

A universal framework to evaluate community-based rehabilitation interventions

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Abstract

Community-based rehabilitation (CBR) aims to improve the quality of life for people with disabilities by promoting social inclusion and equal opportunities. Despite its widespread use, there is no standardised framework to evaluate CBR interventions, particularly in low- and middle-income countries (LMICs). This gap limits the ability to assess programme effectiveness and inform policy and practice. This study aimed to develop and pilot a universal evaluation framework for CBR interventions. A pragmatic, multi-method approach was used across four phases. Phase One involved a scoping review to explore existing CBR evaluation frameworks. Phase Two was a systematised review to identify suitable generic patient-reported outcome measures (GPROMs). Phase Three employed a Delphi study to achieve expert consensus on GPROMs and refine the framework. Phase Four piloted the framework in an LMIC setting to assess feasibility. Thematic analysis was conducted on qualitative data from the reviews and pilot study. The Delphi study involved iterative rounds of quantitative and qualitative analysis to establish expert consensus. The scoping review identified a lack of standardised frameworks, and the systematised review highlighted several relevant GPROMs. The Delphi study reached consensus on integrating selected GPROMs into the framework. Pilot testing confirmed the framework's feasibility, adaptability, and relevance in resource-limited settings. The findings highlight the need for a standardised yet adaptable framework to assess CBR outcomes effectively. The developed framework addresses current gaps by offering consistency and contextual flexibility. This study contributes to the development of a universal CBR evaluation framework, with the potential to improve programme assessment, inform policy, and enhance practice in LMICs.

Keywords: community-based rehabilitation, general patient-reported outcome measures, evaluation framework, toolkit


Declaration

I declare that 'A universal framework to evaluate community-based rehabilitation interventions' is my own work, that it has not been submitted for any degree or examination in any other university, and that all the sources I have used or quotes have been indicated and acknowledged by complete references.

Name: Sarah Manig

Date: 25 March 2025

Signed:

A handwritten signature in black ink, appearing to read 'Manig', written in a cursive style.

Acknowledgements

This journey has been one of perseverance, growth, and deep learning, and I am profoundly grateful to those who have supported me along the way.

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This thesis is a reflection not just of my efforts, but of the love and support that has surrounded me from the very beginning. I am deeply grateful to each of you.

Declaration of interest statement

The authors report there are no competing interests to declare.

Dedication

This work is dedicated to all individuals living in communities where access to healthcare remains a challenge. May this research serve as a step towards improving rehabilitation services and fostering equity in healthcare for those who need it most.

To my family—your unwavering support, love, and encouragement have been the foundation of this journey. Thank you for believing in me, for standing by me through every challenge, and for reminding me why this work matters.

Definition of terms

Community-Based Rehabilitation (CBR): A multi-sectoral strategy designed to enhance the quality of life for people with disabilities by promoting social inclusion and equal opportunities in various aspects of life, including health, education, livelihood, social participation, and empowerment (World Health Organization, 2019).

CBR Matrix: A theoretical framework developed by the World Health Organization (WHO) in 2004 that organises CBR activities into five components: health, education, livelihood, social, and empowerment. It serves as the foundational structure for designing and implementing CBR programmes (WHO, 2010).

International Classification of Functioning, Disability, and Health (ICF): A framework developed by WHO to describe and organise information on functioning and disability. The ICF model integrates both medical and social models of disability and focuses on the interaction between health conditions and contextual factors, including environmental and personal factors (WHO, 2021).

Patient-Reported Outcome Measures (PROMs): Standardised questionnaires completed by patients to assess their perceptions of health status, functional status, and health-related quality of life. PROMs are used to document health outcomes and measure the quality of healthcare from the patient's perspective (Kingsley & Patel, 2017).

Generic PROMs: A type of PROM that is applicable to a broad range of patient groups and conditions, allowing for comparisons across different health conditions and settings. Generic PROMs are particularly useful in evaluating diverse populations, such as those involved in CBR programmes (Devlin & Brooks, 2017).

Delphi Technique: A systematic and iterative method used to achieve consensus among a panel of experts through a series of questionnaires. It is often used in research to refine concepts and reach agreement on specific issues, such as the selection of appropriate PROMs for CBR evaluation (Diamond et al., 2014).

Operational Definitions:

Disability: Defined by WHO as an umbrella term encompassing impairments, activity limitations, and participation restrictions that result from the interaction between a person with a health condition and contextual factors, including environmental and personal influences (WHO, 2021).

Biopsychosocial Model: A holistic approach to understanding health and disability that considers the interaction between biological, psychological, and social factors. This model is integral to the ICF framework (Üstün et al., 2003).

Rehabilitation: The process of enabling individuals with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychological, and social functional levels. Rehabilitation includes interventions designed to optimise functioning and reduce disability in individuals with health conditions (WHO, 2021).

Evaluation Framework: A structured approach used to assess the impact and effectiveness of interventions, such as CBR programmes. The framework may include various tools and methods, such as GPROMs, to measure outcomes and inform decision-making (Cieza et al., 2020).

Empowerment: In the context of CBR, empowerment refers to enabling individuals with disabilities to take control over their lives, make decisions, and participate fully in society. Empowerment is a key goal of CBR interventions, aiming to increase self-efficacy and independence (WHO, 2019).

Social Inclusion: The process of improving the terms of participation in society, particularly for individuals who are disadvantaged or marginalised, such as those with disabilities. Social inclusion is a central aim of CBR programmes (WHO, 2019).

Acronyms and Abbreviations

CBR	Community-Based Rehabilitation
CRPD	Convention on the Rights of Persons with Disabilities
FIM	Functional Independence Measure
GPROMs	Generic Patient-Reported Outcome Measures
ICF	International Classification of Functioning, Disability, and Health
LMICs	Low- to Middle-Income Countries
PWD	Persons with Disabilities
RIT	Roads to Inclusion Toolkit
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
USER	Utrecht Scale for Evaluation of Rehabilitation
WHO	World Health Organization
WHODAS	World Health Organization Disability Assessment Schedule

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CHAPTER ONE: INTRODUCTION TO THE STUDY

1.1 Negative impacts of disability on individual, caregiver and household

Several obstacles hinder the full social and economic inclusion of individuals with disabilities. These include inaccessible environments and transportation, a lack of assistive technologies and devices, communication barriers, gaps in service availability, and widespread societal discrimination and stigma (Ennion & Manig, 2019; WHO, 2022). These unfair conditions exacerbate health inequities and contribute to a cycle of exclusion and marginalisation (Hanass-Hancock & Dehgahye, 2016). People with disabilities tend to experience poorer overall health, lower levels of educational attainment, fewer economic opportunities, and higher rates of poverty compared to those without disabilities (WHO, 2001). Disability affects an estimated 1.3 billion people worldwide, representing 16% of the global population, or one in six individuals (WHO, 2022).

It is widely recognised that poverty and disability are interconnected in a reinforcing cycle, where each aggravates the other (Hanass-Hancock & Dehgahye, 2016). Poverty, along with limited access to education, healthcare, and employment, increases the likelihood of impairment and disability (United Nations: Department of Economic and Social Affairs, 2019). In turn, inadequate support and accommodations for people with disabilities can lead to poverty, as they face greater barriers to accessing education, healthcare, and employment opportunities (Hanass-Hancock & Dehgahye, 2016).

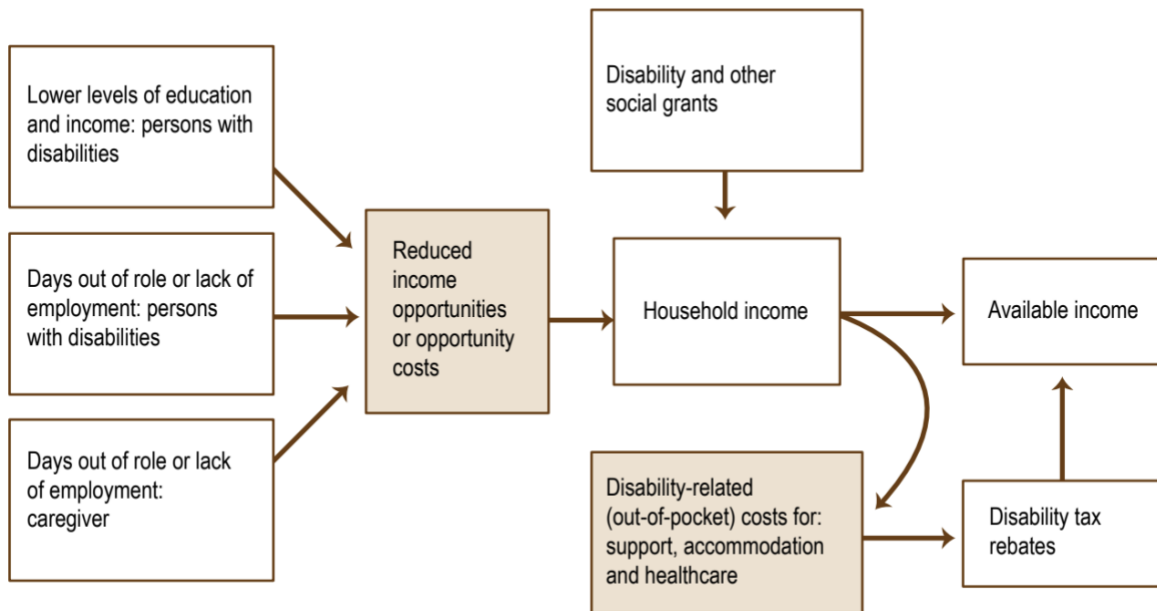


Figure 1.1: The financial and economic costs of disability to households (Hanass-Hancock & Dehgahye, 2016)

The financial and economic challenges faced by households with persons with disabilities (PWDs) are multifaceted and deeply interconnected (Hanass-Hancock & Dehgahye, 2016). One of the major contributors to economic strain is the reduction in income opportunities for PWDs (Louw et al. 2023; Visagie and Swartz 2016). Limited educational attainment and lower income levels significantly reduce employment prospects for these individuals, leading to long-term financial instability (Hanass-Hancock & Dehgahye, 2016). Caregivers, who often play a critical role in supporting individuals with disabilities, may experience reduced employment opportunities themselves, as they are forced to take time off from work or forgo employment entirely to provide care (Keita Fakeye et al., 2023; Moosa-Tayob & Risenga, 2022).

In some cases, social safety nets, such as disability and other social grants, provide partial relief to these households (Moosa-Tayob & Risenga, 2022). However, these grants rarely compensate for

the substantial reduction in earning capacity. The financial pressure is compounded by out-of-pocket expenses directly related to managing disability, including costs for healthcare, support services, and necessary accommodations. These additional expenses place an even greater strain on the household budget (Hanass-Hancock & McKenzie, 2017).

The cumulative effect of reduced employment opportunities, caregiver constraints, and out-of-pocket expenses underscores the financial challenges PWDs and their families face (M’kumbuzi & Myezwa, 2016; Visagie & Swartz, 2016). In LMICs, where resources are already limited, promoting the independence and economic empowerment of PWDs could alleviate some of the pressures on these overburdened systems (Hanass-Hancock & McKenzie, 2017). Rehabilitation initiatives foster economic empowerment and income-generating opportunities for PWDs, which can have a positive impact on local economies (Mousavi, 2015). When PWDs are equipped with the necessary support, skills, and resources to engage in productive activities, they can become active contributors to their communities, thereby enhancing economic growth and reducing reliance on social welfare systems (Shrivastava et al., 2015).

1.1.1 International frameworks for inclusion and health promotion of persons living with disabilities

The Community-Based Rehabilitation (CBR) Guidelines (World Health Organization, United Nations Educational, Scientific and Cultural Organization, International Labour Organization, & International Disability and Development Consortium [WHO, UNESCO, ILO, & IDDC], 2010a–g) represent the most comprehensive international guidance for implementing CBR. Published as seven booklets, they operationalise the 2004 Joint Position Paper and provide detailed direction for stakeholders. The five central booklets correspond to the CBR Matrix domains: Health (WHO

et al., 2010b), Education (WHO et al., 2010c), Livelihood (WHO et al., 2010d), Social (WHO et al., 2010e), and Empowerment (WHO et al., 2010f). These are accompanied by an Introductory Booklet (WHO et al., 2010a), which outlines principles, implementation strategies, and monitoring and evaluation steps, and a Supplementary Booklet (WHO et al., 2010g), which provides cross-cutting considerations.

Of particular importance, the Introductory Booklet emphasises the need for monitoring and evaluation at all stages of CBR. It outlines steps such as identifying indicators, selecting appropriate data sources, and ensuring feedback into programme decision-making. However, while the guidelines provide useful conceptual direction, they do not prescribe standardised outcome measures or tools for assessing individual-level change. This gap reinforces the rationale for the present study, which seeks to develop a framework that can support systematic evaluation of CBR outcomes, particularly in resource-constrained settings.

Countries are obligated under international human rights law, and sometimes national legislation, to address the health disparities experienced by individuals with disabilities. Two key international frameworks are particularly relevant to promoting health equity for PWDs (WHO, 2023).

The Convention on the Rights of Persons with Disabilities (CRPD) represents the most advanced international human rights instrument on the rights of PWDs in terms of scope and depth. The CRPD and its Optional Protocol were adopted by the United Nations General Assembly in 2006 and entered into force in 2008. The CRPD aims to ensure that persons with disabilities—a group often rendered ‘invisible’ in legislation, policies and practices—are able to enjoy their human rights on an equal and equitable basis. The CRPD requires governments to meet the rehabilitation needs of citizens (Gilmore et al., 2017). Over 80% of countries globally ratified the CRPD, but

despite the existence of strategies such as community-based rehabilitation (CBR) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), the rights of PWDs are still frequently violated (Bloese et al., 2021).

The second key framework is the World Health Assembly Resolution WHA74.8. In May 2023, the Resolution on Strengthening Rehabilitation in Health Systems was adopted unanimously by the 194 Member States of the World Health Assembly, the highest health policy-setting body. The resolution aims to scale up and integrate rehabilitation into health systems as part of Universal Health Coverage to address the growing rehabilitation needs due to the global ageing population, the increasing prevalence of non-communicable diseases, and the emergence of new infectious diseases such as COVID-19 (Seijas et al., 2023).

In addition to the Resolution, WHO has developed practical tools to support the integration of rehabilitation into health systems. The Systematic Assessment of Rehabilitation Situation (STARS) tool provides a structured method for assessing national rehabilitation capacity and priorities (WHO, 2017, 2019), while the Template for Rehabilitation Information Collection (TRIC) standardises the collection of data on rehabilitation services (WHO, 2021). These resources demonstrate WHO's emphasis on embedding rehabilitation into universal health coverage and on strengthening system-level monitoring and evaluation. However, they remain primarily oriented toward system and policy assessment rather than individual-level outcome measurement, underscoring the continued need for tools that capture patient-centred outcomes within community-based rehabilitation contexts.

To achieve the identified health goals, it is essential that health services are available across all levels of care and for all health needs, including health promotion, prevention, treatment,

rehabilitation, and palliative care (Conradie et al., 2022). Rehabilitation plays a critical role in this continuum of care. In line with the UNCRPD, rehabilitation is a vital service throughout the lifespan of PWDs, essential at all levels of care, and relevant for a wide range of health conditions (Conradie et al., 2022).

1.2 Positive impact of CBR on disability

Rehabilitation is a vital part of healthcare, bridging the gap between curative services and helping individuals regain their ability to fully participate in all aspects of life (Visagie & Swartz, 2016). CBR was first initiated by the WHO following the International Conference on Primary Health Care in 1978 and the resulting Declaration of Alma-Ata (Khasnabis et al., 2010). CBR was seen as a strategy to improve access to rehabilitation services for people with disabilities in developing countries; however, over the past 30 years its scope has considerably broadened (Bongo et al., 2018). Initially focused on improving access to health and rehabilitation services, CBR has evolved into a broader approach aimed at poverty reduction, social inclusion, and creating equal opportunities by addressing areas such as education, livelihoods, and empowerment (Blöse et al., 2021; Cieza et al., 2020; Hartley et al., 2009).

CBR is carried out through the collaborative efforts of individuals with disabilities, their families, communities, and a range of government and non-governmental organisations across health, education, vocational training, and social services (WHO, 2010). The WHO also highlights that many development initiatives have traditionally been top-down, driven by policymakers distant from the communities they aim to serve. Today, it is recognised that sustainable development depends on involving communities at every stage of the process. Despite its widespread application, there is no consensus on how to effectively evaluate the impact and effectiveness of

CBR programmes, particularly in low- and middle-income countries (LMICs) where resources are limited (Grandisson et al., 2014).

1.3 The challenges of implementing and evaluating CBR

CBR is designed to address the comprehensive needs of PWDs and their family members across various aspects of life (Rahman, 2018). However, rehabilitation services are frequently under-prioritised and remain under-resourced in many countries, leading to significant unmet needs and barriers to access, especially in LMICs (Cieza et al., 2020).

Over the past four decades, various forms of CBR evaluation have been conducted in countries where the programme is implemented. However, there is no clear consensus on the most appropriate methodologies for evaluating CBR (Shumba et al., 2020). Despite the recognised role of CBR in improving outcomes for individuals with disabilities, the absence of standardised evaluation frameworks severely limits the ability to assess its true impact. This gap in evaluation not only impedes the optimisation of CBR programmes but also restricts the scalability of successful interventions, particularly in resource-constrained settings.

The WHO has acknowledged the importance of CBR and emphasised the need for its enhancement through improved monitoring and evaluation (Iemmi et al., 2016; Lukersmith et al., 2013). This focus is a key objective of the recently endorsed Rehabilitation 2030 initiative and the Global Disability Action Plan (Mason et al., 2017).

1.4 A lack of standardised measures to evaluate positive impacts of CBR

Despite numerous claims about the effectiveness, efficiency, and appropriateness of CBR, there is limited scientific evidence supporting these assertions (Cornielje et al., 2008; Hartley et al., 2009;

Shumba et al., 2020; Velema et al., 2008). Much of the existing evidence is drawn from studies in high-income countries, which may not be directly applicable to LMIC settings (Cornielje et al., 2008). Several efforts have been made to establish standardised data collection methods for CBR (Sharma, 2004). These attempts have focused on identifying common CBR domains, proposing evaluation frameworks, and developing specific evaluation indicators to measure the effectiveness of CBR programmes. However, achieving a universally accepted framework remains an ongoing challenge (Mason et al., 2017). For the purpose of this study, a *framework* is defined as an organised set of principles and components that structure how CBR outcomes are assessed. By *evaluation*, this thesis refers specifically to the assessment of outcomes for individuals participating in CBR programmes, rather than to comprehensive programme or systems-level evaluations. This distinction is important, as many CBR evaluations to date have focused on programme implementation, while fewer have developed standardised tools for capturing participant-level outcomes (Proctor et al., 2011)

The lack of universally accepted framework with evaluation tools has hindered efforts to conduct meta-analyses and robust evaluations of CBR programmes. Without these methods, it is difficult to substantiate claims of CBR's effectiveness or to identify best practices. Researchers such as Wirz and Thomas (2002) have advocated for the development of "robust and easy-to-use" indicators tailored to the specific needs of CBR programmes, yet such a framework has not been fully developed. Additionally, the diversity of CBR contexts and stages of development complicates the creation of a one-size-fits-all evaluation model (Grandisson et al., 2014).

A standardised framework with evaluation tools, even with its limitations, would provide crucial insights and facilitate more meaningful comparisons across different programmes (Chung et al., 2011; Cornielje et al., 2008; Velema et al., 2008). Qualitative research is essential to complement

quantitative measures and explore broader outcomes such as quality of life, well-being, and social inclusion (Cornielje et al., 2008). Establishing such a framework would ultimately support evidence-based policymaking, enhance resource allocation, and strengthen advocacy efforts for CBR.

1.5 Aim of the study

The aim of the study is to develop and pilot a universally applicable framework for evaluating CBR interventions.

1.6 Objectives of the study

- 1: To explore the literature on the current frameworks utilised for evaluating CBR interventions.
- 2: To explore the literature on existing generic patient-reported outcomes (GPROMs) used in the evaluation of CBR interventions.
- 3: To reach consensus on the most suitable GPROMs and develop a proposed theoretical framework for the evaluation of CBR interventions.
- 4: To evaluate the feasibility, strengths, and areas for improvement of the newly developed evaluation framework by piloting it in a real-world LMIC context in Africa, thereby generating actionable insights for its refinement and broader applicability.

1.7 Research questions

1. What frameworks are currently being used to evaluate CBR interventions?
2. What generic patient-reported outcomes are available for assessing the effectiveness of CBR interventions?

3. Which GPROMs are most appropriate for evaluating CBR interventions, and how can they be integrated into a cohesive theoretical framework?
4. What insights into feasibility, strengths, and areas for improvement can be gained from piloting the newly developed evaluation framework in a real-world LMIC context in Africa?

1.8 Significance of the study

CBR is a crucial strategy for enhancing the quality of life for individuals with disabilities, particularly in LMICs, where access to rehabilitation services remains limited. Despite its widespread implementation, the absence of a standardised, universally applicable evaluation framework has hindered the ability of policymakers, practitioners, and researchers to assess the effectiveness of CBR interventions. This study addresses this critical gap by developing and piloting a robust evaluation framework tailored to CBR programmes. The significance of this research lies in its potential to provide a structured, adaptable tool for evaluating CBR interventions, ensuring that outcomes are systematically measured and compared across diverse contexts.

By integrating a multi-method approach, including a scoping review, systematised review, Delphi study, and pilot testing in a real-world LMIC setting, this study contributes to the academic discourse on rehabilitation evaluation while also offering practical solutions for improving service delivery. The proposed framework, underpinned by expert consensus and evidence-based selection of GPROMs, enhances the ability of rehabilitation professionals to demonstrate programme impact, secure funding, and refine service provision. Furthermore, by establishing a standardised approach to CBR evaluation, this research supports international efforts to promote disability-inclusive development and aligns with global initiatives such as the WHO's Rehabilitation 2030

agenda. Ultimately, this study advances knowledge in the field of rehabilitation sciences, fosters improved policymaking, and enhances the quality and equity of rehabilitation services for individuals with disabilities in resource-limited settings.

1.9 Structure of thesis

This thesis is organised into eight chapters, each focusing on a distinct aspect of the study. The structure is designed to guide the reader through the research process, from the initial background and literature review to the development, implementation, and evaluation of the proposed framework.

Chapter One: Introduction to the study

This chapter provides an overview of the study, including the background, problem statement, research aims, objectives, and research questions. It introduces the significance of the study and outlines the structure of the thesis. The chapter sets the scene of the need for CBR due to the negative impacts of disability, along with the challenges of evaluating CBR interventions and why a standardised evaluation framework is important.

Chapter Two: Research methodology

This chapter outlines the research design and methodology used in the study. It details the multi-phase research approach, which includes a scoping review, systematised review, Delphi study, and pilot study. The chapter describes the data collection and analysis methods, the selection criteria for participants and studies, and the ethical considerations taken into account during the research process.

Chapter Three: A scoping review of the frameworks used to guide the evaluation of CBR interventions

This chapter presents the findings of the scoping review conducted to identify and analyse existing frameworks for evaluating CBR interventions. It examines the strengths and limitations of these frameworks and discusses their applicability in different contexts. The insights gained from this review inform the subsequent phases of the research.

Chapter Four: A systematised review of generic patient-reported outcome measures in the evaluation of CBR interventions

This chapter focuses on the systematised review of existing GPROMs used in the evaluation of CBR interventions. It identifies the most commonly used GPROMs, assesses their validity and reliability, and evaluates their relevance to the Activity and Participation domains of the International Classification of Functioning, Disability, and Health (ICF). The findings of this review contribute to the selection of suitable GPROMs for the proposed evaluation framework.

Chapter Five: Development of an evaluation framework – a Delphi study

In this chapter, the Delphi study is conducted to achieve consensus among experts on the most appropriate GPROMs for evaluating CBR interventions. The chapter describes the iterative process of the Delphi study, including the design of the questionnaires, the selection of experts, and the analysis of responses. The outcomes of the Delphi study are used to design and refine the proposed evaluation framework.

Chapter Six: Pilot study

This chapter details the development of the proposed evaluation framework based on the findings from the previous chapters. It includes the theoretical underpinnings of the framework, the selection of evaluation measures, and the design of the pilot study. The chapter also discusses the implementation of the pilot study in an LMIC in Africa, including the challenges encountered and the results obtained.

Chapter Seven: Conclusion and recommendations

The final chapter provides a comprehensive discussion of the study's findings, relating them back to the research aims, objectives, and questions outlined in Chapter One. It highlights the contributions of the study to the field of CBR, discusses the implications for policy and practice, and identifies areas for future research. The chapter concludes with recommendations for the adoption of the proposed evaluation framework and its integration into global CBR policy.

CHAPTER TWO: RESEARCH METHODOLOGY

This chapter provides an overview of the overarching methodological concepts employed in this research study, starting with the overarching research paradigm and ending with the limitations of this study.

2.1 Overarching research paradigm

This study is grounded in a pragmatic research paradigm, which emphasises practical concerns and real-world problem-solving of complex phenomena. Pragmatism, as a philosophical tradition, originates from the works of John Dewey, William James, and Charles Sanders Peirce, who highlighted the significance of inquiry focused on addressing real-world issues through practical solutions (Dewey, 1938; James, 1907).

The pragmatic paradigm is particularly well-suited to mixed methods research, as it prioritises practical outcomes and flexibility in the selection of methods. According to Creswell and Plano Clark (2011), the integration of diverse methods under a pragmatic framework allows researchers to address research questions using the most effective tools available, regardless of their traditional association with either qualitative or quantitative paradigms. Morgan (2007) also supports this view, arguing that pragmatism provides a middle ground between the rigid dichotomies of positivism and constructivism, enabling researchers to focus on "what works" in answering the research questions at hand.

This flexibility is crucial in a study of this nature, as it allows for the iterative refinement of the evaluation framework across different phases, ensuring that both exploratory and confirmatory research questions are effectively addressed. The pragmatic approach supports the integration of

diverse data sources and perspectives, enhancing the validity and reliability of the research findings (Patton, 2014).

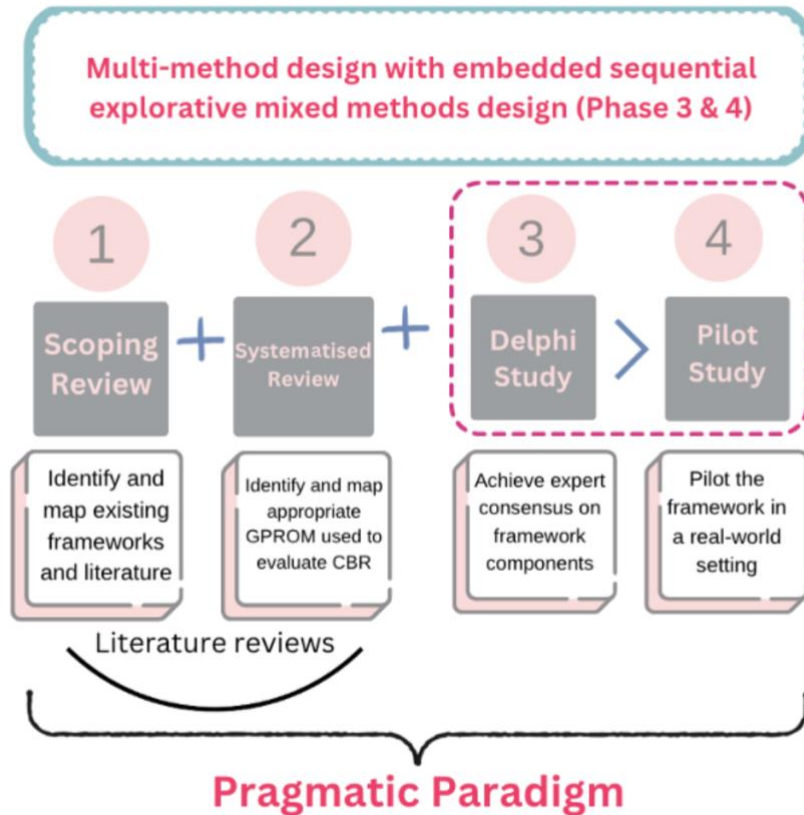


Figure 2.1: Multi-method design with embedded sequential explorative mixed methods design (Author’s own design, 2024)

2.2 Study design

2.2.1 Overall study design

As outlined in Chapter 1, the WHO CBR Guidelines (WHO, UNESCO, ILO, & IDDC, 2010a–g) include steps for monitoring and evaluation but do not prescribe standardised outcome measures. This methodological gap underpins the rationale for the scoping review and subsequent multi-

phase design adopted in this study. This research study utilises a multi-method design, with an embedded sequential explorative mixed method design in Phase Three and Four. Mixed methods research involves the combination of both quantitative and qualitative data collection and analysis within a single study or research programme (Creswell et al., 2004; Schoonenboom & Johnson, 2017). This approach goes beyond merely gathering different types of data; it entails integrating, connecting, or blending the data at some point during the research process to provide a more comprehensive understanding of the research questions. The integration of multiple perspectives within the design of this study—such as scoping review, systematised review, Delphi studies, and pilot testing—aligns with the strengths of mixed methods research in producing a more complete understanding of complex research problems.

In a sequential design, the data collection and analysis of one method (either qualitative or quantitative) occur first, and the findings from this initial phase directly inform and shape the subsequent phase. The sequential element emphasises a dependent relationship between the phases, where the results of the first phase are used to develop or refine the research questions, instruments, or focus of the second phase (Schoonenboom & Johnson, 2017).

By employing this **sequential explorative approach**, the study systematically moves from broad literature exploration to focused expert validation and practical testing. The multi-method design with its embedded mixed methods component supports a comprehensive and iterative research process that is well-suited to the complexity of evaluating CBR interventions, allowing researchers to develop a detailed, multifaceted perspective by integrating insights from both qualitative and quantitative data (Creswell & Plano Clark, 2011).

2.2.2 Rationale for chosen study designs in individual phases

This study was conceptually informed by three main sources: (1) the ICF, which provides a biopsychosocial model for understanding functioning and disability; (2) the CBR Matrix and Guidelines (WHO et al., 2010a–g), which operationalise domains of intervention and evaluation; and (3) contemporary WHO rehabilitation initiatives, including STARS (WHO, 2017, 2019) and TRIC (WHO, 2021), which emphasise system-level monitoring. Together, these frameworks shaped the study's design, ensuring that the development of an evaluation framework was both theoretically grounded and practically applicable.

2.2.2.1 Phase One: Scoping review of CBR evaluation frameworks (Chapter Three)

In Phase One, the study commenced with a scoping review which aimed to meet the first study objective of the research project: To explore the literature on the current frameworks utilised for evaluating CBR interventions.

