training and fewer qualifications to allow for efficient use of human health resources (World Health Organisation, 2008). Dawad and Jobson (2011) argue that when task shifting is planned as part of an integrated health care strategy it can facilitate enhanced access to health care without overburdening existing health workers. CBR utilises a task shifting principle through the use of alternative cadres of workers (Dawad & Jobson, 2011). RCWs or community rehabilitation facilitators are viewed as an essential cadre who can create a bridge between the professionally qualified allied health therapists and medical officers at secondary and tertiary levels of health care and the PWD in the community. The RCW role and training in the Higher Certificate in Disability Practice is envisioned to include aspects across the CBR guidelines and not only focus on health (Lorenzo, Motau & Chappell, 2012). The training curriculum includes theoretical and practical components and by the end of the course the RCW should be able to screen PWD for impairments and functional ability and participation restrictions, apply basic procedure and techniques to address functional limitations experienced by the PWD, do health promotion activities, promote and advocate for the rights of PWD and facilitate the re-integration of PWD into home and community life. However, it is not documented whether the additional training in rehabilitation skills facilitates the RCW in meeting the needs of the PWD and is therefore an essential area to research.

There are many critiques of the task shifting model and a common one relates to the quality of the care provided. The World Health Organisation has highlighted that for task shifting to be effective it is important that it is implemented with mechanisms in place to support and protect the health worker and the patient (Dawad & Jobson, 2011). In the South African context the most appropriate and relevant way of meeting needs in the community is still debatable but research has described that using community rehabilitation workers or CHWs has been useful (Booyens et al., 2015; Lorenzo et al., 2014; Sherry, 2014).

Campbell and Foulis (2004) highlight that little is known on what is needed to create a context for effective care in the home. These authors affirm that mid-level workers and home based carers conduct their tasks despite the most daunting circumstances in relation to HIV/AIDS home-based care. The authors also highlighted challenges such as poverty, stigma, lack of knowledge, skills and inadequate support that undermine carers efficacy in the work they do. These challenges exist across family, household, community and social contexts. Even though partnerships between the carers and patients, society, government, relevant organisations and stakeholders are suggested solutions to the above-mentioned challenges the best methods to activate and sustain these strategies is lacking in the literature. The question remains how does one create and sustain a health enabling environment/context for a carer and the patient. Campbell and Foulis (2004) identify and suggest the concepts of "bonding, bridging and linking social capital" as a method to create a context for effective care in the home and community. It is claimed that healthy communities possess "high levels of trust, reciprocal help and support, positive local identities and participation" which then facilitates an increased chance of "health enhancing support". Bonding refers to the building of trust, reciprocity and positive common identity. Bridging refers to creating relationships across different groups/ communities such as geographic locations, low- middle- and high-income communities. Linking refers to connecting the individual with relevant stakeholders such as government role players, political institutions and local community people. These links could ensure that in the case of carers the government is aware of the needs and interests of the PWDs that the carers serve (Campbell & Foulis, 2004). It is through using principles such as these that a supportive social environment is created and community networks are formed to strengthen and enhance the community's ability to manage health concerns and challenges. Communities can become active in their own health care which enhances effective care.

A fundamental value of CBR is the inclusion of PWD and that PWD should be central in planning and implementing community-based rehabilitation; therefore PWD should make their own decisions and be empowered to change their own lives. Chappell and Johannsmeier (2009) argue that many professionals have been critiqued for implementing CBR in a non- participatory manner without consulting and involving PWD and their families. The abovementioned concepts of bonding, bridging and linking provide a clear strategy for use by RCWs in community based services.

There is an increased interest in health research on the patient's perspective of their health needs as well as the patients' satisfaction with the health services rendered to them. Various studies have been conducted on community- and home-based care and HIV (Estopinal et al., 2012; Uys, 2002). The focus of these studies is often from the perspective of the service provider and is on the link between the service provided and clinical outcomes. It has been argued that there are improved clinical outcomes and adherence to medication in environments with community- and home-based care supporting other in hospital clinical services (Estopinal et al., 2012; Uys, 2002). Limited research has been conducted to reflect what best supports the carers in working with the PWD perspective to address issues such as: does the service meet the perceived health needs of PWD, specifically considering the PWD within the context of their home and community. Knowing how PWD needs are met from their perspective and the most effective support to put in place for the RCW, could be used to inform service training, and service delivery. Furthermore, data of this sort would a indicate whether financial resources allocated are adequate to meet the needs of the PWD (Tousignant et al., 2007).

The study cited earlier about the value of community rehabilitation workers by Binken et al. (2009) found that the record keeping of community rehabilitation workers to be inconsistent and inaccurate and at times difficult to decipher. Therefore, in order to enhance accuracy and the efficacy of records it was recommended that record sheets should be simple and easy to complete. Currently there is no consistent and systematic method in which the RCWs gather information on PWD health and rehabilitation needs. Given the desire to firstly facilitate a context that can support and promote effective relational practice by the RCWs, and secondly support the need to gather relevant data on the needs of PWD from their perspective in a manner that is collaborative, inclusive and participatory, this research study needed to review what tools were available to do this. Doing this review highlighted important information needed in the selection of a contextually relevant resource tool.

2.3 Tools currently available to measure disability and need

Firstly, considering that the researcher was interested in developing a contextually relevant resource tool that could help RCWs systematically collect information related to the health needs of PWD within the home and community setting, it was important to foreground the context that the RCW is working within. The implementation of the RCW cadre as part of community based services is in the pilot phase within the Western Cape province and this strategy is positioned within the Western Cape Department of Health *Healthcare 2030: Road to wellness strategy*, and aligns with the principles and values of the NHI and FDSR. The RCW is envisioned to enhance access to rehabilitation within the home for PWD. The RCW works closely with the intermediate care teams and therefore has the support and supervision from the community based services' team. The role and scope of the RCW is emerging but currently the record keeping and information capturing systems that are used by the RCW are not tools that are specifically tailored for this cadre.

Secondly, it was necessary to look at measurement tools that are currently available to do this. There are reliable, validated and standardised measurement tools that assess disability and functioning namely, the International Classification of Functioning, Disability and Health (ICF) and the World Health Organisation Disability Assessment Schedule II 36 item version (WHODAS-2) (World Health Organisation, 2000) and the World Health Organisation quality of life (WHOQOL-BREF) brief version (WHOQOL Group, 1998). The World Health Organisation developed the ICF as a framework to define and classify disability (Garin et al., 2010). Clinically the ICF is used for needs assessment, appropriate intervention planning, rehabilitation and outcomes measurements (Cieza et al., 2004). The WHODAS 2.0 was developed to assess disability within the conceptual framework of the ICF. Kostanjsek (2011) highlights that the WHODAS 2.0 as a generic tool that provides a summary on the impact of any health condition on function which has been useful in the assessment of health and disability levels and is useful in designing and monitoring health interventions. The WHOQOL-BREF is a measure of quality of life and contains the following four domains: physical capacity, psychological wellbeing, social relationships and environment domains. Disability has an impact on many areas of life and health and therefore measures of health-related quality of life are relevant for PWD to aid in the understanding of the PWD health profile.

Although these are arguably the preferred tools to use to assess disability and functioning it presents a challenge that these tools were designed as generic tools, to be administered in a standardised manner, with the aim of promoting data comparability across conditions and interventions (Kostanjsek, 2011). Although this aim is a strength of the WHODAS 2.0 and the ICF checklist, its generic approach does not take into account the specificity of the context that the RCWs work within in South Africa, which is essential to consider to allow one to tailor specific services for PWD in a personalized, multifaceted and flexible manner which may promote the effectiveness of the RCW services. A critique of these tools is that the domain of mental health-related needs are not adequately addressed in these tools. Lund et al. (2008) highlights that mental health is a public health concern which substantially contributes to the burden of disease in marginalised populations.

In the above-mentioned tools there has been minimal attention to documenting how the needs of PWD are met within the home and community-based context. A thorough literature evaluation of tools of disability revealed that there was no tool to be used by the RCWs, to firstly support them in building a relational practice and in so doing gather information to describe what the health and rehabilitation needs of PWD are, and what methods are being used to meet these needs. Therefore, an appropriate tool is required and this informed the need for the development of such a tool. The methodology chapter elaborates on the use of these above mentioned reliable and validated tools in the development of the RHIT.

The development of a tool that can be used by community health workers and RCWs to help them to systematically gather information on the health needs of PWD will strengthen the data collection within the health care system as well as strengthen the continuum of care and the link between the home, the community and the clinic.

2.4 Considerations in the process of developing a tool

The process of developing a tool is a complex one and involves many factors that could strengthen the development process and the resultant tool. These factors include firstly, a thorough understanding and review of the literature related to the concept to be measured in the tool, so as to inform the development of the tool. Secondly, the process needs to be systematic and rigorous, and thirdly, the tool needs to be contextually relevant to the end user (i.e. RCWs and PWD).

As outlined in the above section of the literature review the researcher sought to have a detailed understanding of literature about CBR and the health and rehabilitation needs of PWD. Secondly in order to follow a systematic and rigorous process of development the researcher adopted the use of the “why, what, who and how” framework of Madden, Fortune, Cheeseman, Mpofu, and Bundy (2013). According to Madden et al. (2013) there are fundamental questions that need to be answered before recording and measuring function and disability, namely: 1.Why do we want to describe or measure a construct; 2. What is the construct that we want to describe; 3. Who do we want to use this tool with (e.g. PWD); and who should administer this tool (e.g. health professional or self-administered or combined); and 4. How do we want to go about describing or measuring the construct?

The first question addresses the purpose of the measurement and is a critical starting point. Once the purpose is clear then that informs all other aspects such as the content to be included, the method of measurement and who will be involved. Madden et al. (2013) highlight the importance of adhering to principles outlined in the UNCRPD when engaging with PWD as well as person-centred services which require a common language among all stakeholders such as the professionals and the PWD. For this research the purpose of the RHIT was to support the RCW in CBR to systematically collect information on the rehabilitation and related health needs of PWD. This information would inform service delivery and planning and allow for the monitoring of progress.

Secondly, Madden et al. (2013) highlight that the “what” allows the researcher to consider the content and the timing of the measurement. This also speaks to the validity of the tool. The ICF can give the high level conceptual framework for a common language and understanding. However, the details of the specific content items for inclusion need to consider all the components of disability (impairments, activity limitations and participation restrictions). The tool needs to take cognisance of the context in which it is being used and the environmental factors which interplay with the experience of disability. The health condition and impairment need to be seen as components of disability and not as a proxy for disability. The authors further advise that disability-related content should give information on functioning and how to enhance function and participation towards promoting the inclusion of PWD (Madden et al., 2013). When to use the tool is also an important consideration as the RCW and health team will want to deliver rehabilitation in a timely manner and use the tool to generate data that supports the achievement of the desired outcomes for the PWD. Therefore the timing of the use of the tool needs to be related to when the need and opportunity arise (Madden et al., 2013).

Thirdly, Madden et al. (2013), argue that who is involved in the recording of the data is important with regard to the accurate representation of the data. For the tool to be truly person-centred it requires the involvement of the “person at the centre”, which in this research project is the PWD and the RCW.

Fourthly, consideration needs to be given to how the tool is administered, looking at whether the information gathered should be self-reported or provided by the health care professional. Using a participatory approach and the combining of perspectives of both the health professional and the PWD in a formalised way can be a strength of the tool as it reflects both perspectives. A practical, easy-to-administer and concise tool may be best suited (Baker, 1999). Furthermore, clear and unambiguous questions need to be developed. Consideration needs to be given to the format, wording, instructions and response criteria on the given tool which can greatly impact on the quality of the data collected (Baker, 1999).

The researcher applied the comprehensive process outlined in the “why, what, who, and how” framework to facilitate the development of a contextually relevant resource tool. Figure 2 outlines the questions of “why, what, who and how” framework (Madden et al., 2013) and the summarised answers for this research project.

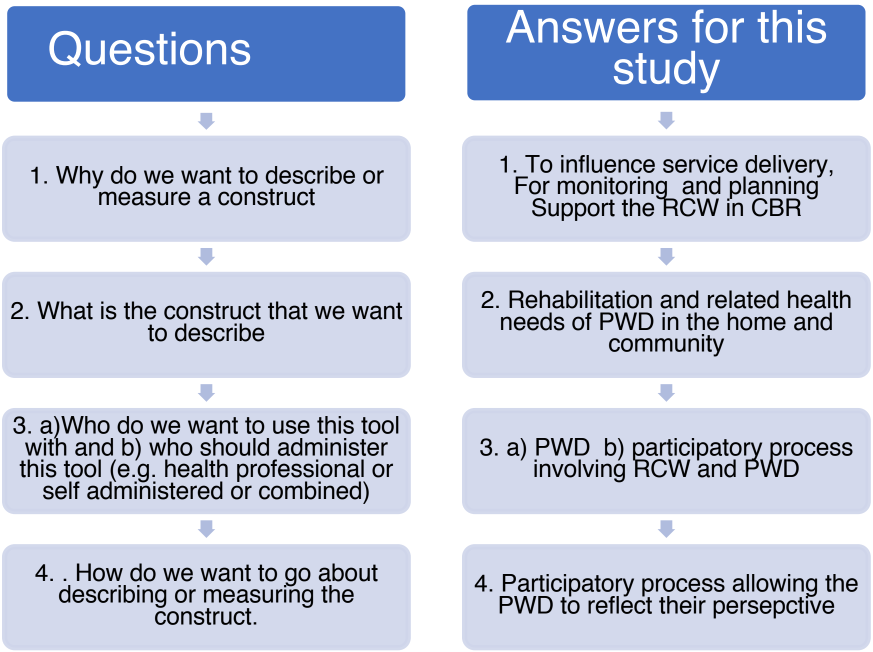

Figure 2: "why, what, who and how" framework questions and answers for this research (Madden et al. 2013)

2.5 Validity and reliability considerations

Careful consideration needs to be given to the validity and reliability of the tool particularly when measuring abstract concepts such as ‘need’. An effective tool must be both valid and reliable.

Validity refers to whether a construct measures what it claims to measure (Babbie & Mouton, 2001). A challenge in assessing content validity is achieving agreement by all parties on the content of the variable (rehabilitation and health needs of PWD) being described. Validity remains a key element in determining the quality of a tool. Many of the constructs such as ‘need’ are difficult to measure directly and an assessment can only be inferred based on observations or behaviours. The challenge is to create an operational manner to measure a construct. The content validity addresses whether items in a developed tool are an adequate representation of the content area to operationalise the construct measured; this decision is often determined by experts in the field as there is no statistical method to determine this (Kimberlin & Winterstein, 2008). The RHIT aimed to document and understand the rehabilitation and health needs of PWD. These are constructs that are not easily measured directly and thus the use of experts in the field and a document review were adopted as methods to strengthen the validity of the tool.

The reliability of the tool looks at whether a tool measures a construct consistently over time, individuals and different situations (Baker, 1999; Bruce, 2008). A good tool is said to produce consistent results when repeated within a short space of time. The different types of reliability include test-retest reliability and inter-rater reliability. A challenge with test-retest reliability is that it presumes there is stability in the construct being measured. A challenge in measuring consistency when assessing need is that health and rehabilitation needs are not static and may change based on circumstances, contexts and improved health and rehabilitation condition.

Therefore, in the case of health and rehabilitation needs that change a test-retest reliability result would be low which would incorrectly indicate an unreliable tool and therefore it may not be the best measure of reliability for a construct that is not static. Other reasons for tools being unable to yield high test-retest scores could be a result of differences in the assessors and the changing contexts in which the tool is administered (Bruce, 2008).

Inter-rater reliability looks at whether the tool is able to produce the same result particularly when it is used by two different researchers. However, as mentioned before needs are not static and therefore achieving the same result could be challenging (Baker, 1999). Furthermore, in the case of the proposed RHIT it is assumed that with trust and rapport developed between the RCW and their client this would facilitate answering the questions truthfully and in depth. Therefore the relationship between different RCWs and their clients may vary and the inter-rater reliability results yielded may vary across different raters.

2.6 Summary

This literature review has indicated that there is still a need to enhance access to quality health care for PWD, and that alternative cadres of health workers such as RCWs are seen as a means to achieve this and to facilitate community-based rehabilitation. There remains a need to support these cadres in the efficiency of their service delivery through various means; for example, adequate supervision and context-specific tools and mechanisms for collecting and reporting relevant data. With this in mind the present study aimed to contribute towards supporting the RCWs in CBR in the Western Cape. This was achieved by developing a contextually relevant RHIT through a systematic development process which involved collaborating with the relevant stakeholders when selecting the most appropriate content and the desired implementation process for the tool. It is hoped that this research study will initiate a process to support the RCW in the Western Cape to effectively and systemically collect information related to the rehabilitation and health needs of PWD in the home and community context.

Chapter 3: Methodology

This chapter outlines the research design selected to address the research aims. A detailed description of the selection criteria and recruitment methods that were used for participants, and the procedures and the data analysis for the two phases of the research study will be covered. The ethical considerations that were taken into account as part of the research process will be highlighted.

3.1 Aim and objectives

This research study aimed to develop a resource tool that would support the RCW to understand and document how the rehabilitation and related health needs of PWD are met in home- and community-based settings. The resource tool was named the Rehabilitation and Health needs Information Tool (RHIT).

In order to achieve this aim the objectives were:

- To develop the content and domains of the RHIT.
- To establish validity (face and content) of the RHIT.
- To test the application of the RHIT on a sample of PWD.

3.2 Research design

The research design adopted for this study was a mixed methods sequential exploratory design. The use of a mixed methods approach for this study provided a more comprehensive description of the research problem. The use of both qualitative and quantitative data was complementary and enriched the interpretation of the findings and strengthened the study (Creswell, Clark, Gutmann, & Hanson, 2003). When choosing the mixed methods study design that best suited the development of the RHIT the following aspects were considered: implementation of data collection, priority of qualitative or quantitative data, stage of integration and the transformative value of the study (Creswell et al., 2003).

A sequential exploratory design is characterized by an initial phase of qualitative data collection and analysis and a second phase of quantitative data collection and analysis. Following these two phases the findings are integrated during the interpretation stage. Figure 3 depicts the steps of the sequential exploratory design (Creswell et al., 2003).

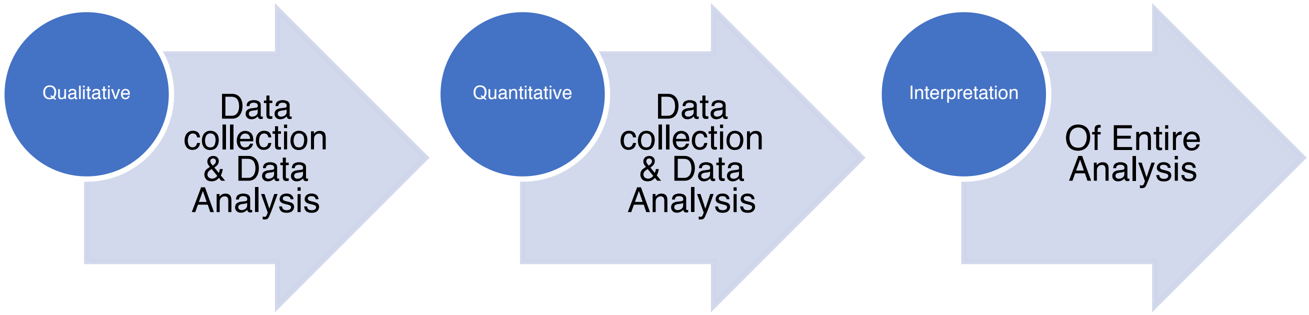

Figure 3: depiction of Sequential Exploratory mixed methods research design (Creswell et. al, 2003, p.180)

For this study the qualitative phase was used to facilitate a contextual understanding of the variables involved and to develop the questions or scale items needed to generate a more comprehensive research tool (Bryman, 2016). The quantitative phase of the study involved field-testing the application of the developed tool. This design allowed for two distinct phases in data collection and analysis and is a design that is particularly valuable in the development of research instruments (Creswell, 2009).

In accordance with the sequential exploratory design, the study had two distinct phases with two distinct sections of data collection and analysis. The first phase involved the development of the RHIT. The second phase of the study involved the field-testing of the application of the RHIT by RCWs with a sample of PWD. The phases occurred consecutively, which is consistent with a sequential methodology (Creswell, 2009). Figure 4 depicts the phases of the research project.

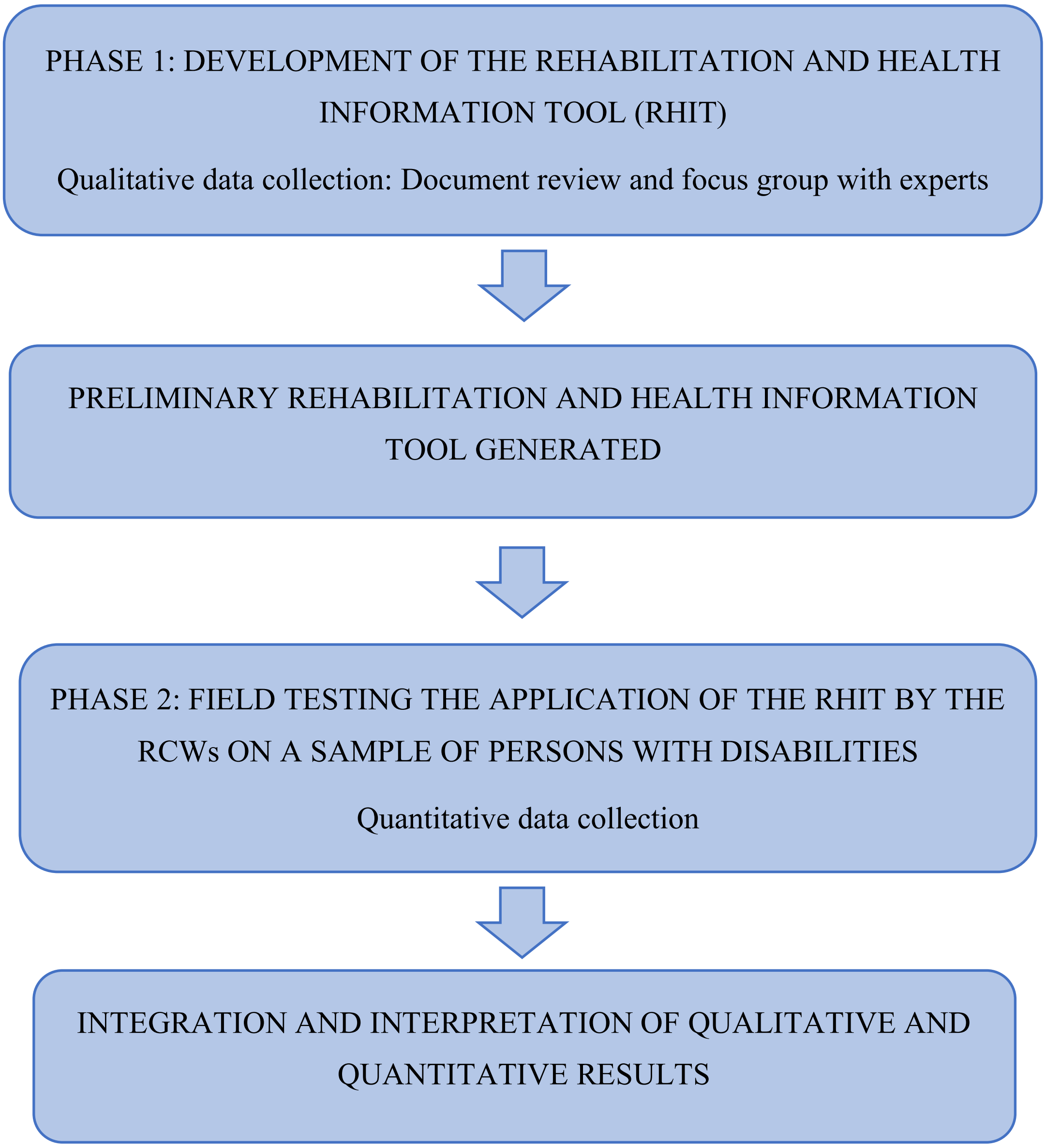

Figure 4: Phases of this research project

As presented in Creswell (2009), the process of the sequential exploratory design that was adhered to for the development of the RHIT is outlined below:

The implementation of data collection and analysis refers to the sequence that the study used to collect qualitative and quantitative data. The sequential exploratory design allowed for an initial stage of qualitative data collection which involved a document review and a focus group interview with experts in the field, thereafter an analysis was carried out to identify the themes and variables and narrow the focus of the RHIT. In the next phase these themes were used to create questions for the RHIT. The proposed RHIT was then member checked to clarify and ensure that the proposed tool was appropriate. The application of the RHIT was then field tested by RCWs on a sample of PWD. For the duration of the data collection the researcher met weekly with the RCWs to receive any feedback on the use of the tool (Creswell, 2009).

