A QUALITATIVE FEASABILITY STUDY TO EVALUATE THE USE OF A SCREENING TOOL TO DETECT NEUROCOGNITIVE DEFICITS AMONG PERINATALLY HIV-INFECTED CHILDREN BY PRIMARY HEALTH CARE WORKERS

ANBRENTHIA MOOS

9605838

A Mini-Thesis submitted in partial fulfilment of the requirements for the degree of Masters in Public Health at the School of Public Health, University of the Western Cape

UNIVERSITY of the
WESTERN CAPE

Supervisors: Prof Tanya Doherty, Dr Darshini Govindasamy, Dr Rene Nassen

November 2020

http://etd.uwc.ac.za/

Keywords

Perinatally HIV-infected children

HAND

Neurocognitive Impairment

Neuropsychological battery

Assessment tool

Screening Tool

http://etd.uwc.ac.za/

ABBREVIATIONS

ART	Antiretroviral therapy
CNS	Central Nervous System
HIV	Human Immunodeficiency Virus
HAND	HIV Neurocognitive Disorders
CHWS	Community Health Workers
CNS	Central Nervous System
ND	Neurocognitive Deficits
PHE	Progressive HIV Encephalopathy
ANI	Asymptomatic Neurocognitive Impairment
MND	Mild Neurocognitive Impairment
HAD	HIV Dementia
PTSD	Post-traumatic Disorder
MDE	Major Depressive Episode
JSAIS	Junior South African Individual Scale
JSAIS revised	Senior South African Individual Scale
IHDS	International HIV Dementia Scale
Y-IHDS	Youth International Dementia Scale
MOCA	Montreal Cognitive Assessment
MMSE	Mini-Mental Assessment
BSID	Bayley Scale of Infant Development
QPNST	Quick Paediatric Neurocognitive Screening Tool
mHealth	Mobile Health

UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

Declaration

I declare that *A Qualitative Feasibility Study to evaluate the use of a screening tool to detect neurocognitive deficits among perinatally HIV-infected children by primary health care workers* has not been submitted for any degree or examination in any other university. All the sources that I have used or quoted have been indicated and acknowledged by complete references.

Full Name: Anbrenthia Moos November 2020

Signed:

http://etd.uwc.ac.za/

ACKNOWLEDGEMENTS

I would like to acknowledge and express my sincere thanks and gratitude to the following people who contributed to this journey and see this process come into fulfilment:

My supervisors, Prof. Tanya Doherty, Ms Darshini Govindasamy and Dr Rene Nassen for their continued patience, encouragement and time dedicated to engage and provide critique and feedback enabling me to complete this work.

The SOPH for providing this excellent course and Ms Corinne Carolissen, UWC SOPH Administrator, for her dedication and commitment to her work.

The participants and facilitators for their willingness to participate and support me throughout this process.

Ms Leigh Story for her meticulous transcriptions of the FGD's.

My colleagues from Lentegeur Child and Mental Health Services for their continued motivation, support and technological input.

UNIVERSITY of the
WESTERN CAPE

My husband Ragenald and my children Autumn, Wyatt and Xenith for their continued support, sacrifice and humour that allowed me to make this become a reality.