A scoping review was selected as the most appropriate method for this initial phase due to its ability to provide a broad and comprehensive overview of the existing literature. Scoping reviews are particularly suited to areas where the literature is diverse and fragmented, making them ideal for exploring under-researched topics or complex fields such as CBR (Levac et al., 2010). Unlike systematic reviews, which are typically more narrowly focused, the flexibility of a scoping review allows for the inclusion of a wide range of study designs and evidence types. This flexibility was crucial in this phase, as it enabled the research to adapt and refine its focus in response to emerging insights, ensuring a thorough and nuanced understanding of the current state of the field (Peters et al., 2015).

Integration with subsequent phases: The scoping review provided a broad yet structured overview of the current research, synthesising knowledge on existing frameworks and highlighting where limitations and inconsistencies exist in evaluating CBR interventions, especially in low-income and rural contexts. The review not only helped outline the foundational knowledge required to understand the evaluation of CBR interventions but also directly supported the research question, “What frameworks are currently being used to evaluate CBR interventions?” by identifying the most appropriate frameworks used to guide the evaluation process.

In this way, the scoping review contributed directly to advancing the study aim by shaping the criteria and key areas that would be researched in subsequent phases. Additionally, the insights from this phase informed the focus of the **Delphi study**, helping to refine the framework based on expert consensus. Ultimately, the scoping review facilitated a strategic and well-targeted research trajectory that moved the study closer to achieving its objectives of creating a robust, applicable evaluation framework for CBR interventions.

2.2.2.2 Phase Two: Systematised review of GPROMs (Chapter Four)

Objective: The second phase of the research involved conducting a systematised review aimed to meet the second study objective: To explore the literature on existing GPROMs used in the evaluation of CBR interventions.

A systematised review was selected for this phase because it effectively balances the rigour of a systematic review with the practical considerations needed for a focused evaluation of specific measures. Systematised reviews are particularly valuable in situations where a comprehensive systematic review is not feasible due to time or resource constraints, but a need exists to evaluate the available evidence in a structured and methodologically sound manner (Grant & Booth, 2009).

The structured methodology of the systematised review, while less exhaustive than a full systematic review, allowed for an efficient yet thorough assessment of the existing literature. This efficiency is critical in emerging research areas such as CBR, where the available literature may not yet be extensive enough to warrant a full systematic review but still requires a rigorous evaluation (Grant & Booth, 2009). Moreover, the systematised review is often employed in academic contexts, making it a pragmatic choice for this phase, where the need to assess GPROMs within a constrained time frame was paramount (Grant & Booth, 2009).

The outputs from the systematised review were instrumental in shaping the next phase, the Delphi study. The systematised review provided a list of GRPOMs, which were described as appropriate tools to evaluate CBR interventions. These GPROMs were presented to experts during the Delphi study and the search was expanded to include any suggested GPROMs that the experts were familiar with. This phase ensured that the measures considered in the Delphi study were both relevant and evidence-based, thereby enhancing the validity of the consensus-building process, preparing for more detailed assessments and practical applications in the subsequent phases of the research (Creswell & Plano Clark, 2011).

2.2.2.3 Phase Three: Delphi study for consensus on GPROMs and framework development (Chapter Five)

Objective: The third phase of the research involved conducting a Delphi study aimed at achieving the third study objective: To reach consensus on the most suitable GPROM and develop a proposed theoretical framework for the evaluation of CBR interventions.

The Delphi study was chosen for this phase due to its suitability in situations where expert opinion is critical for the development and refinement of a framework (Turoff & Linstone, 2011). A Delphi

study is particularly effective as it involves multiple rounds of structured feedback, allowing experts to reach consensus on complex issues without the influence of dominant voices, which can be a concern in face-to-face discussions (Okoli & Pawlowski, 2004). This iterative approach is valuable for continuously refining the proposed framework, ensuring that it is both robust and widely accepted by those with deep knowledge and experience in CBR interventions (Hsu & Sandford, 2012). The structured yet flexible nature of the Delphi study makes it an ideal method for capturing diverse expert perspectives and synthesising them into a cohesive framework that is well-aligned with professional standards and practical needs.

The consensus achieved during the Delphi study provided a solid foundation for the subsequent pilot testing phase. By refining the framework through expert input, the Delphi study ensured that the final framework was well prepared for practical application in a real-world setting. The outputs from this phase—specifically, the finalised components of the framework—were directly implemented in the pilot testing phase, where the framework’s practicality and effectiveness were explored in a real-world context (Creswell & Plano Clark, 2011).

Sequential and Concurrent Elements: The Delphi study is inherently sequential, with each round of feedback building on the results of the previous round to progressively refine the framework. However, there are also concurrent elements, as experts simultaneously contribute their insights during each round of the study (Skulmoski & Hartman, 2007). This combination of sequential and concurrent processes allowed for continuous refinement while ensuring that each iteration of the framework was based on the most current and comprehensive expert input available.

2.2.2.4 Phase Four: Pilot testing of the evaluation framework (Chapter Six)

Objective: The final phase of this research involved pilot testing the proposed evaluation framework in a real-world setting, specifically within the context of CBR interventions in OR Tambo District, Eastern Cape, South Africa. The primary aim of this phase was to meet the fourth study objective: *To pilot the newly developed framework for feasibility in an LMIC in Africa.*

The pilot testing phase was designed as a qualitative study, using semi-structured interviews as the primary data collection instrument. This choice was driven by the need to gather rich, detailed insights from stakeholders directly involved in the implementation of the framework. Semi-structured interviews were particularly suitable for this phase due to their flexibility and depth, allowing for a comprehensive exploration of the experiences and perceptions of practitioners, participants, and other relevant stakeholders. These interviews provided an opportunity to delve into the practical challenges and successes encountered during the framework's application, offering a nuanced understanding that could not be captured through quantitative methods alone (Chan et al., 2017).

The qualitative nature of this phase was central to its purpose. Pilot studies are invaluable for generating insights and lessons that inform subsequent studies (Polit & Beck, 2014). In this case, the semi-structured interviews were designed to understand the ease of use, clarity, cultural relevance, and any challenges encountered with regard to the suggested framework. However, the flexible format of these interviews also allowed for the exploration of emerging themes and issues that arose during discussions, making it possible to gather in-depth, contextual feedback on the framework's implementation.

The pilot testing phase served as the culmination of all the previous phases in the study. The framework tested during this phase had been meticulously developed and refined through the

scoping review, systematised review, and Delphi study. The insights and feedback obtained from the semi-structured interviews during the pilot testing were critical in validating the framework's practicality and ensuring its readiness for broader implementation. This phase provided the final, real-world validation of the framework, linking the theoretical and consensus-driven components developed earlier with practical application in the field (Creswell & Plano Clark, 2011). The iterative feedback loop created during this phase allowed for the final adjustments to be made, ensuring that the framework would be more appropriate when tested in additional settings.

Overall, the pilot phase was essential in reaching a more feasible framework. It provided a critical opportunity to validate the framework in a real-world setting, ensuring that it met the practical needs of those using it in CBR interventions.

2.2.2.5 Integration across phases

Throughout these phases, integration occurs at key points where findings from one phase directly inform the next. Phase One lays a theoretical foundation by identifying the most appropriate frameworks used to guide the evaluation of CBR interventions. Moving into Phase Two, the research proceeds with a systematised review that aimed to explore the literature on existing GPROMs used in the evaluation of CBR interventions. Phase One and Two comprise the literature review component of the study, establishing an evidence base for the development of the evaluation framework.

In Phase Three, the study transitions into a Delphi study, marking the start of the embedded mixed methods design. This phase engages a panel of experts in an iterative process to achieve consensus on the key components of the evaluation framework. By conducting three rounds of feedback and refinement, the Delphi study ensures that the framework is validated by those with specialised

knowledge in the field. This consensus-building approach is critical for ensuring that the framework developed is applicable prior to introducing it into a real-world setting.

The final phase, Phase Four, is the pilot study, which tests the developed framework in a real-world setting. This phase is designed to assess the feasibility and practicality of the framework, providing valuable insights that may lead to further refinement. Testing the framework in an applied context ensures that it is not only theoretically sound but also functional and adaptable in practical settings.

2.3 Research setting

2.3.1 Phase One, Two and Three: Scoping, systematised review and Delphi study

The scoping and systematised review, as a literature-based methodology, was not limited to a particular geographic or institutional setting. For the Delphi study, experts from various locations across the globe were included to ensure a diverse and comprehensive range of perspectives.

2.3.2 Phase Four: Pilot study

2.2.3.1 Geographical location

The pilot study was conducted in the OR Tambo District in the Eastern Cape in South Africa. The municipality spans an area of 12,141 km² and includes a mix of rural and semi-urban areas. The district comprises five local municipalities: King Sabata Dalindyebo, Nyandeni, Mhlontlo, Port St Johns, and Ingquza Hill. This region covers approximately 80% of what was formerly the marginalised Transkei homeland, making it a key focus area for integrated rural development initiatives (O.R Tambo district municipality 2010).



Figure 2.2: Map of OR Tambo District municipalities in the Eastern Cape (O.R Tambo district municipality 2010)

Health services are delivered by one tertiary hospital, two regional hospitals, 12 district hospitals, 11 community health clinics, and 49 clinics (O.R Tambo district municipality 2010). The area is classified as rural because access to services is a major challenge. Basic services are also a major problem. It has been reported that most of the population in the OR Tambo District do not have access to clean water or satisfactory sanitation, with the majority living below the poverty line (Nkamisa et al., 2021). Although many new clinics have been built in rural areas since apartheid in 1994, large differences remain in the number of facilities per population, utilisation rates and staffing levels (Conradie et al., 2022; Maphumulo & Bhengu, 2019). According to Gaede and Versteeg (2011), this reflects under-provisioning in rural areas. The new facilities in rural areas often cannot be adequately utilised due to a lack of human resources (Conradie et al., 2022).

Rural hospitals and clinics form part of a larger referral system, which is not always based on rational planning but rather on historical factors such as location and, perhaps more importantly, availability of services (Gaede & Versteeg, 2011). The district report for the OR Tambo region in

the Eastern Cape reveals that most of its population live in substandard conditions often associated with “rural” living (Schoeman et al., 2010; Dlatu et al., 2023).

2.2.3.2 Population demographics and socio-economic status

It is important to understand the challenges and characteristics of rural areas, as these directly relate to the context in which CBR operates and are critical to framing this thesis. Rural areas, as defined by the United Nations (2006), are often characterised in contrast to urban areas, but inconsistencies in defining "urban" lead to discrepancies in defining what is "rural". This lack of clarity becomes particularly important when comparing factors such as access to services—e.g., healthcare and education—between areas near and far from city centres.

The OR Tambo District, for example, illustrates many of these rural challenges, underscoring the relevance of CBR in addressing the gaps in service delivery and socio-economic opportunities. OR Tambo District is one of the most densely populated rural municipalities in South Africa, with an average population of 1,501,702 people and a population density of 128 people per km² in 2021, significantly higher than the provincial average of 43.8 people per km² and the national average of 49.4 (O.R Tambo district municipality 2010).

The district is characterised by a high dependency ratio, with a significant portion of the population being under 14 or over 65 years old. In 2019, the dependency ratio was 72.97%, indicating that a large proportion of the population relies on a relatively small working-age population. Although this ratio has improved from 80.5% in 2009, it remains higher than the provincial average (O.R Tambo district municipality 2010; Smuts et al., 2008).

The socio-economic conditions in the district are challenging, with limited employment opportunities and a high reliance on government social grants. The main economic sectors in the district include community services (55%), trade (18.5%), finance (16.9%), and agriculture (3.5%). However, the district's financial health is precarious, with liquidity issues and limited cash reserves, which could impact the sustainability of community-based initiatives (Schoeman et al., 2010; Smuts et al., 2008).

2.2.3.3 Healthcare facilities and services

The OR Tambo District in the Eastern Cape faces significant challenges in providing adequate rehabilitation services due to limitations in both infrastructure and resources. The district has a network of nine district hospitals, 146 primary healthcare facilities, and two regional hospitals, which together form the backbone of the healthcare system (Louw et al., 2023). However, rehabilitation services are concentrated primarily at the district hospitals, with outreach services to clinics and community health centres being irregular and often insufficient (Magaqa et al., 2021).

All nine district hospitals in the OR Tambo District offer basic rehabilitation services, including physiotherapy and occupational therapy, but services such as speech and language therapy and audiology are available in only a few facilities (Magaqa et al., 2021). The availability of essential rehabilitation equipment, such as assistive devices, is also severely limited. For example, mobility-related devices such as wheelchairs and crutches are present in only a few facilities, and in limited quantities. This shortage is compounded by inadequate consumable supplies, which are necessary for the effective delivery of rehabilitation services.

Table 2.1: Number of rehabilitation providers by profession at healthcare facilities (HF) (full-time posts) in OR Tambo District hospitals (Magaqa et al., 2021)

Profession	HF 1	HF 2	HF 3	HF 4	HF 5	HF 6	HF 7	HF 8	HF 9	TOTAL
Physiotherapists	2	2	4	1	1	1	1	1	1	14
Occupational Therapists	2	2	3	0	1	0	1	0	1	10
Speech & Language Therapists	0	0	1	0	0	0	1	0	0	2
Audiologists	0	0	1	0	0	0	0	0	1	2
Orthotist and Prosthetists	0	0	0	0	0	0	0	0	0	0
Rehabilitation Physicians	0	0	0	0	0	0	0	0	0	0
Rehabilitation Nurses	0	0	0	0	0	0	0	0	0	0
Physiotherapy Assistant	1	0	0	0	0	0	0	1	0	2
TOTAL	5	4	9	1	2	1	3	2	3	30

The majority of rehabilitation providers employed in the district are community service-level professionals, in their first year of work after university and have not yet obtained independent practitioner status from the Health Professionals Council of South Africa (Magaqa et al., 2021). This lack of adequate staffing further hinders the ability of the district to provide comprehensive rehabilitation services, particularly in rural and underserved areas (Magaqa et al., 2021).

The rehabilitation service capacity is constrained by a low availability of assistive devices, consumables and rehabilitation human resources in health facilities (Magaqa et al., 2021; Louw et al., 2023). In addition, PWDs face significant barriers in accessing rehabilitation services, which are often limited and difficult to reach (Ennion & Manig, 2019). These barriers stem not only from insufficient rehabilitation infrastructure and capacity but also from challenges on the demand side, such as lack of awareness or financial constraints (Butura et al., 2024; Visagie & Swartz, 2016).

2.4 Population and sampling

In order to discuss the population and sampling strategies used in this study, the terms “population” and “sampling” have to be defined. The population refers to the entire group of individuals, studies, or data sources that are of interest to the researcher, or which meet the criteria the researcher is

intent on studying (Hiebl, 2023). However, it is crucial to differentiate between the total population and the accessible population, which is "a subset of the total population that can be feasibly studied" (Harris, 2019). Sampling can be defined as the process through which individuals or sampling units are selected from the sample frame (Martínez-Mesa et al., 2016).

2.4.1 Phase One, Two and Three: Scoping, systematised review and Delphi study

2.4.1.1 Population discussed per phase

The population for each phase of this study was carefully defined to align with the specific research questions and objectives. In Phase One, the focus was on identifying and analysing existing frameworks and models used to evaluate CBR interventions. The actual total population in this context would theoretically encompass all literature on CBR evaluation frameworks globally, across all languages, time periods, and types of publications. However, due to practical constraints, the accessible population was limited to full-text publications available in English and published between 2000 and 2022. These inclusion criteria ensured that the study could capture a broad yet relevant overview of contemporary practices in CBR evaluation, providing a solid foundation for subsequent phases.

In Phase Two, the population was defined more narrowly to include studies that utilised GPROMs within CBR interventions. The actual total population would ideally include all studies on GPROMs across various healthcare settings and geographic locations. However, the accessible population was restricted to studies published in English within the same timeframe (2000–2022) and available in full-text form. This focus allowed the study to examine how GPROMs are used in CBR, particularly in relation to the domains of "Activity limitation" and "Participation restriction" as outlined by the ICF. This targeted approach was essential for understanding the

applicability of GPROMs in evaluating CBR outcomes, particularly within the specific contexts relevant to this research.

For Phase Three, the Delphi study, the population consisted of experts in the field of CBR evaluation. The actual total population in this context would include all global experts with significant experience and publications related to CBR evaluation. The accessible population was defined as those experts who had published relevant literature, contributed to significant reports such as the WHO Rehabilitation 2030 report, or were affiliated with recognised universities in South Africa. This careful selection of experts ensured that the Delphi panel included a diverse range of perspectives, enhancing the robustness and credibility of the consensus achieved through this method.

2.4.1.2 Sampling method

In Phase One and Two, the articles included were defined by the search strategy and inclusion criteria. This will be explained in the relevant chapters.

For Phase Three, the Delphi study was highly dependent on the expertise of its participants, making purposive sampling the most suitable approach for selecting a knowledgeable panel. Individuals were classified as "experts" and invited to participate based on specific criteria, including having published research in the field of CBR, contributed to WHO reports on CBR, worked at healthcare facilities providing CBR services, or held recognised expertise in CBR at academic institutions. This approach ensured that the panel comprised individuals with substantial depth of knowledge in CBR.

The selection process aimed to include a diverse range of perspectives, which was critical for achieving a robust and credible consensus. However, as with all purposive sampling, there is a risk of bias if the selection process is not rigorously conducted. This risk was mitigated by clearly defining the selection criteria and ensuring that the panel was diverse in terms of expertise and geographical representation (Skulmoski & Hartman, 2007).

2.4.1.3 Sample size

The sample size of any study is dependent on the characteristics of the study population, study approach, and specific design, and should be calculated accordingly (Brink & Van der Walt, 2006). A sample that is inappropriately large can become too sensitive to the variables under study, while too small a sample size will result in difficulty detecting clinical and statistically significant differences (Brink & Van der Walt, 2006). The sample sizes for each objective will be discussed in detail in the relevant chapters.

2.4.1.4 Factors affecting sample size

Several factors influenced the determination of sample sizes across the different phases of this study, particularly in the context of CBR research. In Phase One, the broad and diverse nature of the literature on CBR frameworks necessitated a wide initial search, which was subsequently refined through screening processes following the Arksey and O'Malley (2005) method (see Chapter Three, Section 3.3.1.3, pg. 60). The challenges of accessing complete and accurate data, particularly in under-researched areas, also influenced the sample size, as these factors often limit the availability of relevant studies (Asiamah et al., 2017; Marbach-Ad et al., 2009).

In Phase Two, the focus on GPROMs required a targeted approach to sampling, as the study needed to ensure that the selected articles provided relevant and high-quality data on the specific outcomes of interest. The inclusion of studies across different contexts, such as urban versus rural settings, also played a role in determining the final sample size, as it was important to capture a representative range of experiences and outcomes (Asiamah et al., 2017; Whitehead & Whitehead, 2016).

For Phase Three, the Delphi study, the sample size was inherently limited by the availability and willingness of experts to participate. However, the reduction in sample size through the Delphi rounds was anticipated and did not compromise the validity of the study. The final group size of seven experts was sufficient to achieve a reliable consensus, reflecting the depth and quality of the input provided rather than the quantity of participants (Skulmoski & Hartman, 2007).

2.4.2 Phase Four: Pilot study

Research is inherently complex and often involves exploring new or under-researched phenomena, which requires careful planning and methodological rigour to ensure valid and reliable outcomes (van Teijlingen & Hundley, 2002). In this context, a pilot study serves as a crucial step in refining the research process, ensuring that the chosen methods are well-suited to the study's objectives and capable of addressing the research questions effectively.

Pilot studies are particularly important in situations where the research problem or the context in which the study is conducted are not well understood. They provide a critical opportunity to gather preliminary knowledge about the phenomenon under investigation, helping to confirm or refine the research direction, assumptions, and methodologies (Mutz & Müller, 2016). By conducting a pilot study in the OR Tambo District, this research provides a critical first step in ensuring that the

suggested CBR evaluation framework is both practical and applicable in a rural, resource-constrained environment, which is representative of many settings where such interventions are implemented.

A pilot study is typically defined as a “small study to test research protocols, data collection instruments, sample recruitment strategies, and other research techniques in preparation for a larger study” (Hassan et al., 2006, pg. 70). This preparatory phase is critical, as it allows researchers to refine their approach and enhance the quality and reliability of the main study (Hassan et al., 2006).

A pilot study was selected as the most appropriate method to assess the feasibility and suitability of the proposed CBR evaluation framework in a real-world setting. This approach was chosen with the specific aim of identifying and rectifying issues within the suggested framework in order to amend the framework to its most practical and applicable state.

2.4.2.1 Population

The target population for the pilot study in Phase Four was carefully selected to include individuals directly involved in the implementation and evaluation of CBR interventions within the OR Tambo District, Eastern Cape, South Africa and will be elaborated on further in Chapter Six.

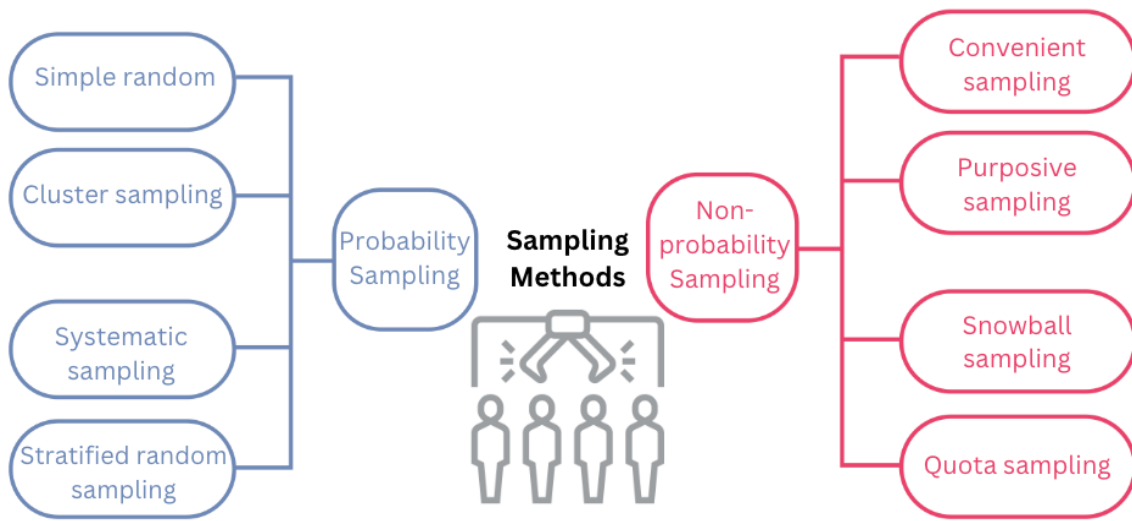


Figure 2.3: Types of sampling (Author's own, 2024)

In probability sampling, every individual in the population has a known and usually equal chance of being selected. This method is favoured when researchers aim to generate results that can be generalised to the broader population. The key advantage of probability sampling is that it reduces bias and increases the likelihood that the sample accurately reflects the population (Makwana et al., 2023).

In this phase, non-probability sampling methods were chosen. Non-probability sampling methods do not give each individual in the population an equal chance of being selected. Instead, participants are chosen based on certain characteristics, availability, or the researcher's judgement, making this approach more subjective. Non-probability sampling is often used in exploratory research or when studying specific populations that are difficult to access (Makwana et al., 2023).

Purposive sampling selects participants based on specific characteristics or criteria that align with the research objectives. For example, if a researcher is studying the impact of a new teaching

method on expert educators, they would specifically choose teachers who have significant experience in the field. This method allows the researcher to focus on individuals who can provide the most relevant information. However, because participants are selected based on the researcher's judgement, it can introduce bias, and the findings may not be representative of the broader population (Makwana et al., 2023). Purposive sampling was justified by the exploratory nature of the pilot study and will be described in the appropriate chapter in more detail.

2.5 Instruments and data collection

The data collection process in this study utilised a mixed methods design with distinct instruments aligned with each phase's objectives. The study was designed to systematically collect data that would inform the development of a comprehensive framework. The choices for each instrument used in each phase will be discussed below.

2.5.1 Scoping and systematised review (literature review) Phase One and Two

The decision to use scoping and systematised reviews for this research study, over other review types, was made based on the specific goals of each phase and the nature of the available literature. In evaluating various types of literature reviews, including narrative reviews, systematic reviews, meta-analyses, and critical reviews, it became clear that these methods had both strengths and limitations in the context of CBR interventions.

RQ1: What frameworks are currently being used to evaluate Community-Based Rehabilitation (CBR) interventions?

RQ2: What generic patient-reported outcomes are available for assessing the effectiveness of CBR interventions?

Review Type	Purpose	Strengths	Weaknesses
Narrative Review	Broad overview of a topic	Useful for generating new theoretical insights	Lacks transparency and replicability, prone to bias
Systematic Review	Comprehensive synthesis of all relevant studies on a focused question	Highly rigorous, useful for decision-making	Time-intensive, limited flexibility, less useful in fragmented or emerging fields
Meta-Analysis	Statistical synthesis of quantitative data from multiple studies	Provides strong statistical evidence for effectiveness	Requires homogeneity in study designs, focuses on quantitative data only
Scoping Review	Mapping the breadth of literature, identifying key concepts and gaps in an emerging field	Flexible, includes a wide range of study designs, comprehensive view	Less focused on specific outcomes than systematic reviews
Systematised Review	Structured approach to synthesising literature with a focused scope but fewer restrictions	More adaptable and pragmatic than systematic reviews	Less rigorous than systematic reviews, but still provides a clear structure for synthesis

Figure 2.4: Summary of reviews for Phase One and Two (Author's own, 2024)

The scoping review was considered the most appropriate choice for the first phase of the research because it allowed for a broad exploration of the available literature on frameworks used to evaluate CBR interventions. It aimed to answer RQ₁: What frameworks are currently being used

to evaluate CBR interventions? Scoping reviews are particularly valuable when the goal is to map the literature, identify key concepts, and highlight knowledge gaps (Grant & Booth, 2009). Given that CBR is an emerging field with diverse methodologies, a scoping review allowed the research to capture a wide range of evidence, including qualitative and quantitative studies, to ensure a comprehensive overview of the existing frameworks.

Scoping reviews are flexible and inclusive, making them ideal for exploring complex and under-researched topics such as CBR, where the literature is fragmented and diverse (Munn et al., 2018). This flexibility enabled the inclusion of various study designs, from observational studies to case reports, which would not have been possible with more restrictive review types such as systematic reviews. Additionally, by mapping the current state of research, the scoping review provided valuable insights into the key frameworks and methodologies used across different contexts, setting the foundation for the more focused systematised review that followed.

This methodological approach aligns with best practices in evidence synthesis and highlights the strength of literature reviews in advancing knowledge in complex and emerging fields. The choice of a scoping review was guided by the specific goals of broad exploration and mapping of the literature, ensuring that the study was well-positioned to address the identified gaps (Munn et al., 2018).

For the second phase, which aimed to answer the more specific research question: What generic patient-reported outcomes are available for assessing the effectiveness of CBR interventions?, a systematised review was chosen. Systematised reviews offer a structured approach to reviewing literature while allowing for more flexibility in scope and time than full systematic reviews (Grant

& Booth, 2009). This flexibility was essential in Phase Two, where the goal was to evaluate available GPROMs and narrow them down for inclusion in the Delphi study.

Unlike scoping reviews, systematised reviews include some elements of a systematic review, such as comprehensive searching and quality assessment, but they stop short of the extensive rigour and time required by full systematic reviews (Grant & Booth, 2009). This made the systematised review an appropriate choice for Phase Two, where a more focused approach was needed to critically appraise GPROMs, while still allowing some flexibility in scope.

The systematised review served as an efficient method to synthesise the available literature on GPROMs, providing evidence-based support for the Delphi study that followed. By critically appraising the most relevant GPROMs, the systematised review ensured that the final set of tools used in the Delphi process was both scientifically valid and aligned with the needs of CBR evaluations.

The choice of scoping and systematised reviews was guided by the specific research goals and the nature of the available literature. The scoping review was invaluable for Phase One, providing a broad overview of the literature on CBR evaluation frameworks, while the systematised review in Phase Two allowed for a more focused appraisal of GPROMs, ensuring that the final recommendations were grounded in evidence. Both review types offered the necessary balance of rigour and flexibility, ensuring that the research objectives were met efficiently and effectively.

2.6 Consensus methods: Delphi study

In situations where unanimity of expert opinion is lacking due to insufficient or contradictory evidence, formal consensus methods offer a structured approach to decision-making. The three

primary consensus methods used in research are the Delphi process, the nominal group technique, and the consensus development conference. Each method is designed to measure the extent of agreement among experts and resolve disagreements (James & Warren-Forward, 2015; Jones & Hunter, 1995).

Phase Three aimed to answer the third research question: Which GPROMs are most appropriate for evaluating CBR interventions, and how can they be integrated into a cohesive theoretical framework? The Delphi study is described as a structured method involving multiple rounds of questionnaires. This approach collects the opinions of experts while maintaining anonymity, making it an ideal method when in-person meetings are not feasible. It also helps reduce the influence of dominant individuals by maintaining anonymity and provides an iterative feedback loop, leading to more reliable group consensus (James & Warren-Forward, 2015; Sankaran et al., 2018; Skulmoski & Hartman, 2007).

The Delphi process allows for the inclusion of a greater number of experts compared to in-person methods such as the nominal group technique or consensus development conferences. Since the Delphi process can be conducted virtually, it enables wide participation from experts across various regions without the need for face-to-face interaction. This was particularly crucial during the COVID-19 pandemic, when travel restrictions and health concerns made in-person meetings impractical or impossible. The ability to conduct the study entirely online ensured that the pandemic did not disrupt the research timeline or limit expert input.

Moreover, the global nature of the study necessitated a method that could accommodate participants from different time zones and locations. The Delphi study's virtual rounds of questionnaires made it an ideal tool for involving international experts, which would have been

logistically and financially prohibitive with other methods. The cost and resource constraints of bringing global participants together in one location would have been significant, further reinforcing the practicality of the Delphi approach.

In addition to logistical benefits, the Delphi study also provided a systematic way to ensure that the experts reached a consensus on the most appropriate GPROMs for evaluating CBR interventions. The iterative rounds of feedback allowed participants to refine their opinions based on the group's evolving responses, ensuring a well-rounded, collective judgement. This process was critical for generating a strong foundational framework and gathering the feedback needed to integrate GPROMs into the study's theoretical model.

Lastly, the anonymity afforded by the Delphi study allowed for unbiased feedback, reducing the risk of dominant personalities influencing the group, which can sometimes occur in face-to-face discussions. This feature was crucial for ensuring that each expert's opinion was weighted equally, fostering a more reliable consensus on the research question and framework.

In summary, the Delphi method was chosen due to its flexibility in accommodating virtual participation, its ability to include a wide range of global experts, and its structured, iterative approach to reaching consensus on a critical research question. These factors, combined with the need for efficient resource use during a time of global restrictions, made Delphi the best consensus method for this study.