Integration refers to the stage/s where the qualitative and quantitative data collection and analyses are integrated or mixed. Integration enhances the usefulness of the mixed methods study. Integration takes place on three main levels, namely: the research design level, the methods level and the interpretation and reporting level. For this study integration occurred at an interpretation and reporting level. Methodological integration can occur in various ways, namely: 1) connecting, 2) building, 3) merging and 4) embedding.

Table 2: Integration methods as outlined by Fetters, Curry and Creswell (2013), p.2140.

Integration approach	Description
Connecting	One database links to the other through sampling
Building	One database informs the data collection approach of the other
Merging	The two databases are brought together for analysis
Embedding	Data collection and analysis link at multiple points

In this study, the methodological integration occurred through building. The results from the qualitative and quantitative phases were analysed separately. The results of the qualitative phase provided items for inclusion in the RHIT. Therefore, the results of the qualitative phase were used to build the tool such as identifying the domains, the questions and the wording to be included. This allowed for the RHIT to be grounded in the views of the people with expertise in this area of interest. This is typical of an instrument design model where the qualitative data is analysed and used in the development of the instrument (Fetters et al., 2013). For this study integration used a contiguous approach which is reflected in Chapter 4 where the findings are presented in one chapter with separate sections for the qualitative and quantitative findings (Fetters et al., 2013).

Priority is concerned with placing emphasis on either the qualitative or quantitative data or an equal emphasis is placed on both forms of data (Creswell, 2004). In this study priority was given to the qualitative phase of data collection and analysis. This is common in the design used for instrument development.

There are both strengths and limitations of using a sequential exploratory mixed method design. Using this methodology allowed for a logical and a distinct approach to conduct the study. A strength of this approach is the systematic two phase process which allows for ease of data research implementation, analysis and reporting. This is a recommended method in the design of a research instrument (Creswell, 2009). A challenge of this methodology is that it is time consuming requiring a significant amount of time to complete both phases of data collection and analysis. Additionally, it requires expertise to code and analyse the data in both the quantitative and qualitative paradigms. To manage these challenges the researcher worked closely with supervisors who had expertise in mixed methods research.

3.3 Methodology of the two phases of the research study

The methodology used for each phase will be addressed separately and will cover the following aspects: participant selection, data collection, procedure, data analysis, reliability and validity/credibility and trustworthiness. The validity testing of the RHIT is embedded in both phase 1 and 2 of the study and the data analysis is described in each phase respectively. Ethical considerations will be jointly addressed for both phases.

Phase 1: Instrument Development Phase

This phase addressed the following objectives:

To develop the content and domains of the RHIT

To establish validity (face and content) of the RHIT

The RHIT was envisaged to be a questionnaire to be used by RCWs or CHWs that would support the RCW in gathering information and provide an opportunity for PWD to state their rehabilitation and health needs and identify how these needs are being met.

The first step of the instrument development involved a document review, and this did not involve participants and the details of this will be discussed further on in this methodology section.

Participants and focus group with experts

An expert for this study was defined as someone who through professional qualification, practical experience and / or technical experience (Stevenson, 2010), had relevant knowledge and experience in the field of disability, rehabilitation, community- or home-based care or questionnaire development.

Since the research aim was to develop a contextually relevant resource tool, the use of experts who were most knowledgeable, information rich and experienced in relation to the research topic was desired. As recommended in Article 4 of the UNCRPD this study intentionally sought to have PWD be actively involved in the development of this resource tool. Furthermore, Article 19 of the UNCRPD states that community services should be responsive to the needs of PWDS and therefore through the inclusion of PWD in the focus group the study aimed to facilitate this (World Health Organisation, 2006). The experience of the experts in the given research field impacted positively on refining the tool (Kelly, 2006) and strengthened the validity of the proposed RHIT (Babbie & Mouton, 2001).

The focus group included different categories of experts and for each type of desired expert the inclusion criteria is specified below:

- Experts in the field of health and rehabilitation. They were chosen based on having a minimum of three years of clinical and research experience in health and rehabilitation, community awareness and tool development experience.
- A questionnaire expert was defined as someone who is recognised as an established professional with in-depth knowledge of the essential components of effective questionnaires and questionnaire development (Babbie & Mouton, 2001).
- CHW or RCW needed to have been trained in community health care (Department of Health, 2001) or the Higher Certificate in Disability Practice. Sufficient knowledge and a thorough understanding of disability, disability-related needs as well as contextually how rehabilitation and health needs are met within the community context was required. At least four years of experience was required.
- PWD needed to be 18 years or older to be included in the study. Persons with intellectual disabilities who were able to give informed consent and partake in

the process of the focus group were eligible to be included, however no participant with intellectual disability participated.

Sample Size

The study was exploratory and required relevant expertise and therefore a small sample size was suitable. A total of six experts participated in the focus group. This sample size was appropriate as information-rich participants with detailed experience was desired as opposed to generalisability. This sample size allowed for sufficient data to be obtained (Kelly, 2006). The sample included two PWD, two experts in the field of health and rehabilitation (one had experience in questionnaire development) and two RCWs.

Sampling Method

The participants were selected using nonprobability purposive sampling. The use of purposive sampling allowed for the selection of participants who could have a wealth of knowledge on the topic and provide the researcher with information that was essential to the study (Creswell, 2009). When sampling for participants the aim was to purposefully select participants with expertise in the area of disability and questionnaire development.

Recruitment Methods

When recruiting participants who met the criteria for the study the following steps were taken into account as outlined by Babbie and Mouton (2001):

- An email with a clear explanation of the purpose and research aims of the study was sent to help identify the experts. The email inviting experts to participate in the research was sent to:

  1.University of Cape Town Department of Health and Rehabilitation inviting lecturers to participate,

  2. Department of Health clinicians and RCWs,

  3. The University of Cape Town Disability Unit requesting them to send it to staff or students with disabilities on their mailing list, and to

  4. Non-governmental organisations working with PWD. The nature of the study as well as the inclusion and exclusion criteria were clearly specified.

- The participants who responded first and met the inclusion criteria were selected to participate. After participants had agreed to take part in the research, an invitation was sent outlining the date, time and venue for the focus group. All contact details of the researcher and supervisors, and the head of the ethics committee were included in correspondence with the participants to allow for any questions to be asked and be addressed.
- Information letters were sent to all participants outlining the purpose and expectations of the research (see Appendix 3).
- A telephonic confirmation of attendance was obtained for the focus group. The focus group took place on the 23 July 2015.

Data Collection Methods

To achieve the objectives for the RHIT development in Phase 1 a document review and focus group interviews were used

Document review to generate the content and domains of the RHIT

A detailed review of the current measurement tools used by the RCWs as well as measurement tools in the literature was carried out. The methodological procedure and the tools reviewed are discussed under the section: ***Document review to generate the content and domains of the tool*** further on in the methodology chapter. The document review highlighted areas for inclusion in the RHIT and facilitated the development of the specific questions in the tool (Bryman, 2016). In reviewing the documents, the researcher considered the following aspects:

- The focus of the reviewed tool
- The content of the tool (domains of the tool)
- The structure of the tool
- The wording of the questionnaire items
- Validity and reliability
- What were the gaps / challenges of the current documents used?

These were coded in a template with these aspects (see Appendix 10) and a criteria list (refer to Results in Chapter 4) of what was to be considered for inclusion in the resource tool was drafted. The criteria list indicated the domains, the format of questions, the layout and other desired features that the draft RHIT should consider. The draft tool was generated after document review and analysis.

Focus group interview with experts

The study used a focus group to obtain information about the proposed tool. The focus group interview allowed the experts to review the draft tool and comment on the relevance and applicability of the questions in the tool (Babbie & Mouton, 2001).

The methodology of the focus group interview facilitated exploration and clarification of the participants' views and attitudes, knowledge and feelings, and beliefs and experiences about particular issues. In this study, the aim was to use the experts to review and refine the draft tool and the focus group interview was the preferred method for data collection. The focus group is advantageous as it allowed the researcher to probe for details while keeping conversations from deviating, making sure every participant had an equal chance to speak (Creswell, 2009). The involvement of the RCW and PWD as experts in the development of the resource tool was important as it facilitated ownership of the instrument as these would be the end users of the health needs tool. An added value was the reflection and learning that took place as part of the focus group process which facilitated a deeper understanding of the experts' perspectives and allowed them to reflect more deeply on the potential context and potential use of the RCW health needs resource tool.

Potential disadvantages of using a focus group include domination of interview and that confidentiality and anonymity could be challenging. These issues were managed by asking the experts to agree to confidentiality and by setting up clear group rules at the beginning of the interview and by facilitating the discussion (Babbie & Mouton, 2001; Kelly, 2006).

Another limitation of focus groups is that this method does not allow the findings to be generalised. However, this was not the focus of the qualitative phase of the study but rather to get an in-depth insight into the experts' opinion of the tool. It allowed for the experts to come together to generate meaning among themselves, providing a space for their existing perspectives and different viewpoints (Kelly, 2006).

Procedure

The researcher obtained approval from the Faculty of Health Sciences Human Research Ethics Committee to conduct the study. Participants received a written information letter and consent form which they were required to sign before commencing the study. Participants provided signed informed consent forms (see Appendices 1, 2, 3, 4 and 5)

Figure 5 depicts the process that was used to develop and validate (face and content) in the RHIT.

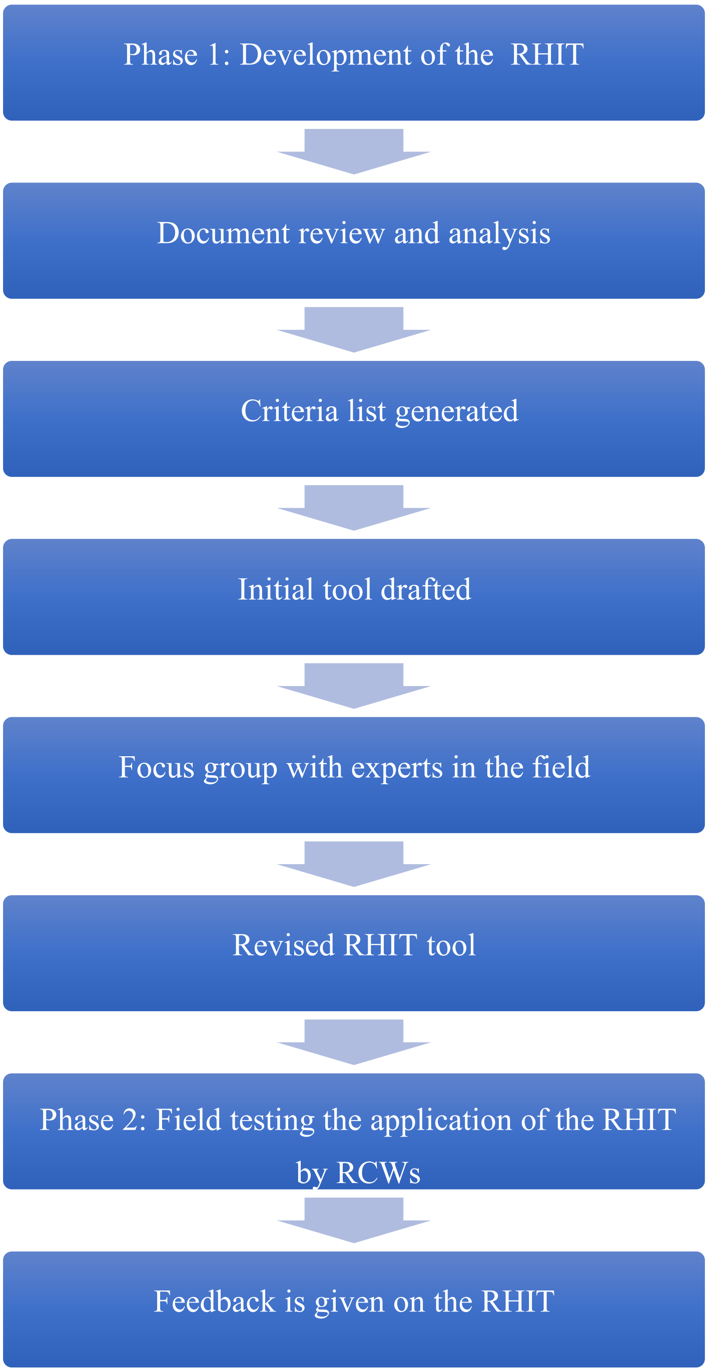

Figure 5: Process for the development and validation of the RHIT

The following procedure was followed when gathering the data needed to establish content and face validity:

Document review to generate the content and domains of the tool

The literature review and the review of various documents and standardised tools was used in the development of the tool. These documents helped develop the draft tool as an initial starting point for the experts to review. The following tools/documents were reviewed; International Classification of Functioning, the WHODAS 2.0 (World Health Organisation, 2000), the Washington group on disability statistics short set, the WHOQOL-BREF (WHOQOL Group, 1998) the RCW screening tool (Disability Studies Programme, 2013), the Wheel of opportunity (Lorenzo, 2016), and participation and the family quality of life conversation guide (Beach Center on Disabilities, 2003). Additionally, the ICF, Community Based Rehabilitation guidelines (World Health Organisation, 2010), the United Nations Convention on Rights of Persons with Disabilities (UNCRPD) (World Health Organisation, 2006), UN 22 standard rules on equalization of opportunities for disabled people (United Nations General Assembly, 1993), as well as the Department of Health National Guideline on Home-Based Care and Community-Based Care (Department of Health, 2001) guided the information that the research instrument would include.

The WHODAS 2.0 and the WHOQOL-BREF both have a scoring system and the WHOQOL-BREF was designed to be administered in a standardised manner. Previous studies conducted on these measurement tools to research their reliability and validity in assessing specific disabilities reported them to be reliable and valid (Cieza et al., 2004; Eide, Jelsma, Loeb, Maart, & Toni, 2008; Garin et al., 2010; Kulnik & Nikoletou, 2014; Trompenaars, Masthoff, Van Heck, Hodiamont, & De Vries, 2005). The ICF and WHODAS 2.0 tools primarily assess the severity of the disability and how the disability impacts on functional ability, thereby assessing what support needs the PWD would require.

The ICF and WHODAS-2 have been shown to be valid, reliable measures of disability and function, and Kostanjsek (2011) reports that the ICF framework and taxonomy is used in the development of disability-related surveys and questionnaires. Therefore a resource tool for the RCW which is developed from this has credibility as it uses an recognised conceptual framework that uses a common language to describe disability and function.

Welman (2001) argues that it is advisable to first look at standardised and validated measures. These instruments were reviewed because they are standardised, validated and reliable instruments used to assess disability (Garin et al., 2010). After reviewing the documents and standardised assessment tools over a period of sessions and in consultation with the research supervisors a criteria list was created to document the elements that the various tools included; as reflected in Chapter 4, the results chapter. The criteria list captured the following elements, namely the focus of the tool, the domains captured, the type of measurement, the reliability and validity, the limitations and the challenges and gaps of the standardised assessments tools as reported in the literature. The data resulting from the document review was summarised and captured in a table (see Appendix 10). All relevant questions that met the criteria were collected to create a pool of questions. The wording of the questions, logical flow of the questionnaire and the structure of the questionnaire were highlighted (Horton, de Lourdes Drachler, Fuller, & de Carvalho Leite, 2008). A draft tool was then generated.

Focus group interviews with experts to validate the content and domains of the draft RHIT tool

One focus group interview with six experts was conducted. The experts were given an information sheet highlighting what the focus group data will be used for and that any form of identification would be removed and pseudonyms would be used in the transcribed data. The experts were asked to agree to keep what was said in the focus group confidential. The issue of confidentiality was raised at both the beginning and the end of the focus group interview.

The session was recorded digitally with the permission of the group members. The focus group interview lasted about 90 minutes and was used to gather data on the draft tool to be used by the RCWs. The purpose and intended use of the tool was explained to the experts. The purpose of the tool was to aid the RCWs in systematically collecting information related to the rehabilitation and health needs of PWD within the home and community setting, that would assist the RCWs in intervention planning and monitoring of their clients. The focus group was given the criteria and domains used for the generation of the draft tool as a reference. The experts were asked to review the tool and were allowed to suggest the modification or rewording of items in the questionnaire. A semi-structured format was used to guide the interview (see Appendix 7) while allowing for flexibility in the process (Kelly, 2006).

Creswell (2009) acknowledges the central role the researcher plays in a focus group and thus it was important for the researcher to be as unbiased as possible in interpretations and description. This was managed by clearly disclosing the researcher's frame of reference and by allowing members of the focus group to ask questions of clarification. Furthermore, the trustworthiness of the data collected was protected by having continuous discussion with research supervisors to facilitate a reflective interpretation of the data collected. The researcher also kept a reflective journal during the process of research to allow for the researcher to be able to reflect back on the process.

The focus group interview did not aim to reach consensus but attempted to explore a range of responses, opinions and perceptions of the research tool. The focus group findings were then analysed to allow for the generation of a revised RHIT which was circulated to the experts who supported this revised version to be tested on a sample of PWD.

The scientific rigour of the study:

Trustworthiness

To ensure quality of the research process in the qualitative phase of the study a trustworthy process needs to be employed. Research that is credible, dependable, transferable and confirmable is considered to be trustworthy (Babbie & Mouton, 2001). These criteria were considered in the following ways for this study:

Credibility

For this study credibility was achieved through member checks, peer debriefing and theoretical triangulation. Focus group interviews were recorded using a digital voice recorder which was managed carefully which improved the trustworthiness. Member checking allowed the participants to comment on the accuracy and interpretation of the research findings. Four of the six experts participated in member checking and reported that the themes had been presented accurately. Peer debriefing involved a senior researcher/ supervisor who reviewed and checked the interpretations of the data. This independent critical review of the research process enhanced the accuracy of the information gathered (Creswell, 2007). Theoretical triangulation involved reviewing the relevant literature which enhanced the credibility of interpretations made in this study (Bryman, 2016).

Transferability

For this study, the researcher provided sufficiently detailed descriptions of the research context as well as the research process. Although generalisability was not an aim of this research study, data was reported precisely and in ample detail, therefore allowing the reader to determine whether the findings could be applied in another similar context (Creswell, 2009).

Dependability

The researcher made use of an audit trail which involved a detailed step-by-step description of the data collection and data analysis process. Additionally, any research notes as well as summaries and emerging themes were included in the audit trail. The audit trail provides evidence for any statements or interpretations made. This facilitated consistency and accuracy in this research (John & Rule, 2011).

Confirmability

The researcher clarified any bias at the onset of the research process to ensure that the researcher's position and assumptions were understood (Creswell, 2009). The audit trail determined whether conclusions and interpretations could be traced to the source. For this study complete transparency and disclosure of the research process and its limitations contributed to ensuring dependability and confirmability (Babbie & Mouton, 2001).

Data analysis

Data management

The focus group interviews were recorded with a digital voice recorder with the permission of the participants. The recording was saved onto a password-protected computer and deleted from the voice recorder and the interview recording was transcribed verbatim for analysis. The researcher also made reflective notes during the interview and information from this was used to aid the analysis of the transcription.

Data analysis

The data analysis method followed a series of steps. Firstly, the researcher immersed herself in the data by re-reading the transcribed data and reflective notes a number of times to gain familiarity with the data. Secondly, the data was analysed using both a deductive and inductive approach. The data was coded and thematically categorised under meaningful headings using the ICF as a framework (deductive) and additional emerging themes emanating from the data were identified and coded (inductive).

These additional themes and categories were compared to the ICF framework to facilitate the development of questions for the RHIT (Creswell et al., 2003). The researcher revised and carefully checked the themes and categories to ensure no valuable information was overlooked. Once this was completed the analysed data from the focus group and the revised RHIT was sent to the experts for member checking, and a meeting was held with available members and the RCWs in September 2015 to check the interpretation of the data. Comments were requested and incorporated into the data and the revised RHIT where indicated.

Rehabilitation and health information tool translation

Once member checking had taken place and the revised RHIT had been validated (face and construct). The RHIT was translated by independent translators into Afrikaans and isiXhosa which are the predominant languages in Mitchells Plain (City of Cape Town, 2006). The forward-backward translation procedure was used in order to achieve a cross-cultural and conceptual equivalent of the English tool (World Health Organisation, 2009). A number of steps were taken in the translation process. These steps are outlined as best practice guidelines by Morso, Albert, Kent, Manniche, & Hill (2011). The translator was conceptually introduced to the aim of the resource tool and the targeted participants. The translator was asked to take notes during the translation process on any items needing clarity or further explanation. The translation process involved translating the resource tool from English into Afrikaans and isiXhosa, thereafter the tool was back-translated from Afrikaans into English and isiXhosa. The contents of the original English resource tool was compared to the back-translated tool and any differences were noted and addressed to reach an equivalent translation. The tool was therefore available in English, Afrikaans and isiXhosa which are the main languages spoken in Mitchells Plain.

Phase 2: Testing the application of the RHIT by rehabilitation care workers on a sample of persons with disabilities

This phase addressed the objective of having the application of the RHIT field tested by the RCW on a sample of PWD.

Participants

Inclusion criteria for phase 2 of the study

The focus of the study was on adults aged 18 years and above. Participants needed to have a disability and have been referred for community- and home-based care (therefore they needed to be on the Western Cape Department of Health district referral database for community- and home-based care). Persons with intellectual disabilities who were able to give informed consent and partake in the RHIT were invited to participate. Participants needed to have been currently receiving home-based care. They needed to reside within the Mitchells Plain/Klipfontein sub-district.

Sample size

Welman (2001) argues that when calculating the sample size one needs to be aware of the general size of the population to be investigated. At the time of data collection, the RCWs provided services to on average 4-5 new clients per month and among the 12 RCWs servicing the community in the Mitchells Plain district there were 60 active clients that they were seeing.

A statistical calculation determined the adequate sample size of 53 for the given study. This was the sample size which was needed to accurately reflect the research population. The calculation was conducted with a confidence level of 95 % and a significance level of 5% and is depicted in Table 3. According to McCrum-Gardner (2010), a calculated sample size should be increased slightly to allow for a reduced response rate. A total of 54 participants signed consent forms and completed the RHIT. The 2 PWD that participated in the development of the RHIT were not included in the pilot of the RHIT as they did not meet the inclusion criteria.