http://etd.uwc.ac.za/

TABLE OF CONTENTS

Keywords i

ABBREVIATIONS ii

Declaration iii

ACKNOWLEDGEMENTS iv

TABLE OF CONTENTS v

ABSTRACT x

CHAPTER 1 1

INTRODUCTION 1

1.1 Background 1

1.2 Overview of HIV/AIDS in children 1

1.3 Problem statement 3

1.4 Outline of this report 5

CHAPTER 2 7

LITERATURE REVIEW 7

2.1 Prevalence of HAND 7

2.2 Defining HAND 8

2.3 Impact and associated problems among children with neurocognitive deficits associated with HIV 9

2.4 A reflection on current assessment tools used to assess HAND 11

2.5 Challenges of screening tools in detection of HAND in children 15

2.6 Current progress towards development of a screening tool 16

2.7 Process of developing a quick paediatric neurocognitive screen tool (QPNST) 16

Chapter 3 19

RESEARCH DESIGN AND METHODOLOGY 19

3.1 Aim 19

3.2 Purpose 19

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

3.3 Framework for assessing feasibility: 19
3.4 Research question 20
3.5 Objectives 20
3.6 Study Design 20
3.7 Study Setting 21
3.8 Study participants 21
3.9 Sampling procedure and selection criteria 22
3.10 Sample Size 22
3.11 Data collection 23
3.12 Study procedures 25
3.13 Data Analysis 26
3.14 Validity and trustworthiness 27
3.15 Ethical Considerations 27
3.16 Study limitations 28
CHAPTER 4 31
RESULTS 31
4.1 Demographic characteristics of participants 31
4.2 Overview of key themes: 32
4.3 Creative nature of the QPNST 33
4.3.1 Playfulness 33
4.4 Ease of implementation into routine health and non-health services 34
4.4.1 Accessibility to all cadres of HCW's 34
4.4.2 Complementary to current screenings and assessment processes 35
4.4.3 Facilitates referrals and identification of at risk children 36
4.5 Context applicability and cultural relevance 37
4.6. Recommendations to the functional composition of the QPNST 39
4.6.1 Orientation task of the tool 39
4.6.2 Comprehension and Language task of the tool 41
4.6.3 Trail making task 43

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

4.6.4 Instruction guide & Tool Layout 43
4.6.5 Completion time 44
4.6.6 Equipment alternatives/replacement and maintenance availability 45
4.6.7 General feedback on activities in the QPNST: 46
CHAPTER 5 47
DISCUSSION 47
5.1 Summary of results 47
5.2 A reflection on mental health tool feasibility 47
5.2.1 Brief (looks short, easy to use) 48
5.2.2 Simplicity (no training required, meanings of ratings is clear) 49
5.2.3 Relevant (accords with clinical judgment, no jargon) 50
5.2.4 Acceptable (acceptable to professions, flexible administration) 51
5.2.5 Available (free, can be photocopied) 53
5.2.6 Valuable (low data entry overhead, meaningful feedback) 53
CHAPTER 6 56
CONCLUSION AND RECOMMENDATIONS 56
6.1 Conclusion 56
6.2 Recommendations 56
6.2.1 Further research 56
6.2.2 Policy and practice 57
References 58
Appendix 1 65
Quick Paediatric Neurocognitive Screening Tool (QPNST) 65
Appendix 2 79
Outline of focus group with MDT 79
Appendix 3 84
Demographic Questionnaire 84
Appendix 4 86
Codes and Themes 86

UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

Appendix 5 117

Participant Information Sheet 117

Appendix 6 122

Consent Form 122

Appendix 7 124

FGD Confidentiality Form 124

UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

LIST OF TABLES

Chapter 2:

Table 1: **Summarised Frascati criteria** **p. 8**

Chapter 4:

Table 2: **Themes and Sub-themes** **p. 30**

LIST OF FIGURES

Chapter 1:

Figure 1: **Proposed referral and intervention pathways for patients needing to be screened for HAND within a resource limited environment** **p. 4**

Chapter 4:

Figure 2: **Picture of toys in the QPNST** **p. 33**

UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

ABSTRACT

Background: Despite the effectiveness and scale-up of antiretroviral treatment (ART), HIV-Associated neurocognitive disorders (HAND) still persist. Currently no gold standard tool exists to detect all forms of HAND, including major and minor cognitive impairments. In light of this, a newly developed screening tool was conceptualised, namely the Quick Paediatric Neurocognitive Screening tool (QPNST). The QPNST has been developed to detect HAND in perinatally HIV-infected children aged 5-10 years.

Methodology: The purpose of this study was to explore perceptions of the feasibility of the QPNST for HAND screening among perinatally HIV-infected children aged 5-10 years in a routine PHC setting by obtaining feedback from health care workers (HCW's) who work or have worked in the PHC setting and across other levels of care in the clinical field.

Study objectives included:

1. To explore HCW's perceptions of the tools structure and layout.
2. To explore how aspects of the QPNST can be improved upon from the perspective of HCW's
3. To explore the perception of the age-appropriateness of the tool with regards to language and tasks that must be completed
4. To explore perception on the use of the tool by specific HCW cadres
5. To explore the perceptions on the ability to integrate the QPNST within existing guidelines and low resource environment

Data were collected through 3 focus group discussions (FGDs) conducted in May-June 2018 with 20 purposively sampled HCW's from PHCs in a peri-urban area in the Western Cape, South Africa. Focus groups discussions (FGDs) took place after the HCW's participated in a training session on the QPNST. Data were audio-recorded, transcribed and coded. Data were analysed using thematic analysis.