2.6.1 Phase Four – Pilot study

The selection of these specific instruments and data collection methods was driven by their alignment with the study's objectives and the need to ensure that the data collected would be both

relevant and actionable. As stated by Malmqvist et al. (2019), "A carefully organised and managed pilot study has the potential to increase the quality of the research as results from such studies can inform subsequent parts of the research process".

The consensus reached in the Delphi study provided a suggested framework that incorporated expert opinions and the latest literature of CBR frameworks and GPROMs in the evaluation of CBR interventions. The suggested framework was then piloted in a real-world setting in order to understand its practical feasibility. Given the need for both depth and focus in this study, semi-structured interviews were selected as the most appropriate method. This approach balances flexibility with a structured framework, allowing for in-depth exploration of complex topics while ensuring that key themes are consistently covered across all interviews. By enabling both probing and comparability, semi-structured interviews provide the necessary rigour for obtaining rich, nuanced data while maintaining analytical coherence.

Interviews are a widely used qualitative data collection method that allows researchers to gather in-depth insights from participants. They come in various forms, each with specific strengths and weaknesses depending on the structure and goals of the research. The key types of interviews include structured, semi-structured, unstructured, and non-directive interviews (Utibe Monday, 2020).

The detailed methodology for employing semi-structured interviews in this research is discussed in Chapter Six. Semi-structured interviews combine structure with flexibility. While guided by a set of key themes, interviewers can adjust the order of questions and ask follow-up questions, enabling a more in-depth exploration of complex topics. This approach is valuable for probing

participants' responses but requires skill to avoid missing important details or straying off-topic. Analysing the varied data can also be more challenging compared to structured formats.

2.7 Data analysis

The concept of integration of data in the analysis of mixed methods research findings and the theory behind the process of mixed methods data analysis will be discussed in the following section. The data analysis relevant to the specific chapters will be discussed in the chapters (three, four, five and six) to which it applies.

2.7.1 Analysis of qualitative data

Analysing qualitative data is described as a process of moving deeper into understanding the data, representing the data, and making an interpretation of the larger meaning (Creswell, 2018; Creswell & Poth, 2016). While Creswell and Poth (2016) outline general steps for qualitative data analysis, this study specifically applied thematic analysis. Following Braun and Clarke's (2006) six-phase framework, a reflexive thematic analysis stance was adopted (Braun & Clarke, 2019, 2022). This approach acknowledges the researcher's active role in knowledge production and emphasises the iterative, interpretive process of theme development. The procedure involved repeated reading of the data to gain familiarity, hand-coding of meaningful phrases, grouping codes into categories, and developing overarching themes. These themes were then interpreted in relation to the study aims, recognising that analysis is an iterative movement between detailed data and broader conceptual insights.

2.8 Scientific rigour

Traditional standards of scientific rigour, such as reliability, validity, and generalisability, have evolved within the context of qualitative research to better align with the interpretive and context-driven nature of qualitative research (Morse, 2015). In qualitative research, the discussion has expanded in recent years to an evolved understanding that rigour is often associated with the quality and attributes of the research process and refers more to the robustness of the research design and the suitability of the methods chosen to address the research questions (Cypress, 2017). From Lincoln and Guba's crucial work in the 1980s, reliability and validity were replaced with the concept of "trustworthiness" (Cypress, 2017). Lincoln and Guba (1985) were the first to address rigour in their model of trustworthiness of qualitative research. Trustworthiness is used as the central concept in their framework to appraise the rigour of a qualitative study. The scientific rigour of this study will be explained through Lincoln and Guba's (1985) model of trustworthiness.

Lincoln and Guba (1985) emphasise that the trustworthiness of a research study is crucial for evaluating its overall worth. Trustworthiness is established through four criteria: credibility, transferability, dependability, and confirmability. Credibility refers to the confidence in the "truth" of the findings, ensuring that the results accurately reflect the participants' experiences. Transferability is the extent to which the findings can be applied to other contexts, showing their relevance beyond the original study setting. Dependability focuses on the consistency of the findings, ensuring that similar results could be obtained if the research were repeated under similar conditions. Finally, confirmability refers to the neutrality of the findings, ensuring they are shaped by the participants rather than researcher bias or personal motivations (Lincoln & Guba, 1985; Schwandt et al., 2007).

Creswell (2018) echoes the importance of these criteria and points out that the ultimate goal in qualitative research is to achieve a deep understanding of a social setting or phenomenon. He highlights that this understanding requires extensive time in the field, engaging with participants and their environments. According to Creswell, verification is a key aspect of evaluating the quality of qualitative research. He supports the use of Lincoln and Guba's criteria of trustworthiness, emphasising the importance of credibility and authenticity when assessing the value and rigour of qualitative studies. By applying these criteria, researchers can ensure that their findings are both reliable and meaningful, providing a more accurate reflection of the studied phenomenon.

2.8.1 Credibility

Credibility refers to the accuracy with which the researcher represents the participants' experiences and the truthfulness of the findings (Polit & Beck, 2012). A qualitative study is deemed credible when its findings are easily recognisable by individuals who share the same experiences (Cope, 2014). Ensuring credibility across the phases of this research was achieved through a combination of techniques. During the scoping review and systematised review, a transparent and systematic approach was used to search, select, and synthesise the literature, with independent reviewers cross-checking findings to reduce bias and ensure accuracy. Member checking was not applicable in these phases, but triangulation of data sources was achieved through the use of multiple databases and types of studies to corroborate key themes.

In the Delphi study, credibility was further enhanced through iterative rounds of expert feedback, allowing panellists to review and validate the emerging consensus at each stage. This iterative process ensured that the results accurately reflected the collective expertise of the panel. Member

checking in this context involved having the Delphi panel validate the final round of results, ensuring the interpretations were credible and aligned with expert consensus.

In the pilot study, credibility was enhanced through prolonged engagement with participants and member checking. Participants reviewed their data and initial interpretations to ensure that their experiences and perspectives were accurately represented. The triangulation of findings from interviews, observations, and other qualitative data sources in this phase further strengthened credibility.

2.8.2 Dependability

Dependability in qualitative research relates to the stability of the findings across time and conditions (Polit & Beck, 2014; Cope, 2014). This criterion is achieved when another researcher can review the study's processes and concur with the decisions made at each stage (Cope, 2014). Dependability is enhanced by providing a comprehensive audit trail, detailing each step of the research process, and allowing similar results to be found under similar conditions. Dependability across all four phases was maintained by ensuring that a detailed audit trail was created. In the scoping review and systematised review, the process of literature searching, selection, and exclusion criteria was clearly documented, allowing other researchers to replicate the methodology under similar conditions.

For the Delphi study, dependability was ensured through transparent documentation of each round, including the specific changes made after each round of expert feedback. The process of compiling and refining expert opinions at each stage was carefully recorded, ensuring that future researchers could reproduce a similar approach.

In the pilot study, dependability was further established by documenting the data collection and analysis processes in detail. This included the recruitment strategies, interview protocols, and the iterative refinement of the research instruments, ensuring the process could be replicated or evaluated by external reviewers.

2.8.3 Transferability

Transferability assesses whether the findings of a qualitative study can be applied to other contexts or populations (Durdella, 2017; Cope, 2014; Polit & Beck, 2014). Achieving transferability requires detailed descriptions of the study's participants, research setting, and data collection process, enabling others to evaluate whether the findings may be relevant in different contexts.

The potential for these findings to be transferred is enhanced through detailed descriptions of the research context, participants, and methodology, allowing other researchers to evaluate whether the findings are applicable to different contexts or populations. This study took place across multiple phases, each contributing to the understanding of the evaluation of CBR.

By clearly outlining the geographical location, population demographics, and the nature of the healthcare systems in the OR Tambo District in Eastern Cape, South Africa, as well as providing in-depth descriptions of the research setting in other phases, the study offers a comprehensive understanding of the local context. This enables readers and researchers to judge the relevance of the findings within their own contexts, thereby enhancing the potential for transferability. Additionally, the diverse sampling methods used across the different phases, including purposive sampling for the Delphi study and semi-structured interviews for the pilot study, ensure that the data collected reflects a wide range of perspectives. The inclusion of global experts in the Delphi study and the specific focus on rural healthcare settings in the pilot phase contribute to the broader

relevance of the research findings, making it easier to assess their applicability in similar contexts (Cope, 2014; Polit & Beck, 2014).

2.8.4 Confirmability

Confirmability concerns the extent to which the findings are shaped by the participants' responses rather than by bias or subjective influence (Polit & Beck, 2014; Creswell & Poth, 2016). Throughout each phase of the study, transparent documentation of the research process was maintained. In the scoping and systematised reviews, a systematic process of data selection and analysis was employed, providing a clear audit trail that allows for external validation of the results.

The Delphi study, with its iterative rounds of expert feedback, further enhances confirmability by ensuring that the framework developed is based on collective expert consensus rather than individual opinions. In the pilot study, confirmability is supported by the use of semi-structured interviews, where the participants' perspectives are captured through transcription and member checking processes. Furthermore, the consistent use of triangulation across data sources—such as the integration of literature reviews, expert consensus, and real-world application—strengthens the objectivity of the findings. The study also maintained an audit trail throughout all phases, documenting the decisions made during data collection and analysis, which allows for external reviewers to trace the research process and verify the accuracy of the results (Lincoln & Guba, 1985; Schwandt et al., 2007).

In summary, establishing trustworthiness through these criteria allows qualitative researchers to provide findings that are credible, applicable, consistent, and neutral, thereby strengthening the study's overall value and impact. The theoretical background of these four criteria will be

described below, while the application thereof to the different studies will be elaborated on in the respective chapters.

2.9 Ethical considerations

Ethical considerations were integral to this research, particularly given the involvement of human participants. The study was conducted in full compliance with ethics standards established by the Biomedical Research Ethics Committee of the University of the Western Cape (Approval Reference: BM20/5/31). The study adhered to the ethics principles outlined in the 2004 Declaration of Helsinki for research in the social sciences (Goodyear et al., 2007). Approval covered all phases of the research, including the scoping and systematised reviews, the Delphi study, and the semi-structured interviews.

Informed consent is a fundamental requirement of ethical research, ensuring participants understand the study, procedures involved, and their rights. Before data collection commenced, all participants were provided with detailed information about the study's purpose, potential risks and benefits, and their right to withdraw at any time without consequences. This information was provided in writing, in a language participants understood, and consent forms were signed prior to their involvement. For the Delphi study in Phase Three, Chapter Five, consent was obtained electronically through a secure platform, maintaining participant anonymity throughout the iterative feedback process. For the semi-structured interviews in Phase Four, Chapter Six, consent was obtained electronically before each interview.

In the Delphi study, responses were anonymised before being presented to the expert panel to prevent bias or undue influence from knowing the identities of other participants. Similarly, qualitative data from the semi-structured interviews were anonymised during transcription to

protect the identities of both practitioners and CBR beneficiaries. All data were securely stored in password-protected databases accessible only to the primary researcher and supervisory team. Upon conclusion of the study, data will be archived in compliance with institutional data retention policies and destroyed after the required period to maintain confidentiality.

The well-being of participants was prioritised throughout the study. In Phase Four, where semi-structured interviews were conducted with healthcare practitioners and patients, care was taken to ensure that participation did not impose undue burden or cause distress. Interviews were scheduled at convenient times and locations to minimise disruption to participants' daily lives. Special consideration was given to participants with disabilities in the CBR context. If any participant experienced discomfort during the interview process, they had the option to pause or withdraw without any negative consequences.

Phases One and Two (scoping and systematised reviews) did not involve direct human participation but adhered to ethical principles of transparency and integrity. All sources were properly cited, and efforts were made to avoid bias in selecting and interpreting data. In the Delphi study, participants were given clear instructions on their roles, and their participation was voluntary. Throughout the research, participants were encouraged to raise any ethical concerns they had.

Protection of Information

Adherence to the Protection of Personal Information Act (POPIA) of South Africa was maintained to ensure the protection of participants' personal and sensitive information. POPIA aims to promote the lawful processing of personal information and safeguard individuals' privacy rights by regulating how data is collected, stored, and managed.

All personal information collected during this study was treated with the highest degree of confidentiality. Participants were informed of their rights under POPIA, and their consent was obtained before any data collection took place. The information gathered was anonymised wherever possible to minimise the risk of identifying individuals. For instance, identifiable data such as names, addresses, or other personal identifiers were not used in reports or shared with third parties.

Data Management and Storage

In compliance with POPIA, the data collected during the research was securely managed and stored. All electronic data was encrypted and stored on password-protected devices, ensuring that only authorised personnel could access it. Physical copies of any data, such as consent forms or field notes, were securely stored in locked cabinets. Access to the data was strictly limited to the research team, and any sharing of information was carried out in accordance with ethical guidelines and only for research purposes.

Data Disposal

POPIA requires that personal information be retained only for as long as necessary to fulfil the purpose for which it was collected. As part of the data management plan, all research data will be securely disposed of five years after the conclusion of the study. Electronic data will be permanently deleted from all storage devices, and any physical documents will be shredded to ensure complete destruction. The process will be conducted in a manner that fully complies with both ethical standards and legal obligations under POPIA.

This research was conducted in accordance with high ethical standards. The principles of informed consent, confidentiality, and participant well-being were maintained at every stage, and the study design was structured to minimise risks to participants. These ethical measures ensured that the research upheld its scientific integrity while prioritising the safety and welfare of all participants involved.

In conclusion, this study adhered to ethical guidelines throughout all phases, ensuring the protection and well-being of human participants. The principles of informed consent, confidentiality, and data protection were applied, in compliance with the Declaration of Helsinki, the University of the Western Cape's Biomedical Research Ethics Committee, and South Africa's POPIA regulations. By safeguarding participant anonymity, minimising risks, and providing avenues for voluntary participation, the research maintained high ethical standards while promoting the integrity of the findings. The secure management and disposal of personal data further reinforced the commitment to ethical research practices, ensuring that all participant information was treated with the utmost confidentiality and respect.

CHAPTER THREE: A SCOPING REVIEW ON THE FRAMEWORKS USED TO GUIDE THE EVALUATION OF CBR INTERVENTIONS

3.1 Introduction

This chapter addresses the first research objective: to explore the current frameworks used for evaluating CBR interventions. Using a scoping review, this chapter aims to identify and map existing frameworks and literature that will serve as the foundation for developing a practical and feasible evaluation framework for CBR.

As emphasised by Kaplan and Reis (2007), effective evaluation models must account for both medical and social factors that impact patient outcomes. This approach aligns with the chapter's goal of exploring and analysing the existing theoretical frameworks for evaluating CBR interventions, ensuring they capture both the quantitative and qualitative aspects of rehabilitation. Understanding these inputs is an important foundation for building a robust, adaptable framework that can drive sustainable and effective CBR outcomes, particularly in low-resource settings.

3.2 Background

Whilst CBR has evolved significantly since its inception, professionals in the field have expressed an urgent need for research and the development of a standardised framework to evaluate CBR interventions effectively (Grandisson et al., 2014). In the context of developing a framework for evaluating CBR, this scoping review serves as a critical foundation, directing the selection of the most suitable tool for assessing specific interventions. A unified evaluation framework would not only help identify areas for improvement within CBR programmes but also facilitate the

comparison of outcomes across different programmes, thereby aiding the formal inclusion of CBR practices into national and international policies (Boyce & Ballantyne, 2000).

3.2.1 Existing theoretical frameworks to guide CBR

In 2004, the WHO introduced the CBR Matrix as a foundational framework to guide CBR efforts globally. The matrix was designed to direct CBR initiatives across five critical areas: health, education, livelihood, social roles and responsibilities, and empowerment (WHO, 2010). It serves as a comprehensive guide for organising CBR activities, ensuring that interventions address the multifaceted needs of individuals with disabilities within community settings. However, despite its value in structuring CBR programmes, the CBR Matrix lacks built-in mechanisms for the systematic evaluation of these interventions (Hartley et al., 2009).

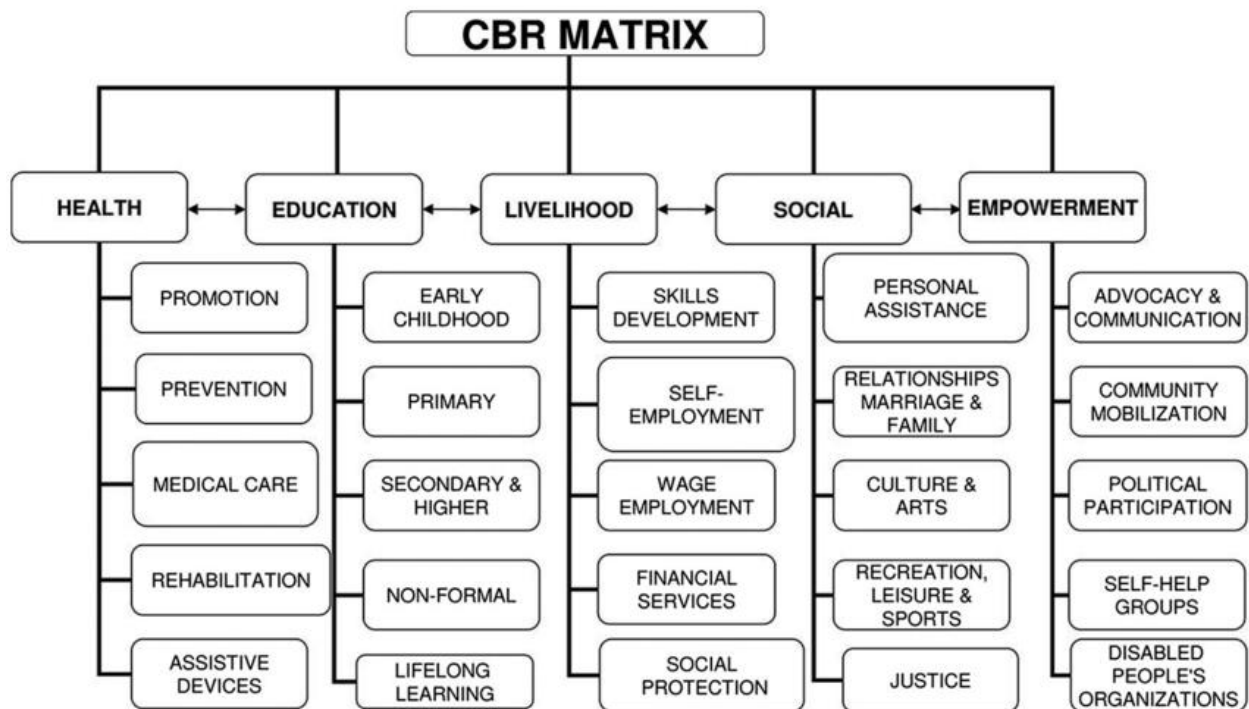


Figure 3.1: The CBR Matrix from van Pletzen et al. (2014)

Without robust evaluation tools, it is challenging to monitor and measure the outcomes of interventions, limiting the scalability of CBR programmes (Tongsiri, 2022). Evaluation is critical for demonstrating efficacy, influencing government agendas, and securing ongoing investment in CBR interventions (Hartley et al., 2009; Thomas & Thomas, 1999). The absence of standard evaluation methods has made it difficult to quantify the impact of CBR programmes, posing significant challenges in scaling successful interventions and replicating them across different contexts.

In 2006, the UNCRPD further expanded the scope of CBR by emphasising a broader view of disability rights, which extended beyond health and rehabilitation to include education, livelihood, social participation, and empowerment (UN, 2006). While the CBR Matrix aligns with these goals, its broad nature presents challenges for developing specific evaluation metrics. Each pillar of the matrix represents essential components of service delivery, but the framework does not offer practical tools for tracking progress or measuring the success of interventions.

Alongside the CBR Matrix, the ICF, also developed by the WHO, offers another framework for guiding rehabilitation services. The ICF conceptualises disability not only as a medical condition but as a dynamic interaction between biological, psychological, and social factors (Kostanjsek, 2011). This biopsychosocial model integrates both the medical model, which views disability as a result of health conditions, and the social model, which sees disability as shaped by societal factors.

The ICF framework recognises the complexity of disability and highlights how environmental and personal factors influence functioning (Ustün et al., 2003). However, similar to the CBR Matrix, the ICF provides more of a conceptual foundation than an operational framework for evaluating CBR interventions (Boyce & Ballantyne, 2000). The ICF includes the addendum ICF Checklist, a

structured evaluation tool for documenting an individual's functioning across domains of body functions and structures, activities and participation, and environmental factors, using qualifiers for severity and performance/capacity (World Health Organization, 2003). However, several limitations reduce its suitability for routine CBR evaluation: it is long and resource-intensive; not explicitly designed to quantify change over time; uses performance vs. capacity distinctions that are difficult to measure reliably in community or low-resource settings; and requires training to use appropriately.

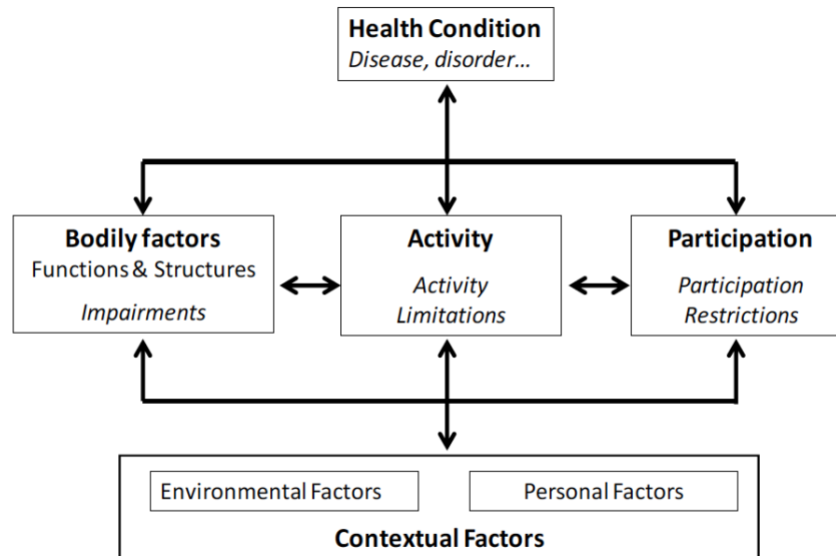


Figure 3.2: World Health Organization. (2001). *International Classification of Functioning, Disability and Health (ICF)*. Geneva: WHO. © World Health Organization. Reproduced with permission.

While the CBR Matrix and the ICF offer vital theoretical underpinnings for rehabilitation, neither framework fully addresses the critical need for standardised evaluation methods. As a result, the effectiveness of CBR interventions remains difficult to measure, which limits the ability to adapt

and scale programmes across diverse settings (Kamenov et al., 2019; Mason et al., 2017; WHO, 2022).

3.3 Statement of the problem

Despite the global implementation of CBR programmes, there is a critical gap in standardised frameworks for evaluating their effectiveness. Theoretical models such as the CBR Matrix and the ICF provide guidance for intervention design but there is no consensus on whether there are other more appropriate frameworks. As a precursor to the next phase, this phase focuses on reviewing the literature on current evaluation frameworks, laying the foundation for developing a comprehensive and adaptable model for assessing CBR interventions.

3.4 Methods

3.4.1 Overall study design for this objective

The data for this phase of the study was collected using a scoping review. The scoping review of the literature aimed to answer the following question: What frameworks are currently being used to evaluate CBR interventions?

3.4.1.1 Population and sampling

In Phase One of this study, the focus was on identifying and analysing existing frameworks and models used to evaluate CBR interventions. While the theoretical population encompasses all global literature on CBR evaluation frameworks, practical constraints limited the accessible population to full-text publications in English, published between 2000 and 2022. These criteria ensured a broad, yet relevant overview of contemporary CBR evaluation practices.

Studies were selected based on their relevance to the research question, allowing the focus on specific characteristics likely to yield useful data. Although this method carries the risk of selection bias, it was mitigated by clear inclusion criteria and a systematic study selection process (Pannucci & Wilkins, 2010).

From an initial pool of 224 titles, 145 remained after duplicate removal, and 37 were further screened. Ultimately, seven full-text articles were included. The small sample size reflects the scoping review's focus on identifying key frameworks rather than exhaustively covering the literature.

3.4.1.2 Data collection instrument

The scoping review was the most appropriate choice for the first phase of the research, as it allowed for an exploration of the available literature on frameworks used to evaluate CBR interventions.

3.4.1.3 Procedure for data collection

The Arksey and O'Malley (2005) framework for scoping reviews was used to guide the procedure of this scoping review. This method ensures the different stages are conducted in a transparent way and in sufficient detail (Arksey & O'Malley, 2005). This approach increases the reliability of the findings, and responds to any suggestion that the study lacks methodological rigour (Lorenz et al. 2024). An overview of the framework is presented below. Each step will be discussed in line with the scoping review conducted for Phase One.

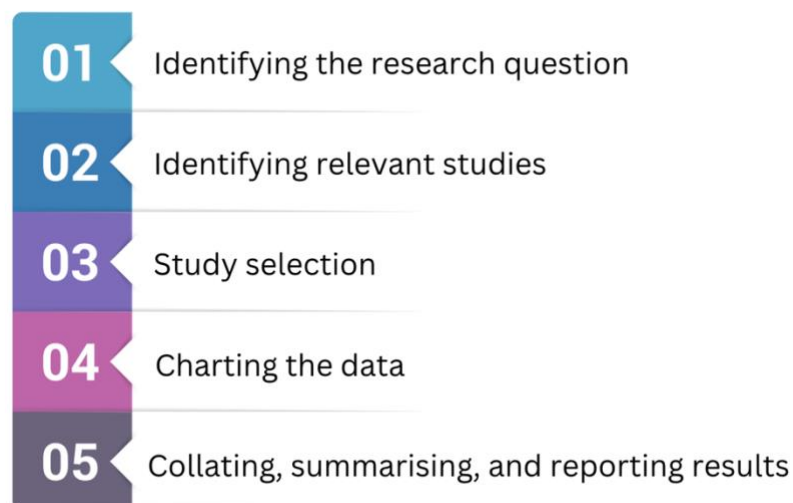


Figure 3.3: Framework for Phase One scoping review (Author's own, 2024)

3.4.2 Identifying the research question

This scoping review aimed to answer the research question: “What frameworks are currently being used to evaluate CBR interventions?”

The researcher acknowledges potential ambiguities within the research question, particularly around the term "evaluate". This term could potentially yield a wide array of results, including both outcome measures and evaluation frameworks. To address this, careful attention was given to the search terms, with a deliberate focus on narrowing the results to frameworks specifically related to CBR evaluation. Additionally, the term “CBR” posed a challenge, as it could generate overly broad results centred on "rehabilitation" rather than "community-based rehabilitation".

To manage these complexities, the researcher adopted an iterative and flexible approach to the search strategy, continually refining the search strings and Boolean operators to ensure relevance. This iterative process allowed for adjustments as the scope of the literature became clearer, while maintaining a balance between breadth of coverage and specificity. By anticipating these

challenges, the search strategy remained adaptable, ensuring that the most relevant and appropriate literature was captured for the study.

Table 3.1: Search string for scoping review (Author’s own, 2024)

Community-based rehabilitation / CBR	Framework	Impact
		Evaluation
		Efficacy
	Evaluation Framework	Impact
	Conceptual Framework	Impact
	Theoretical Framework	Impact
	Methodological Framework	Impact

The following terms were used in combination with each other:

- “Community-based rehabilitation and/or framework and/or impact”
- “Community-based rehabilitation and/or framework and/or evaluation”
- “Community-based rehabilitation and/or framework and/or efficacy”
- “Community-based rehabilitation and/or evaluation framework and/or impact”
- “Community-based rehabilitation and/or conceptual framework and/or impact”
- “Community-based rehabilitation and/or theoretical framework and/or impact”
- “Community-based rehabilitation and/or methodological framework and/or impact”

3.4.3 Identifying relevant studies

The process of identifying relevant studies commenced on 1 September 2021. The following subsections outline the specific strategies and steps used to ensure a comprehensive search for relevant literature. Grey literature (e.g., NGO reports, unpublished evaluation frameworks, and government documents) was not included in this review. While this ensured rigour through peer-reviewed sources, it may have excluded practical tools currently in use in the field. This limitation should be considered when interpreting the findings.

3.4.3.1 Electronic databases

Four electronic databases—PubMed, EBSCOhost, CINAHL, and Web of Science—were selected as key sources for identifying studies. The search was limited to full-text publications in English, published between 2000 and 2022, to focus on recent and relevant research. Boolean search terms were used in various combinations to maintain a broad yet targeted search strategy. The inclusion of all study designs ensured that no relevant frameworks were excluded from the outset, maximising the potential to uncover diverse evaluation models.

3.4.4 Study selection

The initial screening of the citations indicated that the search strategy had captured a considerable number of irrelevant studies, which underscored the importance of defining clear terminology at the outset. This issue was partly due to the broad nature of the search, which aimed to cover a wide range of literature, and the variability in how different countries and studies describe CBR interventions and evaluation frameworks.

To refine the selection process and ensure that only the most relevant studies were included, inclusion and exclusion criteria were developed *post hoc*, as familiarity with the literature grew.

These criteria were based on the following factors:

- **Titles and abstracts** that addressed the research question.
- Interventions that are aligned **with the CBR matrix**.
- The use of an **evaluation model or framework** in the study.

Two independent reviewers then applied these inclusion criteria to all the citations. Full-text articles were obtained for studies that appeared to be the best fit with the research question. If the relevance of a study was unclear from the abstract, the full article was ordered for further review. To maintain consistency and manage the scope of the study, a deadline of 15 October 2021 was set, after which no additional studies were included in the analysis. This was an important step to ensure the process remained timely and focused.

Following this review process, the full articles were thoroughly examined to determine their final inclusion. As noted by Arksey and O'Malley (2005) abstracts do not always represent the full scope of an article, and reading the complete study was necessary for making final decisions. This systematic approach helped to eliminate irrelevant studies while ensuring that key literature was included for a robust analysis of CBR evaluation frameworks.

3.4.5 Charting the data

The next phase involved charting key information extracted from the selected studies. "Charting" refers to the process of synthesising and interpreting qualitative data by organising, sorting, and classifying the material according to key issues and themes (Ritchie & Spencer, 2010). This

approach is similar to the data extraction methods used in systematic reviews, where specific information is extracted for further analysis. In this scoping review, the charting process was designed to capture detailed information on each study, allowing for a descriptive–analytical comparison of different CBR evaluation frameworks.

The relatively small final sample size reflects the focused nature of the scoping review, which aimed to identify key frameworks and models rather than provide an exhaustive review of the literature. The limited number of articles included may introduce some degree of bias, but the comprehensive initial search and rigorous screening process helped to ensure that the most relevant and high-quality studies were selected.