Significance level	5%
Confidence level	95%
Population size	60 (12 RCWs x 5 clients that they see monthly)
Sample size needed	53

Table 3: Statistical calculation to generate the sample size

Sampling method

The participants were selected using non-probability purposive sampling (Babbie & Mouton, 2001). The study is interested in PWD receiving community services including RCW services. All referrals for community- and home-based care on the

Mitchells Plain/ Klipfontein district office database who successfully met the criteria were considered for the study.

Recruitment methods

PWD who met the criteria were recruited for this study. As recommended by (Babbie & Mouton, 2001) the following steps were taken into account when recruiting participants:

- Permission was received from the Western Cape Department of Health to conduct research in the Mitchells Plain/Klipfontein district with clients that receive Department of Health home-based care and community-based services (see Appendix 2).
- A recruitment letter with a clear explanation of the purpose and research aims of the study was sent to the respective Department of Health representatives and the heads of all non-profit organisations that sent RCWs on the Higher Certificate in Disability Practice training. The nature of the study as well as the inclusion and exclusion criteria were clearly specified. The researcher worked closely with non-profit organisations and RCWs and their supervisors to assist in identifying participants who met the inclusion criteria. Additionally, the information sheet contained five questions to assess whether the participant understood the research project and the process and understood his/her rights. The participant was required to answer all questions correctly to be able to take part in the study.
- A confirmation from the client on their willingness to participate was obtained either telephonically or during a visit by RCW. A date and time was set to conduct the RHIT.

Data collection methods

The proposed and revised RHIT that was generated in phase 1 was tested by the RCWs on a sample of PWD. The tool consisted of 16 different content domains, 17 questions (7 closed-ended and 10 open-ended questions). The response categories in the closed-ended questions were allocated predetermined codes which allowed for easier data analysis (Dawson & Trapp, 2004). Demographic information such as age, gender and home language were also requested.

Procedure:

The researcher obtained ethics approval from the Faculty of Health Sciences Human Research Ethics Committee to conduct the study. Permission was then sought from the Western Cape Department of Health representative for the Mitchells Plain community- and home-based care project as well as the involved non-profit organisations.

The researcher received permission to access the community- and home-based care client database and together with the relevant RCWs and supervisors reviewed the participants that successfully met the criteria. An information letter was sent to them to explain the study. Participants signed the written informed consent form and handed this back to the researcher/research assistant on the day the RHIT was conducted.

The participant was assured that all information provided was confidential and that the participant was free to withdraw from the research at any given point without any consequences to the participant (Babbie & Mouton, 2001).

A research assistant who was an RCW assisted in data collection. There were 10 RCWs who assisted in completing the RHIT with their clients. Two of these RCWs were also a part of the expert panel who facilitated the development of the RHIT. These appointed RCW research assistants were trained on the RHIT to better prepare them before the implementation of the tool. They were asked to sign a written agreement acknowledging the required role as a research assistant, and that they are required to act out this role in an ethical manner by upholding confidentiality, autonomy and non-maleficence (Babbie & Mouton, 2001).

The RHIT was administered face to face at the participant's home. The researcher read the questions and recorded the PWD response.

Phase 2: Data analysis

Data coding and cleaning

The written data was captured into an electronic program called Research electronic data capture (Redcap) at the University of Cape Town. This allowed for the data to be easily exported into an excel spreadsheet. The data was then exported into a Statistical Package for Social Sciences and the data set was checked for errors in entry of the data and these errors were corrected without altering the meaning of the given response. The data set was cleaned by the researcher with the assistance of the statistician. Cleaning of the data was a vital step in ensuring valid results of the study (Blanche, Durrheim, & Painter, 2006).

The data was organised and analytically categorised by means of coding. Post-coding was done on the responses to the open-ended questions. The closed- ended questions were analysed using descriptive statistics.

Data analysis

Statistical analysis was conducted using Statistical Package for Social Sciences computer software. Descriptive statistics provided a summary of the data and allowed identification of the most common trends in the sample of PWD. A description of what the rehabilitation and health needs were and who was able to meet these needs was provided. Descriptive analysis such as mean, median and mode, as well as frequency tables were used to describe the sample. Cross tabulations were used to look for patterns in the data. These descriptive measures were sufficient for this study as the qualitative data was prioritised and the data collected did not allow for or warrant the use of more detailed quantitative statistical analysis such as inferential statistical analysis.

Validity and reliability

Content and face validity

The process of document analysis and the focus group interviews with experts addressed the concept of content and face validity as outlined in phase 1 of the study. This process involved assessing whether the given domains and questions in the RHIT completely represented the concept to be studied (Baker, 1999). The researcher analysed each item to identify the possible dimensions each item addressed and to assess whether all aspects of the dimensions had been adequately addressed (Horton et al., 2008). Each of the domains of the proposed RHIT were validated with reference to a valid, reliable and accepted tool. In addition, the domains were compared to the ICF reference framework.

Reliability

The study initially aimed to assess the inter-rater reliability and the internal consistency reliability of the tool using Cronbach Alpha. As the study emerged it became evident that this was not feasible for this stage of the development of the tool. The detailed reasoning is discussed further in Chapter 4: Results and Discussion.

Ethical considerations

Ethical approval was obtained from the Faculty of Health Sciences Human Research Ethics Committee prior to the commencement of the study (see Appendix 1) The present study acted in accordance with the ethical principles outlined in the Declaration of Helsinki (World Medical Assembly, 2013). The following ethical principles were adhered to:

Autonomy and informed consent:

Participation in this study was voluntary. Participants were informed of the requirements of the study, study procedures, commitments and possible advantages. The written information letter and consent form acknowledged that the rights of the participant will be upheld and protected during the study. Participants were also informed of their right to withdraw or refuse participation at any stage of the study (Creswell, 2009). The information sheet contained five questions to review the person's understanding of the research and to assess if he/she understood his/her rights in the research process. The questions were:

Question	Examples of adequate answers given by participants that may demonstrate their understanding of the research.
What is this questionnaire about?	We are going to talk about my health needs and how they are met.
Why did I choose you for this questionnaire?	I was chosen because I have a disability.
Are you taking part in this questionnaire because you want to?	Yes
Are there any bad things about this questionnaire?	No

What do you do if you do not wish to continue with this questionnaire?	I can tell the researcher and ask them to stop.

Confidentiality and privacy:

Participants were informed that all information provided is confidential. Identification information of all participants was replaced with corresponding codes/ pseudonyms once it was no longer needed. Focus group members were asked to agree to keep the focus group interview confidential. All raw data was securely stored and will be destroyed once it is no longer needed.

Non-maleficence:

The present study caused no harm to the participants (Blanche et al., 2006). The subject of rehabilitation and health needs was deemed to be of a sensitive nature therefore participants were offered an optional debriefing session after the administration of the RHIT to discuss any feelings that arose from completing the tool. This debriefing session was also an opportunity to clarify any misconceptions the participant had with regard to the utilisation of the results (De Vos et al., 2011).

Beneficence

According to Blanche et al. (2006), research should aim to be of benefit to the participants or the greater public. The research was conducted in a space that was comfortable for the participant and was sensitive to the participants' needs with regard to the time taken to conduct the survey. This research was not of direct benefit to the participant; however, the research aimed to inform service delivery and may in future therefore improve service delivery as a result.

Justice

The present study upheld the principle of justice by selecting all eligible participants to be included in the study therefore meeting the criteria for fair and equal inclusion of all participants. The results of the research will be published and made available on request, therefore fulfilling the ethical principle of distributive justice (Blanche et al., 2006).

Referral

There was a possibility that in completing the RHIT emotional aspects about the content covered may arise. The research assistants were trained RCWs and were aware of health indicators that require referral for further management and care. Where indicated participants were referred to their nearest health care facility if there was any information identified that required a referral.

Chapter 4: Results and Discussion

This chapter presents the results and discussion of each of the research objectives. The results and discussion of phase one are presented first and then those of phase two.

4.1 Objectives for phase 1: The development of the RHIT

The following were objectives in the development of the RHIT:

- To develop the content and domains of the RHIT
- To establish validity (face, content) of the RHIT

These objectives were achieved through i) Document Review and ii) Focus group interview with experts.

Document review to generate the content and domains of the RHIT

The data resulting from the document review was summarised and captured in the a table (Appendix 10). What emerged from the table was a criteria list that reflected the key elements that were present in the documents reviewed. The criteria list indicated the domains, the format of questions, the layout and other desired features that the draft RHIT should include. The criteria list is captured in Table 4:

Domains	Format of questions & layout	Desired features
• Demographics • Health • Rehabilitation • Support systems • Family Life and personal integrity • Sports and recreation • Accessibility • Religion • Culture • Personal needs • Environmental: physical, psychological; and social • Lifestyle: Nutrtition, exercise, recreation • Personal habits • Sexuality • Activities of daily living	• Questions should be easy to read and understand • Short questions • Related questions to follow each other • Limited professional jargon • Tick boxes or likert Scales	• Quick and easy to administer • Takes into account the skill level of the people using the tool • Collects sufficient information • Economical • Collaborative tool- i.e.Keeping the person with the disability involved throughout

Table 4: Criteria list for the draft RHIT

The draft RHIT

The resultant criteria list in Table 4 was used to compile a draft tool that was informed by standardised tools and embodied content domains and elements that were spread across the reviewed tools. The results reflected that it was essential that the tool included both open- and closed-ended questions. It included the date, demographic information, type of impairment and the date of onset of the impairment. There was a total of 14 questions (nine were closed-ended questions and five were opened-ended questions.) The response method for the closed questions included categorical tick boxes to indicate the response. A content domain was included in the tool because it was common in other tools; and was simple and comparable.

The resultant draft RHIT had the following 12 content domains: overall health, self-care, mobility, communication, relationships, sexual health, general tasks, access to health information, health behaviours, health safety and security, spirituality, and other. For the nine closed-ended questions there were four sub-questions related to each domain: i) Do you have a need? ii) Is your need being met? iii) Who is meeting your need? iv) What is being done to meet your need? Each of these sub-questions had categorical tick boxes to indicate the response. (Refer to the draft tool in Appendix 8). This draft RHIT provided a starting point for the experts to review and critique.

Focus group interview with experts to establish the content and face validity of the draft RHIT

The majority of the experts expressed that the tool was understandable and could be tailored for use by the RCWs. The experts envisioned that the purpose of the tool could be for intervention planning and monitoring and could support the RCW in their daily practice. The data resulting from the focus groups was analysed using both a deductive and inductive approach (as described in Chapter 3) where key themes were matched against the ICF as a theoretical framework. The key themes that emerged were related to: 1) The content of the tool; and 2) the process of using the tool. Figure 6 provides a summary of the themes identified.

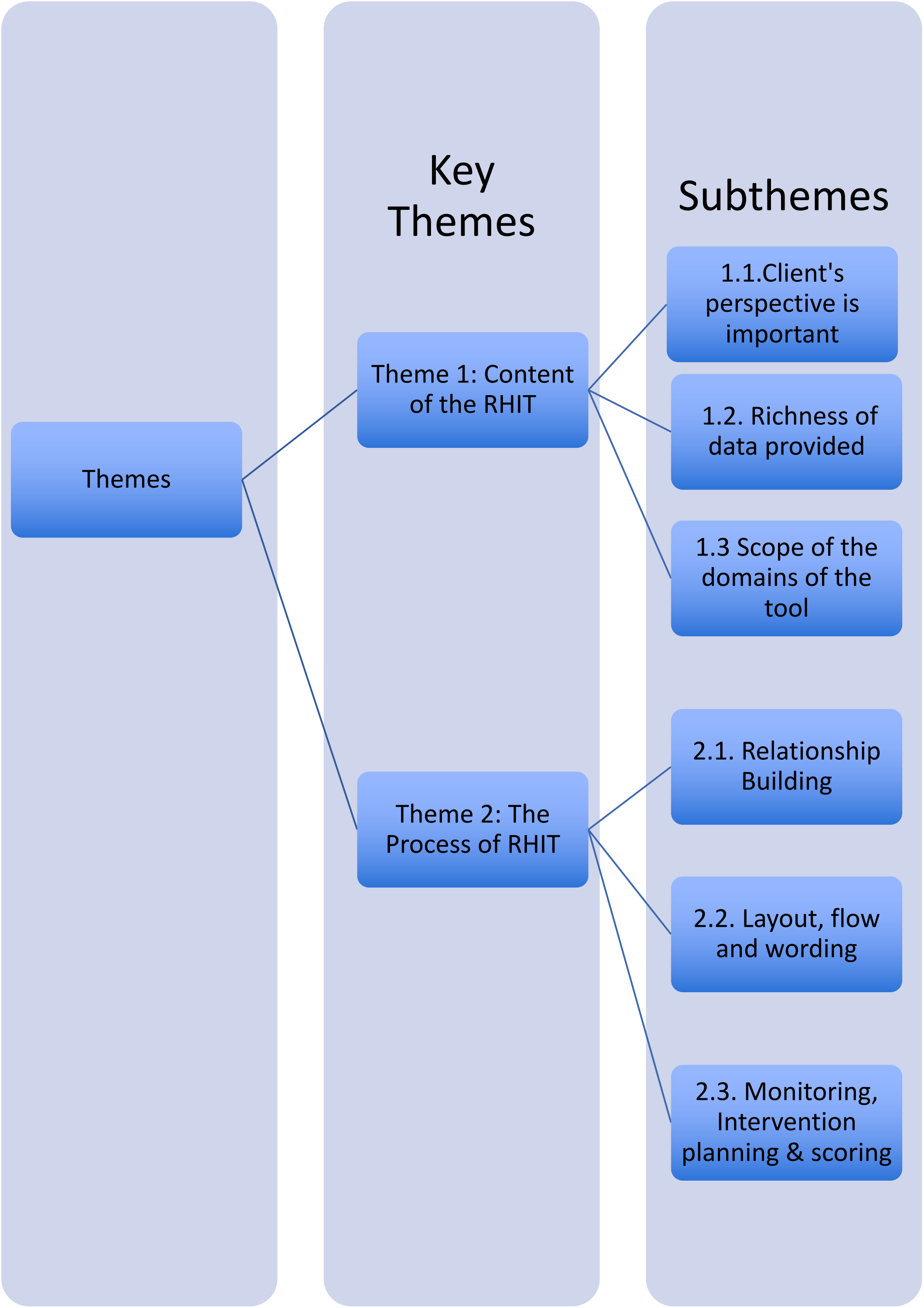

Figure 6: Themes of Focus group interview with the experts

The Client's perspective is important.

The data reflected that creating a resource tool that was client-centred was important to all. The experts reported that there was a need to have the tool reflect the perspective of the client. The experts highlighted that the tool needed to reflect the subjective perspective of the RCW's clients and together with the objective observations of the RCWs this would provide valuable information to inform the management of the client. This is highlighted in the quote below:

> we want the subjective view of the person with disabilities to help us with developing intervention programme. Then if the client feels that they are fair and are okay with self-care even though to me you look like you are going to need self-care now, then if that's your subjective opinion. In most homes that we go to, sometimes the family does support but the client will still say they want to learn how to do it on their own. Even though the need might be met, it doesn't necessarily mean that it shouldn't be addressed. Because he might just say yes all my needs are met because my daughter helps me but that doesn't necessarily say he doesn't need rehabilitation" (Focus group, participant 4).

A concern was raised about the ability of the tool to reflect the perspective of clients with mental illness as well as intellectual disabilities.

"what about that patient who is mentally ill? Who is not able to respond to questions? Do we have a proxy questionnaire? Whereas we could ask the caregiver for responses, that sort of thing?" (Focus group, participant 4).

A few participants reported their experience was that the client and their family had limited understanding of the impairment and disability. Therefore, they suggested that there was a need to know what the client and their family understood about the disability because this could inform intervention planning.

"I would like to see a question there that says do you have knowledge about your disability" (Focus group, participant 2).

Richness of data provided

Participants reported a desire for the tool to provide a rich quality of data that could be used to inform intervention and for monitoring the client.

"I was thinking maybe another column, a space to specify the need that there might be because sometimes it might not be entirely dressing but maybe putting on my socks or tie my laces but with the rest of my extremities I'm independent with that. So maybe some room at the bottom of self-care I don't know whoever is administering this maybe circles the areas of washing, dressing, feeding and adding extra areas" (Focus group, participant 4).

Scope of the domains of the RHIT (ICF framework)

The ICF framework was used to analyse the scope of the domains of the tool. The pertinence of the domains of the tool was discussed and many of the participants reported it to be relevant and useable for the community context. The subthemes that emerged were: a) relevance of the domains, b) focus of the tool, c) comprehensive tool, and d) desired changes.

Relevance of the domains

The domains that were selected were present in reviewed standardised tools and were simple and viewed to be able to integrate different dimensions of rehabilitation and health needs. The experts agreed that the domains were relevant and comparable to standardised tools. The context of SA being a third world country with many inequalities still evident was highlighted as a consideration needed when comparing the tool to the standardised tools from first world countries

> I like question 12 as well I'm just thinking of our seniors in our community about experiencing abuse and neglect and also the safety and security could speak and the gang violence and all that. Violated (Focus group, participant 5)
>
> Have you looked at the Norwegian research? 'They've got a really good community health assessment and a community health plan and it would be useful to see. For me it was efficient. It was very focused but on the other hand the problem or the challenge that you have between the two countries is that first world and third world they are able to direct questions because there are not five answers to that question. In some of our things you have five answers in a question (Focus group, participant 2).

Focus of the tool

Participants reported that the tool should be succinct and focused as it could fit for a screening and monitoring tool that is used as part of the client-centred journey towards health.

Comprehensive tool

Some of the participants had some exposure to working with tools that measure or assess some level of function or need and based their comments on their experience with these other tools. They argued that there was a need for a comprehensive tool that would further support the RCW in client-centred health care.

“from a therapist perspective working with the RCW. The less forms, the less admin, the better. So if this is a tool that can be integrated and aligned ” (Focus group, participant 4)

> and even there is a strong link between 6 and 7, because you will see the overlap. It would be interesting to see if they are saying yes, there is some need and it would be a similar response in question 7 as well. Because often we see that there is dissatisfaction in the sexual health area it ripples over into the interpersonal relationships as well. So it really would be nice if we see the correlation between those two responses whether it’s linked (Focus group, participant 4).

Desired questions

Participants proposed some changes and additions to the proposed questionnaire items to make it more relevant. An important consideration is the potential usefulness of the information gathered by the tool when used within the health system.

“accessing health information where is this choice when it comes to access to health facility?/ community health facilities. I think that’s a very important question. “

> There’s a huge influence, different influence when you can move inside your house but then there’s another category. Do you have a need to get into your house? I mean that’s one thing we are faced with a lot of times. Its ok when you are inside your home you can move around but then when you are inside those people can’t go in or out their homes, never mind moving inside or outside, so there’s three categories we can get there with my mobility at home (Focus group, participant 2).
>
> Ya I think mobility is a very important thing,. I just think that those are three totally different concepts of mobility because there’s community mobility as well but you don’t want to say its community mobility, you want to assist the person’s situation. (Focus group, participant 3).

Participants expressed the need to include an item related to finance and the impact on health and rehabilitation needs given the context of poverty and disability in South Africa.

> I’m just thinking of the younger person with disability seeking vocational rehabilitation or open labour market. That could be another question maybe to explore. Given insight to the household situation because that is one of the major social stresses in our homes, with regard to finances…. 20 people living off a disability grant, that sort of thing. (Focus group, participant 4).

“You touched a very important point there, which I think is also a measurement of finance and that is what do the people eat?” (Focus group, participant 2).

Sexual health and sexual education was reported to be of importance and needed to be included in a sensitive but direct manner. Some participants reported that even though sexual health was important to include it might be difficult for the RCW to ask the client and for the client to report honestly on this topic.

> Sexual health; a lot of them in the community ask for advice around sex and you have to give them sex tips. The husband will look around and the lady doesn’t know but if she knows she can still have sex with the husband. Educate both of them. And it’s working wonders (Focus group, participant 6).

“It's an uncomfortable question. For some it's easier but for some people are shy. I know a lot of people that don't like to talk about that so how are we going to ask that question?” (Focus group, participant 6)

> I think we need to have a more direct question. I think we need to have something like an open question but then say – do you need help getting information about how to be healthy and stay healthy and put a few categories too. Those few things are risk factors like TB, HIV/ AIDS, STI’s, CDL. It depends on what are your risk factors in the Western Cape and then log that under there. Give a space where they can tick in.(Focus group, participant 2).

A few participants expressed that the question item on living arrangements needed to be refined to be more representative of the types of housing in South Africa. Having this specified was reported to collect more meaningful data. This information should be handled sensitively but has a direct impact on rehabilitation such as they type of assistive devices issued need to be tailored for the home context. As reflected in the quote below:

"And the same with living arrangements…rural and urban it actually doesn't give you much, or you would like to know whether they live in a shack or they live in a house. Or maybe do you have your own house or not." (Focus group, participant 2).

Theme 2: The process of using the RHIT

The participants gave feedback on the usability of the tool. For the use of the tool the following sub-themes emerged: 2.1.) Relationship building and 2.2) layout, flow and wording 2.3) monitoring, intervention planning and scoring. Each sub-theme will be discussed below.

Relationship building

In order for the RHIT to be effective in collecting rich quality client-centred data the participants reported that there is a need that during the administration of the tool trust is established. Participants reported the establishment of rapport and trust to be of utmost importance for questions that address sensitive subjects such as sexuality and abuse. This relationship building would facilitate successful intervention. The quote below highlights a discussion around sexual health and wellbeing:

"How honest do you think they will answer that?" (Focus group, participant 5).

> "Give your input and guide them and explain to them. you bring them books, if they can't read then you read it to them, go step by step. There is definitely a need for that. The first time they see you, they look at you, then they will pick up that they can trust you and then they will come with sexual stories and then from there you build a relationship, then they will feel free. They need to trust you and not hear from people. That's when they will open up and then you step in and educate them on that. (Focus group, participant 1).

Participants reported that the tool could have the potential to be far reaching and help the client to develop agency . The questions as well as the flow of the tool could facilitate a process of identifying healthy behavioural attributes that could be enhanced and unhealthy behaviours that needed to be diminished, these behaviours could have a direct impact on the impairment and associated disability. The tool also allowed for clients to specify goals in these areas.

“What I like about this is that it takes the clients through a journey and it’s helping them to identify their good healthy behaviours and as well as those that could negatively impact on their behaviour” (Focus group, participant 4)

Layout, flow and wording

Participants reported the need for the tool to be user-friendly and fit for the purpose of use by community level workers within the multidisciplinary team. Many participants described clearly what they would like to see in the layout and flow of the tool. Comments addressed issues such as the font size, amount of spacing, the order of the questions and the simplicity of use. This is depicted in the comments below:

'Make sure that there is enough space to write because there is nothing more irritating than filling in if you don’t have enough space to write the address, if you write the place of residence like Khayelitsha, Site C etc.” (Focus group, participant 2).

Participants highlighted that the tool needs to be simple and easy to administer.

“this for the CHWs to complete then I think it should be as simple as possible.” (Focus group, participant 5).

“there is space between RCWs/ therapists so maybe change the font size so that there is space between the box cause when you are doing a screening it’s much easier to go through it as well.”(Focus group, participant 4).

Flow

> So like question 11, I know that you said you left that open ended, so do you have any behaviours that could impact on your health positively and negatively? So that sort of reiterates what is said in question 10 and it helps jog their memory and the mind-set in a particular way and then in 11 maybe they can expand on that little bit more. (Focus group, participant 4).