Results: Key themes emerging from the FGDs include:

1. Creative nature of the QPNST
2. Ease of implementation into routine health and non-health services
3. Context sensitive nature of the tool
4. Recommendations to the functional composition of the QPNST

UNIVERSITY of the WESTERN CAPE
http://etd.uwc.ac.za/

Overall, all HCW's perceived the QPNST as feasible to implement. They expressed that the tool was simple to understand, brief, child-friendly, with low costs. Furthermore, they highlighted that the QPNST could be used across different cadres of HCW's and different levels of care. In addition, they emphasised the tool's sensitivity to local context and ability to be used in resource constraint environments. Results also indicate that this tool could contribute to decreased waiting periods, while facilitating referrals to ensure early intervention and support.

Conclusion: Findings suggest that the QPNST is associated with high acceptability among HCW's and could be readily implemented within routine PHC services for earlier detection of HAND.

http://etd.uwc.ac.za/

CHAPTER 1

INTRODUCTION

1.1 Background

Globally 37 million people were living with HIV in 2018, of which 1.7 million were children under the age of 15 years, with 62% of adults aged 15 years and older who were accessing antiretroviral therapy (ART) and 54% of children under 14 years were accessing ART (UNAIDS: Joint United Nations Programme on HIV/AIDS, 2019a). In sub-Saharan Africa (SSA) 9 in 10 children aged 0-19 years were living with HIV in 2018 (UNICEF, 2019b).

1.2 Overview of HIV/AIDS in children

It is estimated that globally 160 000 (110 000 – 260 000) children aged 0-14 years acquired HIV in 2018, a reduction of 41% when compared to 280 000 (190 000-240 000) in 2010 (UNAIDS: Joint United Nations Programme on HIV/AIDS, 2019a). Recent statistics indicate that globally there are 54% of people living with HIV in Eastern and Southern Africa. In this region, the AIDS related mortality has decreased by 44% in the period from 2010-2018. The annual rate of infection declined by 28% during that same period (UNAIDS: Joint United Nations Programme on HIV/AIDS, 2019a).

The estimated number of children and adolescents living with HIV in Eastern and Southern Africa was estimated at 1.8 million in 2018 with an estimate of 460 000 living in South Africa (UNICEF, 2019) . The annual number of perinatal infections in children aged 0-9 years in Eastern and Southern Africa was 44 000 with 61% of HIV-infected children aged 0-14 years on ART (UNICEF, 2019a). Nearly 90% of all children living with HIV reside in Sub Saharan Africa (SSA) with a total number of perinatal HIV-infections amounting to 75 000 in children aged 0-9 years during 2018 (UNICEF, 2019a).

In a systematic review of 56 studies on children under 8 years globally, the majority of studies (51/56; 91%) recorded neurocognitive deficits for children with HIV infection (Sherr *et al.*, 2011). Perinatally HIV-infected (PHIV) children perform poorly in the area of general cognition and are at high risk for developing mental health problems (Laughton *et al.*, 2013). Children living with HIV appear to experience mental health problems such as anxiety, depression, behavioural problems and post-traumatic stress disorder (Sherr *et al.*, 2011). Assessment and screening for HIV associated neurocognitive disorder (HAND) among HIV-infected children may therefore be vital for the prevention and early treatment of cognitive

http://etd.uwc.ac.za/

problems commonly experienced during adolescence. This could then potentially improve scholastic outcomes and as a result enhance mental wellbeing.

A study focused on determining the effect of HIV on neurodevelopment in preschool children in the Democratic Republic of Congo, found that HIV-infected children presented with delay in cognitive function, motor skills, language expression and comprehension (Van Rie, Mupuala and Dow, 2008). A delay in the cognitive functioning, language and motor skills of HIV-infected children younger than 15 years was noted following a review of all studies conducted in SSA evaluating the cognition, development and behaviour in HIV-infected children (Abubakar et al., 2008). Despite severe and progressive neurocognitive impairment becoming rare during the era of ARV's, patients still present with poor outcomes on formal neurocognitive tests (Clifford and Ances, 2013).