After the initial screening of 37 articles that met the inclusion criteria, further inspection and full-text reviews narrowed the selection. The remaining studies were then reviewed in detail using a standardised data extraction form that aligned with the research question. This form was developed to capture descriptive elements, including:

1. Author(s), year of publication, and title
2. Aims of the study
3. Study design and methodology
4. Instruments of data collection
5. Study population
6. Evaluation frameworks identified
7. Areas of the CBR Matrix the study engaged with
8. Level of intervention evaluation (individual, organisational, or contextual)

The data extraction form was used to systematically chart relevant information, ensuring consistency across all studies. This structured approach facilitated a comprehensive analysis, ensuring that key themes, such as the evaluation models used and their application within the CBR context, were highlighted. Although the extraction process aimed to be uniform, there were instances where studies did not present data in a fully accessible format, as noted in similar reviews (Badger et al., 2000). Nonetheless, the standardised data charting process provided a solid foundation for analysing and comparing the frameworks used in CBR interventions.

3.4.6 Collating, summarising and reporting the results

In this final stage, the process involved collating, summarising, and reporting the results of the scoping review. Unlike systematic reviews, which aim to synthesise evidence and assess the quality of studies, the goal of this scoping review was to provide a broad overview of the literature on frameworks used to evaluate CBR interventions. The focus was on mapping the existing research rather than weighing the evidence or aggregating findings.

First, a basic numerical analysis was conducted to examine the extent, nature, and distribution of the included studies. This analysis highlighted the geographical locations of the research, the types of interventions evaluated, the research methods employed, and the areas of the CBR Matrix that were engaged. The data was presented in table form, offering a clear picture of the dominant trends in the literature, such as which evaluation frameworks were most commonly used and where gaps existed in terms of intervention types and regions covered.

Second, the literature was organised thematically, based on the key frameworks identified in the studies. This thematic organisation allowed for a deeper exploration of the different frameworks, while acknowledging the diversity and overlap in how evaluation models were described across

studies. Each theme represented a specific evaluation framework or model, and commentary was provided on its use, effectiveness, and relevance to CBR interventions. Thematic analysis also allowed for the identification of inconsistencies in the application of evaluation models across studies and highlighted areas that require further investigation.

To ensure consistency in reporting the findings, a self-developed standardised template, using the information in the data extraction sheet, was applied to each study. This template included the following key elements: study authors, year of publication, aim, study design, evaluation framework, and the level at which the CBR intervention was evaluated (individual, organisational, or contextual). By adopting a consistent approach, comparisons could be made across studies, and gaps in the evidence base could be identified systematically. This structured reporting also made it easier to pinpoint contradictory evidence and highlight areas of uncertainty or limited research.

The identification of research gaps in this scoping review was primarily informed by two sources: the literature analysis, which revealed areas of weakness in terms of CBR evaluation frameworks and the types of interventions studied, and the consultation of key literature that reflected current issues in the field. This process provided a comprehensive overview of the available research and identified several key areas where further investigation is needed to develop more robust and universally applicable frameworks for evaluating CBR interventions.

3.5 Results

3.5.1 Literature search and study selection

A total of 224 titles were retrieved from all databases during the initial search. After removing 79 duplicates, 145 unique titles remained. These titles were screened for relevance based on

predefined inclusion criteria, such as addressing CBR evaluation frameworks and alignment with the research question. Of these, 108 titles were excluded due to not meeting the inclusion/exclusion criteria, leaving 37 studies for further review.

In the second stage, the abstracts of these 37 studies were reviewed more comprehensively to assess their focus on the evaluation frameworks used in CBR interventions. During this process, 30 articles were excluded for reasons such as focusing solely on rehabilitation without community-based components, not employing any formal evaluation models, or addressing unrelated interventions.

Finally, seven full-text articles met all inclusion criteria, including alignment with the CBR Matrix and the use of evaluation frameworks. These articles were included in the final scoping review for detailed analysis.

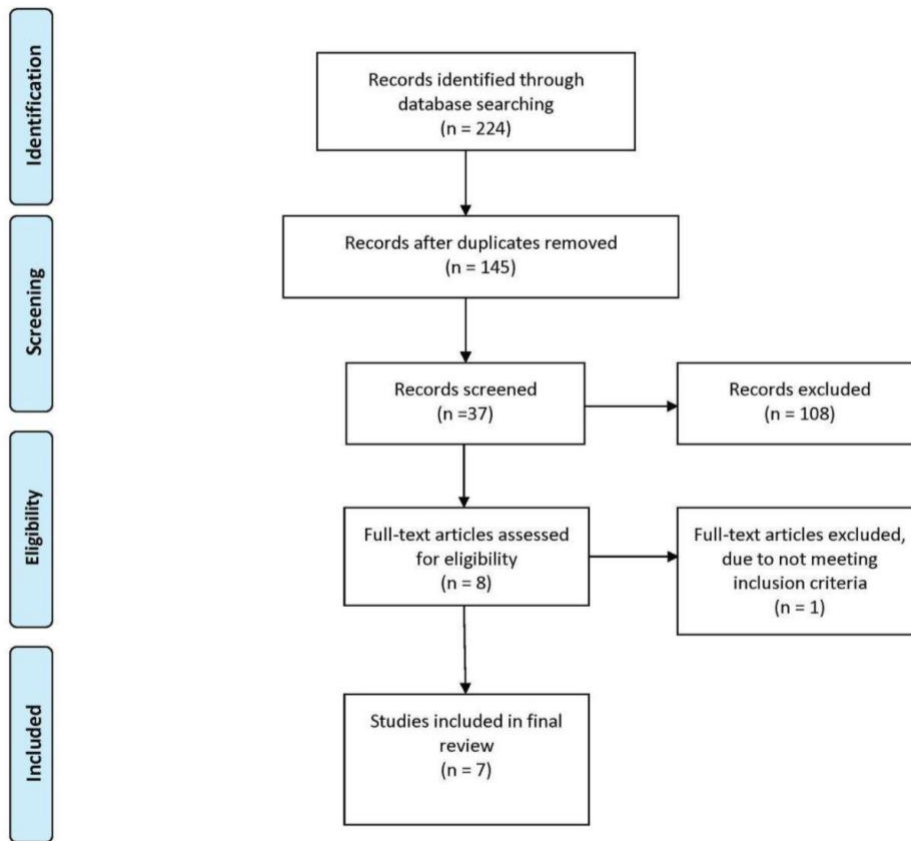


Figure 3.4: Literature search and study selection (Authors own, 2024)

3.5.2 Study characteristics

3.4.2.1 Year of publication

The studies included in this review span a broad time frame from 2003 to 2016, reflecting a growing interest in developing and applying frameworks for the evaluation of CBR interventions over time. The majority of the studies were published between 2010 and 2016, indicating an existing focus on formalising CBR evaluation tools and methods.

3.4.2.2 Geographical distribution

The geographical distribution of the studies highlights their global focus, with significant representation from LMICs. Two studies were conducted in Uganda (Adeoye et al., 2010; Biggerri & Ferrannini, 2014), while others were based in China (Chung et al., 2011), South Africa (Luruli et al., 2016), and the United Kingdom (Scobbie et al., 2013). One study (Grandisson et al., 2016) was an international Delphi study with participants recruited from multiple countries, showcasing the global interest in CBR frameworks. Another meta-analysis (Velema & Cornielje, 2003) provided a broad, cross-country perspective on CBR evaluations.

3.4.2.3 Study design

The study designs varied, with the majority employing case study methodologies (Adeoye et al., 2010; Chung et al., 2011; Biggerri & Ferrannini, 2014; Luruli et al., 2016; Scobbie et al., 2013). These case studies typically focused on evaluating CBR programmes in specific communities or regions. One study used a Delphi method (Grandisson et al., 2016) to generate expert consensus on best evaluative practices for CBR globally. Another study (Velema & Cornielje, 2003) employed a meta-analysis to evaluate the structure of diverse rehabilitation programmes across multiple contexts.

Table 3.2: Table of study characteristics results

Author, Date, Title	Aim	Design	Setting/Population
----------------------------	------------	---------------	---------------------------

<p>Adeoye et al. (2010). Developing a tool for evaluating community-based care in Uganda.</p>	<p>Develop a prototype tool for evaluation of a CBR programme</p>	<p>Case study</p>	<p>Tororo, Uganda Young adults WD¹</p>
<p>Chung et al. (2011). A framework for evaluating community-based rehabilitation programmes in Chinese communities.</p>	<p>Develop a framework to assess quality of Chinese CBR programme</p>	<p>Case study</p>	<p>China Children WD¹</p>
<p>Biggerri & Ferrannini (2014). Opportunity Gap Analysis: Procedures and Methods for Applying the Capability Approach in Development Initiatives.</p>	<p>Analysing complex programming using the capability approach framework and to present an innovative procedure for the systematised assessments of capabilities (opportunity freedom) in development projects</p>	<p>Case study</p>	<p>West-Nile region, Uganda Fourteen young adults (18 to 24 years old)</p>
<p>Grandisson et al. (2016). Expert consensus on best evaluative practices in community-based rehabilitation.</p>	<p>Generate expert consensus on best evaluative practices for CBR</p>	<p>Delphi study</p>	<p>Online (participants recruited globally) 61 experts</p>

Luruli et al. (2016). An improved model for provision of community-based healthcare rehabilitation services in Vhembe, District, Limpopo Province of South Africa.	Suggest an improvement in the model of providing CBR services	Case study	Vhembe District in Limpopo Province of South Africa 2,850 PWD from the CBR programme
Scobbie et al. (2013). Implementing a framework for goal setting in community-based stroke rehabilitation: a process evaluation.	To understand or explore the implementation, acceptability and perceived benefits of the G-AP framework	Case study	United Kingdom Eight patients who suffered a CVA ²
Velema & Cornielje (2003). Reflect before you act: providing structure to the evaluation of rehabilitation programmes.	Evaluating potentially diverse rehabilitation programmes	Meta-analysis	

Footnotes:

¹WD = With Disability

²CVA = Cerebral Vascular Accident

3.5.3 Use of the CBR Matrix as a foundational framework

The CBR Matrix was central to many studies, serving as a guiding framework for evaluating interventions across its five core components: Health, Education, Livelihood, Social, and Empowerment. The matrix was consistently referenced across multiple studies as a conceptual structure guiding the evaluation process. However, its application varied across studies, demonstrating both its flexibility and the need for adaptation in different contexts.

Several studies, including those by Adeoye et al. (2010), Chung et al. (2011), and Grandisson et al. (2016) used the CBR Matrix as an evaluative framework. These studies used the matrix to structure their evaluation processes by ensuring that all relevant pillars were addressed. For example, Adeoye et al. (2010) used the matrix as a guiding framework to develop a tool designed specifically to assess CBR interventions. Similarly, Chung et al. (2011) incorporated the CBR Matrix into an evaluation framework tailored to Chinese CBR programmes, ensuring that the principles of inclusion, participation, and empowerment were integral to the assessment process. Grandisson et al. (2016) took this a step further by combining the CBR Matrix with CBR principles to generate expert consensus on best practices in evaluation. This integration of frameworks highlights the matrix's adaptability and how it can be enhanced through alignment with other evaluative structures.

In contrast, some studies applied the CBR Matrix more loosely or adapted it to fit specific evaluation needs. Luruli et al. (2016) used the matrix in a more limited capacity, focusing on service quality constructs such as empathy and responsiveness rather than conducting a comprehensive evaluation across all pillars. This demonstrates the matrix's flexibility, allowing evaluators to adapt its use depending on the specific goals and constraints of the study.

While the CBR Matrix played a central role in many studies, some evaluations opted for alternative frameworks or tools that were more context-specific. For example, Biggeri and Ferrannini (2014) developed the O-Gapl, which focused on assessing community inclusion and empowerment through participatory role-playing, designed specifically for the intervention’s objectives, offering a more targeted assessment than the broader CBR Matrix. Similarly, Velema and Cornielje (2003) used a reflective framework that employed structured questions to guide the evaluation of services and outcomes. This framework allowed for a more tailored evaluation of the programme's unique characteristics, bypassing the need for the CBR Matrix. Additionally, Scobbie et al. (2013) used the G-AP framework, which focused on individualised goal-setting and action planning in stroke rehabilitation, highlighting that some interventions may require more specific evaluation tools not fully captured by the CBR Matrix.

Table 3.3: Summary of studies utilising the CBR Matrix in evaluation frameworks

Study	Used CBR Matrix	How CBR Matrix was Used
Adeoye et al. (2010)	Yes	Developed a tool to assess CBR interventions, focusing on all pillars of the matrix.
Chung et al. (2011)	Yes	Developed an evaluation framework for Chinese CBR programmes, incorporating the CBR Matrix's five pillars.
Grandison et al. (2016)	Yes	Used the CBR Matrix and CBR principles combined for expert consensus on best CBR evaluative practices.

Luruli et al. (2016)	Yes	Applied the matrix vaguely, focusing on service quality constructs such as empathy and responsiveness.
Biggeri & Ferrannini (2014)	No	Developed an inclusion tool (O-Gap) based on role-play for assessing community inclusion and empowerment.
Velema & Cornielje (2003)	No	Developed a reflective framework with structured questions tailored to the programme's services and context.
Scobbie et al. (2013)	No	Used the G-AP framework, focusing on goal-setting and action planning for stroke rehabilitation.

The Social pillar of the CBR matrix was one of the most consistently addressed across the studies, as it is central to CBR's objective of promoting inclusion and participation for PWDs. Studies such as Adeoye et al. (2010) and Chung et al. (2011) made social inclusion a key focus, integrating it into their frameworks to evaluate how well individuals were incorporated into family and community life. In these cases, social participation was linked directly to the broader goals of community rehabilitation, making it a foundational element of CBR programme evaluation.

In Grandisson et al. (2016), the social pillar was applied through the combination of the CBR Matrix and CBR principles. The study focused on the inclusion of PWDs in decision-making processes, aligning the evaluation with the social and community aspects of the CBR Matrix. Similarly, Velema and Cornielje (2003) explored the social aspects of rehabilitation by examining

the programme's relationship with the community, with particular attention to advocacy and support systems.

Health outcomes were naturally central to studies focused on clinical rehabilitation, such as Scobbie et al. (2013), where the G-AP framework was used to assess goal-setting in stroke rehabilitation. Health was a primary focus in evaluating the effectiveness of the interventions, reflecting the importance of functional recovery in certain CBR contexts. In Luruli et al. (2016), health was also a major component, with the study assessing patient satisfaction with health services in rural South Africa. The health pillar was tied directly to service quality and the improvement of patient outcomes. However, in frameworks more focused on social inclusion or empowerment, such as Velema and Cornielje (2003), health was not the primary focus.

Empowerment is a core element of CBR and was addressed across most studies. Adeoye et al. (2010) emphasised empowerment through the development of a tool that aimed to increase individual autonomy and control over rehabilitation processes. Similarly, Grandisson et al. (2016) focused on empowerment by ensuring that individuals were actively involved in decision-making, reflecting the importance of self-advocacy and autonomy in CBR evaluations. The Biggeri and Ferrannini (2014) study used the empowerment pillar to assess opportunity gaps between individuals and their communities, applying it as part of their dynamic analytical framework. Empowerment in this study was linked to social and economic independence, providing valuable insights into how the empowerment pillar can be used to assess individual agency and societal barriers.

The Education pillar was variably emphasised, depending on the context of the study. In Chung et al. (2011), education was a prominent aspect, where the framework included elements such as

economic independence and leadership roles in the community. Education was linked to the empowerment and participation of individuals, making it a vital component in assessing the effectiveness of CBR programmes in enhancing life skills and self-sufficiency. Luruli et al. (2016) also incorporated education, but in a more focused way, assessing how well patients were educated about their health conditions and the services provided. This study connected education directly to patient satisfaction and health outcomes, indicating that in certain contexts, education plays a crucial role in improving quality of life. However, in other studies such as Grandisson et al. (2016), education was not a primary focus, reflecting the variability in its application across different frameworks.

The Livelihood pillar, which addresses economic independence, was central in some studies, but less emphasised in others. For example, Chung et al. (2011) integrated livelihood as a core domain in their framework, linking it directly to the economic independence and participation of individuals in the community. This reflects a comprehensive approach to CBR, where economic opportunities are considered essential to an individual's overall rehabilitation. In contrast, studies such as Grandisson et al. (2016) and Scobbie et al. (2013) did not prioritise livelihood, focusing more on social participation and health outcomes. However, Biggeri and Ferrannini (2014) placed significant emphasis on livelihood through their opportunity gap analysis, which explored how community programmes could improve the economic inclusion of PWDs.

The Social and Empowerment pillars were the most consistently applied, reflecting their universal relevance to CBR goals. Health and Education were context-dependent, more prominent in studies focusing on clinical or service-related outcomes, while the Livelihood pillar was applied selectively, often depending on the socio-economic focus of the intervention.

3.5.4 Participatory and empowerment approaches in frameworks

The principle of empowerment is central to many CBR programmes and evaluation frameworks, which is reflected in how studies integrate participatory methods into their evaluation designs. Biggeri and Ferrannini (2014) developed a dynamic analytical framework based on the Opportunity Gap (O-Gap) analysis, which focused on participation and empowerment by involving PWDs in role-playing exercises to assess their perception of community involvement and empowerment. This participatory method exemplifies how evaluation frameworks often incorporate empowerment not only as an outcome but as part of the evaluation process itself. The involvement of PWDs in the assessment ensures that their voices are central to the evaluation, reinforcing the empowerment principle of the CBR Matrix.

Grandisson et al. (2016) also emphasised empowerment by recommending that evaluation processes include the voices of PWDs and other relevant stakeholders. This participatory approach ensures that evaluations are not only conducted about PWDs but with their active involvement, promoting inclusivity and ensuring that the evaluations reflect their needs and experiences.

3.6 Discussion

With regard to the question: “What frameworks are currently being used to evaluate CBR interventions?”, the findings of this scoping review reveal a range of evaluation frameworks currently in use, many of which are anchored in the CBR Matrix developed by the WHO. However, while the CBR Matrix provides a solid foundation, the flexibility required in its application across various settings suggests that a universally applicable framework must be adaptable, context-sensitive, and participatory. This discussion focuses on the major findings from the review and

explores their implications for developing a comprehensive and applicable evaluation framework for CBR interventions.

3.6.1 The centrality of the CBR Matrix in evaluation frameworks

The CBR Matrix emerged as a foundational tool in many of the reviewed studies, acting as a conceptual guide for structuring evaluations across multiple dimensions including Health, Education, Social inclusion, Empowerment, and Livelihood. Studies such as Chung et al. (2011) and Grandisson et al. (2016) demonstrate that the CBR Matrix can be adapted to local contexts, ensuring that all key pillars of CBR are considered. This reflects the matrix's ability to provide a comprehensive approach to evaluating CBR programmes, aligning with WHO's global guidelines for CBR, which emphasise participation, inclusion, and sustainability (WHO, 2010). The widespread use of the CBR Matrix highlights its relevance and strength as a starting point for any universal framework.

However, while the matrix is central, the review indicates that not all studies use every pillar equally, indicating that flexibility is needed depending on the intervention's focus. For example, studies such as Scobbie et al. (2013), which concentrated on stroke rehabilitation, address the Health and Social pillars but did not address Education or Livelihood. This variation in pillar focus demonstrates that while the CBR Matrix offers a universal foundation, the final evaluation framework must allow evaluators to emphasise certain pillars depending on the programme's goals and the population's needs. Flexibility in applying the CBR Matrix across various cultural and programmatic contexts is echoed in recent literature, which call for evaluation frameworks that can be tailored to different settings while maintaining core evaluative criteria (Durocher et al., 2016).

3.6.2 Participatory approaches and empowerment

A key theme that emerged from the review is the importance of participatory approaches in CBR evaluation frameworks. Many of the studies, such as Biggeri and Ferrannini (2014) and Grandisson et al. (2016), emphasise the need for empowerment and the involvement of PWDs in the evaluation process. The O-Gap analysis developed by Biggeri and Ferrannini, for instance, uses participatory methods to assess empowerment, highlighting the value of directly involving PWDs in evaluating their own experiences within the community.

The integration of participatory approaches reflects current trends in the literature advocating for participatory evaluation as a means to ensure that the perspectives of beneficiaries are fully captured in the evaluation process. Participation aligns with the empowerment principle of the CBR Matrix and underscores the need for evaluators to include PWDs and other community members in the evaluation process. This participatory approach not only strengthens the validity of the evaluation but also reinforces the principles of self-advocacy and autonomy (Brouwers et al., 2011).

3.6.3 Flexibility and contextual adaptability

While the CBR Matrix provides a strong structure, the review reveals that flexibility is essential for ensuring its universal applicability. Velema and Cornielje (2003) emphasise the importance of adapting evaluation frameworks to specific programme contexts, using a sequential question approach that allows evaluators to focus on different aspects of CBR depending on the programme's design and objectives. This adaptability is crucial for ensuring that evaluations remain relevant across diverse socio-economic and cultural settings, which often have unique barriers to health and rehabilitation services.

The literature supports the need for flexible frameworks in global health interventions. According to Hawkins et al. (2017), global frameworks must be adaptive and responsive to context-specific challenges, particularly in low-resource settings, where infrastructure and access to resources vary significantly. The flexibility seen in studies such as Grandisson et al. (2016), which combined the CBR Matrix with other CBR principles to suit specific cultural contexts, suggests that the ability to modify the framework is essential for ensuring relevance and comprehensiveness. The universal framework should not be rigid but should instead allow for the inclusion of additional principles or methods that are suitable to the intervention's geographic and cultural environment.

3.7 Limitations

The scoping review findings should be interpreted with caution due to several limitations. First, most included studies used case study designs, which provided rich insights but limited the generalisability of findings beyond specific cultural or programmatic contexts. Second, there was a clear geographical bias: while examples from Uganda, China, South Africa, and the UK were included, studies from Latin America, Southeast Asia, and many parts of Sub-Saharan Africa were absent. Third, restricting the review to English-language publications likely excluded relevant work from non-English-speaking regions, particularly those with strong rehabilitation research traditions. These factors reduce the comprehensiveness of the review and highlight the need for more regionally diverse, multilingual, and methodologically varied studies on CBR evaluation frameworks.

3.8 Conclusion

In developing a universal framework for evaluating CBR interventions, it is important to recognise that while all five pillars of the CBR Matrix are important, their relative importance may shift

based on the goals of the intervention, the population being served, and the regional context. Social inclusion and Empowerment appear to be universally relevant across all studies, and whilst Health, Education, and Livelihood are still essential, these pillars may require more flexibility, allowing for context-specific adaptation to ensure that the framework can be applied universally without losing its relevance or comprehensiveness.

Thus, the findings suggest that the CBR Matrix provides a strong foundation for a universally applicable evaluation framework but must be adaptable enough to prioritise different pillars based on the specific context of the CBR intervention. This adaptability is key to ensuring that the framework can be applied across diverse geographic, cultural, and programmatic settings while still capturing the core values of CBR.

CHAPTER FOUR: A SYSTEMATISED REVIEW ON THE GENERIC PATIENT-REPORTED OUTCOMES IN THE EVALUATION OF CBR INTERVENTIONS

4.1 Introduction

Despite the advancement of the CBR matrix to guide CBR interventions to provide a comprehensive service, PWDs remain in a poverty cycle and experience a gross infringement on their human rights (Blose et al., 2021). Limitations exist in evaluating CBR, as no consensus has been reached on the most appropriate tools or generic outcome measures when evaluating CBR interventions. Appropriate evaluation processes allow services to improve by exposing strengths and weaknesses.

To build on the findings from the scoping review in Phase One, the next phase involved a systematised review that aims to identify what GPROMs are most appropriate for the evaluation of CBR interventions. This phase focuses on identifying the tools employed to assess the effectiveness of CBR programmes.

4.2 Background

Community-based rehabilitation has been widely adopted as a strategy to enhance the quality of life for PWDs by integrating health, education, social inclusion, empowerment, and livelihood. The CBR Matrix, which outlines these five pillars, provides a robust framework for guiding interventions. However, the application of this matrix in evaluating CBR interventions remains a challenge, as PWDs continue to face entrenched issues such as poverty and human rights violations (Blose et al., 2021). While the matrix offers a comprehensive approach, its implementation must

be flexible enough to adapt to different contexts, as the relative importance of each pillar may vary depending on the specific goals of the intervention and the population served.

Generic patient-reported outcomes are structured questionnaires completed by patients or service users, designed to measure health outcomes, quality of life, and other subjective experiences from the perspective of the individual (Fitzpatrick et al., 1998). These measures are particularly valuable in capturing multidimensional outcomes, such as physical, mental, and social well-being, which align closely with the broad objectives of CBR.

Generic patient-reported outcomes have been widely used in healthcare settings to evaluate interventions by directly collecting data on patients' perspectives of their own health, well-being, and daily functioning. In general healthcare, they are regarded as reliable tools for providing subjective feedback on the impact of medical interventions. Well-established GPROMS include instruments such as the EQ-5D, the SF-36, and the Patient Health Questionnaire (PHQ-9), which have been validated across various populations and clinical settings (Devlin & Brooks, 2017).

While GPROMS have been extensively applied in healthcare, their use in CBR remains underexplored. The complexity of CBR interventions, which focus not only on health but also on education, livelihood, and social inclusion, requires a broader range of outcome measures. Some studies suggest that certain GPROMS, such as the WHO Disability Assessment Schedule (WHODAS), could be appropriate for evaluating CBR interventions, as they account for a broader scope of daily functioning and social participation (Üstün et al., 2003). However, there is no clear consensus on which GPROMS are most suitable for evaluating the multidimensional impact of CBR programmes (Shumba et al. 2020).

The adaptability of GPROMS in diverse cultural and geographical contexts is a critical consideration. Studies have highlighted the importance of ensuring that outcome measures are culturally sensitive and adaptable, particularly when applied in LMICs where the goals and outcomes of CBR may vary significantly from those in high-income settings (Iemmi et al., 2016). The challenge, therefore, is to identify GPROMS that are flexible enough to be used across various CBR contexts while still maintaining their validity and reliability.

4.3 Statement of the problem

Despite the strengths of the CBR Matrix, one significant limitation is the lack of consensus on appropriate tools and outcome measures for evaluating CBR interventions. This gap hampers the ability to systematically assess the effectiveness of CBR programmes, making it difficult to identify areas for improvement and ensure that interventions are truly benefitting the communities they aim to serve (Iemmi et al., 2016). Appropriate evaluation processes are essential for refining services, as they allow stakeholders to better understand which elements of the CBR interventions are working and which need adjustment (Mannan & MacLachlan, 2013).

In response to this challenge, GPROMS have been proposed as potential tools for evaluating the effectiveness of CBR interventions. Building on the findings of the previous phase, which identified a gap in appropriate evaluation tools for CBR interventions, this phase seeks to conduct a systematised review to identify the most appropriate GPROMS for evaluating the effectiveness of CBR interventions. The goal is to provide clarity on which tools can holistically capture the multidimensional outcomes of CBR, and to inform the next phase of the study, which aims to reach consensus on the framework and most appropriate outcome measures.

4.4 Methods

4.4.1 Overall study design for this objective

The data for this phase of the study was collected using a systematised review.

4.4.1.1 Population and sampling

In Phase Two of this study, the focus was on identifying GPROMS used to evaluate CBR interventions. While the theoretical population encompasses all global literature on GPROMS, practical constraints limited the accessible population to full-text publications in English, published between 2000 and 2022. Purposive sampling was employed to select studies most relevant to the research questions, allowing the focus on specific characteristics likely to yield useful data. Although this method carries the risk of selection bias, it was mitigated by clear inclusion criteria and a systematic study selection process (Pannucci & Wilkins, 2010).

4.4.1.2 Data collection instrument

A systematised review was used to synthesise the most commonly used GPROMS in the evaluation of CBR interventions. Unlike a systematic review, which is comprehensive and time-intensive, a systematised review offers a more streamlined approach, suitable for quickly gathering relevant data without compromising on rigour (Grant & Booth, 2009).

4.4.1.3 Procedure for data collection

The reporting of this systematic review was guided by the standards of the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) statement. Data from the full-text

articles was extracted into a brief narrative table that aimed to elicit the author/s, year of publishing, setting/population/method, GPROM as well as the relevant ICF category.

4.4.2 Identifying research question

This systematised review search aimed to discover which generic patient-reported outcomes are available for assessing the effectiveness of CBR interventions.

4.4.3 Identifying relevant studies

The search commenced on 28 Feb 2022. The following databases were included in the search: PubMed, Medline (EBSCOhost), CINAHL, and Web of Science. Boolean operators ("AND/OR") combined search terms to refine the search.

Table 4.1: Summary of search terms and Boolean operators

			AND	AND	AND
	CONCEPTS	1.	2	3	4
		Generic patient-reported outcome measures	Community rehabilitation	ICF	disability
OR	Synonyms	Patient outcome assessment	CBR	International classification of function	People living with disability
OR		Generic PROM	Community-based rehabilitation		PWD

OR		Patient outcome evaluation	CBR programme		
OR	Broader terms		community healthcare		
	Narrower terms			activity limitation	
				participation restriction	
				Activities of daily living	

4.4.4 Study selection

A total of 1,120 titles were imported from Endnote 20 into “Rayyan” (systematic review software). A duplicate search rendered 58 duplicate titles. The 1 062 unique titles were then revised, and 58 titles found to answer the research question and match inclusion criteria. Hereafter, 25 abstracts were included after following the same revision protocol as the title phase. This sample size was sufficient to provide a detailed evaluation of GPROMs within the specific context of CBR, ensuring that the findings were robust and reliable. However, the exclusion of non-English-language studies and those published outside the specified time frame may have limited the generalisability of the findings.

A search for the full text of the 25 abstracts was performed and only two were not found. The remaining 23 full-text articles were revised against the same criteria as the title/abstracts and four articles were excluded as they did not answer the research question: “What generic patient-reported

outcome measures are being used to evaluate CBR interventions under the domains of ‘Activity limitation’ and ‘Participation restriction’ in accordance with the ICF?”