Wording

A few participants made direct comments on how the questions should be worded to allow for clearer understanding and less ambiguity. The comments also addressed issues related to literacy and how to adapt the tool so that it is easy to read.

“I wouldn’t say diet, I would say eating habits.” (Focus group, participant 5).

“People get confused, especially when they struggle with reading…. We’ve done all those questionnaires and it makes a difference not to have to write too much or to read too much.” (Focus group, participant 2).

“so when we look at this tool we must look on their level how they would understand it.” (Focus group, participant 5).

Monitoring, intervention planning and scoring system

All the participants expressed the need for a simple resource tool that incorporated aspects that were pertinent when screening for rehabilitation and health needs. It would be used as a continuous form of assessment as well as monitoring the progress of intervention. Many participants reported that having no scoring system may be better for the RCW as it was simpler than other tools such as the WHODAS.

> The less forms, the less admin, the better. So if this is a tool that can be integrated and aligned then I would rather use something that’s more comprehensive and integrated and then I know I can use one tool that can be for screening, for measuring, monitoring, evaluating and all of that (Focus group, participant 4).

> so we would want to evaluate like say initial assessment and then 6 weeks then say 12 weeks. And obviously the biggest thing for me is if you look at question 1 the self-rating of the client’s perception of their own health so if when we initially got them to tell us how they feel about their health compared to 6 weeks later we could look at that as well. (Focus group, participant 4).

> Because I know in other tools they put scores in it, so like usually when we use WHODAS we want to see the score go higher because that shows that the patient is improving. So with this particular tool you want ticks in all the no column and not necessarily put scoring to it (Focus group, participant 4)

Revised RHIT tool after focus group with the experts

Throughout the focus group the experts shaped the tool in a manner that they thought would best suit the purpose for the tool. The purpose of the tool was also refined during the process. The envisioned purpose of the tool as shaped during the focus group is reflected in figure 7:

Figure 7: The re-imagined purpose of the RHIT as defined by the focus group interview.

The focus group with experts provided input that resulted in a revised RHIT that changed in three main ways. One is referenced to the socio- demographic information; another to the rehabilitation and health needs additional questions/ domains that were included and the third is revisions to the wording and structure of the tool.

Firstly, the socio-demographic questions were refined, so in addition to name, age, gender and contact details, context specific information is gathered on living arrangements (i.e. alone, with family members, with friends); type of housing (i.e. shack/informal housing, house or flat) and a description of the living environment. Secondly, in reference to the rehabilitation and health needs questions the revised tool changed to have a total of 17 questions (seven were closed-ended questions and ten were-opened ended questions). Additional domains were added such as understanding disability, health services accessed, finance and barriers and facilitators.

Thirdly, the wording of questions were refined to make it easier to read and to consider the literacy of the RCW and their clients. The layout and font was refined and additional columns were added to include the client's specific goal and evaluator's general observations. A summary table was included at the end of the tool to be used as part of the monitoring aspect of the tool. The table included a summary of the client's goals and evaluator's observations that could be captured over four visits to the client (initial visit, first and second and further follow-up visits). The revised tool is in Appendix 9. Table 4 captures a summary of the changes between the initial draft tool and the revised RHIT tool.

The systematic process taken to arrive at the revised RHIT enhanced the face and content validity of the tool. This is addressed in greater detail in the discussion of phase 1 results.

Table 5: Summary of the changes between the draft and revised RHIT

	Initial draft RHIT	Revised RHIT
Domains	12 content domains including the domain other: Overall Health Self-care Mobility Communication Relationships Sexual health General tasks Access to health information Health behaviours Health safety and security Spirituality Other	16 content domains Additional domains added to the initial draft included: Understanding disability Health services accessed Finance Barriers and facilitators.
Questions	14 questions 9 closed ended questions 5 open-ended questions	17 Questions 7 closed ended questions 10 opened ended questions
Changes	N/A	Changes were made to:

		Layout and flow Wording Socio-demographic questions made more context specific Client's goals & evaluator's observations were included Summary table included at the end for monitoring purposes

Discussion of phase 1: The development of the RHIT

The purpose of phase 1 of the study was to develop a RHIT to be used by the RCW that could support the RCW and allowed for a systematic manner in which the key dimensions for exploring the rehabilitation and health needs of PWD who are in a home- community-based setting. The discussion for this phase will address the methodological factors outlined in the literature that informed the development of the tool and the results of the focus group with the experts, which included the RCW and PWD who are the end user of the tool.

The development and testing of the tool involved multiple methods that enhanced its credibility. Triangulation of the data from the document review and the focus group with experts allowed for a more comprehensive and deeper understanding of the purpose of the tool and enhanced the validity of the tool (Klein & Olbrecht, 2011). The document review provided a conceptual basis to generate a draft of the content and the questions that the tool would include.

The literature reflects that the ICF conceptual framework has been implemented in numerous ways including use in health and disability data collection in surveys; and in the development of disability related question sets. The use of the ICF in assessing health and rehabilitation needs and outcomes of interventions is evident in the WHODAS 2.0 (Kostanjsek, 2011). Madden et al. (2014), conducted a study to review the relevance of the ICF in the monitoring and evaluation of CBR. These authors highlight that although CBR guidelines mention the importance of measuring outcomes there has been no common method, approach, tools or standards suggested for monitoring and evaluation. Madden et al., (2014) argue that improved monitoring and evaluation measures will facilitate the efficiency and effectiveness of CBR programmes as well as enhance the evidence base for CBR. The findings of this study suggested that the ICF was a relevant framework for the documenting, monitoring and evaluation of rehabilitation and health needs by the RCW. Approximately one third of the literature examined in the study could be coded against the ICF domains and categories. Madden et al., (2014) argue that the ICF framework provides a common language to capture data on functioning and disability; is reflective of the complex nature of CBR and could be applicable across various cultures and CBR programmes. Therefore, the ICF framework could be used as an approach to systematically capture information and build an evidence base for the outcomes of community-based rehabilitation. The limitations of the study is related to the criteria used for the literature selected which included only literature in English and if literature in other languages was used it could alter the findings of the study.

The developed draft RHIT is grounded in the ICF framework and it recognises that the health and rehabilitation needs of PWDs will be influenced by the interaction with the environment. Therefore, the needs will vary depending on the barriers and facilitators that interact with the person's impairment. This conceptual framework allows for this proposed tool to acknowledge that the needs of PWDs are multidimensional and are to be viewed within the context that the individual is found within. Thus in using the ICF as a conceptual framework it enriches the quality and facilitates a more comprehensive picture of the client's rehabilitation and health needs and the management of these needs. In addition to the strengths of using the common language of the ICF the tool is designed together with the RCW and for the RCW.

The principal approach for developing the RHIT was to include the participation of experts in the field. The focus group interview with experts comprised of people with disabilities, RCW and other experts. The integral participation and involvement of the experts in identifying the content domains and in evaluating the tool strengthens the content validity of the tool. The experts helped shape the essence of the tool as they are intimately aware of the context in which this tool will be used and therefore have a unique advantage to understand the social and community determinants of health. This methodology allowed for the RHIT to have items that make it more suitable and specific to the interests of the end user. The methodology of using experts as part of a tool/ measurement development process has been documented in the literature to be effective and enhance the validity of the tool (Kelly,2006).

Calheiros, Lopes, and Patrício (2011) developed and validated a Residential care Youth needs assessment instrument (RCYNA) and included the youth as participants to shape the instrument. Calheiros et al. (2011) reported using the youth in the process allowed the instrument to have greater specificity and made it more suitable to the target audience and the specific context. Whiteneck et al., (2004) also used experts as part of their methodology in the development of the CHIEF an instrument to assess the environmental barriers experienced by PWD and those without disabilities. To strengthen the content validity of the CHIEF PWD, clinicians and researchers were central to identifying the environmental elements to include and in the evaluation of the instrument. The literature supports the findings of these two studies, that the use of and consultation with experts in the field of interest contributes to a robust methodology and enhances the validity of a developed tool (Hennike, Myers, Realon, & Thompson, 2006; Horton et al., 2008; Milne, Aranda, Jefford, & Schofield, 2013).

Taking into account the aforementioned literature on expert participation and consultation in tool development, it was noted that with the existence of other standardised tools that could gauge rehabilitation and health needs, none were specifically designed for and with the RCW working in the home and the community; therefore those tools do not consider the practice of the RCW and the particular aspects of health needs that were highlighted to be of great importance for the RCW such as finance and sexuality and the impact it has on health. In the development of the tool the experts highlighted the importance of including sexual health as a domain. This is in accordance with what Article 23 and 25 of the UNCRPD highlight around the rights of PWD to marry and have access to sexual and reproductive health care. This type of RHIT provides an opportunity to facilitate the empowerment of the client and to move away from the deficit approach of identifying rehabilitation and health needs.

The role of the RCW in shaping the vision for the resource tool

The involvement of the end users (RCW and PWD) has been an extremely valuable process. According to Chappell & Johannsmeier (2009), there is a complex interaction between intervention and the impact that rehabilitation workers have on PWD and their families. The impact that the RCWs have is evident beyond the interventions they deliver but also importantly in the social aspects, such as building relationships. Therefore “it is not just the WHAT of rehabilitation but the HOW that’s important”(Chappell & Johannsmeier, 2009).

The RCWs were pivotal in allowing the focus group to understand that this RHIT would work towards strengthening their practice, specifically their relational practice. Their vision for the RHIT was for it to allow them to have a structured form of information gathering on topics that are taboo and sensitive. RCWs would be able to facilitate an understanding of the real needs of PWD in the community as opposed to the health professionals' clinical or academic opinion of the rehabilitation and health needs (Lorenzo et al., 2014). In strengthening their relational practice this motivates and encourages the PWD to address their challenges and work towards their goals. The PWD enhanced hope and self-satisfaction and their perceptions of improved relationships with others, as a result of RCWs, are important in reflecting the value that the RCWs bring (Chappell & Johannsmeier, 2009). RCWs can be seen as catalysts for change because their socio-cultural context-specific knowledge of their community allows them to build partnerships and networks that facilitate change across many domains for PWD. Additionally, they can empower their clients to identify their needs and the underlying causes of the experienced health challenges so that they are able to work together to help PWD determine and implement solutions to these challenges. (Lorenzo et al., 2014).

In summary the results of phase 1 reinforces the importance of the collaborative approach in the design of the RHIT which contributed to a contextually relevant tool with properties that were desirable for the end user (RCW and PWD). The triangulation of data from the literature and focus group strengthened the methodology and the face and content validity of the tool. Therefore, in summary the results of phase one were achieved in relation to the objectives and a RHIT that displayed face and content validity was developed. The first phase was necessary to develop the RHIT and the next step in the sequential design was to test the application of the RHIT by the RCW on a sample of PWD.

4.2 Phase 2: Field Testing the application of the RHIT by the RCWs on a sample of persons with disabilities

The RHIT was developed to support the RCW to document information about rehabilitation and health needs of PWD. The final objective of the study was to test the application of the RHIT by the RCWs on a sample of PWD. This in itself is a pilot of the RHIT to inform its further development. The field-testing generated both quantitative and qualitative results and these will be discussed separately.

Quantifiable results

A description of the sample and the results of the field-testing of the RHIT are presented below.

Demographic characteristics

A total of 54 PWD completed the RHIT of which all 54 PWD returned and completed the informed consent. The participants were known to the RCW and had received care from them before. There were 26 males (48.1 percent) and 28 (51.9 percent) females. The mean age of the participants was 64 years old (Std. dev. 12.6).

All participants were clients seen by the RCWs and were from the Mitchells Plain sub-district (see Figure 8 for a breakdown of the areas that participants were from. There were three missing responses for the specific area in Mitchells Plain).

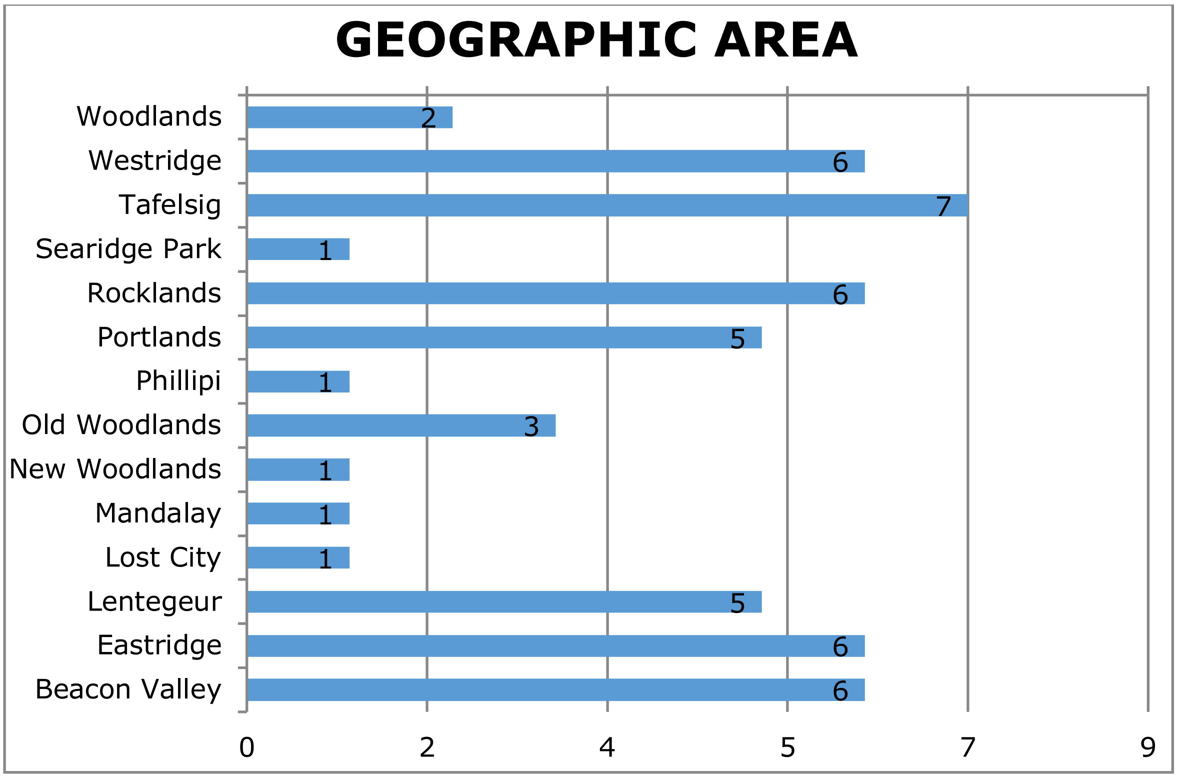

Figure 8: Residential areas of 54 participants (PWD)

Language

English (n=29) and Afrikaans (n=33) were the main languages for the participants with (n=20) reporting both English and Afrikaans and there were 12 missing responses.

Housing and Living arrangement

53 participants reported living with family members (98.1%) and one participant lived alone (1.9%). Participants reported to living in the following types of housing: 2 (3.7%) participants lived in informal dwellings, 17 (31.5%) lived in a flat and 34 (63%) lived in a house. There was one missing response.

Education

A total of 42 participants gave an indication of their highest level of education. Of these participants, 40.5% completed some level of primary schooling (grade 1-7) only and 59.5% completed some level of secondary schooling (grade 8-12). A total of 12 participants' highest education level is unknown for reasons such as being unsure or having forgotten and missing values. No participant reported tertiary education.

Marital status

A total of 50 participants reported on their marital status. 7.4% were single, 46.3% married, 31.5% widowed and 7.4 % divorced.

Employment

Most of the participants (35%) were unemployed, 31% were pensioners and 22% received some form of grant. 3.7% indicated self-employment and 1.9% indicated employed.

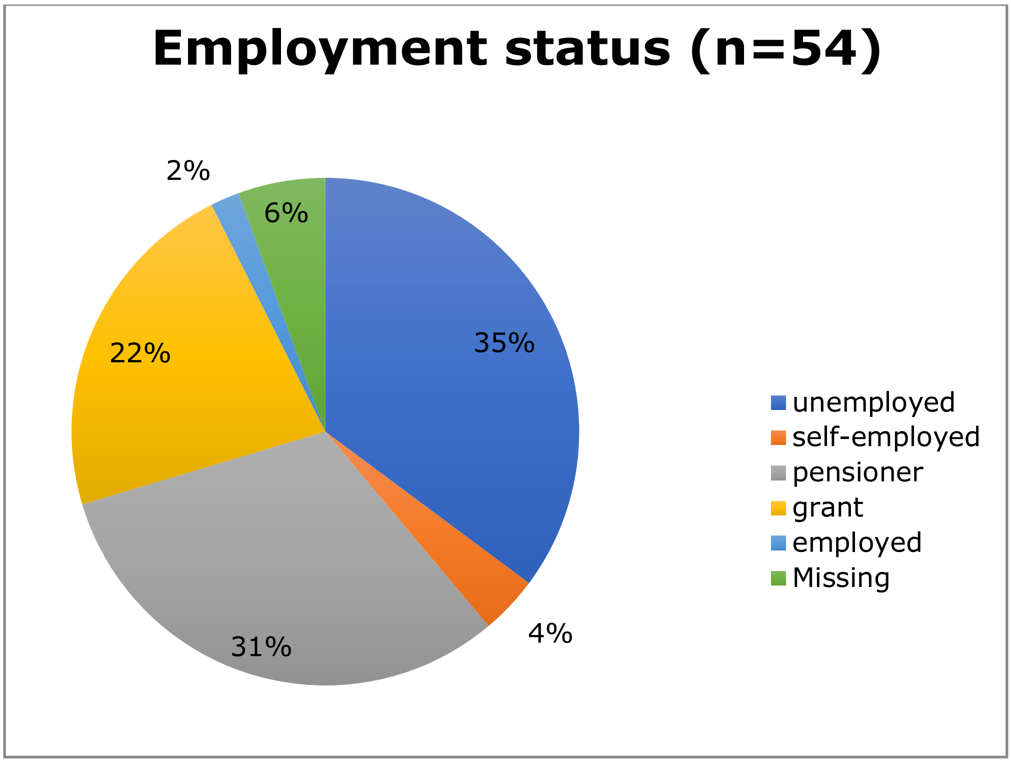

Figure 9: Employment status of participants

Participants' diagnoses

The participants reported a variety of diagnoses with the top four being: Cerebral Vascular Attack (CVA) (n=34), chronic medical condition (n=26), high blood pressure (n=25) and Diabetes Mellitus (n=11). Majority of the participants reported to having more than one diagnosis. 38.9% of patients reported 2 diagnoses, 14.8 % reported 3 diagnoses, 18.5% reported 4 diagnoses and 7.4% reported 5 diagnoses.

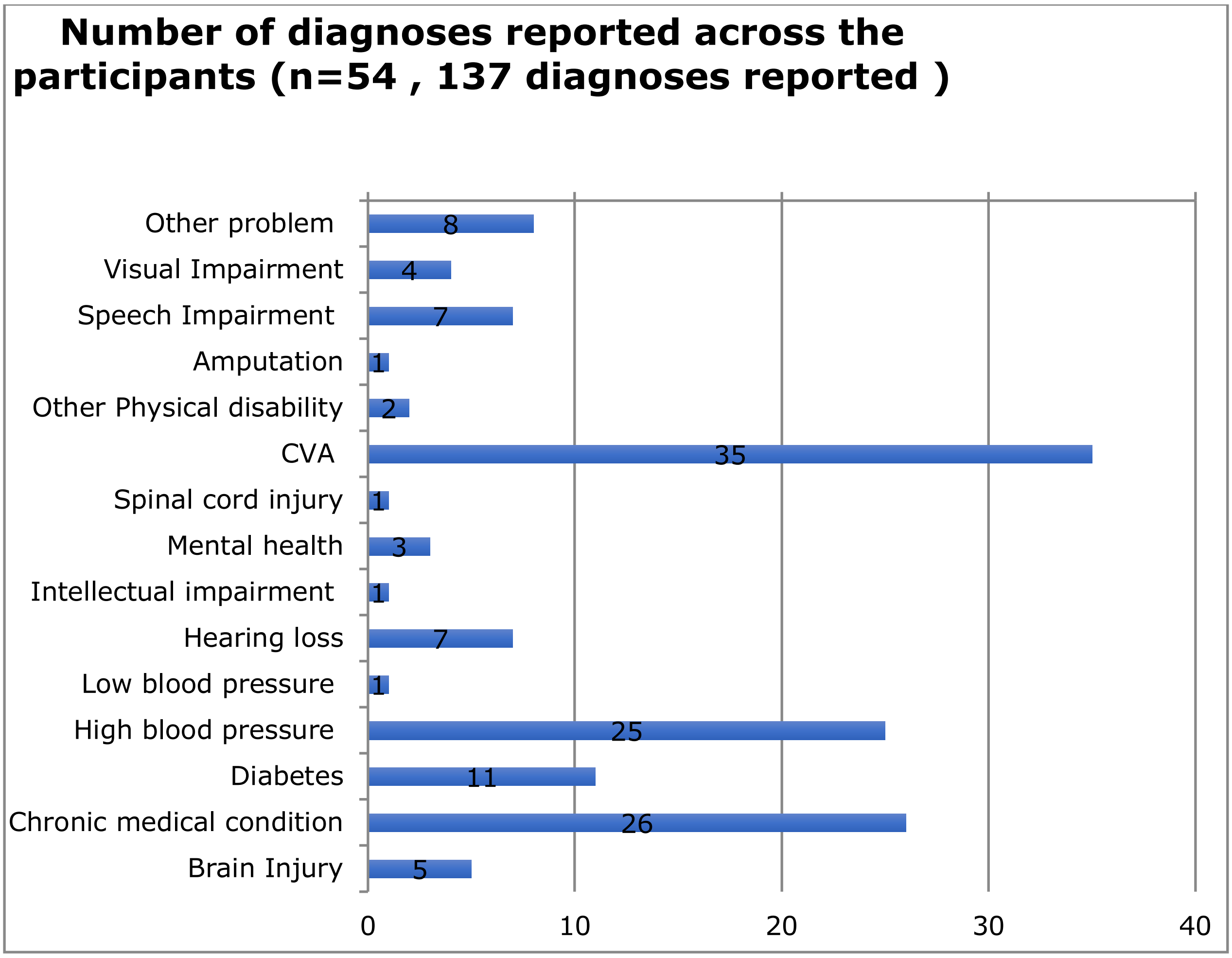

Figure 10: Diagnoses reported by participants

Understanding diagnosis and related disability

Participants gave qualitative feedback on whether they understand their disability, which was then classified into three categories (yes they understood, No they did not understand and yes they had some understanding). A total of 47 participants provided feedback on this of which 27 participants reported that they understood their diagnoses and related disability, 13 participants reflected some basic understanding of their diagnosis and disability and seven participants indicated no understanding. There were seven missing responses.

Needs of participants

Participants had to respond to the following in relation to their needs:

Do you have a need? b) Is your need being met? c) who is meeting your need? d) what is being done to meet your need (i.e. how is your need being met) e) Client specific goals related to this specified need.

The results are reflected below:

Table 5 summarises the reported needs across the six domains namely; self-care, movement, communication, interpersonal relationships, sexual health and general tasks. Sexual health was an area with the majority of participants (87.2%) reporting no need.