In untreated children, HIV impacts on an immature brain which results in a static or progressive HIV encephalopathy (PHE) and the symptoms include a triad of acquired microcephaly, delay or loss of developmental milestones (motor, mental and language) and pyramidal tract motor deficits (Belman A *et.al.,* 1988 cited by Van Rie *et al.*, 2007: p3)**.** Neurocognitive impairment among HIV-infected children can manifest in delays in the areas of cognition, motor function, speech and language functioning. Impaired language and motor skills, cognitive deficits, impaired visual-spatial integration ability, and impaired executive functions are the major developmental deficits associated with HIV (Van Rie *et al.,* 2007). Although some children on ART function within the comparable limits when they are compared to their HIV uninfected peers, a pattern of impaired cognitive functioning is observed among a subset who present with central nervous system (CNS) disease.

Currently no gold standard paediatric screening tool for HAND exists internationally (Nassen *et al.*, 2014) . The development of a HAND screening tool, which considers the context of South Africa, i.e. language used within our local communities, is necessary to provide clinicians with results to appropriately guide assessment and intervention.

Current assessment tools used are expensive, lengthy and time consuming to administer (Kammerer, Isquith and Lundy, 2013). Barriers including the lack of validated screening tools and staff shortages contribute to the lack of routine assessment for HAND (Robbins *et al.*, 2011). The development of a child-friendly tool that can be applied by various members of the multidisciplinary team (MDT), including antiretroviral (ARV) counsellors, at primary health care (PHC) level would therefore make an important contribution as a public mental health prevention tool.