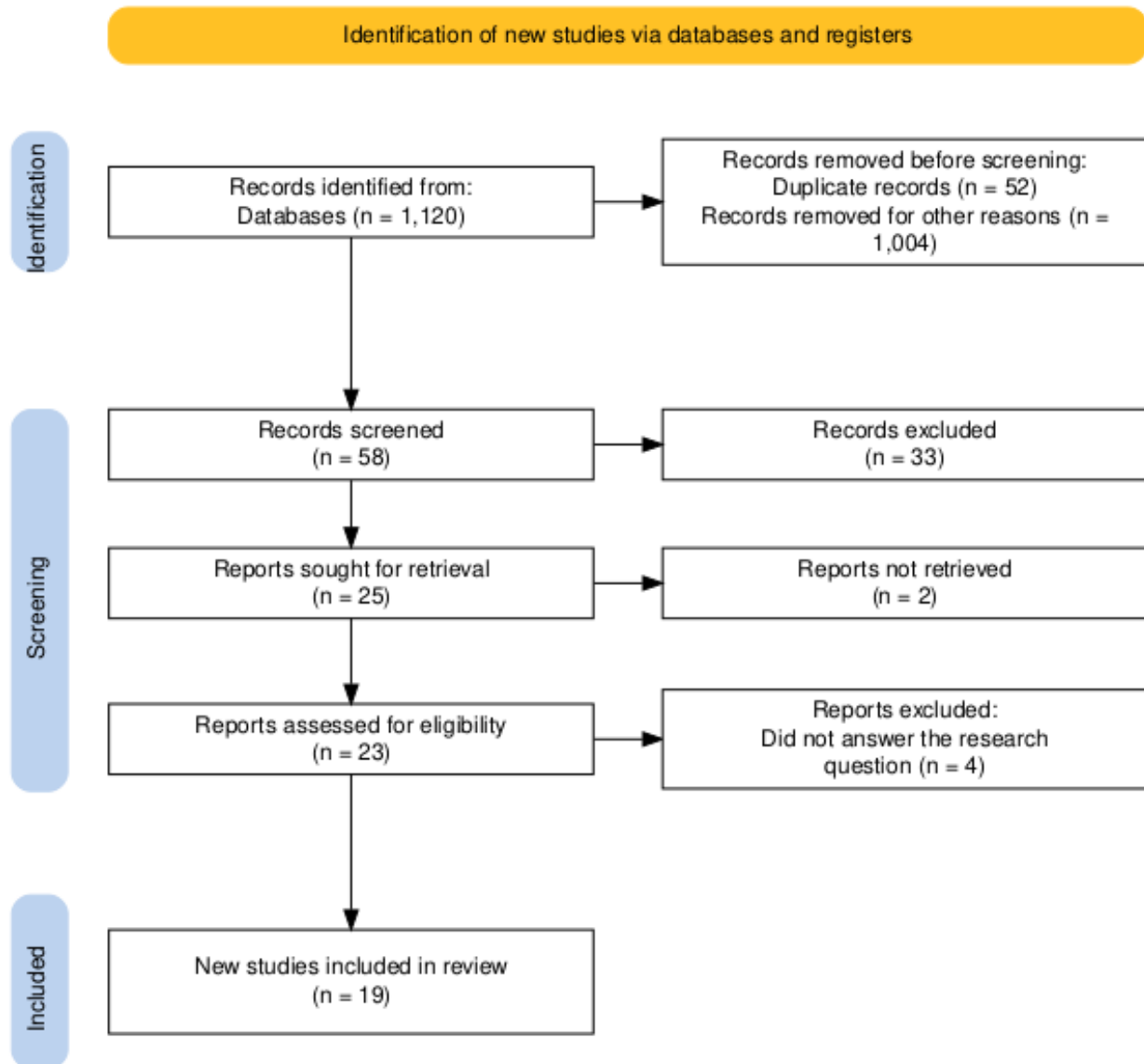


Figure 4.1: PRISMA flow diagram of study process (Page et al., 2022)

4.4.5 Synthesis methods

Due to the heterogeneity in the GPROMs used across different studies, a meta-analysis was not feasible. Instead, a descriptive synthesis was conducted, focusing on summarising the characteristics, reliability, validity, and usage contexts of the identified GPROMs. The synthesis

categorised the PROMs under the ICF domains of "Activity limitation" and "Participation restriction" to facilitate a structured comparison. Studies were grouped based on the specific PROMs they utilised and the ICF domains they targeted. This approach allowed for the identification of patterns in the use of PROMs across different CBR interventions and settings. The findings were tabulated to present a clear comparison of the PROMs used in each study, highlighting their key characteristics, such as reliability, validity, and the specific ICF domain they addressed. This tabulation facilitated the identification of commonalities and differences among the PROMs.

Articles were included or excluded based on these criteria:

Inclusion criteria:

- English
- Full-text articles
- 2000 to 2022
- All study types were considered
- Generic PROM (no condition-specific outcome measures will be considered)

Exclusion criteria:

- Articles that did not answer the research question
- Paediatric-specific outcome measures excluded

4.4.6 Sensitivity analyses

Sensitivity analyses were performed by excluding studies that were identified as having a high risk of bias, particularly those with unclear methods of outcome measurement or insufficient reporting on the reliability and validity of the GPROMs used. The impact of excluding these high-risk bias

studies on the overall conclusions was evaluated. The findings indicated that the exclusion of these studies did not significantly alter the overall conclusions, suggesting that the results of this review are robust despite the potential biases in the included studies. Given the substantial heterogeneity in GPROMs, study designs, populations, and reporting practices, a meta-analysis was deemed infeasible for this systematised review. Instead, a descriptive synthesis was conducted to summarise and compare the identified GPROMs, providing valuable insights into their use in evaluating CBR interventions across different contexts.

4.5 Results

4.5.1 Introduction

The systematised review identified and synthesised 19 studies that applied various GPROMs to evaluate CBR interventions across diverse settings. The selected studies focused on a range of health conditions, including physical disabilities, mental health, and chronic illnesses.

The GPROMs identified include:

- **WHOQOL-BREF** (n = 6 studies)
- **WHODAS 2.0** (n = 5 studies)
- **SF-36** (n = 7 studies)
- **EQ-5D** (n = 4 studies)
- **LIFE-H** (n = 3 studies)
- **IMPACT-S** (n = 2 studies)
- **USER-P** (n = 3 studies)

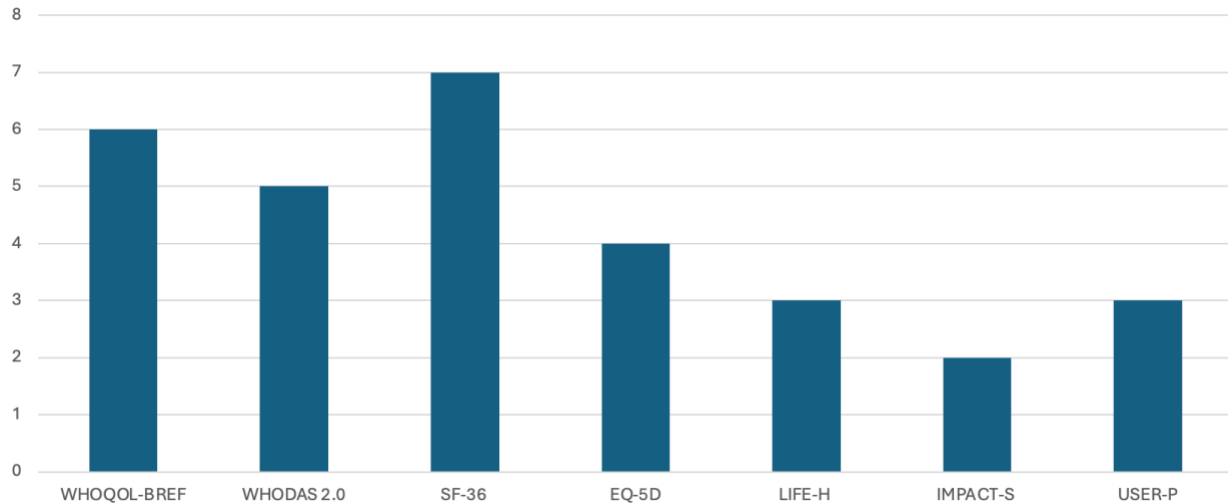


Figure 4.2: GPROMs to evaluate CBR interventions identified in the systematised review

4.5.2 Study characteristics

The 19 studies in this review typically employed multiple outcome measures, with a primary emphasis on the Participation domain of the ICF. Many studies also included measures for Activity and Quality of Life, highlighting the multidimensional nature of CBR interventions.

These studies used various GPROMs to evaluate health, participation, and daily functioning across different populations, from those with chronic illnesses to individuals in rehabilitation after accidents or strokes. The choice of GPROMs depended on the intervention's goals, the target population, and the cultural or regional context. While many instruments covered multiple domains, such as physical health and social participation, others were more specialised, focusing on specific areas such as social integration or cognitive functioning.

The table below provides a summary of the identified GPROMs, highlighting their usage across various CBR interventions, the populations they have been applied to, and the ICF domains they address.

Table 4.2: Descriptive summary of GPROMs used in CBR evaluations

AUTHOR	YEAR	POPULATION / SETTING	GPROM	ICF DOMAIN
Weenink et al.	2014	A total of 300 patients in three general practices were invited to participate in the study and provided with seven generic PROMs – follow-up was four weeks later.	Patient empowerment (PAM-13 or EC-17), Quality of life (EQ-5D or SF-12) Mental health (GHQ-12), Enablement (PEI) Perceived treatment effect (GPE)	Participation
Oude Voshaar et al.	2017	1,128 people living with disability in a Dutch community.	SF-36 compared to the Reach assessment of everyday activity limitations (REAL) item	Activity
Post et al.	2009	Outpatients (n = 47) from two rehabilitation centres and a university hospital in the Netherlands.	ICF Measure of Participation and Activities Screener (IMPACT-S), Participation Scale, Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P)	Participation
Post et al.	2008	Road accident victims were recruited through	IMPACT-S	Activity

		several Dutch hospitals and rehabilitation centres. A total of 276 patients participated and 197 took part in both measurements.		Participation
Chung et al.	2014	A systematic search with an independent review process selected relevant articles to identify outcome measures in participation in traumatic brain injury. Instruments used in two or more studies were linked to the ICF categories, which identified categories in participation for comparison with the ICF core sets for traumatic brain injury.	Community Integration Questionnaire, Craig Handicap Assessment and Reporting Technique, Mayo-Portland Adaptability Inventory-4 Participation Index, Sydney Psychosocial Reintegration Scale Version-2, Participation Assessment with Recombined Tool-Objective, Community Integration Measure, Participation Objective Participation Subjective, Community Integration Questionnaire-2, Quality of Community Integration Questionnaire	Participation
Benson	2020	A coherent family of short generic PROMs and	Benson's taxonomy of short generic PROM	Activities

* Not tested for validity and reliability *		PREMs that can be used in combination in a pick-and-mix way.	and PREM	Participation
Chang et al.	2013	A systematic search.	ICI Index of Community Involvement Maastricht Social Participation Profile (MSPP) KAS Katz Adjustment Scale covers community participation most extensively (eight of the nine domains of community participation) MSPP, and SFS evaluate only the frequency of participation	Participation
Cieza & Stucki	2005	Comparison of the relationship between six HRQOL instruments (the SF-36, the NHP, the QL-I, the WHOQOL-BREF, the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) and the EQ-5D) and the ICF. All six HRQOL instruments were linked to the ICF separately by two trained health professionals according to 10 linking rules developed specifically for this purpose using Kappa coefficient.	Two most widely used, short generic health profiles: SF-36 NHP Spitzer's Quality of Life Index (QL-I) WHO: WHOQOL-BREF WHODAS 2.0	Participation

			EQ-5D	
Jenkinson et al.	2019	<p>Survey. Follow-up survey.</p> <p>Results on the Ox-PAQ Single Index and Short Form-Ox-PAQ Single Index are compared with results from another generic measure, the EuroQol EQ-5D-5L.</p>	OX-PAQ	Activities Participation
Resnik & Plow	2009	<p>Systematic review design.</p> <p>Participants: 40 generic and condition-specific self-report measures that met study inclusion criteria were evaluated.</p>	<p>Community Living Skills Scale,</p> <p>The LIFE-H,</p> <p>Mayo-Portland Adaptability Inventory</p>	Participation
Skevington & McCrate	2012	<p>Cross-sectional with nested repeated measures.</p> <p>Settings/Part: 27 disease groups or health conditions and healthy people were recruited at 38 UK sites, in a wide range of settings (n = 4 628).</p>	Compared SF-36 and WHOQOL	Participation
Tse et al.	2013	Systematic review.	<p>The Stroke Impact Scale (SIS),</p> <p>London Handicap Scale, Assessment of Life Habits (LIFE-H),</p> <p>Frenchay Activities Index, and Activity Card Sort (ACS)</p>	Participation

			No single measure met criteria across all psychometric indices, and not one covered all nine of the ICF Activities and Participation domains	
van der Zee et al.	2014	<p>Convenience sample of persons with long-term SCI living in the Netherlands.</p> <p>Validation of the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) in persons with spinal cord injury (SCI) using two ICF-based instruments: the ICF Measure of Participation and Activities-Screener (IMPACT-S) and the WHODAS 2.0.</p>	<p>USER-Participation,</p> <p>IMPACT-S,</p> <p>WHODAS 2.0</p>	Participation Activity
Post et al.	2009	<p>Design: (1) Inter-rater reliability study and (2) responsiveness study with measurements at admission and at discharge from clinical rehabilitation.</p> <p>Setting: Three rehabilitation facilities in the Netherlands.</p> <p>Patients: Rehabilitation inpatients (n = 319).</p> <p>Objective: The Utrecht Scale for Evaluation of Rehabilitation (USER) is a measure of functional independence that covers physical functioning (mobility, self-care), cognitive functioning and additional domains of pain, fatigue and mood.</p>	USER	Activity

Kulnik & Nikolettou	2014	<p>A convenience sample of 10 community rehabilitation service users participated in semi-structured interviews and completed the WHODAS 2.0.</p> <p>Content analysis and a constant comparative method of analysis were applied. Participants' accounts were compared with the measure's content and its underlying construct of disability.</p>	WHODAS 2.0	Activity Participation
Darzins et al.	2017	Descriptive study that compared FIM and PC-Part Outcome measures to ICF activities.	FIM PC-Part	Activities Participation
Hartman-Maeir et al.	2007	A total of 56 stroke patients (mean age: 57.7) who completed an in-patient rehabilitation programme were evaluated one year post onset in their homes.	<p>Functional Independence Measure (FIM),</p> <p>Instrumental Activities of Daily Living Questionnaire (IADLq),</p> <p>Activity Card Sort (ACS), a work questionnaire,</p> <p>Life-Satisfaction Questionnaire (Li-Sat 9),</p> <p>Geriatric Depression Scale (GDS)</p>	Activities Participation

Raggi et al.	2010	Pilot study of adult in-patients issued with AT. WHODAS 2.0 was administered on admission and two months post intervention with AT.	WHODAS 2.0	Activities Participation
Ackerly et al.	2009	Cohort study consisting of 55 outpatients from rehabilitation facilities. All patients completed WHOQOL-BREF and LHS on admission and discharge.	WHOQOL-BREF London Handicap Scale LIFE-H	Participation

Table 4.3 presents an overview of key characteristics of selected GPROMs commonly used in the evaluation of CBR interventions. In addition to outlining the number of items, dimensions assessed, and typical usage contexts, each instrument was systematically mapped against the International Classification of Functioning, Disability and Health (ICF) domains (impairments, activity limitations, participation restrictions, and environmental factors). This alignment demonstrates the extent to which individual tools capture different aspects of functioning, participation, and context, providing a clearer basis for comparing their relevance across diverse populations and health conditions.

Table 4.3: Overview of key characteristics of selected GPROMs

Instrument	Number of Items	ICF Domains	Dimensions	Usage Contexts
WHOQOL-BREF	26	Activity Limitation, Participation Restriction, Contextual factors (Environment and personal)	Physical, Psychological, Social, Environmental	General population, chronic illness
WHODAS 2.0	36	Activity Limitation, Participation Restriction, Contextual factors (Environment and personal)	Cognition, Mobility, Self-care, Getting along, Life activities, Participation	Disability, chronic illness
SF-36	36	Activity Limitation, Contextual factors (Environment and personal)	Physical Functioning, Bodily Pain, General Health, Vitality, Social Functioning, Emotional well-being, Mental Health	General population, various health conditions

EQ-5D	5	Activity Limitation, Contextual factors (Environment and personal)	Mobility, Self-care, Usual Activities, Pain/Discomfort, Anxiety/Depression	General population, various health conditions
LIFE-H	77	Activity Limitation, Participation Restriction, Contextual factors (Environment and personal)	Daily Activities, Social Roles	Disability, rehabilitation
IMPACT-S	16	Participation Restriction, Contextual factors (Environment and personal)	Work, Leisure, Social Interaction	Rehabilitation, chronic illness
USER-P	31	Activity Limitation, Participation Restriction,	Mobility, Self-care, Domestic Life	Rehabilitation, spinal cord injury, stroke
FIM	18	Activity Limitation	Self-care, Sphincter Control, Mobility, Communication, Social Cognition	Rehabilitation, stroke, spinal cord injury

Most studies use GPROMs focusing on the Participation domain, which aligns with the central objective of CBR interventions: enhancing individuals' engagement in daily life and community activities to improve their quality of life and social integration. Tools such as SF-36 and WHOQOL-BREF were frequently used, highlighting the importance of measuring participation as a key indicator of CBR programme effectiveness.

The application of GPROMs limits their broader applicability.

Notably, several GPROMs including WHOQOL-BREF, WHODAS 2.0, and SF-36 offer multidimensional approaches, covering physical, psychological, social, and environmental aspects. Such comprehensive measures align closely with the holistic goals of CBR, as they capture a wide range of outcomes beyond physical rehabilitation, addressing broader health determinants and well-being. These instruments are essential for evaluating CBR interventions comprehensively.

Despite the variety of GPROMs used, the review identifies a gap in the coverage of all ICF domains. While many studies emphasise Participation and Activity, other domains such as Body Functions and Environmental Factors are less frequently assessed. This suggests that although current GPROMs effectively capture certain aspects of CBR interventions, they may not provide a complete picture. The review also highlights variability in the length and complexity of GPROMs, impacting their practicality. Shorter instruments such as EQ-5D are practical and less burdensome for respondents, but may lack the scope needed to capture the full impact of CBR interventions. Conversely, longer tools such as LIFE-H, while offering comprehensive assessments, may pose logistical challenges in low-resource settings due to their time and resource

demands. This highlights the need for balancing comprehensiveness with practicality when developing or selecting GPROMs for CBR evaluation.

There is also strong evidence supporting the reliability and validity of several GPROMs, such as WHOQOL-BREF, WHODAS 2.0, and SF-36, which have been extensively validated across different populations and contexts. However, some GPROMs, particularly those designed for specific conditions (e.g., FIM for stroke rehabilitation), show high reliability but are limited in their broader applicability. While effective for targeted interventions, these tools may require adaptation to fit within a universal CBR framework.

4.5.3 Reliability of GPROMs

The reliability analysis of the GPROMs identified in this systematised review reveals notable variability in their internal consistency, as measured by Cronbach's alpha scores, which range from 0.70 to 0.95. This range reflects different levels of consistency across various settings and suggests that the suitability of these measures for evaluating CBR interventions can vary significantly based on context.

Table 4.4: Reliability categories of GPROMs

Reliability Category	GPROMs	Cronbach's Alpha Range
Acceptable (0.70–0.79)	SF-36	0.70–0.79
Good (0.80–0.89)	WHOQOL-BREF, LIFE-H, IMPACT-S	0.75–0.90
Excellent (0.90–0.95)	WHODAS 2.0, USER-P, FIM	0.90–0.95

4.6 Discussion

This systematised review provides key insights into the use of GPROMs in evaluating CBR interventions, reinforcing the need for a comprehensive and adaptable evaluation framework. The discussion below integrates these findings with existing literature to build the case for a universal framework that can be applied across diverse settings.

4.6.1 Emphasis on participation as a core outcome

The review highlights a predominant focus on the Participation domain, closely aligned with the core objective of CBR: enhancing individuals' ability to engage in community and daily activities (WHO, 2010). As CBR interventions aim to promote social inclusion and functional independence, measuring participation is critical (Mannan & MacLachlan, 2013). GPROMs such as WHOQOL-BREF and SF-36 have demonstrated their effectiveness in capturing these outcomes, thus supporting their inclusion in a universal evaluation framework (Üstün et al., 2003).

However, the literature indicates that GPROMs validated in high-income countries may not perform consistently in LMIC settings due to cultural and environmental variations (Iemmi et al., 2016). This variability underlines the necessity for a framework that not only emphasises participation but also adapts to different cultural contexts, ensuring its relevance across diverse populations (Shumba et al. 2020).

4.6.2 Versatility and adaptability of GPROMs

The review underscores the versatility of GPROMs such as WHODAS 2.0 and LIFE-H, which are adaptable to a variety of conditions and contexts. Their flexibility is crucial for a universal framework, enabling consistent application across different healthcare systems and population

groups. The WHODAS 2.0, validated globally, proves effective in various cultural contexts, making it a strong candidate for a universal evaluation tool (Üstün et al., 2003). Similarly, LIFE-H offers valuable insights into daily activities and social roles, aligning with CBR's goals of fostering social participation and functional independence (Noreau et al., 2004).

Other tools, such as FIM and USER-P, are context-specific, designed primarily for specific rehabilitation scenarios, such as stroke or spinal cord injury recovery (Cieza & Stucki, 2005). While highly reliable in these settings, they may require adaptation for broader use. This aligns with Grant and Booth's (2009) findings that evaluation tools must be flexible enough to capture the complexity of outcomes across different CBR interventions.

4.6.3 Multidimensional measures and holistic evaluation

The integration of multidimensional GPRoMs such as WHOQOL-BREF and SF-36 into a universal framework is essential for achieving a holistic evaluation of CBR interventions. These instruments go beyond physical outcomes to assess psychological, social, and environmental dimensions, which are crucial for rehabilitation success (Fitzpatrick et al., 1998). Their use aligns with the multidimensional nature of CBR, which aims to address a broad range of health determinants.

However, the review identified gaps in coverage across all ICF domains. While the focus on Participation and Activity is prevalent, domains such as Body Functions and Environmental Factors are often under-assessed. This gap suggests that existing GPRoMs may not provide the comprehensive evaluation needed for a truly holistic assessment of CBR outcomes. A universal framework must therefore incorporate multidimensional tools that cover a broader range of health determinants (Cieza et al., 2020).

4.6.4 Balancing practicality and comprehensiveness

The review revealed significant variability in the length and complexity of GPROMs, which poses challenges for developing a universally applicable framework. Shorter instruments such as EQ-5D are practical and efficient, especially in low-resource settings, but they may lack the depth needed to fully evaluate the impact of CBR (Rabin & de Charro, 2001). Conversely, longer tools such as LIFE-H offer more comprehensive assessments, but may be impractical due to the time and effort required for their administration (Noreau et al., 2002).

Balancing comprehensiveness with practicality is crucial for a universal framework, as noted by Whitfield et al. (2006). A modular approach that combines core short measures with optional, more detailed modules could provide the necessary flexibility, ensuring the framework is both comprehensive and feasible in diverse settings.

4.6.5 Reliability and validity as cornerstones of a universal framework

Several GPROMs, including WHOQOL-BREF, WHODAS 2.0, and SF-36 have demonstrated strong reliability and validity across different populations and contexts. These findings are consistent with the literature, which highlights the robust psychometric properties of these instruments (Fitzpatrick et al., 1998; Devlin & Brooks, 2017). Their inclusion in a universal framework is essential to ensure consistent and reliable evaluations of CBR interventions.

However, tools such as FIM, while reliable for specific conditions such as stroke rehabilitation, may not be applicable in broader contexts without adaptation. This supports the need for a framework that prioritises validated tools with broad applicability while remaining flexible enough to adapt to different cultural and socio-economic environments (Iemmi et al., 2016).

This review provides strong evidence supporting the development of a universal framework for evaluating CBR interventions. The predominance of GPROMs focused on Participation, the adaptability of multidimensional tools, and the reliability and validity of instruments such as WHODAS 2.0 offer solid foundations for such a framework. However, to be effective globally, this framework must address gaps in ICF coverage, balance practical application with comprehensive assessment, and ensure the cultural adaptability of the measures. By integrating these elements, the framework can significantly improve the evaluation and effectiveness of CBR programmes across diverse contexts.

This review also underscores the variability in the application of GPROMs such as WHOQOL-BREF, SF-36, LIFE-H, and IMPACT-S, reflecting the need for contextual adaptation. While these tools are validated and widely used in general and rehabilitation settings, their relevance and applicability vary based on the specific intervention and population. This reinforces the importance of ensuring that reliability and cultural sensitivity are balanced in the development of a universal CBR evaluation framework.

In conclusion, achieving a balance between the reliability, comprehensiveness, and adaptability of GPROMs is critical for developing a robust framework that can be universally applied across various CBR settings.

4.6.6 Bias considerations

In this review, efforts were made to mitigate publication bias by including studies from a variety of reputable databases, including PubMed, Medline, CINAHL, and Web of Science. However, the restriction to English-language publications and the focus on major databases may have introduced a risk of publication bias, as studies published in other languages or less prominent journals might

not have been captured. The review included all GPROMS from the identified studies to reduce the risk of selective reporting bias. The GRADE (Grading of Recommendations, Assessment, Development, and Evaluations) approach was employed to assess the certainty or confidence in the body of evidence. This systematic framework evaluates several domains: Risk of Bias, Assessment, Inconsistency, Indirectness, Imprecision, and Publication Bias.

The review also excluded paediatric-specific outcome measures, which might have limited the scope of the findings to adult populations only. Studies with significant or positive results are more likely to be published and indexed in major databases, which may have led to the overrepresentation of such studies in this review. This could skew the findings and overestimate the effectiveness or reliability of certain PROMs. The diverse range of PROMs identified, selected based on the preferences or resources of individual researchers or institutions, may have introduced measurement bias. This variability complicates comparisons across studies and might affect the generalisability of the results. There is a potential for reporting bias due to the reliance on published studies, as unpublished studies or those with null results might not have been captured in the review. This could lead to an incomplete representation of the available evidence.

Based on the GRADE assessment, the overall certainty of the evidence in this review is considered moderate. While the findings provide valuable insights into the use of PROMs in CBR evaluations, the identified risks of bias, inconsistency, indirectness, and imprecision suggest that the conclusions should be interpreted with caution. Further high-quality research is needed to strengthen the evidence base, particularly studies that address the identified limitations and biases.

4.7 Limitations

While the systematised review provided valuable insights into the use of GPROMs for evaluating CBR interventions, several limitations are evident that may influence the generalisability and comprehensiveness of the findings. These limitations highlight areas where caution must be exercised in interpreting results and where future research efforts could focus to address these gaps.

One significant limitation is the restriction of the search to English-language publications. By excluding non-English studies, the review may have overlooked important research conducted in non-English-speaking regions, particularly in LMICs where CBR programmes are often implemented. This introduces a language bias, potentially limiting the diversity of cultural perspectives and contexts represented in the review. Given that CBR is a global approach applied in varied cultural and socio-economic environments, the exclusion of studies in other languages may reduce the applicability of the findings and the selection of GPROMs suitable for diverse populations (Iemmi et al., 2016).

Another limitation is the reliance on full-text articles available through specific databases, such as PubMed, Medline, CINAHL, and Web of Science. While these databases provide access to a broad range of medical and rehabilitation literature, they may not capture all relevant studies, particularly those published in less prominent journals or in grey literature sources such as government reports or local programme evaluations. This selection bias could result in the exclusion of studies that offer different methodological approaches or insights into GPROM application, especially in resource-limited or rural settings where such literature may be more prevalent (Grant & Booth, 2009).

The exclusion of paediatric-specific outcome measures is another limitation that affects the scope of the review. By focusing only on GPRoMs relevant to adult populations, the review may have missed important tools and data applicable to children and adolescents, a demographic often involved in CBR interventions. This exclusion narrows the applicability of the findings and may limit the development of a universal framework that effectively encompasses all age groups. Given the importance of early intervention and rehabilitation for children, the absence of these measures represents a gap that must be addressed in future studies to ensure that the evaluation of CBR is inclusive across the lifespan.

A further limitation lies in the heterogeneity of the studies included. The studies reviewed utilise various GPRoMs with differing lengths, complexities, and psychometric properties. This diversity makes it difficult to conduct meta-analyses or to synthesise findings in a way that offers clear comparisons. Instead, the review relies on a descriptive synthesis, which, while informative, does not provide the same level of statistical robustness or the ability to draw definitive conclusions about the most effective GPRoMs for CBR evaluation across all contexts. As a result, the conclusions drawn may be influenced by the specific characteristics of the included studies rather than being reflective of broader patterns.

Additionally, the potential for publication bias cannot be ignored. Studies with significant or positive results are more likely to be published and indexed in major databases, which may lead to an overrepresentation of successful CBR interventions and GPRoM applications. This could skew the findings, as studies with null results or those identifying challenges in GPRoM use might be underreported. Consequently, the review's findings may provide an overly optimistic view of the current tools' effectiveness, necessitating a cautious interpretation of the results.

Finally, while the review aimed to provide a streamlined approach through a systematised methodology, this approach inherently lacks the comprehensiveness and rigor of a full systematic review. Systematised reviews often utilise streamlined processes for study selection and data extraction, which may overlook subtle nuances or critical methodological differences between studies. As a result, some aspects of GPROM application or the specific conditions under which they were validated may not have been fully explored.

The limitations identified in this systematised review suggest areas for improvement in future research. Addressing language bias, expanding search criteria to include grey literature, considering paediatric-specific GPROMs, and conducting more robust analyses can enhance the comprehensiveness and applicability of future evaluations. By acknowledging these limitations, researchers can develop a more inclusive and representative understanding of GPROMs in CBR, ultimately informing the development of a truly universal evaluation framework.

4.8 Conclusion

The findings from this systematised review provide critical insights into the research question for this phase: *What generic patient-reported outcomes are available for assessing the effectiveness of CBR interventions?* The review highlights a wide range of GPROMs currently employed to evaluate CBR outcomes, with many instruments focusing predominantly on the Participation domain—a core component of CBR objectives. Tools such as WHOQOL-BREF, SF-36, and WHODAS 2.0 are identified as versatile, multidimensional measures that align well with the holistic goals of CBR, offering evaluations of physical, psychological, and social outcomes.

However, the review also uncovers limitations in the comprehensive coverage of all relevant domains within the ICF, particularly with respect to Body Functions and Environmental Factors.

The findings suggest that while current GPROMs can effectively capture certain aspects of CBR, they may not provide a complete picture necessary for fully evaluating these interventions. This gap points to the need for developing new or adapted instruments that can address these neglected areas to ensure a balanced and comprehensive assessment.

Additionally, the variability in GPROM application across diverse settings and populations underscores the importance of adaptability in developing a universal framework. Instruments such as WHODAS 2.0 and LIFE-H show promise due to their flexibility, but others, such as FIM and USER-P, remain context-specific and may require further adaptation to fit broader CBR applications. Furthermore, the review highlights the challenge of balancing practicality with comprehensiveness, particularly when considering the use of GPROMs in low-resource settings.

In conclusion, while several GPROMs are suitable for inclusion in a universal CBR evaluation framework, gaps in domain coverage and adaptability must be addressed. The findings of this phase build a strong foundation for developing a comprehensive, multidimensional, and adaptable framework that can effectively evaluate the diverse and complex outcomes associated with CBR interventions. Future research must focus on expanding the scope of GPROMs to cover all ICF domains, ensuring cultural and contextual relevance, and validating these measures in diverse populations to achieve a truly universal framework.