Table 6: Summary table of needs across 6 domains

	NO NEED		SOME NEED		A GREAT NEED		Total
	Count	%	Count	%	Count	%	Count
Self-Care	11	20.8%	21	39.6%	21	39.6%	53
Movement	4	7.4%	24	44.4%	26	48.1%	54
Communication	34	65.4%	8	15.4%	10	19.2%	52
Interpersonal relationships	36	66.7%	8	14.8%	10	18.5%	54
Sexual health	41	87.2%	5	10.6%	1	2.1%	47
General Tasks	12	24.0%	16	32.0%	22	44.0%	50

Great Need

The participants reported a variety of needs. The results reflected that movement was a significant need (n=26) whereas sexual health (n=1) was not significant for this sample of participants. It was interesting to note that in the development of the resource tool the experts had reflected that sexual health was a major concern but this was not evident in the results.

The area where the most number of participants reported a great need was movement (n=26), followed by general tasks (n=22) and self-care (n=21). For communication and interpersonal needs, 10 participants reported this as an area of great need. One participant reported sexual health as an area of great need.

As depicted in Table 6 movement had the highest need. It was interesting to note that for the domains of movement, Self-care and general tasks the needs were mostly met by family members. Whereas for the domains of Communication and Sexual health education these were met by rehabilitation services. Across all domains faith based organisations were cited as one of the top 3 per domain for having met rehabilitation and health needs of the participants. It was interesting to note that a very low proportion of participants indicated that they met their own needs related to self-care (n=8). Table 7 reflects the domains of need and the top 3 categories of who met the need.

Table 7: Need and who is meeting the need

Domains	Need (some & great)	Need met (mostly met & met a little) (%)	Who met the need (top 3 reported)
Self-Care	N=42	75.9%	1)Family members (n=45), 2) Rehabilitation services (n=41) 3) Faith based organisations (n=17)
Movement	N=50	85.2%	1)Family members (n=41), 2) Rehabilitation services (n=37) 3) Faith based organisations (n=15).
Communication	N=18	38.9%	1) Rehabilitation services (n=17) 2)Family members (n=12) 3) Faith based organisations (n=6)
Interpersonal relationships	N=18	31.5%	1)Family members (n=19) 2) Rehabilitation services (n=12) 3) Faith based organisations. (n=9)
Sexual Health	N=6	29.6%	1) Rehabilitation services (n=5) 2) Family members (n=4).

			3)Faith based organisations (n=3)
General tasks	N=38	61.1%	1)Family members (n=28) 2) Rehabilitation services (n=18) 3) Faith based organisations (n=7).

Qualitative results as derived from the open-ended questions

Open-ended questions

The following domains were open-ended questions: access to health information, habits, health safety and security, spirituality, finance, barriers and facilitators to health, and other. These questions yielded qualitative data, which will be discussed below.

Access to health information

In this domain 19 participants indicated that they had need for health information on how to be healthy and stay healthy. Additionally, 17 participants indicated they had a need for health information on chronic diseases of lifestyle, 13 participants had a need for information on substance abuse and 10 participants had a need for health information on infectious diseases.

Habits

Participants expressed that habits such as eating healthy, exercising, drinking water, socialising and stopping substance abuse were habits that have affected their health in a positive way. This is reflected in the quote below:

“By eating healthy and drink lots of water and taking my medication at the right time”(RHIT, participant 12)

Participants expressed that habits such as substance abuse (smoking and excessive alcohol use), unhealthy eating and incorrect use of medication were habits that affected their health in a negative way.

Health Safety and security

In response to the following questions: Have you been abused? Do you feel unsafe? Would you like to talk about it? Majority of the participants (n=36) indicated that they have not been abused and do not feel unsafe. A few (n=11) participants indicated feeling unsafe and the reasons cited were related to unstable relationships, gang-related violence in the community, substance abuse by family members as reflected in the quotes below.

“Yes my other children are on drugs and my house is not buggie friendly it is also very unsafe due to gun shots in the area”(RHIT, participant 37)

“A lot of gangsterism in her area, her son is involved and she is very scared of him, both sons are drug addicts” (RHIT, participant 25)

Spirituality

All participants that completed this question indicated that spiritual beliefs and practices contributed positively towards their health and wellbeing. Participants expressed the significant role of support given by members of their faith-based organisations. Participants also expressed the emotional wellbeing and strength that praying and going to church provided. This is supported by the quantitative findings with faith-based organisations being in the top 3 categories of who met the need. These aspects are reflected in the quotes below:

“It helps me a lot, it uplifts me through my circumstances, emotional and physical wellbeing” (RHIT, participant 48)

“I get hope and motivation every time I pray and when I have been to church”(RHIT, participant 13)

Finance

Participants expressed that through the support of children and family their financial needs are met. Children worked to support the financial needs related to costs of daily living. This is expressed in the following quote below:

“My family brings money and food for us.”(RHIT, participant 4)

For participants that only received some form of financial grant such as a disability grant or pension funds, although grateful for the grant many expressed that the finances were not enough to meet their costs of daily living. Participants expressed that the grant is sometimes the only source of income within the household and this could not meet all the needs of the household, which in return impacted negatively on their health. For example, some participants expressed that they did not have enough money for the transport costs for hospital visits and the costs of adult diapers.

“I get my disability grant, it is not enough since I have children and no one is working in the house.” (RHIT, participant 19)

“he gets a disability grant but can't cope because he uses a lot of kimmbies (diapers)” (RHIT, participant 49)

Barriers and facilitators to health

Participants expressed a range of barriers and facilitators towards health. Facilitators highlighted by participants included access to health services and resources such as RCW, home-based carers, medication and being able to speak about their disability. Lack of adequate finances, transport, inaccessible homes and communities, unhealthy eating habits, substance abuse, lack of assistive devices and stress were expressed as barriers to health. Furthermore, participants expressed the attitudes of others towards their disability and their need to be dependent on others as barriers to health, this can be seen in the quotes below:

“When people feel sorry for me and think I am helpless it makes me angry” (RHIT, participant 29)

“I am stripped of my ability to have my own pension card to see to my need and to buy what I need” (RHIT, participant 25)

How were needs met

Across all participants this was a question that was not answered or it was answered incorrectly. In majority of the captured responses this section was left blank. For cases where a response was recorded it was a record of who was meeting the need or what the client specific goal was in relation to that domain and need as opposed to the desired response of “How the need was met” i.e. what measures were taken to address the need.

Feedback on the RHIT

RCWs had the opportunity to express how they experienced using the RHIT and any challenges they experienced with the tool. This was captured in the researcher’s journal. The qualitative results are outlined below:

Creating expectations

Some RCWs expressed that while completing the RHIT and having their clients divulge personal information some clients had an expectation that the RCW would “now solve all my problems”. They had to be careful not to create that expectation and indicated that as RCWs they would assist where possible and refer where necessary.

Holding back

RCWs expressed that it was not always possible to complete the resource tool while the client was completely alone and that on certain questions they felt that the clients may not have given all the relevant information. The RCWs indicated that possible reasons for this could be because of fear of the family members' reactions or because of not being ready to divulge this information. RCWs highlighted that this could be the case for the questions related to health safety and security, finance, and sexuality.

Making adjustments

RCWs indicated if they thought that the client did not understand them they would phrase the questions differently. They indicated that at times they did not ask the questions exactly as it was written but that they used the RHIT to stimulate conversation on the specific topic. The RCWs indicated that completing the tool could take more than an hour long, although it provided a rich discussion this was extremely time consuming.

Sensitivity of certain questions

All the RCWs were female and expressed that the sexuality question was particularly difficult to ask if they had a male client and at times this question could illicit inappropriate responses from certain male clients. The question was phrased as "Do you need help with sexual education" but some males responded to this in a way that made the RCW feel uncomfortable.

Discussion of phase 2: The field-testing of the RHIT

The discussion for phase 2 addresses two aspects firstly the findings of the field-testing of the RHIT which reflect the rehabilitation and health needs of PWD and secondly the considerations in the use of the tool in itself.

As depicted in the results movement was the area that most participants reported great need in. These results may link to that the highest proportion of participants reporting a diagnosis of cerebral vascular accident although these type of associations were not statistically analysed as this was beyond the scope of the study. Literature reflects that mobility links to PWD's sense of empowerment, self-care and sense of social inclusion (van Pletzen, 2014).

In the development of the tool the experts highlighted the importance of including sexual health as a domain, however in this research study only six participants reported a need for sexual education. Sherry, (2014) highlighted that the attitudes of health care providers as barriers to health care for PWD and noted that PWD have been excluded from specific health care programmes such as HIV care and sexual and reproductive health. The reasons for a lack of response on the important issue of sexuality are unknown, it may be linked to what is reported in the literature around the continued misperceptions around asexuality for PWD which perpetuates silences around the issue of sexuality (World Health Organisation, 2011a). A further reason for the lack of response on sexuality could be linked to the differences in the perceptions of the RCW and the PWD on needs. A study conducted by Bengtsson-Tops and Hansson (1999), showed that there was poor correlation between the staff and patients perceptions of a need and whether the need has been met in relation to many domains of need including the area of the expression of sexual interest which displayed the poorest agreement. Additionally, the World Disability report (2011) indicated that health care workers identified the need for themselves for continuing education for issues such as sexuality and reproductive health for PWD. In the development of the tool experts queried how the issue of sexual health would be addressed as it is a sensitive topic, therefore the researcher needs to question whether the RCW felt equipped to broach this topic with their client as well as the client’s willingness to open up on this sensitive information so as to facilitate an appropriate referral.

It was evident that family members were frequently reported as meeting the needs of PWD. In this study for the domains of movement, self-care and general tasks the needs were mostly met by family members. The local and international literature supports that the family play a large role in the care and support of PWDs (Chappell & Johannsmeier, 2009; Grut et al., 2012; Sherry, 2014; Tousignant et al., 2007). The literature also reports that families expressed feelings of frustration and heightened stress because of lack of information on the rehabilitation home programme and a lack of support in the transition from hospital to home (Kahonde et al., 2010; Setswe et al., 2009).This reinforces the importance of those nearest to the PWD as having great potential to facilitate the achievement of health care and wellbeing and thus they should be an area of focus and involvement when planning service delivery and skills transfer. There is a need to provide meaningful support for family members and reflect on how rehabilitation services within the home and community can move towards a shared responsibility among family members, rehabilitation personnel and other significant stakeholders to work towards the social inclusion of PWD.

The challenge of empowering the PWD to meet their own needs still remains. For this study a very low proportion of participants (n=8) indicated that they were able to meet their own needs in relation to self-care. It is important to involve the PWD in rehabilitation to empower the PWD. Kahonde et al.s', (2010) study highlighted in many instances that rehabilitation was implemented it was done without explaining the process to the PWD thereby leaving the PWD with mixed feelings about their involvement in rehabilitation, and were unaware of their right to participate in rehabilitation. The study highlighted that many PWD still view the therapist as knowing everything and rely solely on what the therapist advised.

Phase 2 results also reflect that rehabilitation services were one of the top categories that met the needs for the study's sample population. Although the sample was too small to allow the results to be generalised, the literature argues that bringing health care especially rehabilitation closer to the home of the PWD can greatly enhance the wellbeing of PWD and promote participation. The literature recommends that healthcare workers be trained in matters related to disability specifically health care and available services. It is further argued that these health workers should include rehabilitation trained workers (Sherry, 2014). Given that the study's sample population received management from RCWs this could be linked to them reporting their health and rehabilitation needs as met. Chappell & Johannsmeier's (2009) study on the impact of CBR on PWD implemented by community rehabilitation facilitators in South Africa reflected that the most significant impact was at an individual level. The authors argued that the community rehabilitation facilitators' intervention facilitated independence in activities of daily living (ADLs), social interaction and enhanced mobility. The availability of RCW to this sample population could allow them to work together with the PWD to empower the PWD to address social and environmental barriers that impose participation restrictions for the PWD (Sherry, 2014). Furthermore, the RCW as trained rehabilitation professionals are in a unique position that while they are in the home they are able to support and capacitate family members and other health workers to better support the PWD within their own specific context.

In using the RHIT the RCW also provided feedback on the tool and reported that they preferred using this resource tool as they did not have to do any scoring or calculations. They reported that it was easier to administer but still maintained the comprehensiveness that was present in the other tools such as the WHODAS that they used. However, more training was still needed for the RCW to ensure correct administration, reporting and recording of data on the RHIT. There were sections not completed (i.e. how were your needs met question), the reasons for this need to be investigated further.

The RHIT was successful in identifying the rehabilitation and health needs of PWD in the sample population and was useful in identifying client specific goals which could be used to plan intervention. It was evident from the results that the tool was useful in stimulating conversation on various topics and provided a structured manner to review these topics. From this perspective the tool was in alignment with the vision that was outlined in the focus group interview with the experts as part of phase 1 of this study.

The RHIT was quite long to complete and it would be recommended to look at how it could be further condensed to reduce the potential of developing fatigue when completing it.

4.3 Conclusion

The development and testing of the RHIT involved a systematic approach including numerous forms of data collection which strengthened the face and content validity of the tool. The RHIT was deemed to have face and content validity. The conceptualizing of the RHIT through a document review and a focus group interview with experts in the field facilitated the RHIT to contain the key domains related to rehabilitation and health. This followed emic and etic processes which emphasises the importance of using the "insiders" perspective (emic knowledge) which allowed domains and variables to be included that tailored the resource tool making it more suitable for the intended context as well as the etic knowledge which would be the RCW observations of the context (Cloete, Wilson, Petersen, & Kathard, 2015). The tool reflected core domains and issues that were pertinent in the context the RCW worked in. Thus this RHIT is a unique type of measure grounded in the ICF framework, which is tailored to the needs of the RCW and the role that they play in community-based services in the Western Cape Department of Health. The RHIT tool is structured in a way that meets the current skill set and the emerging scope of practice of the RCW.

Involving the RCWs and the experts facilitated an evolution of the proposed tool that tailored it to have a purpose beyond merely documenting rehabilitation and health needs of PWD. The RHIT was envisioned to facilitate a clinical process of firstly documenting the rehabilitation and health needs of PWD, and secondly intervention planning and monitoring of the PWD. The proposed RHIT tool for the current context also has relevance for use in other contexts.

According to Schneider et al., (2015) the reorientation of community based services is challenging which includes the establishment of different roles, relationships and mindsets in primary health care. The authors reflect on the Western Cape Department of Health care 2030 vision as outlined in table 8: Policy recommendations for community based services in Healthcare 2030. What is notable is the value system of Healthcare 2030 includes "community embeddedness, stable long-term relationships with households which build on empathy and trust" as well as the implementation of a standardised monitoring and evaluation systems with key indicators. Taking this into consideration the vision of the RHIT is in alignment with the Western Cape Department of Health Healthcare 2030 plan.

Table 8: Policy recommendations for community based services in Healthcare 2030 (Schneider et al., 2015, p.3)

Policy dimension	Policy recommendation
Roles	Comprehensive orientation including preventive, promotive, care and rehabilitation; Community-based action on determinants of health as part of a broader inter-sectoral focus on wellness; Outcome oriented approach focused on major causes of ill-health in the province: HIV/AIDS and TB, chronic non-communicable diseases, violence and injury, mental health, maternal (parent) infant and child health, early childhood development;
Target population	Population based model in which teams are responsible for the health of a defined population (electoral wards in urban/metro areas, sub-district rural areas); Proactive approach to all households;
Links to health care system	Integral part of public primary health care system, supervised and supported by facility based staff;
Team structure and ratios	Each CHW works 8 hours a day and responsible for 270 households; Team of 10 CHWs to be supported by one Clinical Nurse Practitioner; One RCW per 8 CHWs;
CHW training	Core roles and training standardised, based on a nationally accredited curriculum;

M&E system	Standardised M&E systems reporting on key indicators; Use of mHealth strategies for M&E;
Value system	Person/patient centred; Community embeddedness: stable, long-term relationships with households which build empathy and trust.

In conclusion it is evident from the findings that the proposed RHIT is contextually relevant for supporting the RCWs in their engagement around health-related needs of PWDs. Despite the RCW reflecting the contextual relevance of the tool and the usefulness when field-testing the tool, much work remains to be done in refining and validating of the tool before the tool can be fully implemented. This study only started the process of the development of such a resource tool. The next chapter discusses the limitations and future recommendations and implications.

Chapter 5: Future applications, Limitations and Research implications

The findings highlight the complexities that RCWs deal with in relation to the rehabilitation and health needs of their clients which brings about challenges in their daily work. This chapter includes a discussion on the limitations of the study and the implications for future research.

5.1 Limitations of the study

Although the RHIT is still to be refined and further enhanced it can provide a starting point for a comprehensive resource for the RCW to systematically collect information on the PWD's rehabilitation and health needs.

A limitation of the study was that it did not evaluate the reliability of the tool. The research project initially aimed to determine the internal consistency reliability of the tool through the use of Cronbach Alpha. Additionally, the RHIT was used by RCWs as research assistants, and thus correlation between all parties conducting research i.e. a high inter-rater reliability was desirable. The RCW were provided with training and practice in the administration and use of the measurement tool to facilitate better inter-rater reliability (Babbie & Mouton, 2001). However, inter-rater reliability and internal consistency were not evaluated. As the project commenced it became evident that the needs of the PWD were dynamic and that the tool was engaging in a dynamic process which made the evaluation of inter-rater reliability challenging. Furthermore the completion of this RHIT relies on empathy and trust among the RCW and their clients. Each RCW has a unique method of engaging with their clients and thus it would be difficult to ensure that the RHIT was all completed in the same manner. However, this can be seen as a strength as well. Therefore, the relationship between different RCWs and the clients would not be the same and it would be expected that results yielded may vary and inter-rater reliability would be affected.

A limitation of the tool was also related to the concept of need. The literature argues that a tool should be clear on what it is measuring. Given the multidimensional, subjective and complex nature of needs it is not possible to clearly limit the concept of needs and thus the tool could tap into a wider range of needs than was necessary. Given the vision for the RHIT it would be better to not have a pre-existing definition of need, but to allow it to truly reflect the engagement process and what emanated from this. The RHIT was also limited to rehabilitation and health-related questions, and as outlined in the ICF and UNCRPD disability and ill-health is complex and influenced by both environmental, social and personal factors which this tool did not tap into in detail for example the tool could be refined to include environmental barriers as well.

The RCW reported that it was too time consuming to complete the RHIT, therefore in the revision of the RHIT it needs to be considered how the tool can be shortened to reduce fatigue of RCW and PWD when completing it.

5.2 Recommendations and Implications for future research

The burden of care in the community is predominately placed on the family and therefore when gathering data on the rehabilitation and health needs of the PWD, one must be careful not to assume that health needs reported to be of "lesser intensity/little need" means that there is an informal support system required. Therefore, it is important to have a method of determining what the desired intervention is. The inclusion of patient-centred goals in the RHIT is one such method and is an important element to be investigated in future research. How do these goals align with the service providers clinical recommendations?

The RHIT displayed potential to be used as a tool for data gathering and monitoring of PWD. However, the sample size for this population was small, therefore it is advised that once the tool has been revised that it is tested on a larger sample of PWD. Based on the findings of this study it is recommended that when revising the tool, consideration be given to the wording, layout and amount of questions.

As outlined in the CBR guidelines effective and efficient data collection and monitoring and evaluation mechanisms are needed. Further as highlighted in Chapter 4 in the World Disability report (2011) health professionals required additional training on matters related to the health needs of PWD. Therefore, this tool could be introduced into the curriculum of training for the RCW which would provide them with theoretical and practical training on the use of the tool. Based on the findings of this study it is recommended that when training on the use of the tool , consideration be given to the category "how were needs met", this is valuable information that was not adequately completed in this study.

Schneider et al. (2015), noted that the CHWs were treated subordinately by other health professional despite having significant insights into the community life, being accepted, supported and valued by community members. Community members viewed CHWs more favourably than other health professionals because of the direct engagement in the home and community (Schneider et al., 2015). The trust in CHWs "suggests a degree of community embeddedness and the potential role as a mediator between the communities and health system"(Schneider et al., 2015). In view of opportunities such as these Schneider et al. (2015) cautions that the current health system is limited in its scope of interventions and that measures need to be put in place that allow the redefining or roles and relationships in a comprehensive manner that allows for adaptation to dynamic and changing health needs and contexts.

Taking into consideration the context of this research study being in Western Cape with the RCW it is unclear how the CHW/RCW will best be equipped to embody and implement the proposed Healthcare 2030 value system and therefore a tool such as the RHIT is seen to be contextually relevant, applicable and in alignment with Western Cape Department of Health and ICF standards. Therefore, more evidence is needed concerning the value of this tool since it is important that structures and systems are put in place to support the RCW in effectively delivering CBR in terms of capturing and reporting information. Once the tool has been revised it is recommended that it is implemented in the daily use of the RCW and further research is done of the value of the tool.

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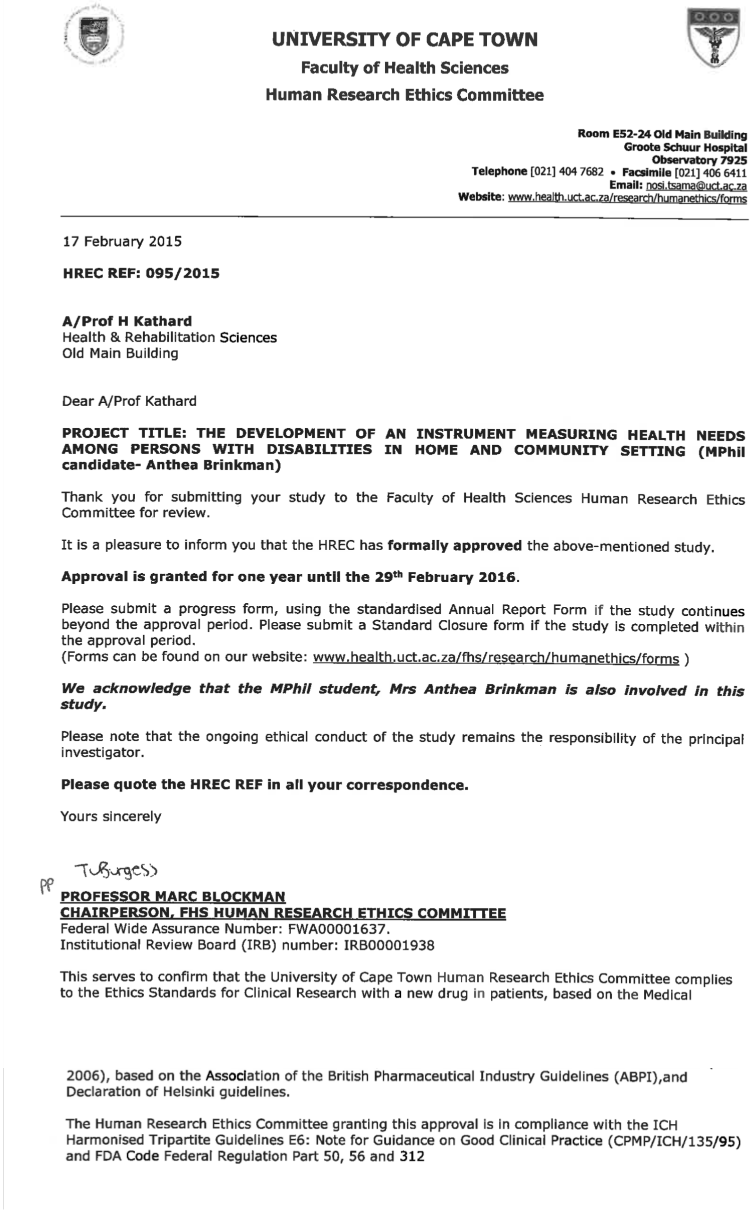
Appendices

Appendices from Methodology

Appendix 1: Ethics Approval



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 404 7682 • **Facsimile** [021] 406 6411
Email: nosi.tsama@uct.ac.za
Website: www.health.uct.ac.za/research/humanethics/forms

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17 February 2015

HREC REF: 095/2015

A/Prof H Kathard
Health & Rehabilitation Sciences
Old Main Building

Dear A/Prof Kathard

PROJECT TITLE: THE DEVELOPMENT OF AN INSTRUMENT MEASURING HEALTH NEEDS AMONG PERSONS WITH DISABILITIES IN HOME AND COMMUNITY SETTING (MPhil candidate- Anthea Brinkman)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 29th February 2016.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

We acknowledge that the MPhil student, Mrs Anthea Brinkman is also involved in this study.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC REF in all your correspondence.