CHAPTER FIVE: DEVELOPMENT OF AN EVALUATION FRAMEWORK – A DELPHI STUDY

5.1 Introduction

This chapter presents the third phase of the research project, a Delphi study, designed to establish expert consensus on the most appropriate GPROMs and a framework for evaluating CBR interventions. Community-based rehabilitation has emerged as a key strategy for enhancing the quality of life for individuals with disabilities, particularly in low-resource and rural contexts. However, despite its widespread implementation, the evaluation of CBR interventions remains inconsistent due to the absence of a universally accepted framework.

Building on the findings from the previous phases, this Delphi study addresses the gap in evaluating CBR interventions by systematically identifying suitable GPROMs and incorporating relevant theoretical frameworks. The aim is to develop a cohesive framework for evaluating CBR interventions that integrate these GPROMs into a standardised evaluation framework that works across diverse contexts.

The proposed framework is grounded in evidence-based practices derived from prior research and literature. The Delphi method's structured approach, in turn, allows for the convergence of expert opinion, ensuring that the framework also reflects the nuanced challenges of diverse rehabilitation settings.

5.2 Background

Community-based rehabilitation is an approach endorsed by the WHO to enhance the quality of life for individuals with disabilities by promoting social integration, equal opportunities, and

access to essential services (WHO, 2010). Since its inception following the Alma-Ata Declaration in 1979, CBR has evolved as a key strategy for delivering rehabilitation services in low-resource and rural settings, focusing on holistic, community-oriented solutions (Finkenflügel et al., 2008). The CBR model integrates various dimensions of health and well-being, encompassing medical, educational, social, and livelihood aspects (Mauro et al., 2014).

The evaluation of CBR often relies on theoretical frameworks such as the CBR Matrix and the ICF, but both have limitations when applied to outcome measurement. The CBR Matrix was designed to guide the development and implementation of CBR programmes by categorising interventions into five domains: health, education, livelihood, social inclusion, and empowerment (WHO, 2010). While this framework ensures a holistic approach to addressing the diverse needs of communities, it does not extend to evaluating the effectiveness of these interventions, as it lacks specific outcome measures or indicators.

Similarly, the ICF provides a biopsychosocial model that conceptualises disability as a complex interaction between health conditions, personal factors, and environmental contexts. This makes it a valuable framework for organising evaluations and understanding the multifaceted nature of disability. However, the ICF does not offer concrete tools or standardised outcome measures, which poses challenges for consistent evaluation of CBR programmes across diverse settings (Kostanjsek, 2011). Together, these limitations underscore the need for supplementary evaluation tools tailored to the unique demands of CBR programmes.

Generic patient-reported outcome measures offer an avenue to fill this gap. These standardised tools capture self-reported health status, functional ability, and quality of life across various conditions and populations, providing essential insights into the patient's perspective (Basch,

2017). Examples of commonly used GPROMs include the WHO Quality of Life (WHOQOL-BREF), the Short Form Health Survey (SF-36), and the WHODAS 2.0. These tools align with the holistic goals of CBR, offering robust evaluations of physical, psychological, and social outcomes (Devlin & Brooks, 2017; Herdman et al., 2011).

The findings from the systematised review in the previous phase revealed that while many GPROMs, such as WHOQOL-BREF, SF-36, and WHODAS 2.0 are versatile and multidimensional, their coverage of essential ICF domains is not comprehensive. The review highlighted that most of these instruments focus predominantly on the Participation domain, a core component of CBR objectives, but provide limited information on other critical domains such as Body Functions and Environmental Factors (Fayers, 2001). This gap suggests that while existing GPROMs can effectively capture certain aspects of CBR, they may not provide the complete picture needed for fully evaluating these interventions, indicating the necessity for developing new or adapted instruments that can address these neglected areas.

To address these challenges, this Delphi study focused on refining the understanding of which GPROMs are most suitable for evaluating CBR interventions. By engaging a panel of CBR experts through a Delphi study, the aim was to identify and integrate GPROMs while also developing a theoretical framework that incorporates findings from Phases One to Three. This framework will seek to balance the adaptability and broad applicability of GPROMs and theoretical frameworks with the need for context-specific tools that capture the full spectrum of CBR outcomes.

5.3 Methods

5.3.1 Overall study design

This study employed a Delphi study to reach expert consensus on the most appropriate GPROMs for evaluating CBR interventions, specifically focusing on the domains of Activity and Participation as defined by the ICF. A Delphi study was selected for its structured, iterative design, which enables a systematic approach to achieving convergence of expert opinion through multiple rounds of controlled feedback (Hsu & Sandford, 2012). Given the need for a widely applicable framework that reflects diverse perspectives within the CBR field, the Delphi study was particularly suitable, as it minimised bias and allowed for the synthesis of insights across a broad range of expertise.

5.3.1.1 Population and sampling

Experts were recruited based on established criteria designed to ensure both the relevance and depth of their contributions to CBR research and evaluation. Specifically, participants qualified as experts if they satisfied all of the following conditions: they had published in the field of CBR, contributed to the WHO Rehabilitation 2030 initiative, and held academic appointments at recognised institutions in South Africa or internationally. This rigorous identification process yielded an expert panel of 12 individuals, who were invited via email to participate in the Delphi rounds. Ultimately, seven experts completed all three rounds, a retention rate in line with typical Delphi studies, where the iterative nature can result in attrition due to time demands (Hsu & Sandford, 2012). Despite this reduction, the final panel size was sufficient to provide comprehensive feedback, as the depth and quality of responses were prioritised over participant numbers.

5.3.1.2 Procedure for data collection

The data collection process for this Delphi study was conducted in multiple iterative rounds, each round progressively refining the consensus on suitable GPROMs and advancing the development of a comprehensive framework for evaluating CBR interventions. The structured and methodical nature of this process enabled a synthesis of expert insights across rounds, fostering a structured approach to reaching consensus. In keeping with Delphi study standards, consensus was defined as a minimum agreement level of 70% on the inclusion or exclusion of specific items. This threshold was chosen to balance substantial agreement with the recognition that expert opinion in a diverse field may vary.

Round 1: Initial Data Collection

Data collection commenced with the development of an open-ended questionnaire (see Appendix B) informed by prior phases of research and a systematised literature review. This initial questionnaire was designed to capture a broad range of expert opinions on key CBR evaluation dimensions, particularly focusing on the relevance of the ICF domains, familiarity with existing GPROMs, and suggestions for additional PROMs that may be applicable to CBR.

Upon completing informed consent procedures, the expert panel accessed the questionnaire through a secure online platform, Google Forms, which facilitated both ease of access and anonymity in responses. The open-ended nature of the questionnaire encouraged detailed responses, which were downloaded securely for qualitative analysis.

Round 1 Analysis and Development of Round 2 Questionnaire

Qualitative thematic analysis was conducted on Round 1 responses, identifying recurrent themes and patterns that highlighted key areas of consensus, potential GPROMs, and challenges related to cultural and contextual relevance. This analysis informed the creation of a more focused, structured questionnaire for Round 2 (Appendix B). In the second round, a list of GPROMs emerging from Round 1 feedback was provided. Experts were asked to rate these GPROMs based on their suitability for CBR, with emphasis on the domains of Activity and Participation as outlined by the ICF, as well as to recommend additional GPROMs that might not have been presented by the researcher.

Round 2: Refinement and Ranking

In Round 2, data collection shifted towards a more quantitative approach, where experts ranked each GPROM in terms of appropriateness for CBR intervention evaluation. Structured feedback was collected via Google Forms, a platform that ensured anonymity by separating individual responses from participant identities and providing secure access for participants.

The quantitative data from Round 2 were subjected to descriptive statistical analysis, including mean and median rank calculations, to determine consensus on the most suitable GPROMs. The aggregation of expert ratings allowed the identification of the top three GPROMs, forming a focused set of tools to be integrated into the proposed CBR evaluation framework.

Round 2 Analysis and Development of Round 3 Questionnaire

Following the analysis of Round 2 data, the top-ranked GPROMs were incorporated into an initial draft of the proposed framework. This draft was then embedded within the Round 3 questionnaire (Appendix B), where experts were asked to evaluate the framework's design, strengths, and

practical applicability. Specific questions were crafted to gather feedback on the framework's clarity, usability, and potential for adaptation across diverse CBR contexts.

Round 3: Framework Evaluation and Final Feedback

Round 3 represented the final phase of data collection, with experts providing qualitative feedback on the proposed framework. This feedback focused on areas for improvement, perceived limitations, and potential challenges in real-world application. The experts' responses were collected with the same secure platform, maintaining consistency in data handling and confidentiality.

Final Analysis and Consensus Evaluation

Qualitative data from Round 3 were categorised thematically, with attention given to feedback that could inform refinements of the framework, including cultural relevance, clarity, and practical feasibility. The consensus threshold was set at 70%, which allowed for robust expert agreement while accommodating a range of perspectives.

The iterative and cumulative nature of this data collection process ensured that each round built upon previous findings, progressively refining both the framework and expert consensus. This structured approach enabled the systematic synthesis of expert insights, culminating in the development of a framework that is adaptable and capable of providing a standardised evaluation of CBR interventions across varied contexts.

5.4 Results

The first round of the Delphi study revealed language barriers as a primary concern in the implementation of PROMs. Participants highlighted the difficulty patients face when interpreting severity scales, particularly when terms such as "mild" or "severe" do not translate accurately or intuitively across languages. This linguistic challenge can lead to misinterpretations and inconsistencies in responses, ultimately affecting the reliability of the assessments.

Another key issue identified was the length of existing PROMs, which participants noted could be burdensome, particularly in time-limited or resource-constrained settings. Long questionnaires not only place an additional cognitive and time burden on patients but may also reduce completion rates, impacting data quality and usability.

Cultural relevance emerged as another critical factor, with participants emphasising the importance of ensuring that both question phrasing and activities of daily living reflect the cultural contexts of diverse patient populations. Without appropriate adaptation, PROMs risk being less meaningful or applicable in certain communities, potentially undermining their effectiveness in capturing patient experiences accurately.

Refer to the table below for participant quotes.

Table 5.1: Descriptive results of participant quotes of Round 1 of Delphi study

Consideration	Description	Participant Responses
Language Barriers	Difficulty in translating complex terms across languages	P7: <i>“Another factor would be ensuring that the outcome measure itself can be available in</i>

		<p><i>different languages and if not, to ensure that it can easily translate into other languages.”</i></p> <p>P13: <i>“Level of language use, time taken, complexity in terms of scoring and contextualisation of activities and participation. Contextual factors appropriate to LMICs should also be considered.”</i></p>
<p>Measure Length</p>	<p>Outcome measures (GPRoMs) can be burdensome in low-resource settings</p>	<p>P14: <i>“WHODAS2 and WHOQOL-BREF: simple in use, does not take too much time and is applicable in rural setting and covering entire ICF.”</i></p> <p>P13: <i>“WHODAS 2.0 I mainly have experience with research as it was too long and complex in terms of language use and time spent on the assessment for the</i></p>

		<i>clinical setting where I worked. It has, however, been useful for research, especially with relation to the ICF.”</i>
Cultural Relevance	Some questions may not apply to all cultural contexts	<p>P9: <i>“Cultural and gender roles, and spirituality in the community and at home are important considerations.”</i></p> <p>P13: <i>“Contextual factors appropriate to LMICs should also be considered.”</i></p>

The participants identified Participation and Activity as the most important dimensions of the ICF to consider for generic PROMs evaluating community rehabilitation interventions. (Refer to Figure 5.1 below.) Within the Participation dimension, community participation was highlighted as the most critical subset to address.

Most important ICF domains to consider

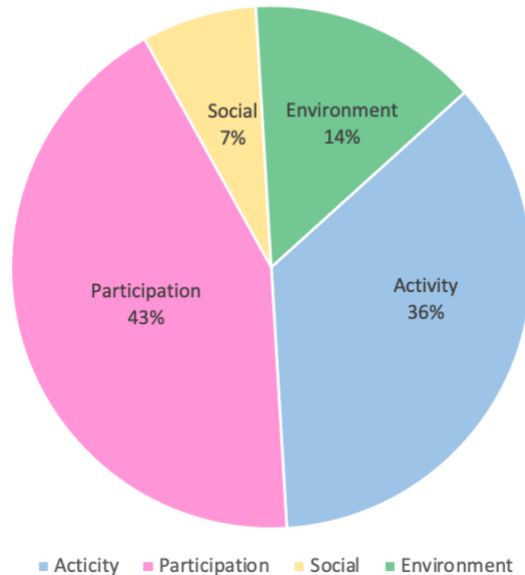


Figure 5.1: Pie chart showing the dimensions of the ICF valued most by the participants

In addition to these considerations, several additional GPRoMs were recommended, including the Most Significant Change (MSC) tool, PIE toolkit, Barthel Index, Allen Cognitive Level Screen (ACLS), WEEFIM for children, Goal Attainment Scale, Roads to Inclusion Toolkit, and SALSA scale. These tools were suggested for their specific strengths in assessing outcomes related to CBR. Participants consistently highlighted the strengths and limitations of existing tools such as WHODAS 2.0 and WHOQOL. Although participants recognised the ease of use and broad applicability of these tools, they highlighted the potential to combine their strongest features to more effectively address existing gaps.

P1 recommended a hybrid model: *"I think the WHODAS 2.0 is the best of these tools for ease of use and broad areas covered. I think, however, that it could have a greater focus on QoL. I am suggesting some sort of combination of the WHODAS and WHOQOL tools (taking the 'best' of both)."*

The objective of the second round was to determine the top three most appropriate GPROMS for evaluating CBR interventions, based on the findings and recommendations from Round 1. In this round, eight experts were asked to rank the suggested PROMs in order of suitability for CBR evaluation, with lower-weighted averages indicating higher appropriateness.

The results identified the following as the top three ranked PROMs:

1. Roads to Inclusion Toolkit (RIT)
2. Functional Independence Measure (FIM)
3. WHODAS 2.0 (World Health Organization Disability Assessment Schedule 2.0)

The RIT emerged as the highest-ranked PROM, with a weighted average of 4.88. This toolkit provides a comprehensive framework for promoting inclusion and community living for PWDs, aligning well with the holistic objectives of CBR interventions. The RIT was consistently placed within the top five by six participants ($n = 6$), highlighting strong consensus regarding its relevance in capturing social participation and community integration outcomes.

The FIM ranked second, also with a weighted average of 4.88. The FIM is a widely used tool for assessing physical and cognitive disability, focusing on the level of assistance required for activities of daily living. Despite sharing the same weighted average as RIT, FIM was less frequently ranked in the top three, with four participants ($n = 4$) placing it in these positions. This indicates that while FIM is valued for its ability to assess functional independence, it may not fully capture the broader community aspects that CBR interventions aim to address.

The WHODAS 2.0 ranked third, with a weighted average of 5.00. The WHODAS 2.0 assesses disability across six life domains: understanding and communicating, mobility, self-care,

interpersonal interactions, life activities, and participation. While WHODAS 2.0 had a slightly higher weighted average, it was still considered highly appropriate by participants, with five participants ($n = 5$) ranking it within the top five. Its strong performance suggests that experts value globally standardised assessment tools capable of providing a comprehensive picture of disability across diverse settings.

A comparative analysis of the weighted averages shows a minimal difference between the top three PROMs, with only 0.12 points separating the third-ranked WHODAS 2.0 from the joint first-ranked RIT and FIM. This narrow range indicates broad consensus among experts, with RIT and FIM each being ranked first by two participants ($n = 2$). The consistency of RIT and FIM in top-five placements further underscores their perceived relevance, while the slightly more variable rankings for WHODAS 2.0 suggest some differences in opinion regarding its applicability in certain contexts.

In summary, the quantitative analysis of Phase Two confirms RIT, FIM, and WHODAS 2.0 as the most appropriate GPROMs for evaluating CBR interventions, with weighted averages of 4.88 (RIT, FIM) and 5.00 (WHODAS 2.0). The close clustering of these averages highlights a strong level of agreement among experts ($n = 8$), indicating that these PROMs best capture the multidimensional outcomes associated with CBR, balancing assessments of functional independence, disability, and community inclusion.

The researcher used the results from Rounds 1 and 2 to develop a suggested framework for evaluating CBR interventions, which was subsequently presented in Round 3 (Figure 5.2) for further validation and refinement.

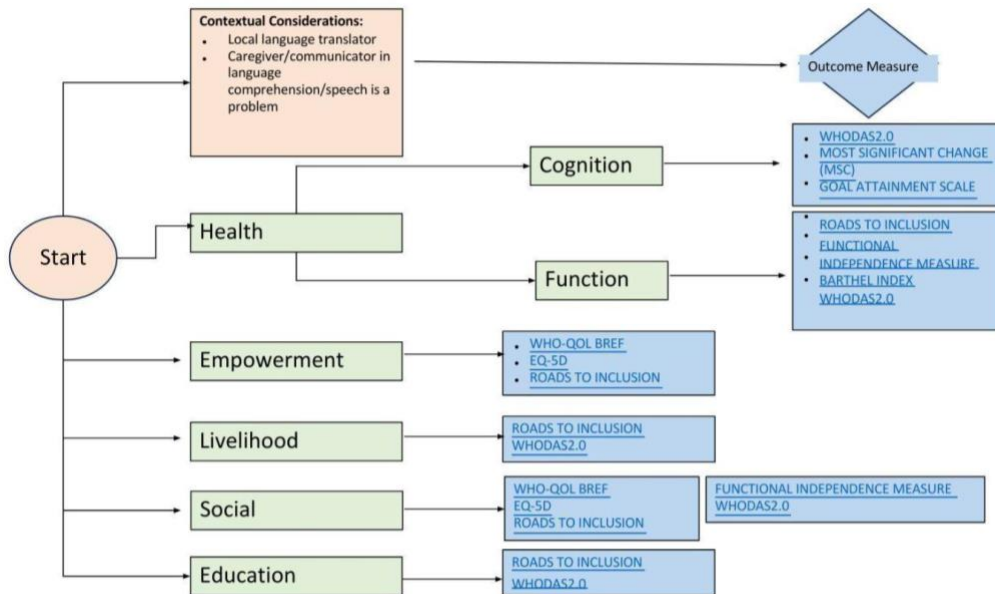


Figure 5.2: First draft of the framework presented in Round 3 for expert input

The final round of the Delphi study provided insights into participant perceptions of the CBR evaluation framework, offering both support and recommendations for refinement. Participants recognised the need for standardisation in evaluating CBR interventions and acknowledged the framework’s potential to address the lack of cohesive evaluation tools. However, while participants generally found the framework clear and comprehensive, several areas for improvement were identified, particularly in relation to usability, cultural relevance, and adaptability.

One of the main findings was the need for enhanced training and guidance to ensure consistent and effective implementation. Participants noted that without adequate training, the framework’s usability could be compromised, particularly in settings where evaluators have varying levels of expertise. Providing detailed instructions and structured training resources was suggested as a way to improve clarity and accessibility.

Another key theme in the feedback was the importance of cultural and contextual sensitivity in evaluating CBR outcomes. Participants emphasised that standardised tools should be adaptable to local norms, languages, and practices to ensure they align with the realities of communities. Without appropriate adaptation, evaluation tools risk being misaligned with real-world rehabilitation experiences.

Participants also recommended broadening the framework’s scope beyond health and physical function. While these aspects are integral to CBR, feedback from the experts suggested that the framework should better incorporate other key CBR pillars, including education, livelihoods, and social inclusion. This reflects a need for a multi-sectoral approach that ensures a more representative evaluation of rehabilitation outcomes.

Adaptability to local contexts was also identified as a priority. Participants noted variability in resources, cultural expectations, and stakeholder priorities across different regions, highlighting the need for flexible implementation strategies. Allowing for context-specific modifications while maintaining the integrity of the framework was seen as an important consideration for its applicability.

A detailed account of participant perspectives is presented in Table 5.2, which provides direct quotes illustrating these key themes.

Table 5.2: Emerging themes from Round 3

Theme	Participant No. (P#)	Related Quote
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Perceived Need for the Framework	P2	<i>"CBR has been implemented for over three decades, but little is known about its impact, especially in countries with limited resources. Through such frameworks, the impact of CBR would be measured and contribute to policy change in order to effect change."</i>
	P7	<i>"There is a need for a conceptual universal framework to evaluate CBR interventions... This, in turn, will enable a user-friendly and universally applicable tool to facilitate informed decision-making."</i>
Clarity and Applicability of the Framework	P12	<i>"The framework can be used in different countries and cultures. Training will assist to standardise the use of the tools, thereby standardising implementation."</i>
	P7	<i>"It considers various contexts, promotes sustainability, and can identify gaps to further improve CBR interventions."</i>
	P13	<i>"I think it's great to have a tool to guide which evaluation tools should be used to evaluate specific components. Perhaps include more information on what each tool evaluates and how it aligns with the components."</i>

Cultural Sensitivity	P7	<i>"Ensure that the outcome measure/toolkit used considers cultural norms and is culturally sensitive."</i>
	P9	<i>"Language plays a big role. Assessments must reflect content that is familiar to the culture and adapted for rural and low-resource settings."</i>
Scope of Disabilities and Sectors	P5	<i>"It seems too focused on physical/mobility impairments and not enough on other groups. Consider broader inclusion of different types of disabilities."</i>
	P5	<i>"The approach appears too focused on health; include the other pillars/sectors of CBR."</i>
Simplified Implementation	P2	<i>"Training is needed to ensure the tools are implemented effectively. Accessibility and simplicity will determine uptake."</i>
	P12	<i>"Training will assist to standardise the use of the tools, thereby standardising implementation."</i>
	P13	<i>"Perhaps include more information on what each tool evaluates and how it aligns with the components."</i>

Positive Feedback and Endorsements	P7	<i>"The framework promotes effective evaluation of CBR interventions and ensures sustainability for future years."</i>
	P7	<i>"The contextual considerations have included imperative aspects and make this framework comprehensive and user-friendly."</i>

Whilst refinements were encouraged to ensure that the framework remains inclusive, culturally sensitive, and adaptable to the diverse realities of CBR programmes, no specific suggestions for improvement were given and it was decided to take this note through to the pilot study phase and investigate further.

5.5 Discussion

This phase of the research aimed to establish expert consensus on the most suitable GPROMs for evaluating CBR interventions and to develop a theoretical framework integrating these measures. By focusing on GPROM selection and creating a cohesive evaluation model, this phase provides foundational elements for constructing a framework that effectively addresses the complex, multidimensional goals of CBR.

5.5.1 Balancing comprehensiveness and simplicity

The ranking results from Phase Two indicate that the expert panel valued PROMs that adopt a holistic approach, addressing community integration, functional independence, and participation—core components of CBR. The consistent selection of the RIT, FIM, and WHODAS

2.0 suggests a clear consensus on their suitability for comprehensively evaluating the multifaceted goals of CBR programmes. Although other PROMs were suggested in earlier rounds, these three emerged as the most appropriate choices based on cumulative expert input.

A key challenge identified throughout the analysis was the tension between comprehensive evaluation and practical feasibility. PROMs such as WHODAS 2.0 and FIM were acknowledged for their breadth and robust assessment capabilities. However, their length and complexity may limit usability, particularly in resource-constrained or time-limited settings. This tension is well-documented in the literature, where Pawson et al. (2018) argue that while comprehensive tools are desirable, they can undermine practical usability if they are too burdensome. Similarly, Stolk et al. (2010) highlight that shorter tools, though efficient, may fail to capture the complexity of rehabilitation outcomes.

This reflects a broader challenge in CBR: reconciling the need for thorough evaluation of multidimensional outcomes with the practicalities of implementation across diverse contexts. The biopsychosocial model of health underpins CBR, placing emphasis on both functional and participatory outcomes (WHO, 2001; Khasnabis et al., 2010). PROMs such as WHODAS 2.0 align closely with this framework by measuring functioning across domains including mobility, self-care, and interpersonal relationships (Üstün et al., 2003), while the RIT specifically addresses community participation, reflecting CBR's central objective of fostering social inclusion, which is critical for improving quality of life (Finkenflügel et al., 2008).

Together, these tools present complementary strengths, but careful selection and adaptation are required to balance comprehensiveness and simplicity, ensuring they remain relevant and feasible in various settings.

5.5.2 Participation as a core dimension

The prioritisation of participation emerged as a consistent theme, with experts identifying this as the most critical dimension in evaluating CBR interventions. Within the ICF framework, participation refers to an individual's involvement in life situations, underscoring its centrality in promoting social inclusion and empowerment.

The selection of RIT as the top-ranked PROM highlights its strong emphasis on community-level outcomes, such as empowerment and inclusion. This finding aligns with Mayo et al. (2022), who argue that participation is both an outcome of rehabilitation and a determinant of long-term success. However, participation outcomes are highly context-dependent, influenced by environmental, social, and cultural factors (Cieza et al., 2020).

Thus, while PROMs such as RIT effectively capture participation-related outcomes, their applicability requires contextual adaptations. This reinforces the need for culturally adaptable tools that can meaningfully assess participation across diverse settings, ensuring the evaluation process remains relevant, inclusive, and impactful.

5.5.3 Language and cultural relevance

Language and cultural relevance were also highlighted as key considerations in the selection and application of PROMs. Tools developed in high-income settings often fail to reflect the lived realities of individuals in LMICs. For PROMs to be truly effective, they must be linguistically accessible and culturally relevant, considering local norms, practices, gender roles, and spiritual values.

This perspective is supported by Gadsby and Wilding (2024), who emphasise that cultural adaptation extends beyond simple translation. Instead, it requires a holistic approach that aligns with local contexts. More recent literature advocates for co-creating tools with local communities, which ensures that PROMs are not only relevant but also engaging and accurate (Fitzpatrick et al. 2024)

The framework proposed in this study integrates these considerations by allowing for the selection of culturally appropriate supplementary measures to complement core GPROMs. This flexible approach ensures that the evaluation process remains context-sensitive while maintaining standardised assessment criteria.

5.5.4 Hybrid and adaptive approaches

Another emerging theme was the recognition that no single PROM can comprehensively capture the diverse needs of CBR evaluation. Experts highlighted the potential of hybrid or adaptive approaches, where elements from multiple PROMs are combined to overcome the limitations of individual measures.

The literature supports this pragmatic approach, with McDermott et al. (2021) arguing that hybrid models enable a more comprehensive assessment by addressing functional, cognitive, and participatory dimensions of rehabilitation. However, Butura et al. (2024) caution that these approaches must be implemented carefully to maintain consistency, validity, and reliability across different settings.

The findings of this study suggest that combining the strengths of tools such as WHODAS 2.0, FIM, and RIT could provide a balanced evaluation framework. However, such hybrid models

would require clear guidelines to ensure that adaptations do not compromise measurement integrity.

5.5.5 Challenges and limitations

While the Delphi study provided valuable insights, certain limitations were identified. Participant attrition across rounds reduced the size of the expert panel (Hsu & Sandford, 2012), potentially narrowing the diversity of perspectives. Although initial recruitment strategies aimed for broad representation, the reduction in participant numbers may have limited the inclusion of alternative viewpoints.

Additionally, reliance on expert consensus introduces the potential for bias, as experts may share similar perspectives based on professional networks or common frameworks. This could limit the exploration of divergent perspectives that may be equally relevant in CBR evaluation.

These limitations underscore the need for supplementary studies to further validate the proposed framework and explore its applicability across diverse cultural and geographical settings. Future research should also consider testing hybrid models in real-world contexts to examine their feasibility, reliability, and impact.

5.6 Conclusion

This phase of the study provided critical insights into the complexities of CBR evaluation, shedding light on the multifaceted nature of interventions and their evaluation. The need to balance comprehensiveness with simplicity emerged as a recurring theme, as overly complex evaluation frameworks risk becoming impractical in resource-limited settings, while overly simplified tools may fail to capture the nuanced impacts of CBR interventions. The integration of core GPROMs

with supplementary tools offers a pathway to achieving this balance, enabling the framework to address diverse domains such as health, education, and empowerment, while also allowing for contextual adaptation.

A key finding is the role of cultural relevance in CBR evaluation, which requires deeper consideration of how tools can reflect the values and priorities of local communities. This raises important questions about whether global standards for CBR evaluation can ever fully accommodate cultural diversity without becoming overly fragmented. The inclusion of both quantitative measures and qualitative approaches seeks to bridge this gap, offering a way to quantify outcomes while capturing the lived experiences of participants. Furthermore, the prioritisation of capacity building addresses a critical gap in the current evaluation landscape, however, it also highlights the need for ongoing investment in training and support for CBR stakeholders. These findings demonstrate the potential of the proposed framework to advance the standardisation of CBR evaluation while addressing its inherent complexities, but they also call for further research and refinement to fully operationalise this approach on a global scale.

CHAPTER SIX: PILOT STUDY

6.1 Introduction

Phase Four of this research involved piloting a newly developed evaluation framework for CBR interventions within an LMIC in Africa. This phase directly addressed the research question, *“What insights into feasibility, strengths, and areas for improvement can be gained from piloting the newly developed evaluation framework in a real-world LMIC context in Africa?”* By applying the framework in a real-world setting, this phase aimed to gather practical insights to help balance and refine the theoretical insights established in earlier phases of the study. Implementing the framework in a specific context allowed for an initial assessment of its applicability, strengths, and limitations, providing a grounded understanding of how it functions within the typical constraints of a CBR environment in an LMIC.

The pilot phase is a key step towards initiating standardisation in CBR evaluation methods by identifying areas where theory aligns with practice, as well as areas that require further adaptation. While the framework is not yet intended to be universally applicable, testing it in a real-world LMIC context enables researchers to make essential refinements based on practical challenges and successes encountered during implementation. Insights from this phase will guide adjustments to enhance the framework's relevance and adaptability, contributing to a more structured approach to evaluating CBR interventions that could be tailored to different settings in the future. This chapter, therefore, provides a foundational step towards a more adaptable and standardised approach to CBR evaluation, balancing the structured insights from theory with the flexibility required for real-world impact.

6.2 Background

In recent years, global health research has increasingly recognised the need for context-sensitive evaluation frameworks, particularly in LMICs, where healthcare resources, social systems, and infrastructure vary greatly from high-income settings (WHO, 2018). Traditional evaluation models are often developed in more resource-abundant contexts and do not tend to capture the complexities and context-specific impacts of programmes such as CBR (McCormack et al., 2002). There is a need for adaptable frameworks that consider local socio-political, cultural, and economic factors to ensure effective and sustainable programme evaluation in LMICs (McCormack et al., 2002).

In the evolving field of implementation science, there is increasing recognition of the need for adaptable frameworks that can be tailored to diverse and localised contexts, ensuring more meaningful evaluations of interventions. Effective use of implementation frameworks is critical for guiding the design, execution, and evaluation of interventions, as it facilitates the translation of evidence-based practices into real-world settings and enhances stakeholder engagement throughout the process (Moullin et al., 2020). The pilot phase of this study is strategically aligned with this approach by testing the proposed CBR evaluation framework within the LMIC context of the Eastern Cape, South Africa. By embedding stakeholder engagement and contextual analysis into the framework's application, this pilot aims to uncover potential barriers and enablers, ultimately refining the framework to better support sustainable implementation efforts.

Through stakeholder engagement and contextual analysis, the study will explore how well the framework accommodates the variability of LMIC contexts, including resource constraints and cultural nuances, ultimately providing actionable insights to refine its practical application and

enhance its utility for sustainable implementation (Vanderkruik & McPherson, 2017; Van Pelt & Beidas, 2022).

6.2.1 The dual burden of disease and disability in the Eastern Cape Province: Implications for healthcare and rehabilitation services

The Eastern Cape Province faces a considerable burden of disease, characterised by both communicable and non-communicable conditions that strain the healthcare system. The region has one of the highest HIV prevalence rates in South Africa, with Nxasana et al. (2022) reporting HIV prevalence at 52% among the population attending primary healthcare facilities in rural districts, particularly among individuals aged 30–59 years. This high prevalence of HIV is compounded by a rising incidence of non-communicable diseases such as hypertension, diabetes, and obesity, which are becoming increasingly common across the province (Mayosi et al., 2009). Hypertension affects 29% of the population, while diabetes and obesity are present in 14.7% and 42.4% of individuals, respectively. The co-occurrence of these conditions with HIV presents complex healthcare challenges, further stretching the limited resources in the province.

In addition to the significant burden of disease, the Eastern Cape has also experienced an increase in the prevalence of disability, rising from 8.6% in 2011 to 10.7% in 2020 (Mbali, n.d). This is particularly relevant in the context of this study, as the OR Tambo District, a rural and economically disadvantaged area within the province, faces unique challenges related to healthcare access and service delivery. Disabilities in this district are frequently linked to chronic diseases, injuries, and the high prevalence of HIV/AIDS and tuberculosis, which if not adequately managed, can result in long-term impairments (Pillay-van Wyk et al., 2016). Understanding the intersection

of disease and disability in this region is critical to addressing the broader health inequities and strengthening rehabilitation services where they are most needed.

Poverty and limited access to healthcare services further restrict the ability of those with disabilities to receive necessary care and support, leading to decreased quality of life and increased dependency on already strained resources (Rheeder et al., 2017). The combination of a high prevalence of disability and insufficient healthcare services places a significant burden on both individuals and the healthcare system in the OR Tambo District. Without adequate rehabilitation services, many people with disabilities are unable to achieve optimal functioning, resulting in greater reliance on family and community support structures, which are often inadequate to meet the demand.

This dual burden of disease and disability underscores the critical need for enhanced healthcare and rehabilitation services in the Eastern Cape, particularly in rural and underserved areas such as the OR Tambo District. The district's high prevalence of communicable and non-communicable diseases, coupled with the rising rates of disability, makes it an important and relevant context for this study. Understanding how these challenges intersect provides an opportunity to evaluate the feasibility and potential impact of the newly developed evaluation framework in addressing these complex healthcare issues. By piloting the framework in this district, the study aims to generate insights that can guide the development of effective interventions to improve the quality of life for individuals with disabilities while reducing the broader social and economic impacts on the community.

6.3 Methods

6.3.1 Overall study design

The pilot phase of this study adopts a qualitative, field-based approach and an explorative design, aimed at exploring the feasibility of the newly developed CBR evaluation framework in a real-world setting. This phase focused on gathering practical insights through semi-structured interviews (Appendix C) with community workers and healthcare professionals who actively used the framework to evaluate their CBR interventions. This approach is designed to capture the experiences, challenges, and perspectives of those applying the framework, providing in-depth, contextualised feedback on its usability and relevance in the field (Grandisson et al., 2014; Sharma, 2004).

6.3.2 Study setting

In April 2024, initial contact was made with the Jabulani Rural Health Foundation (<https://www.jabulanifoundation.org/>), a non-profit organisation dedicated to fostering community development and improving the well-being of rural communities in the village of Zithulele, Eastern Cape, South Africa. Jabulani's mission, rooted in creating opportunities that bring "reasons to celebrate" for all, focuses on providing vital healthcare, supporting early childhood development, promoting environmental stewardship, and empowering individuals to improve their livelihoods.

The region's unique healthcare landscape offers valuable opportunities to assess how well the framework accommodates resource constraints, cultural nuances, and the interplay between disease and disability, ultimately generating actionable insights to refine the framework and

enhance its broader applicability. The OR Tambo District provides a relevant and complex real-world context within an LMIC setting in Africa, enabling the evaluation of the feasibility, strengths, and areas for improvement of the newly developed evaluation framework.

6.3.3 Study population

At the time of data collection, Jabulani employed six community disability workers and one occupational therapist. Community rehabilitation workers played a critical role in the study due to their position as frontline providers of CBR services in rural areas. Given their personal experience in resource-limited settings, these workers were in a unique position to offer valuable feedback on the framework's adaptability and usability in challenging environments. Their participation ensured that the study captured the realities of CBR service delivery in rural, economically disadvantaged areas.

6.3.1.3 Sampling method

The sampling method employed in the pilot study for Phase Four was purposive sampling, a deliberate and strategic choice designed to ensure that the participants selected would provide the most relevant and insightful feedback on the CBR evaluation framework. Purposive sampling, also known as judgmental or selective sampling, is a non-probability sampling technique where the researcher selects participants based on specific characteristics that align closely with the study's objectives (Makwana et al., 2023).

To ensure the relevance and applicability of the study findings, specific eligibility criteria were established. Healthcare professionals and community rehabilitation workers were required to have at least one year of experience in providing CBR services within the district. This criterion was set

to ensure that participants had sufficient exposure to CBR interventions, allowing them to provide meaningful and informed feedback.

In the context of this pilot study, purposive sampling was particularly appropriate because the primary aim was not to generalise findings to a broader population, but to gather in-depth, qualitative feedback from individuals who had direct and relevant experience with CBR interventions in the OR Tambo District. This method allowed the study to focus on participants who were most likely to encounter and understand the challenges and nuances of implementing the CBR framework in a rural, resource-constrained environment.

Participants were recruited through Jabulani's project manager, who facilitated initial permission to approach staff. Recruitment followed a non-coercive process: once permission was granted, individual staff members were invited to participate voluntarily. The recruitment process is detailed step-by-step in the pilot study protocol (Appendix D). They were assured that refusal would not affect their employment, workload, or relationship with the organisation. This step was essential to reduce potential power imbalances between the facility manager and staff and to ensure informed, independent consent.

In summary, purposive sampling was the most appropriate method for this pilot study, as it allowed the research to focus on a select group of participants who were best positioned to provide valuable insights into the CBR evaluation framework. The approach ensured that participants had relevant experience while also safeguarding voluntary and non-coercive recruitment. This method therefore enabled the study to achieve its goals of testing and refining the framework in a context that closely mirrors the environments where it will ultimately be implemented.

6.3.4 Sample size

The sample size for the pilot study in Phase Four was deliberately chosen to balance the need for detailed qualitative insights with practical constraints such as participant availability, and the specific goals of the study. A total of three participants—comprising one healthcare professional and two community rehabilitation workers—were involved in the study. This focused sample was deemed sufficient for the pilot study's objectives, which centred on evaluating the feasibility and practicality of the proposed CBR evaluation framework in a real-world setting.

Exclusion criteria were also applied to maintain the focus of the study. Healthcare professionals and community rehabilitation workers with less than one year of experience, who fell ill or moved away were excluded from the study. In this case, all participants met the inclusion criteria. The focus of this pilot study was not on generating statistical inferences but on refining the piloted framework. By selecting a small, purposive sample, the study was able to gather detailed, context-specific feedback that was crucial for the future refinement of the CBR evaluation framework (Lancaster et al., 2004).

6.3.5 Data collection procedure

Following an invitation to participate in the study, consent was obtained from the facility manager of Jabulani Rural Health Foundation in July 2024. An introductory call was conducted with representatives from Jabulani to outline the study's aims, explain the procedures, and discuss their role in piloting the evaluation framework. During this meeting, the importance of contextual relevance and their input to refine the framework was emphasised. After this discussion, Jabulani was provided with a detailed information sheet and a draft of the evaluation framework for their review, ensuring they had sufficient time to familiarise themselves with its components. The

participants were briefed over an online video meeting on how to implement the framework, any questions or concerns raised by Jabulani were addressed, and practical arrangements for the pilot were finalised.

This included confirming a sample of three participants, consisting of one occupational therapist and two community care workers, each representing key pillars of Jabulani's operational focus. The sample size of three is due to availability within the organisation. Jabulani employs six community disability workers, but at the time of data collection, one occupational therapist was employed to provide support to the rural disability clients (health, inclusive education, livelihoods, social inclusion, empowerment). The occupational therapist applied the framework under the "health" pillar, while the two community care workers focused on the "education/livelihood" and "social" pillars. This approach ensured the framework was tested across diverse operational areas, providing a comprehensive understanding of its feasibility and relevance within Jabulani's work.

At the time of the pilot, Jabulani did not employ any standardised outcome evaluation tools; routine practice primarily consisted of staff feedback and basic service statistics. The pilot therefore introduced a structured protocol to guide use of the framework. This protocol involved: (a) an online briefing session with participants to familiarise them with the framework and address questions; (b) a three-month implementation period during which the framework was applied in practice; and (c) structured documentation of its use, including the setting, time taken, barriers encountered, and any adaptations made. The complete pilot study protocol, including recruitment, briefing, implementation and documentation steps, is provided in Appendix D. This systematic approach helped ensure fidelity to the pilot design and provided sufficient detail for replication in similar community-based rehabilitation contexts.

After a three-month period of framework application, individual semi-structured interviews were conducted via a virtual meeting to gather insights from each participant and lasted 45 minutes (Reference Interview guide in Appendix C). These interviews were recorded, transcribed, and thematically analysed to identify key insights, challenges, and areas for framework refinement based on participants' practical experiences. All participants were proficient in English, therefore no interpreter or translation was required.

6.3.6 Data analysis

The results were analysed thematically using an inductive approach, following Braun and Clarke's (2006) six-phase framework. Building on their later work, a reflexive thematic analysis approach was adopted (Braun & Clarke, 2019, 2022), which emphasises flexibility, researcher subjectivity, and the iterative nature of interpretation. This method was selected as it allows themes to emerge directly from the data, ensuring analysis remains grounded in participants' experiences rather than constrained by pre-existing theory.

The process began with repeated reading of the transcripts for familiarisation, followed by systematic coding of meaningful features across the dataset. Codes were then organised into broader themes that captured recurring patterns and insights related to the feasibility, strengths, and areas for improvement of the framework. These themes were reviewed and refined to ensure they were distinct, representative, and firmly grounded in participants' accounts. Finally, themes were defined and synthesised into a coherent narrative, linking the findings back to the study objectives and highlighting actionable implications for refining the framework.

6.4 Results

This section presents the findings from the pilot study, which explored the feasibility of an evaluation framework within a CBR initiative in the rural Eastern Cape, South Africa. Using an inductive thematic analysis approach (Braun & Clarke, 2006, 2019, 2022), four key themes emerged: adaptability and contextual fit of the framework, gaps in addressing holistic rehabilitation needs, practical challenges in framework implementation, and strengths and limitations in outcome measurement. These themes illuminate the framework's strengths, limitations, and areas for improvement as identified by participants in real-world conditions.

6.4.1 Adaptability and contextual fit of the framework

The first theme concerns the framework's adaptation to the rural context. Participants consistently highlighted the disconnect between the framework and the realities of informal livelihoods, which dominated economic activity in the Eastern Cape. Unlike formal employment or schooling, informal livelihoods include subsistence farming, casual labour, and small-scale trading, yet the framework did not account for these critical dimensions. These gaps highlight limitations in the framework's ability to fully capture the realities of informal livelihoods. By not addressing these aspects, the framework may overlook important contributions clients make to their households and communities.

P2: "The framework feels siloed; it's very functional based and not necessarily quality-of-life based."

This disconnect not only reduces the accuracy of evaluations but also undermines the framework's ability to inform resource allocation and intervention strategies. These shortcomings also created

practical challenges for evaluators, who often struggled to adapt irrelevant questions to the local context, a challenge that is explored further under *Barriers to implementation*.

6.4.2 Barriers to implementation

Participants highlighted the need for clearer guidance and additional training, while also noting that time constraints posed a challenge to effective implementation.

P3: "If someone unfamiliar with healthcare terms used the framework, they might misinterpret questions."

Despite the initial training with participants, further "use-case" training tailored to evaluators' varying levels of expertise were required to ensure that users developed confidence in applying the framework. Participants suggested streamlining certain aspects of the tool, such as consolidating overlapping questions and refining assessment criteria, to reduce redundancy without compromising the depth of evaluation.

Beyond logistical considerations, participants identified gaps in the framework's ability to capture the broader scope of rehabilitation within a CBR context.

P1: "Social inclusion only had a few questions; it needs to balance better with health-focused measures."

Rehabilitation extends beyond individual health outcomes to encompass caregiver experiences, family dynamics, and community perceptions. However, these social dimensions were not comprehensively integrated into the framework. This omission may limit its ability to reflect

systemic changes, particularly in rural settings where social reintegration and community support play a crucial role in rehabilitation success.

While the framework was recognised for its effectiveness in documenting immediate health improvements, its capacity to measure long-term outcomes and social inclusion was seen as an area for enhancement. The absence of longitudinal tracking restricts its potential for informing resource allocation and programme adjustments. Expanding the tool to include broader outcome measures, such as livelihood and social participation, would strengthen its ability to assess rehabilitation impact more holistically.

A thematic analysis of the results from the pilot study is presented in Table 6.1 below.

Table 6.1: Thematic analysis of results from the pilot study

Theme	Categories	Supporting Quotes
Adaptability and Contextual Fit	<ul style="list-style-type: none"> - Livelihood focus absent - Siloed approach - Unemployment/school issues 	<p><i>"Most of our clients are neither employed nor school-going... the WHODAS framework couldn't address that because the questions didn't apply." (P1)</i></p> <p><i>"The framework feels siloed; it's very functional based and not necessarily quality-of-life based." (P2)</i></p>

<p>Barriers to Implementation</p>	<ul style="list-style-type: none"> - Caregiver burden - Family focus missing - Health focus strong - Livelihood/social inclusion weak - Lacking longitudinal view - Time constraints - Terminology complexity 	<p><i>"We are working with the whole family... but the tools don't account for that level of interaction." (P2)</i></p> <p><i>"Caregivers often answered questions for clients, but there were no tools to evaluate their experience or burden." (P1)</i></p> <p><i>"The tools identified gaps in health but missed other critical areas like economic stability or independence." (P3)</i></p> <p><i>"Social inclusion only had a few questions; it needs to balance better with health-focused measures." (P1)</i></p> <p><i>"If someone unfamiliar with healthcare terms used the framework, they might misinterpret questions." (P3)</i></p> <p><i>"It would have been easier if there were definitions for each section to guide the evaluators." (P2)</i></p>
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6.5 Discussion

The findings from this pilot study provide critical insights into the feasibility of the proposed framework for evaluating CBR interventions in an LMIC context. The framework demonstrated notable strengths, particularly in its ability to capture health-related outcomes and its alignment with some core CBR objectives. The inclusion of perspectives from diverse healthcare providers, including community care workers and an occupational therapist, ensured that the framework was evaluated across multiple operational contexts, offering a nuanced understanding of its utility.

However, the pilot study also revealed key limitations that constrain the framework's adaptability and holistic applicability in rural, resource-constrained settings. Specifically, the framework struggled to address livelihood-focused outcomes and informal economic activities, which are critical components of rehabilitation in LMICs. Additionally, it lacked tools to evaluate family dynamics, such as caregiver burden, and community-level influences, including social stigma and perceptions of disability. These omissions highlight areas for improvement in the framework, ensuring a more comprehensive representation of CBR outcomes.

6.5.1 Barriers to implementation

Barriers to implementation include the need for training users of varying skill levels to implement the framework independently. Addressing these issues requires targeted training and simplified materials, particularly for community workers with limited formal education. Accessible tools, such as visual guides and multilingual resources, can enhance framework usability (O'Donovan et al., 2018). Streamlining the framework with illustrative case studies and simplified scoring systems could improve efficiency without compromising data quality.

Practical challenges related to implementation also emerged. Participants highlighted time constraints, training needs, and difficulties navigating complex sections of the framework. These challenges underscore the tension between comprehensiveness and usability, particularly in resource-limited environments where time and capacity are constrained. Although the framework offers a structured approach, its siloed design limited its utility in reflecting the interconnected realities of clients' lives, where health, livelihoods, and social inclusion are deeply intertwined.

6.5.1.1 Addressing the role of caregivers in rehabilitation

An area for further development in the framework is the systematic assessment of caregiver contributions and challenges. Given their central role in CBR—particularly in LMICs, where caregiving often complements or substitutes for formal healthcare (Eide & Ingstad, 2011)—integrating this perspective could enhance the framework's ability to capture a more complete picture of CBR outcomes. Caregivers frequently shoulder significant physical, emotional, and financial burdens, yet their well-being and stress levels remain unassessed within this framework. This gap is particularly concerning given the well-documented bidirectional relationship between caregiver well-being and rehabilitation outcomes (Schulz & Sherwood, 2008).

6.5.1.2 Integrating community-level perceptions in CBR evaluation

Another critical challenge identified in the findings is the framework's lack of attention to community-level attitudes and stigma, which are central to social reintegration and inclusion efforts in CBR. Research highlights that community acceptance and attitudinal change are key determinants of rehabilitation success, yet these dimensions are often underrepresented in traditional evaluation models (Rauch, 2021). Without capturing these broader societal factors, the framework risks overlooking crucial enablers or barriers to long-term rehabilitation success.

To address this, future iterations of the framework could explore ways to capture community perceptions and stigma reduction within existing evaluation components. For instance, incorporating qualitative insights from community discussions or stakeholder feedback could provide valuable context without requiring substantial modifications to the framework. This aligns with Rauch's (2021) argument that assessing programme impact at the community level enhances both inclusivity and sustainability while maintaining the framework's existing structure.

6.5.1.3 Balancing health, livelihood, and social outcomes

While participants acknowledged the framework's strength in capturing immediate health outcomes, concerns were raised about its limited scope in assessing livelihood and social inclusion, which are fundamental to holistic rehabilitation. This reflects a broader challenge in rehabilitation evaluation, where linear, health-focused metrics often fail to capture systemic, long-term changes (Wegner et al., 2020). Systems thinking highlights the importance of multidimensional assessment tools that acknowledge the interdependence of health, economic participation, and social well-being.

One potential approach is integrating tools such as the Greenpoint Survey, which participants identified as useful for measuring economic participation and social mobility alongside health metrics. Additionally, the absence of longitudinal measures in the framework limits its ability to track incremental progress over time, a key element in assessing sustained rehabilitation success (Wegner et al., 2020). Long-term evaluation strategies, including delayed follow-ups and cross-sectional tracking, would enable a more nuanced understanding of programme impact and support evidence-based decision-making for future interventions.

6.5.2 Addressing the barriers to implementation

Addressing these limitations requires an approach that captures the dynamic, interconnected nature of CBR interventions. Research by Frances et al. (2007) suggests that this challenge can be addressed through participatory framework development, involving local practitioners and community members in the design and adaptation of evaluation tools. Such an approach ensures that frameworks are not only culturally appropriate but also responsive to local realities. For example, incorporating livelihood-specific metrics relevant to subsistence farming or informal economic activities could enhance the relevance of PROMs in rural African contexts. These adaptations are critical for capturing the multidimensional outcomes of CBR interventions in a way that standardised tools alone cannot achieve (Hillier et al., 2010).

Although not originally embedded within the framework, systems-thinking principles align closely with the holistic ethos of CBR. This approach provides a structured methodology for understanding how changes in one domain, such as health improvements, can influence outcomes in other areas, such as economic participation and social inclusion (Elhadi et al., 2024). The relevance of systems thinking to community health has been widely acknowledged in the literature, with studies highlighting its ability to address the complex, multi-layered nature of public health interventions and health inequalities (Homer & Hirsch, 2006; Wright & Meadows, 2009; Carey et al., 2015).

Systems thinking moves beyond linear cause-and-effect models, focusing instead on feedback loops and interdependencies (Morgan et al., 2024). For example, gains in health may enable individuals to participate in livelihood activities, which in turn foster social inclusion and empowerment. This aligns with broader applications of systems thinking in healthcare, where

interventions are increasingly evaluated within their contextual landscapes rather than as isolated programmes (Homer & Hirsch, 2006; Carey et al., 2015).

6.5.3 Enhancing the framework through systems thinking

Beyond cultural and contextual relevance, participants also pointed to the siloed nature of some existing frameworks. Tools such as WHODAS 2.0 often fail to reflect the interconnected realities of clients' lives, where health, social inclusion, education, and livelihoods are deeply intertwined. This fragmentation limits the holistic assessment of CBR interventions, which inherently operate across multiple domains. Addressing this limitation requires an evaluation approach that can capture the complex interdependencies between these domains, offering a more comprehensive understanding of intervention outcomes.

This is where a systems-thinking approach becomes particularly relevant. Given that CBR interventions do not function in isolation but are influenced by a variety of social, economic, and cultural factors, adopting an evaluation framework that recognises these dynamic relationships is essential. Systems thinking provides a structured methodology for understanding how changes in one domain—such as health improvements—can lead to outcomes in other areas, such as increased participation in livelihood activities and enhanced social inclusion (Felmingham et al., 2023). By focusing on feedback loops and interconnections, this approach moves beyond linear cause-and-effect models, offering a more holistic understanding of how CBR interventions influence, and are influenced by, the broader community context (Trbovich, 2014). This perspective aligns with broader applications of systems thinking in healthcare, where interventions are increasingly evaluated within their contextual landscapes rather than as isolated programmes (Hawe et al., 2009).

However, while conceptually compelling, the feasibility of integrating systems-thinking tools into CBR evaluation requires careful consideration and further investigation. Techniques such as causal loop diagrams and systems mapping could provide valuable visualisations of these relationships, illuminating how progress in one domain can influence outcomes in others (Stankov et al., 2023).

These tools enable evaluators to identify hidden dynamics and interdependencies that traditional evaluation methods may overlook. By illustrating how improvements in health could enable participation in livelihood activities, which in turn foster social inclusion, systems thinking helps to capture the dynamic interactions that shape rehabilitation outcomes.

Moreover, the systems-thinking approach would facilitate the integration of livelihood-specific metrics, directly addressing participants' concerns about the framework's limited scope in recognising the importance of informal economic activities (Felmingham et al., 2023). In many LMICs, informal livelihoods represent critical components of community resilience and well-being (Manlosa, 2022). Therefore, incorporating these metrics would ensure that evaluations reflect the realities of the communities they serve. Additionally, by including caregiver assessment tools and community-level perception measures, the framework could better account for the broader social determinants influencing rehabilitation outcomes. Such enhancements would provide a more comprehensive understanding of how social, economic, and health-related factors intersect within CBR programmes.

6.5.4 Future integration and research opportunities

While this study highlights the potential of systems thinking to enhance the proposed framework, its full integration was beyond the scope of this study. These complexities underscore the need for

further research to assess the practical implementation and potential impact of systems thinking within CBR evaluations.

Future research should focus on applying systems-thinking tools to map the dynamic relationships between health, livelihood, and social inclusion outcomes. Such an approach would provide deeper insights into how progress in one domain can drive changes in others, thus capturing the interconnected realities of rehabilitation. Moreover, investigating the role of caregiver well-being and community perceptions could enrich the framework, offering a more comprehensive understanding of the social determinants influencing rehabilitation outcomes.

Additionally, longitudinal studies and cross-sectional analyses would be crucial in evaluating the long-term sustainability of CBR interventions. Tracking outcomes over extended periods would ensure that CBR programmes remain responsive to the evolving needs of communities. Collectively, these research avenues hold significant potential to refine the framework, making it a robust tool for evaluating CBR interventions in diverse LMIC contexts.

6.6 Limitations

This pilot study faced several limitations that should be considered when interpreting its findings. Insights were contextually rich but did not capture the diversity of experiences that might be observed with a larger or more varied participant group. The study's focus on the OR Tambo District, a rural and resource-constrained area with unique socio-economic challenges, further limits the applicability of findings to other settings, particularly those with different healthcare systems or community dynamics.

Additionally, the study prioritised the feasibility of the WHODAS outcome measures within specific operational domains, such as health and education, without exploring systemic barriers or broader dimensions of rehabilitation, such as political and policy-related challenges. Another limitation was the lack of comprehensive training for evaluators, which may have influenced their ability to apply the framework consistently and adapt it effectively to local realities. Participants noted challenges in interpreting and navigating the framework, which could have affected the reliability of the feedback provided.

Finally, the relatively short three-month implementation period did not allow for the evaluation of long-term outcomes or the framework's adaptability over time. Addressing these limitations in future research will be critical to refining the framework and enhancing its utility in diverse CBR settings.

6.7 Conclusion

This pilot study has provided valuable insights into the feasibility and applicability of the proposed framework for evaluating CBR interventions in LMICs. The framework demonstrated notable strengths, particularly in its ability to capture health-related outcomes and align with core CBR objectives. Its utility was enhanced by incorporating the perspectives of diverse healthcare providers, offering a nuanced understanding of its operational relevance.

However, the pilot study also uncovered gaps in the framework's adaptability to local contexts, particularly regarding its inability to address livelihood-focused outcomes and informal economic activities, which are critical in rural LMIC settings. Themes such as gaps in holistic needs and challenges in implementation point to the framework's limited scope in capturing family

dynamics, caregiver burden, and community-level impacts. These omissions reduce its capacity to provide a comprehensive picture of CBR outcomes.

Barriers to implementation, such as training needs, time constraints, and practical usability challenges, further hinder the framework's scalability and effectiveness. Addressing these issues requires simplifying the framework through accessible tools, targeted training, and digital solutions that can streamline data collection and analysis. Moreover, integrating caregiver assessment tools and community perception measures would enhance the framework's comprehensiveness, ensuring it captures the broader social determinants of rehabilitation.

A significant contribution of this study is the identification of systems thinking as a potential solution to the framework's siloed design. Systems thinking offers a structured approach to understanding the interdependencies between health, livelihood, and social inclusion outcomes, moving beyond linear evaluation models. By incorporating systems-thinking methodologies, such as causal loop diagrams and systems mapping, the framework could better capture the dynamic interactions that shape rehabilitation outcomes in LMIC contexts. However, integrating these methodologies requires further research, multi-stakeholder engagement, and longitudinal data collection.

Future research should explore the practical integration of systems thinking into CBR evaluation frameworks, with a focus on mapping dynamic interactions between health, economic participation, and social inclusion. Additionally, longitudinal studies would provide deeper insights into the long-term sustainability of CBR interventions. Such research would not only refine the framework but also contribute to evidence-based decision-making in CBR programming.

In conclusion, while the proposed framework shows promise for evaluating CBR interventions, its refinement is essential to ensure it captures the multidimensional and interconnected realities of rehabilitation in LMICs. By addressing identified gaps and leveraging systems thinking, the framework can evolve into a more holistic, contextually relevant tool that supports sustainable rehabilitation outcomes in diverse settings.

CHAPTER SEVEN: CONCLUSION AND RECOMMENDATIONS

7.1 Introduction

This chapter will provide a brief overview of the study and the main findings of the individual chapters will be presented. This will be followed by a reflection on the research journey from the researcher's perspective, and then the limitations of the study, generalisability of findings, and implications of the study in terms of clinical practice and research will be considered. Finally, the recommendations based on the findings of the study will be presented and the thesis will be concluded.

This chapter synthesises findings across all phases, clarifies the scope of the evaluation framework developed in this thesis (participant-level outcomes within CBR programmes), reflects on rigour and limitations, and presents implications and recommendations for practice and research. The summary explicitly situates the work within the WHO CBR Guidelines (2010, seven-booklet series) and the ICF, including recognition of the ICF Checklist as a comprehensive alternative for outcomes coverage.

7.2 Aim of the study

To develop and pilot a universally applicable framework for evaluating CBR interventions.

7.3 Objective and summary of results of each chapter

Objective 1: (Chapter Three) To explore the literature on the current frameworks utilised for evaluating CBR interventions.

The review showed a fragmented landscape: most frameworks anchor on the CBR Matrix but are adapted idiosyncratically, limiting cross-programme comparability. It reinforced the need for a unifying participant-level outcomes framework aligned to CBR domains and current WHO directions on monitoring and evaluation. (See also Arksey & O'Malley structuring applied in Ch.3.)

Objective 2: (Chapter Four) To explore the literature on existing generic patient-reported outcomes (GPROM) used in the evaluation of CBR interventions.

The systematised review identified WHODAS 2.0 and WHOQOL-BREF as core tools for assessing activity, participation, and quality of life. However, significant gaps were noted in domains such as livelihoods and social inclusion, critical components of the CBR Matrix. This highlighted the need for supplemental tools, such as the Roads to Inclusion Toolkit, to address these gaps. The findings emphasised the importance of selecting context-sensitive measures that resonate with stakeholders in LMICs, ensuring cultural relevance and practical applicability.

Objective 3: (Chapter Five) To reach consensus on the most suitable GPROM and develop a proposed theoretical framework for the evaluation of CBR interventions.

The Delphi study refined the framework by incorporating inputs from a diverse panel of global experts. This iterative approach resulted in a robust framework that prioritises adaptability and inclusivity. Experts prioritised adaptability and inclusivity, emphasising economic participation and empowerment. These contributions shaped a framework that balances theoretical rigor with practical utility, making it a versatile tool for diverse CBR settings.

Objective 4: (Chapter Six) To pilot the newly developed framework for feasibility in an LMIC in Africa.

The pilot confirmed contextual fit of core measures but foregrounded barriers to implementation (training/time/usability) and scope gaps (livelihoods, caregiver/family dynamics, community level)

7.4 Impact of the limitations on the rigour of the study

The scoping review was restricted by its inclusion criteria, which focused on English-language studies and excluded grey literature, limiting the comprehensiveness of the evidence base. The systematised review revealed variability in the quality of GPROMs, with many tools lacking robust psychometric evaluations, particularly for LMIC contexts. The Delphi study, while achieving consensus, was constrained by a small sample size and attrition across rounds, which narrowed the diversity of perspectives. Finally, the pilot study was conducted in a single district with a limited participant pool and duration, precluding an assessment of long-term applicability and scalability. Despite these challenges, the study provided critical insights into the development of a universal and adaptable evaluation framework for CBR interventions, highlighting areas for further research and refinement.