Yours sincerely

pp T.Burgess

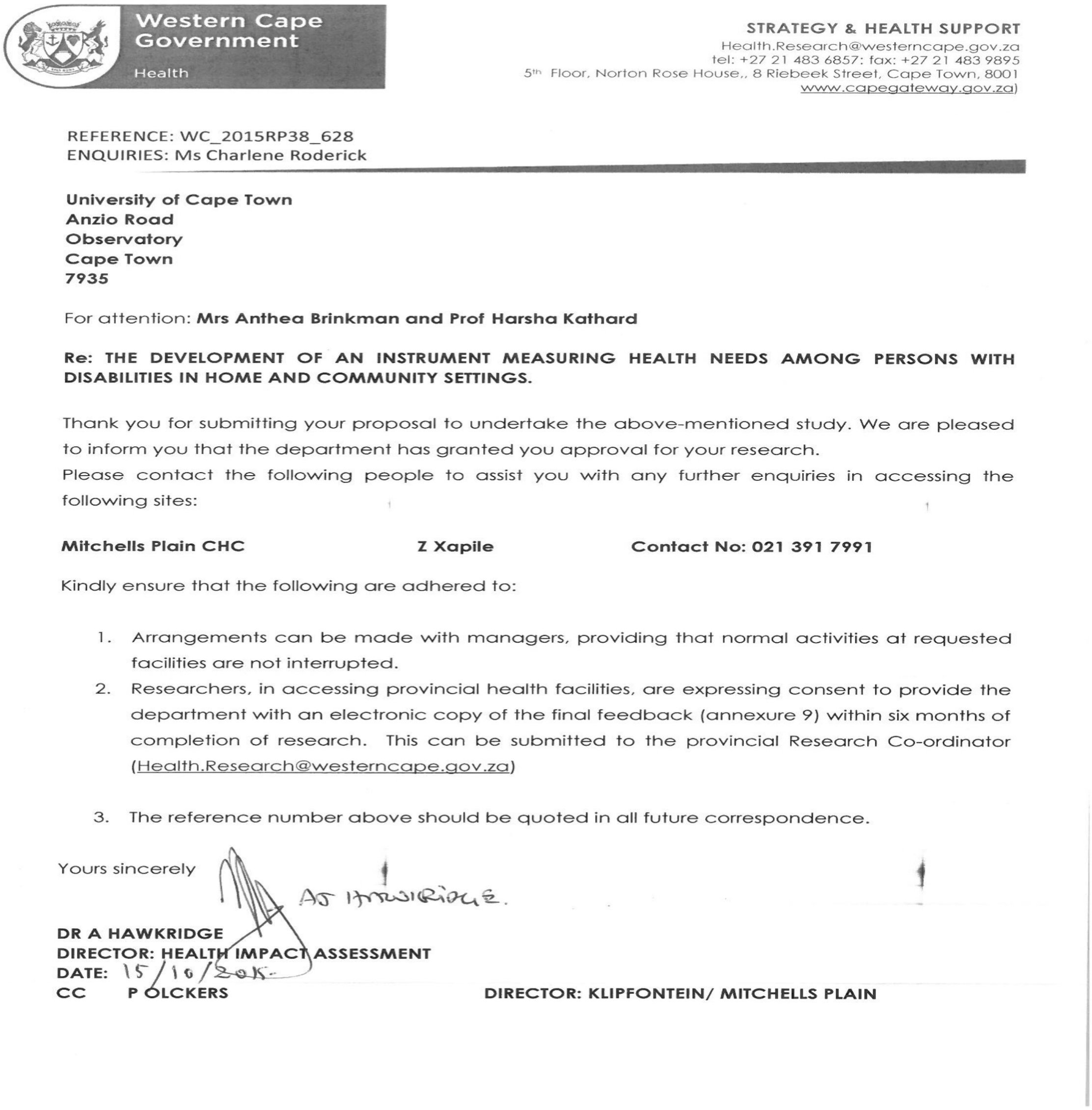
PROFESSOR MARC BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical

2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI),and Declaration of Helsinki guidelines.

The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312

Appendix 2: Western Cape Department of Health Approval



Western Cape Government
Health

STRATEGY & HEALTH SUPPORT
Health.Research@westerncape.gov.za
tel: +27 21 483 6857; fax: +27 21 483 9895
5th Floor, Norton Rose House,, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za)

REFERENCE: WC_2015RP38_628
ENQUIRIES: Ms Charlene Roderick

University of Cape Town
Anzio Road
Observatory
Cape Town
7935

For attention: **Mrs Anthea Brinkman and Prof Harsha Kathard**

Re: THE DEVELOPMENT OF AN INSTRUMENT MEASURING HEALTH NEEDS AMONG PERSONS WITH DISABILITIES IN HOME AND COMMUNITY SETTINGS.

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

Mitchells Plain CHC	**Z Xapile**	**Contact No: 021 391 7991**

Kindly ensure that the following are adhered to:

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

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

Yours sincerely

AJ HAWKRIDGE.

DR A HAWKRIDGE
DIRECTOR: HEALTH IMPACT ASSESSMENT
DATE: 15/10/2015
CC P OLCKERS DIRECTOR: KLIPFONTEIN/ MITCHELLS PLAIN

Appendix 3: Informed Consent form for the focus group with experts

UNIVERSITY OF CAPE TOWN

School of Health & Rehabilitation Sciences

Faculty of Health Sciences

Divisions of Communication Sciences & Disorders · Nursing & Midwifery · Occupational Therapy · Physiotherapy

Old Main Building · Groote Schuur Hospital · Observatory · 7925

Telephone: + 27 21 406 6628

Fax: + 27 21 406 6323

DATE:

TO: ________________________

Re: Conducting a research project from the University of Cape Town

I am a student registered for the Masters degree in Disability Studies at the University of Cape Town. As part of my degree requirements I am conducting a research project, under the supervision of Prof. Kathard and Mrs. Cloete. Ethics approval has been obtained from the Human Research Ethics Committee of the Faculty of Health Sciences, University of Cape Town.

This study aims to develop a tool that will be used to identify and describe how the rehabilitation and health needs of persons with disabilities are met within the home and community context. This will contribute to the identification of the rehabilitation and health needs of people with disabilities as well determine what measures are being taken to meet these needs. It is important to understand what measures are being taken to address persons with disabilities rehabilitation and health needs, as well as who has been meeting these needs particularly from the perspective of the person receiving this care. This study aims to inform intervention planning particularly within the health domain. It is envisaged that the tool be used by rehabilitation care workers or community health workers. Based on the literature, it is evident that no tool exists that reflects the person with disability perspective and therefore the development of such a tool is needed.

In order to achieve these aims, I would like to request your participation in this research study. As an expert in the field of disability and/or questionnaire development your participation is of great importance.

What will be required of you?

Participation in this study is voluntary. If you agree to participate in this study, you will form part of a focus group that will come together/meet for one session of approximately two hours (including breaks), in which the tool will be rated and critiqued. With the permission of the focus group members the focus group will be audio recorded.

All participant responses will be treated with confidentiality and all identifying information will be removed and replaced with pseudonyms in the transcribed documents. This is to ensure the confidentiality of the participants at all times. All information obtained will be used for the purposes of this study only as well as academic papers and conferences pertaining to the study. Any participant may withdraw from participating in this study at any time, without having to give a reason for doing so. Furthermore, the focus group will be conducted at a time that is best suited and convenient to the all.

What will be the benefit to the participants?

There are no direct benefits to you. You will benefit from having the opportunity to contribute to the development of the tool. There will be no remuneration for taking part in this study.

What will be the risks involved?

There are no risks involved in this study.

I hereby invite you to participate in the study and would greatly appreciate a written confirmation of your consent to attach to my research project proposal if consent is granted.

Your assistance in this regard will be much appreciated. Hoping you take this request into kind consideration.

Yours sincerely,

Ms. A Brinkman	Prof. H Kathard	Mrs. T Cloete
Student	Supervisor	Co-Supervisor

Should you have any questions, please do not hesitate to contact me on 0815933240 or Anthea.brinkman@uct.ac.za or my supervisors:

Prof Harsha Kathard: harsha.kathard@uct.ac.za /(w) 021 4066041

Mrs Tracey-lee Cloete: tracey-lee.cloete@uct.ac.za/ (w) 021 4066582

You may also contact the Faculty of Health Sciences Human Research Ethics Committee (HREC) if you have any questions or concerns your rights and welfare as a research participant.

Dr Blockman University of Cape Town: Faculty of Health Sciences Chair of Human Research Ethics Committee (HREC)
Email: Marc.Blockman@uct.ac.za Tel: 021 406 6496

WRITTEN CONSENT FORM FOR PARTICIPATION IN THE STUDY: FOCUS GROUP WITH EXPERTS

I understand my rights as a research participant and I voluntarily consent to participating in this study. I understand the nature of and rationale for this study. I understand what my participation in this study entails and I have had all my questions answered. I do not feel that I am forced to take part in this study and I am doing so of my own free will. I am aware that I may withdraw from the study at any time if I so wish and that it will have no negative implications for me. I have received a copy of this consent form.

I have read the information sheet and know what the focus group interview is about.

I understand what is required of me and I have had all my questions answered.

I do not feel forced to take part in this study and I am doing so of my own free will.

I agree to comment on and critique the proposed tool

I know that I can contact the researchers and project leaders anytime if I have any questions.

I agree to take part in this project.

I agree to have the focus group session audio recorded.

I agree to keep the discussion that unfolds during the focus group confidential.

Signed:

_______________________________ _____________________________

Participant date and place

_______________________________ ______________________________

Researcher date and place

_______________________________ ______________________________

Witness date and place

Appendix 4: Information sheet and consent form for the rehabilitation care workers

UNIVERSITY OF CAPE TOWN

School of Health & Rehabilitation Sciences

Faculty of Health Sciences

Divisions of Communication Sciences & Disorders · Nursing & Midwifery · Occupational Therapy · Physiotherapy

Old Main Building · Groote Schuur Hospital · Observatory · 7925

Telephone: + 27 21 406 6628

Fax: + 27 21 406 6323

DATE:

TO: ________________________

Re: Conducting a research project from the University of Cape Town

I am a student registered for the Masters degree in Disability Studies at the University of Cape Town. As part of my degree requirements I am conducting a research project, under the supervision of Prof. Kathard and Mrs. Cloete. Ethics approval has been obtained from the Human Research Ethics Committee of the Faculty of Health Sciences, University of Cape Town.

This study aims to develop a tool that will be used to identify and describe how the rehabilitation and health needs of persons with disabilities are met within the home and community context. This will contribute to the identification of the rehabilitation and health needs of people with disabilities as well as determine what measures are being taken to meet these needs. It is important to understand what measures are being taken to address persons with disabilities rehabilitation and health needs, as well as who has been meeting these needs particularly from the perspective of the person receiving this care. This study aims to inform intervention planning particularly within the health domain. It is envisaged that the tool be used by rehabilitation care workers or community health workers. Based on the literature, it is evident that no tool exists that reflects the person with disability perspective and therefore the development of such a tool is needed.

In order to achieve these aims, I would like to request your participation in the proposed research study. As a rehabilitation care worker in the Mitchells Plain sub-district your participation is of great importance.

What will be required of you?

Participation in this study is voluntary. If you agree to take part in this study, you will be asked to complete the designed Rehabilitation Health Information Tool with the Persons with disabilities that you are currently providing services to. You will also be required to provide written feedback about the usefulness of the tool. The Rehabilitation Health Information Tool should take approximately 20 minutes per person and the feedback form should take a maximum of 10 minutes to complete. You will receive brief training (one session) before using the Rehabilitation Health Information Tool. The primary researcher will be available to assist you where necessary. Furthermore, the study's activities will be conducted in such a way that it interferes only minimally with the rehabilitation care worker's/your work responsibilities. Thus, all times will be confirmed with you and participants to ensure that the time is convenient.

What the information from the Rehabilitation Health Information Tool will be used for.

The responses will be used to describe the rehabilitation and health needs of people with disabilities, to describe who is meeting the need and to describe what is being done to meet the need.

Confidentiality Agreement

All participant responses will be treated with confidentiality. Information collected with the Rehabilitation Health Information Tool will be coded; all participants and rehabilitation care workers names will be replaced with pseudonyms to ensure contributions are kept confidential.

What will be the benefit to the participants?

There are no direct benefits to you. You will benefit from having the opportunity to contribute to the development and testing of the Rehabilitation and Health information tool.

What will be the risks involved?

There are no risks associated with this research project. All information obtained will be used for the purposes of this study only as well as academic papers and conferences pertaining to the study. Any participants may withdraw from participating in this study at any time, without having to give a reason for doing so.

I hereby invite you to participate in the study where you will have the opportunity to field test the rehabilitation and Health information tool.

I would greatly appreciate a written confirmation of your consent.

Your assistance in this regard will be much appreciated.

Yours sincerely,

Ms. A Brinkman	Prof. H Kathard	Mrs. T Cloete
Student Supervisor	Supervisor	Co-Supervisor

Should you have any questions, please do not hesitate to contact me on 0815933240 or Anthea.brinkman@uct.ac.za or my supervisors:

Prof Harsha Kathard: harsha.kathard@uct.ac.za /(w) 021 4066041

Mrs Tracey-lee Cloete: tracey-lee.cloete@uct.ac.za/ (w) 021 4066582

You may also contact the Faculty of Health Sciences Human Research Ethics Committee (HREC) if you have any questions or concerns your rights and welfare as a research participant.

Dr Blockman
University of Cape Town: Faculty of Health Sciences
Chair of Human Research Ethics Committee (HREC)

Email: Marc.Blockman@uct.ac.za
Tel: 021 406 6496

WRITTEN CONSENT FORM FOR PARTICIPATION IN THE STUDY: REHABILITATION CARE WORKERS

I understand my rights as a research participant and I voluntarily consent to participating in this study. I understand the nature of and rationale for this study. I understand what my participation in this study entails and I have had all my questions answered. I do not feel that I am forced to take part in this study and I am doing so of my own free will. I am aware that I may withdraw from the study at any time if I so wish and that it will have no negative implications for me. I have received a copy of this consent form.

I have read the information sheet and know what the research is about.

I understand what is required of me and I have had all my questions answered.

I do not feel forced to take part in this study and I am doing so of my own free will.

I agree to conduct the Rehabilitation and Health information tool on persons with disabilities to gather information.

I know that I can contact the researchers and project leaders anytime if I have any questions.

I agree to take part in this project as a research assistant and to undergo training.

I agree to keep the information of the person with disability on whom I conduct the RHIT confidential.

I agree to keep the discussion that unfolds during the RHIT administration confidential.

Signed:

______________________________ ____________________________

Participant date and place

______________________________ ____________________________

Researcher date and place

______________________________ ____________________________

Appendix 5: Consent form for the participants

UNIVERSITY OF CAPE TOWN

School of Health & Rehabilitation Sciences

Faculty of Health Sciences

Divisions of Communication Sciences & Disorders · Nursing & Midwifery · Occupational Therapy · Physiotherapy

Old Main Building · Groote Schuur Hospital · Observatory · 7925

Telephone: + 27 21 406 6628

Fax: + 27 21 406 6323

DATE:

TO: ________________________

Re: Conducting a research project from the University of Cape Town

I am a student registered for the Masters degree in Disability Studies at the University of Cape Town. As part of my degree requirements I am conducting a research project, under the supervision of Prof. Kathard and Mrs. Cloete. Ethics approval has been obtained from the Human Research Ethics Committee of the Faculty of Health Sciences, University of Cape Town.

This study aims to develop a tool that will be used to identify and describe how the rehabilitation and health needs of persons with disabilities (PWD) are met within the home and community context. This will contribute to the identification of the rehabilitation and health needs of people with disabilities as well determine what measures are being taken to meet these needs. It is important to understand what measures are being taken to address PWD rehabilitation and health needs, as well as who has been meeting these needs particularly from the perspective of the person receiving this care. Approval to conduct this study has been obtained from the Health

Sciences Faculty Research Ethics Committee, University of Cape Town and the director of Health, City of Cape Town.

In order to achieve these aims, I would like to request your participation in the proposed research study. As a person with a disability your participation is of great importance.

What will be required of you?

Participation in this study is voluntary. If you agree to take part in this study, you will be asked to complete the designed Rehabilitation and Health Information Tool (RHIT). You will have a chance to share information on how your health-related needs are met. The questionnaire will ask about your health-related needs, who is meeting these needs and what they are doing to meet your health-related needs. The Rehabilitation and Health information tool should take approximately 20 minutes. A rehabilitation care worker that has been assigned to provide health care services to you will conduct the questionnaire with you. The meeting times will be confirmed with rehabilitation care workers and participants to ensure that the time is convenient.

What the information from the rehabilitation and health tool will be used for?

Information gathered from the rehabilitation and health tool will help inform the services delivery and can help improve primary health care services within the community context to people with disabilities.

Confidentiality Agreement.

All participant responses will be treated with confidentiality. Information collected with the RHIT will be coded; all participants and rehabilitation care workers' names will be replaced with pseudonyms to ensure contributions are kept confidential

What will be the benefit to the participants?

The benefit to partaking in this study is that you will have the opportunity to contribute to documenting the needs of people with disabilities which may inform service delivery. There will be no remuneration for taking part in this study.

What will be the risks involved?

There are no risks associated with this research project. All information obtained will be used for the purposes of this study only as well as academic papers and conferences pertaining to the study. All participants may withdraw from participating in this study at any time, without having to give a reason for doing so.

I hereby invite you to participate in the study. I would greatly appreciate a written confirmation of your consent.

Your assistance in this regard will be much appreciated.

Yours sincerely,

____________________	________________________	____________________
Ms. A Brinkman	Prof. H Kathard	Mrs. T Cloete
Student Supervisor	Supervisor	Co-Supervisor

Should you have any questions, please do not hesitate to contact me on 0815933240 or Anthea.brinkman@uct.ac.za or my supervisors:

Prof Harsha Kathard: harsha.kathard@uct.ac.za /(w) 021 4066041

Mrs Tracey-lee Cloete: tracey-lee.cloete@uct.ac.za/ (w) 021 4066582

You may also contact the Faculty of Health Sciences Human Research Ethics Committee (HREC) if you have any questions or concerns your rights and welfare as a research participant.

Dr Blockman
University of Cape Town: Faculty of Health Sciences
Chair of Human Research Ethics Committee (HREC)

Email: Marc.Blockman@uct.ac.za
Tel: 021 406 6496

Question	Examples of adequate answers given by participants that may demonstrate their understanding of the research.
What is this questionnaire about?	We are going to talk about my health needs and how they are met.
Why did I choose you for this questionnaire?	I was chosen because I have a disability.
Are you taking part in this questionnaire because you want to?	Yes
Are there any bad things about this questionnaire?	No
What do you do if you do not wish to continue with this questionnaire?	I can tell the researcher and ask them to stop.

WRITTEN CONSENT FORM FOR PARTICIPATION IN THE STUDY: PARTICIPANTS

I understand my rights as a research participant and I voluntarily consent to participating in this study. I understand the nature of and rationale for this study. I understand what my participation in this study entails and I have had all my questions answered. I do not feel that I am forced to take part in this study and I am doing so of my own free will. I am aware that I may withdraw from the study at any time if I so wish and that it will have no negative implications for me. I have received a copy of this consent form.

I have read the information sheet and know what the research is about.

I understand what is required of me and I have had all my questions answered.

I do not feel forced to take part in this study and I am doing so of my own free will.

I know that I can withdraw at any time and it will have no negative implications for me.

I agree to partake in the Rehabilitation and Health information tool to allow for the gathering of information.

I know that I can contact the researchers and project leaders anytime if I have any questions.

I understand that all information I give will be kept safe, private and confidential; unless people are at risk of being harm. I will not be named in any reports.

Signed:

_______________________________ _____________________________

Participant date and place

_______________________________ ______________________________

Researcher date and place

_______________________________ ______________________________

Witness date and place

Appendix 6: Agreement by rehabilitation care workers for data collection

AGREEMENT BY RESEARCH ASSISTANT DATA COLLECTION

Title of Project:

I _______________________ (Name), the rehabilitation care worker assisting with the data collection during the field-testing of Rehabilitation and Health information tool, hereby agree that I am fully aware of the participants' rights to:

a) Confidentiality: I understand that my signature indicates that I commit to protect all identifying information and that I will only refer to participants and the institutions by means of identifying numbers and codes in any communication outside of the research study environment (with the exception of communication with the researcher).

b) Autonomy: I understand that my signature indicates that I will refrain from using any form of coercion, intimidation, pressure or persuasion with the participants to force them to co-operate with me during data collection.

c) Non-maleficence: I further commit to be respectful of the participants in the way I address and interact with them. I commit not to use any language or engage in any act that is potentially embarrassing and emotionally or physically damaging to participants.

I understand that I will be remunerated for my services during data collection at the rate of _______ per hour for the duration of the study and that I may not make any financial or other claims beyond this agreement. I agree to strictly adhere to the data collection dates, times and venues agreed on in conjunction with the researcher. I also agree to not hold the researcher or the University of Cape Town responsible for any loss or damage to my person or property during the period that I act as research assistant in this project. My signature indicates that I voluntarily agree to perform this task and that I was not coerced or forced in any way to participate as a research assistant in the above project.

Signature: ____________________________ Place _______________ Date:_______

Research assistant

Signature ____________________________ Place ________________Date:_______

Researcher

Appendix 7: Interview guide for focus group with the expert panel

What aspects do you think the tool should address?

What aspects of health and rehabilitation needs should be addressed in this tool?