7.5 Generalisability

By integrating a multi-phase design—scoping reviews, a systematised review, Delphi consensus, and pilot testing—the study establishes a foundational framework for the evaluation of CBR interventions. However, its generalisability is inherently contextual. While the scoping and systematised reviews draw insights from global literature, the pilot phase focuses on an LMIC

setting in South Africa, potentially limiting direct applicability to other geographical contexts. Nevertheless, the study's emphasis on adaptability and cultural relevance in diverse settings enhances its potential for broader application. The inclusion of expert consensus further strengthens its validity, suggesting the framework's use across varying resource-constrained settings. However, future validation in different socio-economic and healthcare environments is recommended to confirm its universal applicability.

7.6 Implications of the study

7.6.1 Clinical implications

Overall, the clinical implications of this research are twofold. First, the proposed framework offers a structured, evidence-based approach for evaluating CBR interventions, enabling healthcare practitioners to assess outcomes beyond traditional health metrics. Secondly, the study highlights the need for developing and refining context-specific GPROMs that capture comprehensive aspects of community rehabilitation, including livelihoods, informal economies, social dynamics, and caregiver experiences.

7.6.2 Implications for research

This study makes several important contributions to the field of CBR research, offering a foundation for future exploration and development. The multi-phase, mixed methods design employed in this study—spanning a scoping review, systematised review, Delphi study, and pilot testing—demonstrates a comprehensive and iterative approach to framework development. Future research can build on this methodology by conducting large-scale, multi-country studies to validate and refine the framework across diverse cultural and socio-economic contexts. Incorporating

mixed method designs will allow for deeper insights into the effectiveness and adaptability of the framework.

The study identifies significant gaps in existing GPROMs, particularly in evaluating livelihood-focused outcomes, informal economic activities, and caregiver and community-level impacts. Future research should focus on developing or adapting context-specific GPROMs that comprehensively assess these overlooked domains. Collaborative research with local stakeholders will be essential to ensure that these tools are culturally appropriate and practically applicable in LMICs.

Exploring the integration of digital tools and technologies for data collection and real-time monitoring could enhance the framework's utility. Future research should investigate how mobile health (mHealth) applications and digital platforms can streamline data collection, improve user engagement, and support continuous evaluation in resource-constrained settings.

This research contributes to the theoretical advancement of CBR evaluation by integrating established models such as the CBR Matrix and ICF with practical, context-sensitive tools. Future research should continue exploring how theoretical frameworks can be operationalised through participatory methods and evidence-based tools to bridge the gap between theory and practice.

Overall, this study lays the groundwork for continued innovation in CBR evaluation research, advocating for the development of more holistic, inclusive, and adaptable assessment tools to strengthen rehabilitation services globally.

7.7 Recommendations

The following recommendations, grounded in the study's findings, are structured around the framework's core components—inputs, processes, and outcomes—to strengthen the evaluation and implementation of CBR interventions.

7.7.1 Inputs: Framework refinement and capacity building

To address critical gaps in the current framework, it is essential to develop and validate culturally sensitive GPROMs. These tools should capture underrepresented domains such as livelihood-focused outcomes, informal economic activities, caregiver burden, and community-level impacts. Flexibility and adaptability across diverse LMIC settings are crucial for their effectiveness.

Additionally, the framework should be expanded to incorporate evaluation tools that measure Body Functions and Environmental Factors within the ICF. This expansion will support a more comprehensive and holistic assessment of CBR interventions.

Equally important is the design and implementation of targeted training programmes for healthcare providers, community workers, and mid-level rehabilitation personnel. These programmes must prioritise cultural competence, participatory methodologies, and inclusive service delivery to ensure consistent and effective use of the framework across varying contexts.

7.7.2 Processes: Enhancing implementation and evaluation

To validate and refine the framework's practical application, it is recommended to conduct multi-site pilot studies across diverse LMICs. These pilots should evaluate the framework's adaptability and effectiveness in different cultural and socio-economic contexts. Incorporating longitudinal

study designs will be vital for assessing the sustainability and long-term impact of interventions. The integration of digital technologies, particularly mHealth platforms, should be explored to optimise data collection, enable real-time monitoring, and strengthen feedback mechanisms in remote and resource-limited environments.

Active engagement with community stakeholders—including service users, caregivers, and local leaders—is critical. Their involvement in refining and adapting the framework will ensure it remains contextually relevant, practically usable, and responsive to the unique needs of each setting.

7.7.3 Outcomes: Policy integration and sustainable impact

Strategic advocacy is necessary to encourage the adoption of the refined framework by national and international health organisations. Aligning the framework with existing health and rehabilitation policies will facilitate its integration and promote widespread utilisation.

Governments of LMICs should be urged to incorporate the framework's metrics into national health systems and rehabilitation programmes. This integration will enable standardised evaluation of CBR interventions, enhance accountability, and guide informed resource allocation. To support sustainable, long-term implementation, targeted strategies must be developed. These should focus on securing consistent funding, fostering cross-sector collaboration, and embedding the framework within existing healthcare infrastructures.

By systematically addressing inputs, processes, and outcomes, these recommendations are designed to enhance the effectiveness, sustainability, and global impact of CBR interventions. Ongoing research, iterative refinement of the framework, and alignment with policy structures will

be pivotal to advancing comprehensive and equitable CBR evaluation and service delivery worldwide.

7.8 Summary of the thesis

This thesis proposes a participant-level outcomes framework for CBR grounded in the CBR Matrix and aligned with ICF constructs. A systematised review and Delphi process yielded a core GPROM bundle and design principles (adaptability, cultural fit). The pilot confirmed feasibility while exposing integration gaps (livelihoods/caregiver/community), training/time barriers, and the need for modular, context-chosen add-ons. Future iterations should broaden instrument coverage (and grey literature), benchmark against the ICF Checklist, and streamline implementation through protocolised workflows and digital tools.

7.8.1 Background

Community-based rehabilitation interventions are critical for addressing the rehabilitation needs of individuals in resource-limited and rural settings. They are guided by international policies such as the UNCRPD and the WHO's CBR guidelines. These frameworks emphasise inclusive development and the integration of individuals with disabilities into their communities. Despite these guidelines, the evaluation of CBR programmes remains a significant challenge due to their complex, context-specific, and multidimensional nature.

In South Africa, national policies also highlight the importance of addressing disparities in rehabilitation services, particularly in underserved rural areas. The National Rehabilitation Policy and related frameworks advocate for expanding access to services and promoting inclusivity. However, the implementation of these policies has been inconsistent, with limited evaluation

mechanisms to assess their impact on health outcomes and social inclusion. This study contributes to filling this gap by developing a framework that integrates theoretical and practical dimensions of CBR evaluation, ensuring relevance to both local and global contexts.

The study's foundation was informed by the recognition of gaps in existing CBR evaluation models, including the inability to capture non-health outcomes such as livelihoods and participation. Additionally, the unique challenges faced by LMICs, including cultural diversity, limited resources, and structural inequities, necessitate the development of adaptable and inclusive evaluation tools. This research responds to these needs by proposing a framework that not only aligns with global standards but also addresses the specific realities of LMIC settings.

7.8.2 Theoretical foundations

7.8.2.1 CBR Matrix and ICF

The study built on the CBR Matrix (WHO, 2010) and the ICF by integrating their theoretical strengths into a practical evaluation framework. In addition, the CBR Guidelines (WHO, UNESCO, ILO, & IDDC, 2010a–g) were considered, which outline practical steps for monitoring and evaluation, including the identification of indicators, data sources, and mechanisms for feeding information back into programme decision-making. While these guidelines are valuable for guiding programme implementation, they stop short of providing standardised outcome measures at the individual level. The framework proposed in this thesis builds on these principles by retaining their emphasis on multi-domain assessment while extending beyond them to identify and pilot generic patient-reported outcome measures (GPROMs) that can provide consistent, comparable evidence of CBR impact across diverse low-resource settings.

Similarly, more recent WHO tools such as STARS (WHO, 2017, 2019) and TRIC (WHO, 2021) provide valuable mechanisms for system-level assessment and data collection but do not address the need for standardised individual-level outcome measurement. This study therefore complements these initiatives by focusing specifically on patient-reported outcomes within community-based rehabilitation contexts. By incorporating GPROMs to assess multidimensional outcomes such as participation, social inclusion, and livelihoods, the framework advances existing models and contributes to a more comprehensive approach to evaluating CBR interventions across health and non-health domains.

7.8.2.2 Participatory and pragmatic paradigms

Grounded in a pragmatic paradigm, the study employed participatory methods, engaging stakeholders at every stage. The iterative Delphi process ensured the framework was shaped by expert consensus, enhancing its relevance and credibility. This participatory approach also aligned with the fundamental principles of CBR, ensuring that the framework reflects the lived experiences of the individuals and communities it seeks to serve.

7.9 Reflection of the research journey

Working full time while conducting a PhD required perseverance and unwavering commitment. At the heart of this journey was the recognition of my deep desire to contribute to improving access to rehabilitation services in areas where such services are difficult to access. This motivation built upon the foundation of my Master's research, which explored the rehabilitation needs of individuals living with lower limb amputations in rural South Africa. The findings from that study underscored the critical role of CBR in addressing these needs and reinforced the necessity of evaluating the effectiveness of such services to create meaningful impact.

Undertaking this research was both challenging and rewarding, especially given the nuanced and context-specific nature of CBR. Evaluating services that are deeply embedded in local contexts and shaped by unique socio-economic and cultural factors required a careful and thoughtful approach. Conducting research that was not patient-facing or tactile was particularly difficult, as I have always enjoyed fieldwork and direct interaction with individuals and communities. However, the constraints imposed by the COVID-19 pandemic made such engagement impractical, if not impossible. This reality made the scoping and systematised review phases both a practical

necessity and an essential step from a research perspective, providing a comprehensive foundation for the development of the framework.

Towards the end of the study, I encountered unexpected challenges related to piloting the framework. Initially, I had planned to test it outside of South Africa, but difficulties in obtaining ethics approval in other countries proved insurmountable within the study's timeline. While this was a limitation that had not been anticipated, piloting the framework in a South African context revealed valuable, real-world insights. The pilot study offered a grounded perspective on how the framework could be refined to better reflect the lived experiences of stakeholders and the practical realities of implementing CBR in resource-constrained settings.

This journey reinforced my understanding that impactful research often requires adaptability and resilience. It has strengthened my resolve to contribute to the improvement of rehabilitation services and has provided me with tools and insights to advocate for evidence-based practices that address the unique challenges faced by underserved communities.

7.10 Conclusion

This study offers a contribution to the field of CBR by addressing the evaluation and implementation challenges of CBR interventions in LMICs. Through the development and piloted evaluation framework, this research highlights gaps in existing CBR evaluation practices, particularly in capturing livelihood outcomes, informal economic activities, caregiver burden, and community-level impacts. These findings underscore the need for culturally sensitive and contextually relevant tools that can more holistically assess the effectiveness of CBR interventions.

The study also reveals that limitations in training, stakeholder engagement, and evaluation mechanisms hinder the sustainable impact of CBR programmes. The involvement of healthcare providers, community workers, and local stakeholders is essential for tailoring the framework to diverse cultural and socio-economic environments. Integrating digital technologies and participatory approaches can further enhance data collection, real-time monitoring, and feedback systems, ultimately strengthening CBR service delivery.

Addressing these identified gaps through targeted capacity building, adaptive implementation strategies, and policy integration is important for improving CBR outcomes. The recommendations provided in this study offer actionable pathways to foster a more inclusive, effective, and sustainable approach to rehabilitation services.

Future research should continue to refine the framework and evaluate its adaptability across varied settings, while policymakers and practitioners must collaborate to embed these practices within national health systems. By doing so, CBR interventions can achieve greater reach, equity, and impact, ultimately improving the quality of life for individuals with disabilities and their communities.

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APPENDICES

Appendix A: Consent forms



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 81 86 21795 or +27 83 609 7565
E-mail: manigsarah@gmail.com

CONSENT FORM

Title of Research Project: A universal framework for the evaluation of community-based rehabilitation interventions.

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

Yes I hereby give permission to be audio-recorded.

___ I Do NOT give permission to be audio-recorded.

Participant's name... Chwayota Sogoni

Participant's signature... [Signature]

Date... 05/11/2024



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 81 86 21795 or +27 83 609 7565

E-mail: manigsarah@gmail.com

CONSENT FORM

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Yes I hereby give permission to be audio-recorded.

____ I Do NOT give permission to be audio-recorded.

Participant's name... S. Simindile.....

Participant's signature... M. S......

Date... 05/11/2024.....



26 April 2019

Dear CEDIL Grant Committee,

RE: Letter of support for application from the University of the Western Cape

The Jabulani Rural Health Foundation has been consulted during the development of this funding proposal, on the basis of the fact that we manage a Community Based Rehabilitation (CBR) programme, called Rural Ability Programme (RAP), in a deeply rural part of the Eastern Cape Province of South Africa. As such, we have been involved in the planning of this project and support the objectives of the intended research. We will be involved in the actual research, in the capacity of implementing the final methodology developed in order to assess its suitability effectiveness in the field.

We have robust Monitoring and Evaluation systems in place in our RAP, to record programme activity and interventions conducted with beneficiaries of the programme, but have struggled to find a suitable tool or method to assess overall impact of the programme on individuals, families and communities. Available tools are often too complicated for our beneficiaries to engage with or not culturally or contextually relevant.

We are therefore eager to participate in, and support this study, as the potential success of it holds the potentially to be of benefit to our ongoing ability to fund and manage our CBR programme.

For more information on the Jabulani Rural Health Foundation, go to www.jabulanifoundation.org and feel free to contact me on cath@jabulanifoundation.org if you have any further questions or require any further information.

Yours Faithfully,

A handwritten signature in black ink that reads "C Young".

Catherine Young
Operations Manager

JABULANI RURAL HEALTH FOUNDATION
(Association incorporated under Section 21)
Registration No. 2006/009074/08 PBO No. 930 027 691 NPO Reg. No. 086-315-NPO
Account Details: ABSA, Frere Square, Branch Code: 632005 Acc No: 4069520005 Swift Code: ABSAZAJJ
Address: Zithulele Village, Mqanduli, Eastern Cape, 5080. Postal Address: PO Box 682, Mqanduli, 5080
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Web: www.jabulanifoundation.org Email: info@jabulanifoundation.org
Directors: Dr CB Gaunt (RSA), Dr KWDP le Roux (RSA), Rev JK Nlatywa (RSA)
Patrons: Desmond & Leah Tutu

Appendix B: Delphi study questions and information

Delphi – Round 1 consent and questions

Section 1:

Project Title: A universal framework for the evaluation of community-based rehabilitation interventions.

What is this study about?

This is a research project being conducted by Sarah Manig (M.Sc Physiotherapy) at the University of the Western Cape, South Africa. I am inviting you to participate in this research project because you are an expert in the field of community-based rehabilitation and/or rehabilitation. This study aims to explore existing methods of evaluating CBR interventions globally and to discover if consensus can be reached on a single standardized framework to assess the impact of CBR interventions. This study also aims to reach consensus on and pilot a concept digital toolkit for the evaluation of a CBR intervention.

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

You will be asked to participate in a Delphi study that will be performed over three rounds. The researcher will present findings from the scoping reviews from the previous phase. These findings will be current evaluation frameworks of CBR interventions as well as the tools used to evaluate these frameworks.

In the first round you will be asked to brainstorm and discuss viewpoints, make suggestions and highlight issues. Following this round, the second round will refine findings from the first round as well as incorporate that additional suggestions. In this round you will receive feedback from the first round will be asked to rank the statements / suggestions in order of perceived priority or relevance. In the final round, you will be asked to rank the shortened list again and statements that do not meet the 60% consensus criteria will be excluded.

Would my participation in this study be kept confidential?

The Delphi survey will be anonymous. Responses will be coded for data analysis. No personally identifiable information will be disclosed in the write-up of any publications.

What are the risks of this research?

There may be some risks from participating in this research study. All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any challenges during this study.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about community-based rehabilitation services in your country and how best to evaluate this services in order to improve it in the future. The aim is to motivate for CBR to be formally included in global policy and to investigate the potential for translation of a digital toolkit for the evaluation of CBR services in the future.

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

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time.

What if I have questions?

Sarah Manig is conducting this research from the Physiotherapy Department at the University of the Western Cape. If you have any questions about the research study itself, please contact Sarah at +27 81 862 1795 or manigsarah@gmail.com.

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

Prof Liezel Ennion

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lennion@uwc.ac.za

Prof Anthea Rhoda

Dean of the Faculty of Community and Health Sciences

University of the Western Cape

Private Bag X17

Bellville 7535

chs-deansoffice@uwc.ac.za

This research has been approved by the University of the Western Cape's Biomedical Research Ethics Committee.

Biomedical Research Ethics Committee

University of the Western Cape

Private Bag X17

Bellville

7535

Tel: 021 959 4111

e-mailresearch-ethics@uwc.ac.za

REFERENCE NUMBER: BM20/05/31

Section 2: Consent

1) Please read through each statement and click the relevant box

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

2) Do you understand the purpose of this study, and voluntarily consent to participate?

- Yes
- No

Section 3: Generic Patient-Reported Outcome Measures (GPROM) used to evaluate community rehabilitation interventions.

The suggestions for the following section is based on a systematised review that investigated which generic patient reported outcome measures are being used to evaluate CBR interventions under the domains of “Activity limitation” and “Participation restriction” in accordance to the ICF.

The search commenced on 28 Feb 2022. The following databases were included in the search: PubMed, Medline (EBSCOhost) including CINAHL and Web of Science.

2.1 Please rank these dimensions in order of importance when considering generic patient reported outcome measures (1 - being most important)

- Activity
- Participation
- Social
- Environment

2.2 Please indicate whether or not you have experience using any of these outcome measures in practice.
(YES/NO)

WHODAS 2.0

WHOQOL-BREF

LIFE-H

FIM

Utrecht (USER)

2.3 If you answered yes to any of the checkboxes in 2.2, please name the outcome measure you have experience with and elaborate on how you experienced using this outcome measures in terms of; simplicity, time taken to complete, accessibility of the instruments, suitability for the rural context and appropriateness for evaluation of standardised constructs, user friendliness.

2.4 These 5 were most frequently reported generic PROM. Rank them in order of suitability from most suitable (1) to least suitable (5) according to your experience.

WHODAS 2.0

WHOQOL-BREF

LIFE-H

FIM

Utrecht (USER)

2.5 Can you add any additional outcome measures that you have experience with and consider a standardised outcome measure for CBR interventions that was not identified in the systematised literature search?

2.6 What else do you think needs to be included or considered in creating a gold standard outcome measure for the evaluation of community rehabilitation interventions? For example, most important domains of the ICF to include, at which level does the evaluation take place (individual/community), time taken to complete, etc.

Section 4: Demographic details

3.1 How old are you?

3.2 Gender (Male, Female, prefer not to say)

3.3 What is your professional title? (Lecturer, Senior Lecturer, Clinician, Associate professor, Full professor, Other)

3.4 How many publications do you have in peer-reviewed journals (if any)?

3.5 Do you have any experience working in rural or remote clinical environments?

3.6 If you answered yes to the previous question, please provide details of your experience. For example, how many years you spent working in a rural environment, what role were you occupying in this setting?

Thank you for taking the time to complete this survey. If you have any questions or concerns about the process, please contact Sarah Manig at manigsarah@gmail.com. Once I have analysed this data I will be in touch with respect to the second round of the Delphi.

Delphi study Round 2

Project Title: A universal framework for the evaluation of community-based rehabilitation interventions.

A summary of the results from Round 1 is presented below for your perusal. You will then be asked to rank the 11 suggested Patient Reported Outcome Measures (PROMs) from most to least appropriate (please make sure to rank all 11 – scroll all the way to the right) with regard to your perception of them as an outcome measure in the evaluation of CBR interventions.

Please note that by completing this form, you are consenting to participate.

Summary of Round 1 findings:

Participation and Activity were reported to be the most important dimensions of the ICF to consider with regards to generic PROM. Community participation was the most popular subset to the "participation" dimension of the ICF and was recommended for consideration when creating a gold standard outcome measure. Community participation was explained to be both the “buy-in” of community stakeholders as well as the patient and their direct community members being actively involved in their community.

Participants were most familiar with WHODAS 2.0 and WHOQOL-BREF and least familiar with LIFE-H, FIM, and the Utrecht (USER) as outcome measures used in CBR practice. WHODAS 2.0 was reported to be the most used outcome measure in the field with WHO-QOL and FIM mentioned to be user-friendly and suitable to the rural context. However, it was highlighted that the FIM outcome measure is not free to the public and that this was a limiting factor for its use in practice.

Participants mentioned that language barriers, particularly when patients are asked to rate their experience on a scale of mild to severe, is an important parameter that needs to be considered when reaching consensus on the most appropriate, generic, PROM used for CBR evaluation.

Additionally, participants complained that the proposed outcome measures in the first round of the Delphi study are lengthy to complete and that time is a factor that needs to be considered. In addition, culturally relevant questions/ADLs should be considered when creating a gold standard outcome measure.

Most Significant Change (MSC), PIE toolkit, and the Barthel Index were mentioned among the group of participants as other outcome measures to use. The Allen cognitive level screen (ACLS), WEEFIM (standardized for children), Goal attainment scale, Roads to Inclusion toolkit, and the SALSA scale were other outcome measures reported as suitable for CBR intervention evaluation.

Aim of Round 2 Delphi study

To determine the top three most appropriate, generic PROM used to evaluate CBR interventions

Round 2: Question

Please rate the outcome measures listed below (*combination of those presented in Round 1 as well as other PROM suggested by participants in this Delphi study*) in terms of their suitability as generic PROM used for the evaluation of CBR interventions.

The PROMs listed below are recommended to be suitable for the evaluation of CBR interventions.

Review the list and rank the PROMs from most to least appropriate.

Rows		Columns	
1. 1 (Most appropriate)	×	<input type="radio"/> WHODAS 2.0	×
2. 2	×	<input type="radio"/> WHOQOL-bref	×
3. 3	×	<input type="radio"/> Functional Independence Measure (FIM)	×
4. 4	×	<input type="radio"/> Most Significant Change (MSC)	×
5. 5	×	<input checked="" type="radio"/> PIE toolkit	×
6. 6	×	<input type="radio"/> Barthel Index	×
7. 7	×	<input type="radio"/> The Allen cognitive level screen (ACLS)	×
8. 8	×	<input type="radio"/> WeeFIM (standardized for children)	×
9. 9	×	<input type="radio"/> Goal attainment scale	×
10. 10	×	<input type="radio"/> Roads to Inclusion toolkit	×
11. 11 (Least appropriate)	×	<input type="radio"/> SALSA scale	×

Delphi study Round 3 Questions

Project Title: A universal framework for the evaluation of community-based rehabilitation interventions.

Recap of the Project's Purpose: You have been invited to participate in the final round of Sarah Manig's (M.Sc. Physiotherapy) at the University of the Western Cape, South Africa, Delphi study due to your expertise in community-based rehabilitation. This research project aims to delve into the existing approaches to evaluating community-based rehabilitation (CBR) interventions globally and seeks to ascertain the feasibility of creating a standardized framework for evaluating the impact of CBR interventions. Additionally, this study will undertake a pilot of the framework across three CBR initiatives in various regions of Africa.

Please note: The framework outlined below is currently in its initial stages, serving as a draft proposal that has been created with the intention of further refinement through your valuable expertise. This conceptual framework has evolved based on the fundamental insights derived from an extensive scoping review and the outcomes of a previous Delphi study. The experts involved in the study identified the Roads to Inclusion Toolkit (RIT) as the most suitable intervention, followed by the Functional Independence Measure (FIM) and the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0). Within this proposed framework, the researcher has carefully selected the most appropriate tools, in addition to other recommended instruments, aligning them with the domains of the Community-Based Rehabilitation (CBR) matrix. This alignment creates a comprehensive framework that can effectively guide interventions in determining the most suitable evaluation method for any specific context.

The primary objective of this framework is to provide a user-friendly and universally applicable tool for the evaluation of CBR interventions, facilitating informed decision-making for individuals and organizations as they tailor their choices to the unique requirements of their interventions.

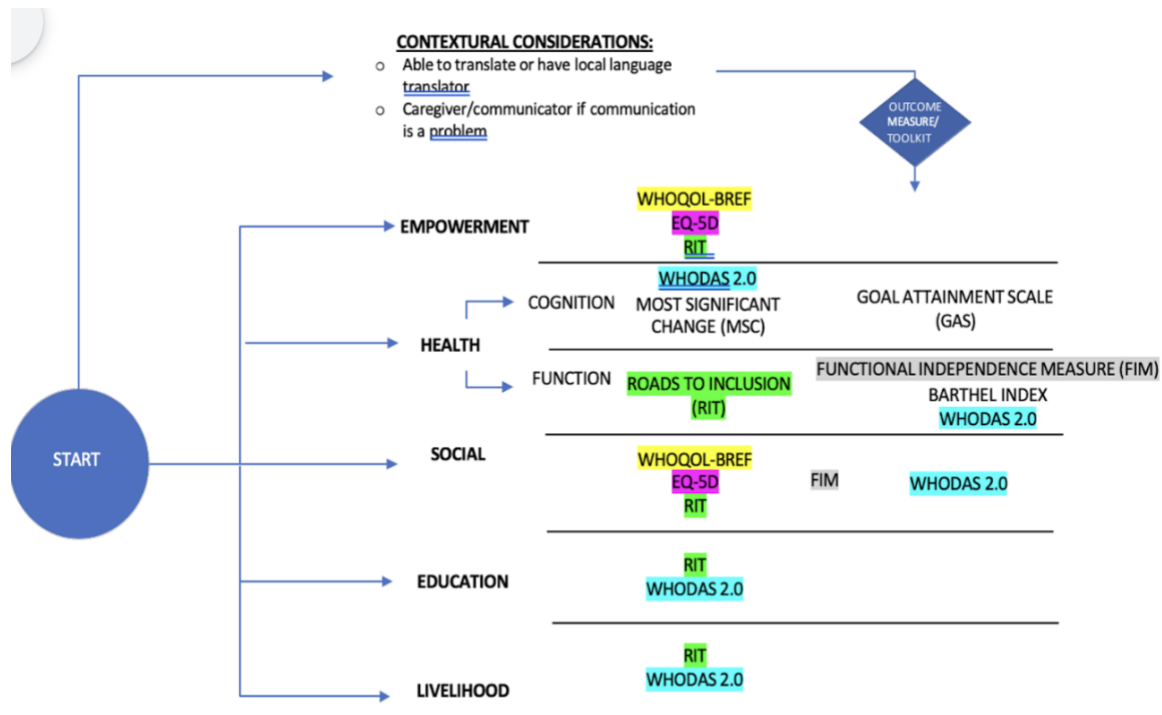
Glossary:

- WHODAS 2.0 (World Health Organization Disability Assessment Schedule 2.0)
- WHOQOL-BREF (World Health Organization Quality of Life)
- Functional Independence Measure (FIM)
- Most Significant Change (MSC)
- Barthel index
- Goal Attainment Scale (GAS)
- Roads to Inclusion Toolkit (RIT)

I hereby consent to participating in the final round of this Delphi study: Yes or No

Conceptual Universal framework to evaluate CBR interventions

Link to high resolution: [High resolution version of conceptual framework](#)



1. Do you feel that there is a need for this framework?
2. Please elaborate on your answer above.
3. Is the framework clear?
4. Do you feel that this can be used to standardise evaluation of different CBR programmes across different contexts?
5. Please elaborate on your answer above.
6. Do you have any suggestions for improvement or considerations? If so, please explain.

APPENDIX C – PILOT STUDY QUESTIONNAIRE

Semi Structured Interview Questions for Phase four Pilot study Participants

1. How easy was it for you to understand and apply the evaluation framework?
2. Did you encounter any difficulties in using specific tools or measures within the framework (e.g., WHODAS 2.0, WHO-QOL BREF)? If so, please describe them.
3. How well did the framework address the specific needs and context of your CBR program?
4. Were there any contextual factors (e.g., language, cultural considerations) that the framework did not adequately address?
5. Did the framework's tools and measures seem appropriate for evaluating the outcomes of your program? Why or why not?
6. To what extent did the framework help in accurately measuring the key outcomes (e.g., health, education, livelihood, social inclusion, empowerment) of your program?
7. How effective was the framework in capturing the most significant changes in the participants' lives?
8. Did you feel that the framework allowed for a comprehensive evaluation of the program's impact on participants' quality of life?
9. Were there any important changes or impacts that the framework did not capture?
10. How time-consuming was it to implement the framework during the evaluation process?
11. Were there any parts of the framework that you found to be too complex or cumbersome?
12. How could the framework be streamlined or simplified without losing its effectiveness?
13. What suggestions do you have for improving the framework?
14. Are there any additional tools, measures, or methods you think should be included in the framework?

APPENDIX D: PILOT STUDY PROTOCOL FOR PHASE FOUR

This protocol provides a structured outline of the steps followed during the pilot study of the CBR evaluation framework at Jabulani Rural Health Foundation. It is intended to ensure transparency and replicability across different community-based rehabilitation contexts.

1. Recruitment and Consent

- Obtain initial permission from the facility manager to approach staff.
- Invite eligible staff (minimum 1 year CBR experience) to participate voluntarily.
- Provide information sheet and draft framework in advance.
- Confirm voluntary participation; emphasise that refusal carried no negative consequences.
- Obtain written informed consent.

2. Participant Eligibility

- Healthcare providers with direct involvement in CBR services and at least one year of relevant experience.
- Eligible cadres include:
 - Allied health professionals (e.g., occupational therapists, physiotherapists, speech therapists).
 - Medical doctors engaged in community rehabilitation or primary care linked to CBR.
 - Community-based rehabilitation workers or community disability workers.
- Recruitment aimed to secure representation across different pillars of the CBR Matrix (health, education, livelihood, social, empowerment).

- Final sample size at Jabulani: three participants (one occupational therapist and two community disability workers), reflecting availability within the organisation.

3. Pilot Briefing

- Conduct online introductory call with participants.
- Present aims and procedures of the pilot.
- Provide training on framework use.
- Address questions and practical arrangements.

4. Implementation Phase

- Duration: 3 months.
- Application of framework across different CBR pillars (health, education/livelihood, social, empowerment).
- Participants complete structured documentation for each use, including:
 - Date and setting
 - Time required to apply framework
 - Barriers or challenges encountered
 - Adaptations made

5. Data Collection

- Conduct individual semi-structured interviews (45 minutes) via virtual meeting at end of 3-month period.
- Use interview guide (see Appendix C).
- Record and transcribe interviews.

6. Data Analysis

- Apply reflexive thematic analysis (Braun & Clarke, 2006, 2019, 2022).
- Identify feasibility, strengths, and areas for improvement of the framework.

7. Ethical Considerations

- Participation voluntary and non-coercive.
- Confidentiality of responses maintained.
- No impact on employment or role at Jabulani.