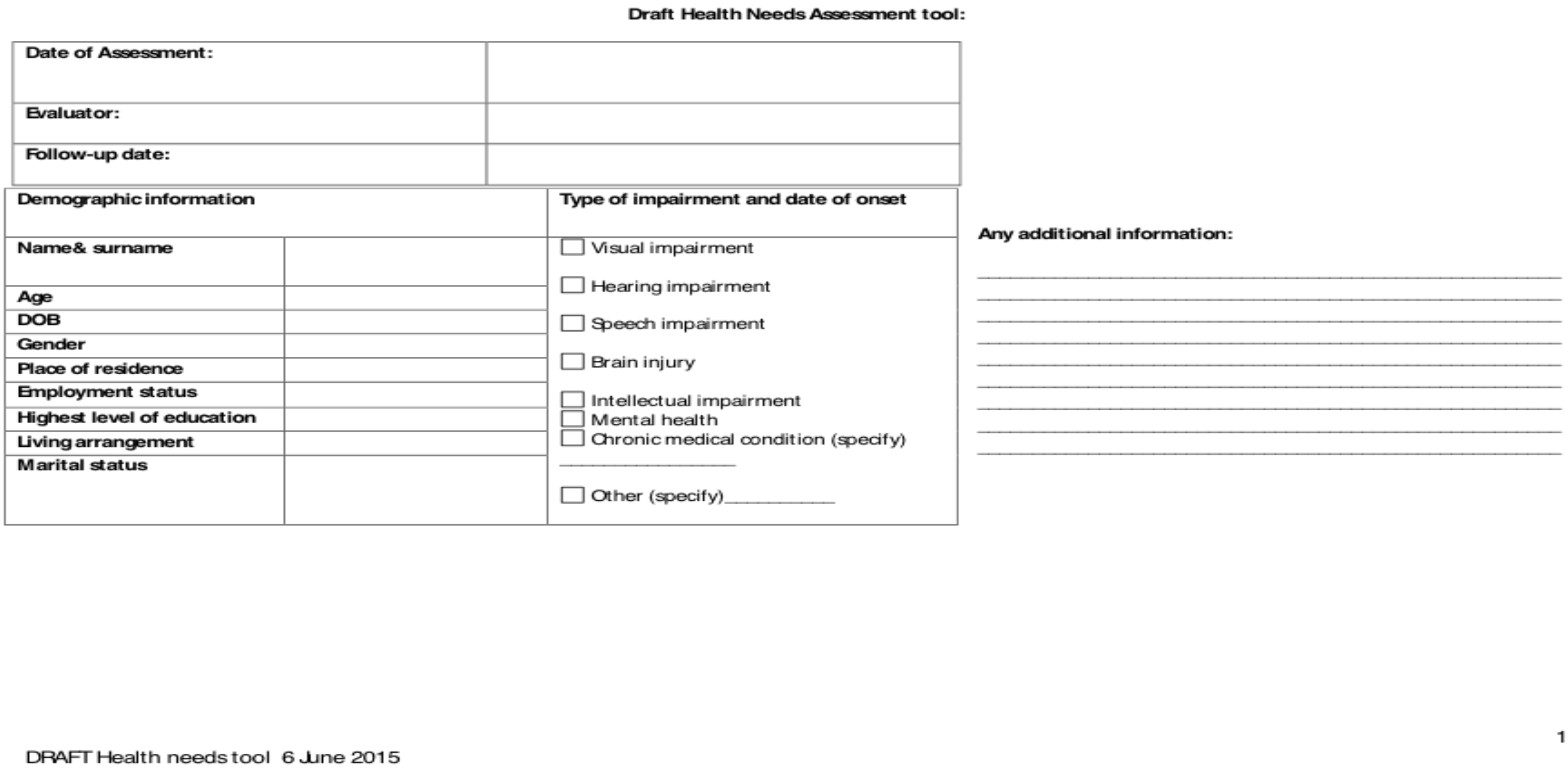
What should the format of the tool look like?

What are your thoughts on the wording and questions in the draft tool?

What guidelines would you give as to how this tool is administered?

What would you name this proposed tool?

Appendix 8: Draft Rehabilitation and Health information tool that was reviewed by the focus group with experts



Draft Health Needs Assessment tool:

Date of Assessment:	
Evaluator:	
Follow-up date:	

Demographic information	
Name& surname	
Age	
DOB	
Gender	
Place of residence	
Employment status	
Highest level of education	
Living arrangement	
Marital status	

Type of impairment and date of onset

☐ Visual impairment

☐ Hearing impairment

☐ Speech impairment

☐ Brain injury

☐ Intellectual impairment
☐ Mental health
☐ Chronic medical condition (specify)
____

☐ Other (specify)__________

Any additional information:

____
____
____
____
____
____
____
____
____

1

DRAFT Health needs tool 6 June 2015

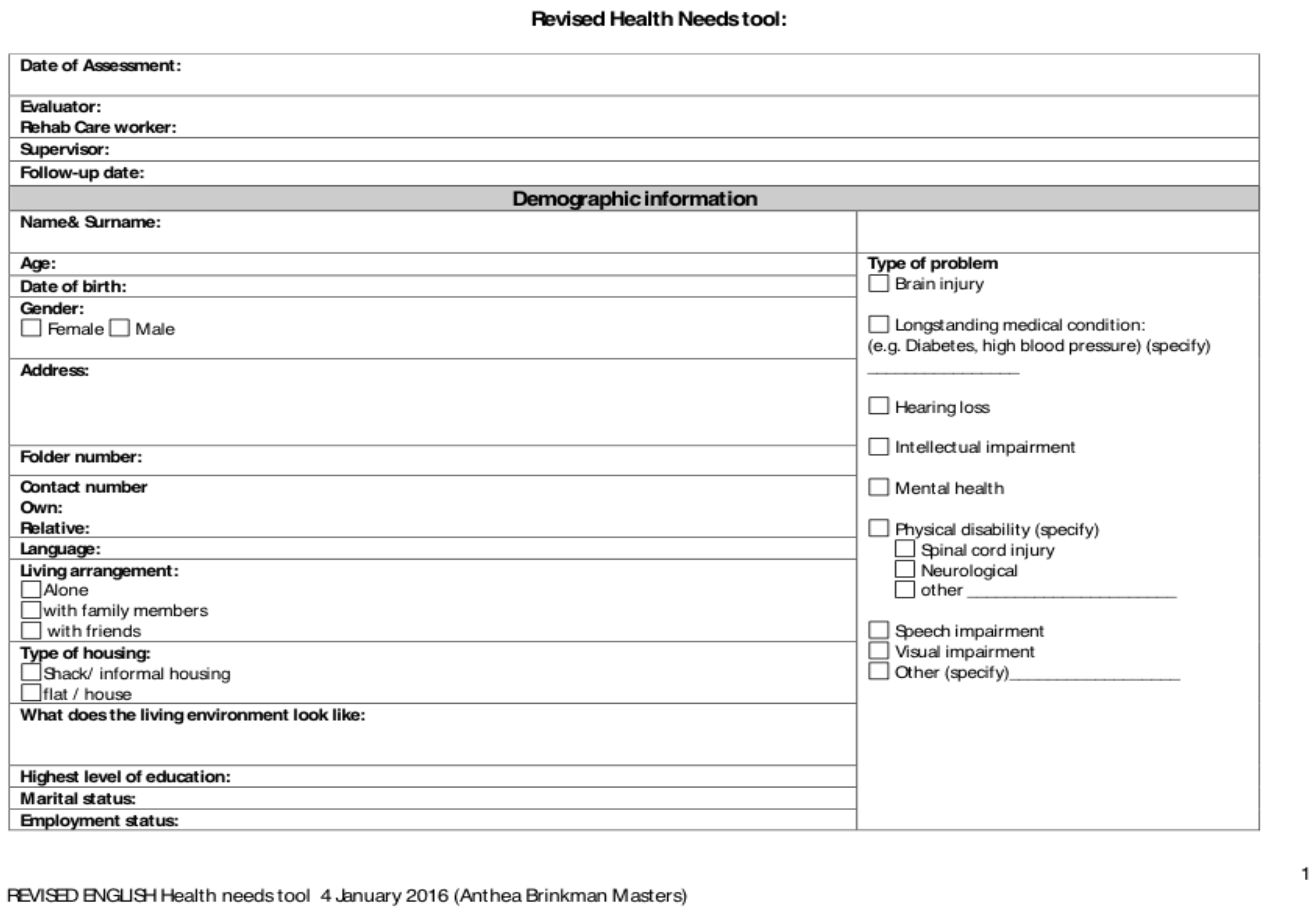
Instruction: Please indicate your current health needs and how your need is being met

Q1	**Overall Health:** How would you describe your overall health in the last few days? Please tick the response that best describes you	☐ Excellent ☐ Good ☐ Fair ☐ Poor			
Q2	What is the main difficulty you face in trying to improve your health?				
	Description	**Do you have a need?**	**Is your need being met**	**Who is meeting your need (tick all that apply) (allow the person to name it)**	**What is being done to meet your need? (How is your need being met?)**
Q3	**Self care:** Do you need help with self care such as bathing, washing, feeding,dressing, using the toilet	☐No- no need ☐Yes- some need ☐Yes- a great need	☐No- not at all ☐Yes- a little ☐Yes- mostly being met	☐Myself ☐ Doctor ☐Rehabilitation services (RCW/ therapist) ☐Home based carer ☐Community health center ☐Faith based organisation (e.g. church/mosque) ☐Traditional healer ☐Family member ☐Other (specify)	
Q4	**Mobility:** Do you need help with moving around inside your home and away from your home (inside your home- such as getting out of bed, going to the bathroom, walking)	☐No- no need ☐Yes- some need ☐Yes- a great need	☐No- not at all ☐Yes- a little ☐Yes- mostly being met	☐Myself ☐ Doctor ☐Rehabilitation services (RCW/ therapist) ☐Home based carer ☐Community health center ☐Faith based organisation (e.g. church/mosque) ☐Traditional healer ☐Family member	

	Description	Do you have a need?	Is your need being met	Who is meeting your need (tick all that apply) (allow the person to name it)	What is being done to meet your need? (How is your need being met?)
Q5	**Communication and understanding:** Do you need help communicating with others such as family members, friends, strangers	☐No- no need ☐Yes- some need ☐Yes- a great need	☐No- not at all ☐Yes- a little ☐Yes- mostly being met	☐Myself ☐ Doctor ☐Rehabilitation services (RCW/ therapist) ☐Home based carer ☐Community health center ☐Faith based organisation (e.g. church/mosque) ☐Traditional healer ☐Family member	
Q6	**Interpersonal relationships and interactions:** Do you need help making friends and keeping friends? Do you need help interactig with family, friends and other people?	☐No- no need ☐Yes- some need ☐Yes- a great need	☐No- not at all ☐Yes- a little ☐Yes- mostly being met	☐Myself ☐ Doctor ☐Rehabilitation services (RCW/ therapist) ☐Home based carer ☐Community health center ☐Faith based organisation (e.g. church/mosque) ☐Traditional healer ☐Family member	
Q7	**Sexual Health:** Do you need help with sexual behaviour, sexual health practices and sexual education	☐No- no need ☐Yes- some need ☐Yes- a great need	☐No- not at all ☐Yes- a little ☐Yes- mostly being met	☐Myself ☐ Doctor ☐Rehabilitation services (RCW/ therapist) ☐Home based carer ☐Community health center ☐Faith based organisation (e.g. church/mosque) ☐Traditional healer ☐Family member	
Q8	**General tasks and demands:** Do you need help with community and household tasks such as shopping,house cleaning, cooking, travelling	☐No- no need ☐Yes- some need ☐Yes- a great need	☐No- not at all ☐Yes- a little ☐Yes- mostly being met	☐Myself ☐ Doctor ☐Rehabilitation services (RCW/ therapist) ☐Home based carer ☐Community health center ☐Faith based organisation (e.g.	

				church/ mosque) ☐Traditional healer ☐Family member	
Q9	**Access to health information:** Do you need help getting information about how to be healthy and stay healthy?	☐No- no need ☐Yes- some need ☐Yes- a great need	☐No- not at all ☐Yes- a little ☐Yes- mostly being met	☐Myself ☐ Doctor ☐Rehabilitation services (RCW/ therapist) ☐Home based carer ☐Community health center ☐Faith based organisation (e.g. church/ mosque) ☐Traditional healer ☐Family member	
Q10	**Health Behaviours:** Do you need help with your health behaviours to help you to stay healthy? E.g. do you need help to stop drinking alcohol, to stop smoking, to stop substance abuse	☐No- no need ☐Yes- some need ☐Yes- a great need	☐No- not at all ☐Yes- a little ☐Yes- mostly being met	☐Myself ☐ Doctor ☐Rehabilitation services (RCW/ therapist) ☐Home based carer ☐Community health center ☐Faith based organisation (e.g. church/ mosque) ☐Traditional healer ☐Family member	
Q11	Do you have any behaviours that impact on your health and wellbeing (postively and negatively)				
Q12	**Health safety and security** Has you rights ever been violoated? Do you feel vulnerable				
Q13	**Spirituality** How does your spirituality contribute to your health and well-being				
Q14	**Other:** Is there anything else you would like to tell me about your health and well-being				

Appendix 9: Revised Rehabilitation and Health information tool



Revised Health Needs tool:

Date of Assessment:	
Evaluator: **Rehab Care worker:**	
Supervisor:	
Follow-up date:	
Demographic information	
Name& Surname:	
Age:	**Type of problem** ☐ Brain injury ☐ Longstanding medical condition: (e.g. Diabetes, high blood pressure) (specify) ________________ ☐ Hearing loss ☐ Intellectual impairment ☐ Mental health ☐ Physical disability (specify) ☐ Spinal cord injury ☐ Neurological ☐ other ______________________ ☐ Speech impairment ☐ Visual impairment ☐ Other (specify)________________
Date of birth:	
Gender: ☐ Female ☐ Male	
Address:	
Folder number:	
Contact number **Own:** **Relative:**	
Language:	
Living arrangement: ☐ Alone ☐ with family members ☐ with friends	
Type of housing: ☐ Shack/ informal housing ☐ flat / house	
What does the living environment look like:	
Highest level of education:	
Marital status:	
Employment status:	

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REVISED ENGLISH Health needs tool 4 January 2016 (Anthea Brinkman Masters)

Instruction: Please indicate your current health needs and how your need is being met

Q1	**Overall Health:** How would you describe your health in the last few days? Please tick the response that best describes you	**1____2____3____4____5____6____7____8____9____10** **Poor** **Fair** **Good** **Excellent**	**Initial Assessment**	**First Follow-up (_______ weeks)**	**Second Follow-up (_______ weeks)**
Q2	What is the main problem you face in trying to improve your health?				
Q3	What do you understand about your disability?				
Q4	What health services do you use?				

	Description	**Do you have a need?**	**Is your need being met**	**Who is meeting your need (tick all that apply) (allow the person to name it)**	**What is being done to meet your need? (How is your need being met?)**	**Client Centered Goals (Specific)**	**Evaluator's General Observations**
Q5	**Self care:** Do you need help taking care of yourself, such as: ☐bathing ☐washing ☐eating ☐dressing ☐using the toilet	☐ No need ☐ Some need ☐ A great need	☐not at all ☐a little ☐mostly being met	☐Myself ☐Doctor ☐Rehabilitation services (RCW/ therapist) ☐Home based carer ☐Community health center ☐Faith based organisation (e.g.church) ☐Traditional healer ☐Family member ☐Other (specify)________________			

	Description	Do you have a need?	Is your need being met	Who is meeting your need (tick all that apply) (allow the person to name it)	What is being done to meet your need? (How is your need being met?)	Client Centered Goals (Specific)	Evaluator's General Observations
Q6	**Movement:** Do you need help with moving around ☐getting in and out of your home ☐inside your home (e.g. getting out of bed, going to the bathroom, walking) ☐away from your home (e.g. in community, in shops)	☐ No need ☐ Some need ☐ A great need	☐not at all ☐a little ☐mostly being met	☐Myself ☐Doctor ☐Rehabilitation services (RCW/ therapist) ☐Home based carer ☐Community health center ☐Faith based organisation (e.g.church) ☐Traditional healer ☐Family member ☐Other (specify)________________			
Q7	**Communication and understanding:** ☐Do you need help telling people about your needs and wants e.g. such as family, friends and strangers ☐Do you need help understanding people and getting people to understand you	☐ No need ☐ Some need ☐ A great need	☐not at all ☐a little ☐mostly being met	☐Myself ☐Doctor ☐Rehabilitation services (RCW/ therapist) ☐Home based carer ☐Community health center ☐Faith based organisation (e.g.church) ☐Traditional healer ☐Family member ☐Other (specify)________________			
Q8	**Interpersonal relationships and interactions:** Do you need help socializing with family, friends and strangers	☐ No need ☐ Some need ☐ A great need	☐not at all ☐a little ☐mostly being met	☐Myself ☐Doctor ☐Rehabilitation services (RCW/ therapist) ☐Home based carer ☐Community health center ☐Faith based organisation (e.g.church) ☐Traditional healer ☐Family member ☐Other (specify)________________			

	Description	**Do you have a need?**	**Is your need being met**	**Who is meeting your need (tick all that apply) (allow the person to name it)**	**What is being done to meet your need? (How is your need being met?)**	**Client Centered Goals (Specific)**	**Evaluator's General Observations**
Q9	**Sexual Health:** Do you need help with sexual education	☐ No need ☐ Some need ☐ A great need	☐not at all ☐a little ☐mostly being met	☐Myself ☐Doctor ☐Rehabilitation services (RCW/ therapist) ☐Home based carer ☐Community health center ☐Faith based organisation (e.g.church) ☐Traditional healer ☐Family member ☐Other (specify)_______________			
Q10	**General tasks** Do you need help with community and household work such as shopping,house cleaning, cooking, travelling, work	☐ No need ☐ Some need ☐ A great need	☐not at all ☐a little ☐mostly being met	☐Myself ☐Doctor ☐Rehabilitation services (RCW/ therapist) ☐Home based carer ☐Community health center ☐Faith based organisation (e.g.church) ☐Traditional healer ☐Family member ☐Other (specify)_______________			
	Description					**Client Centered Goals (Specific)**	**Evaluator's General Observations**
Q11	**Access to health information:** Do you need help getting information about ☐ how to be healthy and stay healthy? ☐ infectious diseases (e.g. TB, HIV, sexuality transmitted infections) ☐chronic diseases of lifestyle (e.g. Diabetes, High blood pressure) ☐Substance abuse						

	Description		Client Centered Goals (Specific)	Evaluator's General Observations
Q12	**Habits** Do you have any habits that affect your health and wellbeing in a good way and in a bad way.	**Good:** **Bad:**		
Q13	**Health safety and security** Have you been abused? Do you feel unsafe? (Would you like to talk about it?)			
Q14	**Spirituality** How does your spiritual beliefs and practices contribute to your health.			
Q15	**Finance** How does your financial situation affect to your health and daily living in a good way and in a bad way	**Good:** **Bad:**		
Q16	**Barriers and facilitators** What are some things that helps your health What are some things that take away from your health a	**Helps:** **Takes away from:**		
Q17	**Other** Is there anything else you would like to tell me about your health			

Assessment Rubric:	Date	Client centered Goals	Evaulator's General Observations	Progress
Initial visit				
First follow-up visit _____ weeks				
Second follow-up visit _____ weeks				
Further follow-up _____ weeks				

Appendix 10: Summary of the document review of the tools and instruments

List of the tools/ instruments reviewed in the development of the Rehabilitation and Health information tool to be used by rehabilitation care worker in home and community-based settings.						
Tool/ document	ICF	WHODAS 2.0	Washington Group on Disability Statistics Short Set	The RCW screening tool	Wheel of opportunity and participation	The family quality of life conversation guide
Focus	The World Health Organisation developed the International Classification of Functioning, Disability and Health (ICF) as a framework to define and classify disability (Garin, et al., 2010). Clinically the ICF is used for needs	The WHODAS-2 was developed to assess disability within the conceptual framework of the ICF. It therefore measures health needs and intervention outcomes and is	Was developed as a disability measure to be used in census surveys to inform policy development on the equalization of opportunities for PWD	The tool was designed to be used as part of the training of RCWs in the HCDP. The tool is used for inpatient and home-based patients to screen for disability and	Adapted from the UN22 Standard Rules on Equalization of Opportunities for disabled people (UN, 1994) Used as a tool for all PWD to visually capture the level of participation a PWD has in	The tool was designed by Beach centre as a tool to elicit a conversation with the family and PWDs, it aims to identify what the families' priorities for support and services are. Families, caregivers and service

	assessment, appropriate intervention planning, rehabilitation and outcomes measurements (Cieza, Ewert, Ustun, Chatterji, Konstanjsek &Stucki, 2004)	used in a variety of health settings.		as a basis for referral for specialized rehabilitation services	specified target areas. Additionally it is used to identify what the barriers and facilitators to participation are. This tool focus is on community participation.	providers can use the tool.
Domains (what it includes)	Includes biological, psychological, social & environmental and looks at the interactive effects it has on functional status of PWD. The areas included are: Impairment of Body Function and Body structures	Understanding and communication Getting around Self-care Getting along with people Life activities Participation in society	6 functional domains seeing hearing walking cognition self-care communication	Demographic information Socio-demographic and medical information Physical environment The tool incorporates the	Preconditions and target areas include: Health care Rehabilitation Support systems Public awareness Family life and personal integrity	Family interactions Parenting Physical/material wellbeing Emotional wellbeing Disability related supports

	Activity limitations and participation restrictions Environmental factors Contextual information The ICF lists 9 relevant domains in “activities and participation” these domains are: Communication, mobility, self-care, domestic-life, interpersonal interactions and relationships, learning and applying knowledge, community social and civic life, general tasks	Overall		Washington Group on Disability Statistics Short Set questions related to the domains of: Seeing Hearing Walking Self-care Communication	Education Employment Culture Religion Accessibility Sports and recreation Social security and income maintenance	

	and demands, major life areas					
Type of measurement	Questionnaire	Questionnaire using a Likert Scale with the following options: None Mild Moderate Severe Extreme/ cannot do it at all	Questionnaire using a Likert scale with the following options: No-no difficulty Yes-some difficulty Yes a lot of difficulty Cannot do it at all	Questionnaire	The PWD needs to indicate what the level of participation is.The options are: Low Average High	Families discuss and rate whether a need has a low, medium or high priority in terms of whether services are required to meet the need
Reliability & Validity of the tool	These measurement tools primarily assess the severity of the disability as well as how the disability impacts on functional ability, thereby	Studies conducted are in agreement that the WHODAS-2 has good reliability and validity for the assessment of	The tool has been cited to have good reliability and validity	No studies have been conducted to assess reliability and validity of the tool	No studies have been conducted to assess reliability and validity of the tool.	The tool has been found to have a degree of reliability and validity and to have potential to be used as a research tool to explore

	assessing what support needs the PWDs would require.	disability and functioning.				family dynamics and families perceptions of services (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006) However the researchers acknowledge that in some instances a single family member completed the guide and the use of a single person's report on the family opposed to the entire family could have had an impact on this finding.

Challenges/Gaps	In-depth training is needed on use of the ICF, Using the ICF for assessment of needs in daily practice is challenging	More research is needed on the psychometric properties and the cultural adaptations of various translated versions of the WHODAS-2 Limited research has been done in the African context.	Short set does not capture all at risk for experiencing disadvantage associated with disability Does not address functioning with vs. without assistive devices/technology Age of onset of the difficulty is also not reflected	Did not include cognition question from WGDS	No published research has been conducted on this tool. However when the rehabilitation care workers used the tool they reported challenges: with the using the tool in the hospital context as the conditions in the hospital were not reflective of the community with PWDs not having comprehensive knowledge of the barriers and	The tool has not been validated for use in the South African community context and the researchers that validated the tool acknowledge that the structure of the tool reliability within low -income families has not been established.

					facilitators to participation in their community.	

Appendix 11: Afrikaans version of the rehabilitation and health information tool

Draft Health Needs Assessment tool:

Datum van waardebepaling:	
Evalueerder **Rehabiliteer voorsorg werker:**	
Toesighouer:	
Datum van opvolg:	
Demografiese Inligting	
Naam en Van:	

Ouderdom:	**Tipe van probleem**
	☐ **Breinbeserings**
	☐ **Jarelange mediese toestand (bv diabetes, hoë bloeddruk) (spesifiseer)________________**
	☐ **Gehoorverlies**
	☐ **Intellektuele gestremdheid**
	☐ **Geestesgesondheid**
	☐ **Fisiese gestremdheid (spesifiseer)**
	  ☐ **Dwarslaesie**
	  ☐ **Neurologiese**
	  ☐ **Ander(spesifiseer) _________________**
	☐ **Spraakgebrek**
	☐ **Visuele gestremdheid**
	☐ **Ander (spesifiseer) __________________**

Geboorte datum:	
Geslag: ☐ **Vroulik** ☐ **Manlik**	
Adress:	
Leer nommer:	
Kontak nommer: **Uie:** **Famielid:**	
Taal:	
Leefwyse: ☐ **Alleen** ☐ **met familie lede** ☐ **met vriende**	
Tipe behuising ☐ **Pandok/informele huis** ☐ **woonstel/huis**	
Soos wat luik die leefstyl omgewing?	
Hoogste graad van opvoeding:	
Huwelikstatus:	
Werkstatus:	

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AFRIKAANS Health needs Assessment tool 4 January 2016 (Anthea Brinkman Masters)

Instruksie: Verduidelik asbelief jou gesondheid behoftes en hoe jou behoeftes nakom word.

Q1	**Algemene gesondheid:** Hoe sal jy jou gesondheid beskryf in die laaste paar dae? Merk asseblief die reaksie wat jou die beste beskryf	**1___2___3___4___5___6___7___8___9___10** **Swak Goed Baie Goed Uitstekend**	**Aanvanklike assessering**	**Eerste Opvolg (_______ weke)**	**Tweede Opvolg (_______ weke)**
Q2	Wat is die grootste probleem wat jou in die gesig staar om jou gesondheid te verbeter?				
Q3	Wat verstaan jy rondom jou gestremte?				
Q4	Wat gesondheidsdienste gebruik jy?				

	Beskrywing	Het jy 'n behoefte?	Is jou behoefte voldoen?	Wie sal jou behoeftes nakom? (Merk al wat van toepassing is) (die persoon toelaat om dit te noem)	Wat word gedoen om jou behoefte te voldoen? (Hoe is jou behoefte voldoen?)	Kliëntgesentreerde Doelwitte (Spesifieke)	Evalueerder se algemene waarnemings
Q5	**Self sorg:** Het jy hulp nooding om na jouself te sorg , soos bevoorbeeld: ☐bad ☐eet ☐aantrek ☐die gebruik van die toilet	☐Geen behoefte ☐Sommige behoefte ☐'n groot behoefte	☐glad nie ☐'n bietjie ☐meestal voldoen	☐myself ☐dokter ☐Rehabilitasie dienste (RCW / terapeut) ☐Tuisgebaseerde versorger ☐Gemeenskap gesondheids-sentrum ☐Geloof gebaseerde organisasie (e.g. kerk) ☐Tradisionele geneser ☐Familielid ☐Ander (spesifiseer) _____________			

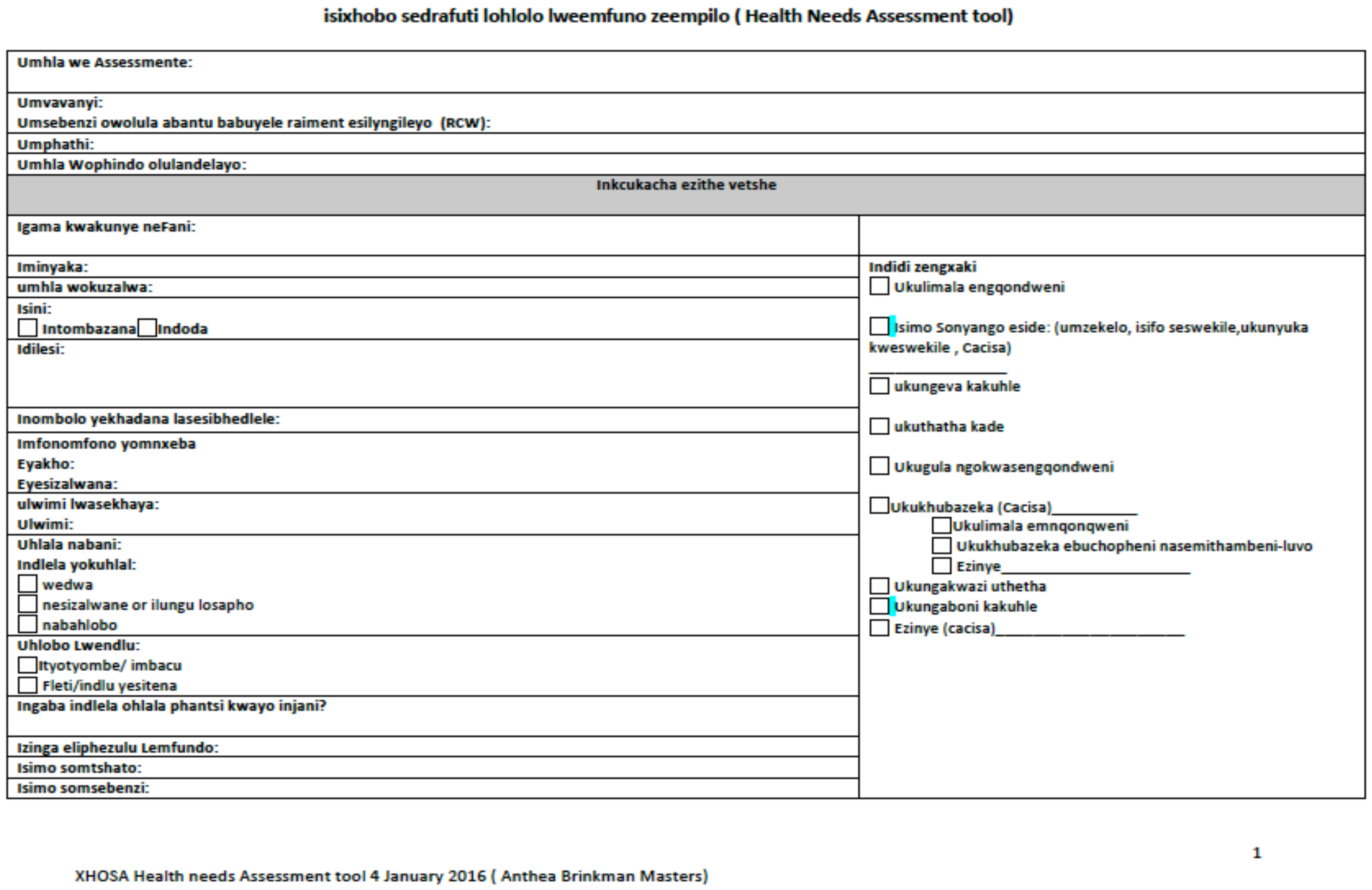
	Beskrywing	Het jy 'n behoefte?	Is jou behoefte voldoen?	Wie sal jou behoeftes nakom? (Merk al wat van toepassing is) (die persoon toelaat om dit te noem)	Wat word gedoen om jou behoefte te voldoen ? (Hoe is jou behoefte voldoen ?)	Kliëntgesentreerde Doelwitte (Spesifieke)	Evalueerder se algemene waarnemings
Q6	**Beweging:** Het jy hulp nodig om rond te beweeg ☐om in en uit na jou huis ☐in jou huis (om in en uit die bed te klim, om na die badkamer toe te gaan, loop) ☐weg van jou huis (in die gemeenskap , in die winkels)	☐Geen behoefte ☐Sommige behoefte ☐'n groot behoefte	☐glad nie ☐'n bietjie ☐meestal voldoen	☐myself ☐dokter ☐Rehabilitasie dienste(RCW/terapeut) ☐Tuisgebaseerde versorger ☐Gemeenskap gesondheids-sentrum ☐Geloof gebaseerde organisasie (e.g. kerk) ☐Tradisionele geneser ☐Familielid ☐Ander (spesifiseer) _____________			
Q7	**Kommunikasie en begrip:** ☐Het jy hulp noodig om mense te vertel van behoeftes soos familie, vriende en vreemdelinge ☐Het jy hulp noodig om mense te verstaan en dat mense jou moet verstaan	☐Geen behoefte ☐Sommige behoefte ☐'n groot behoefte	☐glad nie ☐'n bietjie ☐meestal voldoen	☐myself ☐dokter ☐Rehabilitasie dienste(RCW/terapeut) ☐Tuisgebaseerde versorger ☐Gemeenskap gesondheids-sentrum ☐Geloof gebaseerde organisasie (e.g. kerk) ☐Tradisionele geneser ☐Familielid ☐ Ander (spesifiseer) _____________			
Q8	**Interpersoonlike verhoudings en interaksies:** Het jy hulp nodig om saam met familie, vriende en vreemdelinge te kuier en gesels.	☐Geen behoefte ☐Sommige behoefte ☐'n groot behoefte	☐glad nie ☐'n bietjie ☐meestal voldoen	☐myself ☐dokter ☐Rehabilitasie dienste(RCW/terapeut) ☐Tuisgebaseerde versorger ☐Gemeenskap gesondheids-sentrum ☐Geloof gebaseerde organisasie (e.g. kerk) ☐Tradisionele geneser ☐Familielid ☐ Ander (spesifiseer) _____________			

	Beskrywing	Het jy 'n behoefte?	Is jou behoefte voldoen?	Wie sal jou behoeftes nakom? (Merk al wat van toepassing is) (die persoon toelaat om dit te noem)	Wat word gedoen om jou behoefte te voldoen ? (Hoe is jou behoefte voldoen ?)	Kliëntgesentreerde Doelwitte (Spesifieke)	Evalueerder se algemene waarnemings
Q9	**Seksuele Gesondheid:** Het jy hulp nooding met seksuele opvoeding.	☐Geen behoefte ☐Sommige behoefte ☐'n groot behoefte	☐glad nie ☐'n bietjie ☐meestal voldoen	☐myself ☐dokter ☐Rehabilitasie dienste (RCW/ terapeut) ☐Tuisgebaseerde versorger ☐Gemeenskap gesondheids-sentrum ☐Geloof gebaseerde organisasie (e.g. kerk) ☐Tradisionele geneser ☐Familielid ☐Ander (spesifiseer) _____________			
Q10	**Algemene take:** Het jy hulp noodig met gemeenskap en huishoudelike werk soos inkopies , huis skoonmaak, kook , vervoer, werk	☐Geen behoefte ☐Sommige behoefte ☐'n groot behoefte	☐glad nie ☐'n bietjie ☐meestal voldoen	☐myself ☐dokter ☐Rehabilitasie dienste (RCW/ terapeut) ☐Tuisgebaseerde versorger ☐Gemeenskap gesondheids-sentrum ☐Geloof gebaseerde organisasie (e.g. kerk) ☐Tradisionele geneser ☐Familielid ☐Ander (spesifiseer) _____________			
	Beskrywing					Kliëntgesentreerde Doelwitte (Spesifieke)	Evalueerder se algemene waarnemings
Q11	**Toegang tot inligting oor gesondheid:** Het jy hulp nodig het om inligting oor: ☐hoe om gesond te wees en gesond te bly ? ☐ aansteeklike siektes (bv TB , MIV , seksualiteit oordraagbare infeksies) ☐chroniese siektes van lewenstyl (bv diabetes, hoë bloeddruk) ☐ Middelmisbruik						

	Beskrywing		Kliëntgesentreerde Doelwitte (Spesifieke)	Evalueerder se algemene waarnemings
Q12	**Gewoontes** Het jy enige gewoontes wat jou gesondheid en welstand beïnvloed in 'n goeie manier en in 'n slegte manier.	**Goeie gewoontes:** **Slegte gewoontes:**		
Q13	**Veiligheid en sekuriteit Gesondheid** Was jy ooit mishandel ? Voel jy onveilig? Wil jy om daaroor praat?			
Q14	**Spiritualiteit** Hoe dra jou geestelike oortuigings en praktyke by tot jou gesondheid?			
Q15	**Finansies** Hoe beïnvloed jou finansiële omstandighede jou gesondheid en daaglikse leefstyl in 'n goeie manier en in 'n slegte manier.	**Goeie manier:** **Slegte manier:**		
Q16	**Hindernisse en fasiliteerders** Wat is 'n paar dinge wat jou gesondheid help Wat is 'n paar dinge wat weg neem van jou gesondheid	**Help:** **Neem weg van:**		
Q17	**Other** Is daar enigiets anders wat jy vir my wil vertel oor jou gesondheid			

Assesseringsrubriek	Datum	Kliënt gesentreerde Doelwitte	Evaulator se algemene waarnemings	Progress
Aanvanklike besoek				
Eerste opvolgbesoek (_____ weke)				
Tweede opvolgbesoek (_____ weke)				
Verdere opvolg (_____ weke)				

Appendix 11: isiXhosa version of the rehabilitation and health information tool



isixhobo sedrafuti lohlolo lweemfuno zeempilo (Health Needs Assessment tool)

Umhla we Assessmente:

Umvavanyi:
Umsebenzi owolula abantu babuyele raiment esilyngileyo (RCW):

Umphathi:

Umhla Wophindo olulandelayo:

Inkcukacha ezithe vetshe

Igama kwakunye neFani:

Iminyaka:

umhla wokuzalwa:

Isini:
☐ **Intombazana** ☐ **Indoda**

Idilesi:

Inombolo yekhadana lasesibhedlele:

Imfonomfono yomnxeba
Eyakho:
Eyesizalwana:

ulwimi lwasekhaya:
Ulwimi:

Uhlala nabani:
Indlela yokuhlal:
☐ **wedwa**
☐ **nesizalwane or ilungu losapho**
☐ **nabahlobo**

Uhlobo Lwendlu:
☐ **Ityotyombe/ imbacu**
☐ **Fleti/indlu yesitena**

Ingaba indlela ohlala phantsi kwayo injani?

Izinga eliphezulu Lemfundo:

Isimo somtshato:

Isimo somsebenzi:

Indidi zengxaki
☐ **Ukulimala engqondweni**
☐ **Isimo Sonyango eside: (umzekelo, isifo seswekile,ukunyuka kweswekile , Cacisa)**
____
☐ **ukungeva kakuhle**
☐ **ukuthatha kade**
☐ **Ukugula ngokwasengqondweni**
☐ **Ukukhubazeka (Cacisa)____________**
  ☐ **Ukulimala emnqonqweni**
  ☐ **Ukukhubazeka ebuchopheni nasemithambeni-luvo**
  ☐ **Ezinye___________________________**
☐ **Ukungakwazi uthetha**
☐ **Ukungaboni kakuhle**
☐ **Ezinye (cacisa)____________________________**

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XHOSA Health needs Assessment tool 4 January 2016 (Anthea Brinkman Masters)

Imiyalelo: Uyacelwa uchaze ukuba isimo sakho sempilo nendlela esihoywe ngayo

Q1	Uquko lwezempilo: Ingaba ungayichaza kanjani impilo yakho kwezintsuku zidlulileyo? Uyacelwa utikishe impendulo echaza nkcakasana impendulo yakho.	1____2____3____4____5____6____7____8____9____10 **Kubi** **Kungcono** **Kubhetele** **Kubalasele**	utyelelo lovavanyo	utyelelo loku landlela lokuqala (_______iiveki)	utyelelo loku landlela lwesibini (_______iiveki)
Q2	Yeyiphi eyona ngxaki ojongene nayo ukuzamazama ukuphucula impilo yakho?				
Q3	Yintoni oyaziyo malunga nokukhubazeka kwakho?				
Q4	Zeziphi iinkonzo zempilo ozisebenzisayo?				

	Ingcazelo	Ingaba uyalifuna uncedo	Ingaba izidingo zakho zifezekisiwe	ngubani ofezekisa izidingo zakho (khetha kwezi zikhoyo) (vumela umntu azichaze)	Yintoni eyenziwayo ukufikelela kwizidingo zakho? (Zifikelelwa kanjani isidingo zakho) Ingaba isidingo sakho sifezekisiwe.	iinjongo ozifunayo(cacisa)	iimbono jikelele zomvavanyi
Q5	**Ukuzikhathalela** Ingaba uyaludinga uncedo ekuzinakekeleni njengo: ☐ ukuzihlamba ☐ ukuhlamba ☐ ukutya ☐ ukunxiba ☐ ukuya kwindlu yangasese /ukusebenzisa indlu yangasese	☐Asikho isidingo ☐ Zikhona ezinye zeemfuno ☐ Ikhona kakhulu imfuno	☐Akukhomfuno ☐Zincinci ☐Zifezekisiwe kakhulu	☐ mna ☐ ugqirha ☐ inkonzo yolukeko ngokwasengqondweni(umntu onyanga abantu babuyele kwisimo esilungileyo ☐Home based carer ☐ iziko le zempilo loluntu- ☐ Ezenkolo (umzekelo, icawe) ☐ Igqirha ☐ ilungu losapho ☐enye (cacisa)________________			

	Ingcazelo	**Ingaba uyalifuna uncedo**	**Ingaba izidingo zakho zifezekisiwe**	**ngubani ofezekisa izidingo zakho (khetha kwezi zikhoyo) (vumela umntu azichaze)**	**Yintoni eyenziwayo ukufikelela kwizidingo zakho? (Zifikelelwa kanjani isidingo zakho) Ingaba isidingo sakho sifezekisiwe.**	**iinjongo ozifunayo(cacisa)**	**iimbono jikelele zomvavanyi**
Q6	**Intshukumo** ingaba uyalifuna uncedo ukujikeleze- ☐ ukuphuma ungena ekhayeni lakho ☐ Phakathi ekhayeni lakho (umzekelo, ukuphuma ebhedini, ukuya kwigumbi lohlambela,ukuhamba-hamba)- ☐ kude nekhaya lakho (ekuhlaleni, ezivenkileni)	☐ Asikho isidingo ☐ Zikhona ezinye zeemfuno ☐ Ikhona kakhulu imfuno	☐ Akukhomfuno ☐ Zincinci ☐ Zifezekisiwe kakhulu	☐ mna ☐ ugqirha ☐ inkonzo yolukeko ngokwasengqondweni(umntu onyanga abantu babuyele kwisimo esilungileyo ☐ Home based carer ☐ iziko le zempilo loluntu- ☐ Ezenkolo (umzekelo, icawe) ☐ Igqirha ☐ ilungu losapho ☐ enye (cacisa)_______________			
Q7	**Unxulumelwano nokuqondisisana-** ☐ Ingaba uyaludinga uncedo ukuxelela abantu ngezidingokwakuny neemfuno njengo sapho,isihlobo kwakunye nabantu ongabaziyo? ☐ ingaba uyalifuna uncedo ekuqondisiseni abantu nabo bakuqondisise	☐ Asikho isidingo ☐ Zikhona ezinye zeemfuno ☐ Ikhona kakhulu imfuno	☐ Akukhomfuno ☐ Zincinci ☐ Zifezekisiwe kakhulu	☐ mna ☐ ugqirha ☐ inkonzo yolukeko ngokwasengqondweni(umntu onyanga abantu babuyele kwisimo esilungileyo ☐ Home based carer ☐ iziko le zempilo loluntu- ☐ Ezenkolo (umzekelo, icawe) ☐ Igqirha ☐ ilungu losapho ☐ enye (cacisa)_______________			
Q8	**Ukuhlobana phakathi kwabantu ababini nangaphezulu** Ingaba uyaludinga uncedo ngokunxulumana nosapho,abahlobo kwakunye nabantu ongabaziyo	☐ Asikho isidingo ☐ Zikhona ezinye zeemfuno ☐ Ikhona kakhulu imfuno	☐ Akukhomfuno ☐ Zincinci ☐ Zifezekisiwe kakhulu	☐ mna ☐ ugqirha ☐ inkonzo yolukeko ngokwasengqondweni(umntu onyanga abantu babuyele kwisimo esilungileyo ☐ Home based carer ☐ iziko le zempilo loluntu- ☐ Ezenkolo (umzekelo, icawe) ☐ Igqirha ☐ ilungu losapho ☐ enye (cacisa)_______________			

	Ingcazelo	Ingaba uyalifuna uncedo	Ingaba izidingo zakho zifezekisiwe	ngubani ofezekisa izidingo zakho (khetha kwezi zikhoyo) (vumela umntu azichaze)	Yintoni eyenziwayo ukufikelela kwizidingo zakho? (Zifikelelwa kanjani isidingo zakho) Ingaba isidingo sakho sifezekisiwe.	iinjongo ozifunayo(cacisa)	iimbono jikelele zomvavanyi
Q9	**Olwezocantsi olusempilweni** Ingaba uyaludingauncedo ngolwazi lwezocantsi	☐Asikho isidingo ☐ Zikhona ezinye zeemfuno ☐ Ikhona kakhulu imfuno	☐Akukhomfuno ☐Zincinci ☐Zifezekisiwe kakhulu	☐ mna ☐ ugqirha ☐ inkonzo yolukeko ngokwasengqondweni(umntu onyanga abantu babuyele kwisimo esilungileyo ☐Home based carer ☐ iziko le zempilo loluntu- ☐ Ezenkolo (umzekelo, icawe) ☐ Igqirha ☐ ilungu losapho ☐enye (cacisa)______________			
Q10	**Imisebemnzi jikelele** Ingaba uyalifuna uncedo ngomsebenzi wasekuhlaleni no wasendlini njengo kuya ezivenkileni, ukucoca indlu, ukuhamba-hamba, ukusebenza	☐Asikho isidingo ☐ Zikhona ezinye zeemfuno ☐ Ikhona kakhulu imfuno	☐Akukhomfuno ☐Zincinci ☐Zifezekisiwe kakhulu	☐ mna ☐ ugqirha ☐ inkonzo yolukeko ngokwasengqondweni(umntu onyanga abantu babuyele kwisimo esilungileyo ☐Home based carer ☐ iziko le zempilo loluntu- ☐ Ezenkolo (umzekelo, icawe) ☐ Igqirha ☐ ilungu losapho ☐enye (cacisa)______________			
	Ingcazelo					iinjongo ozifunayo(cacisa)	iimbono jikelele zomvavanyi
Q11	Ufikeleleko kwizaziso zezempilo: Ingaba uyafuna ukuncedwa ngokufumana ulwazi nge- ☐ ungasempilweni uphinde uhlale njani usempilweni ☐ Izifo ezosulelayo (umzekelo, isifo sephepha,intsholongwane ka Gawulayo, isifo sendibano						

	ngezesondo ☐ Isifo zobomi/izifo ezinganyangekiuo (umzekelo, Isifo seswekile, ukonyuka kwegazi ☐ Uxhaphazo lwezinto-			
	Ingcazelo		**iinjongo ozifunayo(cacisa)**	**iimbono jikelele zomvavanyi**
Q12	**Imikhwa** Ingaba unayo imikhwa echaphazela impilo yakho kwakunye nendlela ophila ngayo,kakuhle okanye kakubi-	**Kakuhle:** **Kakubi:**		
Q13	**Ukukhuseleka nokukhuselwa kwezempilo** Wakhe wahlukunyezwa? Ingaba iziva ungakhuselekanga ? (ungathanda ukuthetha ngayo?)			
Q14	**Ezomiya** Ingaba iinkolelo zomoya nezithethe zidlala galelo lini empilweni yakho.			
Q15	**Ezezimali** Ingaba ingxaki zezimali zakho ziyichaphazela kakuhle okanye kakubi impilo yakho nendlela ophila ngayo mihla lee?	**Kakuhle:** **Kakubi:**		
Q16	**Imiqobo nezifundiso** Zeziphi ezinye izinto ezinceda impilo yakho,Iphinde ikwazeziphi ezinye zezinto ezithatha impilo yakho	**Ezincedayo:** **Ezithathayo:**		
Q17	**Enye** Ingaba ikhona enye into othanda ukundixelela yona ngempilo yakho?			

Imiqathango yohlolo	**Umhla:**	**iinjongo ozifunayo(cacisa)**	**iimbono jikelele zomvavanyi**	**isaqhubekeka**
Utyelelo				
Utyelelo loku landlela lokuqala (______iiveki)				
Utyelelo loku landlela lwesibini (______iiveki)				
Utyelo oluzophinde lulandele (______iiveki)				