UNIVERSITY of the
WESTERN CAPE

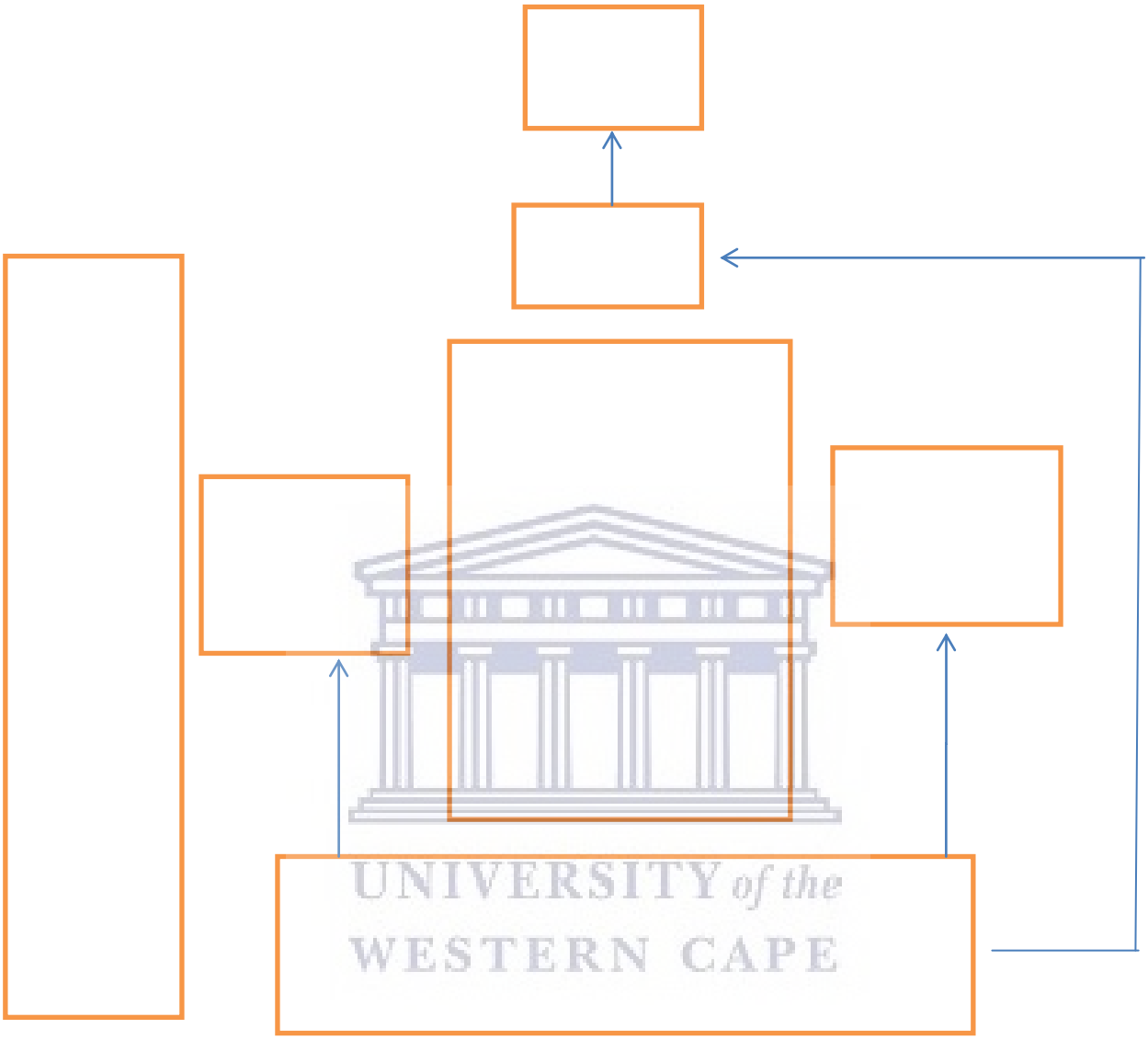
http://etd.uwc.ac.za/

1.3 Problem statement

Regardless of the developments in the treatment of HIV and the HIV survival rate improving over the years, HAND still remains highly prevalent and presents a significant health problem (Woods *et al.*, 2009).

The researcher works as an Occupational Therapist (OT) in the Child and Adolescent unit at Lentegeur Hospital and conducts assessments and treatment interventions to children presenting with mental health illnesses combined with cognitive and/or sensory difficulties which negatively affects their functioning in all areas of daily life. To the researcher's knowledge, there are no gold standard or internationally validated screening tools available to screen for HAND in the paediatric HIV population. Shortage of resources in Low and Middle Income countries (LMICs) can negatively affect the intervention and care of HIV associated neurocognitive impairment in children (Van Rie *et al.*, 2007).

http://etd.uwc.ac.za/



UNIVERSITY of the
WESTERN CAPE

Figure 1: Proposed referral and intervention pathways for patients needing to be screened for HAND within a resource limited environment (proposed by researcher)

Figure 1 shows a proposed referral and intervention pathways for patients needing to be screened for HAND. Patients present at PHC level for the first time and from there are referred to secondary or tertiary level service if needed. Patients at PHC level who are identified and need to be screened for HAND should be referred to available psychologists at their level of service in the PHC setting. However, upon enquiry and confirmation with the psychologist working in Khayelitsha Sub-district, the researcher found in practice, that currently it is not the pathway that is followed as these cases are frequently referred to secondary and tertiary level of care dependent on the availability of a psychologist and the screening tools. Screenings can also be conducted by occupational therapists, but not all

http://etd.uwc.ac.za/

PHC facilities have access to these services. Due to the unavailability of assessment tools, high caseloads, and the needs of patients, these screenings do not necessarily occur due to the context needs in which the clinician operates. Patients are thus put on a long waiting list to be assessed. These long waiting periods influence not only the detection of the deficits, but also appropriate intervention which can be provided such as remedial intervention and correct placement.

Although there are a broad range of psychometric assessments available to assist in detecting HAND, they are lengthy, time consuming, expensive and may not be practical to apply within the PHC setting. Most paediatric assessment tools originated and have been validated in high income populations and it is important that it suits the local context, as it can become challenging due to language and cultural issues (Kammerer, Isquith and Lundy, 2013). The lack of validated assessment tools and the importance of developing tools that are context sensitive and practical to implement have been highlighted in the literature (Robbins *et al.*, 2011). These assessments can also only be used by clinicians (psychologists or occupational therapists), who are inundated with the number of referrals and limited staff within health facilities. To effectively address learning difficulties caused by HAND, a screening tool needs to be developed to aid clinicians and health care workers (HCW's) at PHC level for early detection.

This study focuses on the feasibility of use of a new HAND screening tool, namely the Quick Paediatric Neurocognitive Screening tool (QPNST), by a multidisciplinary team (MDT) at PHC level. The QPNST has been developed to detect HAND in perinatally HIV-infected children aged 5-10 years and consists of nine subtests to screen for the specific cognitive domains. The domains assessed are: Fine motor, visuo-spatial, spatial relations, auditory memory, visual memory, visual-motor, comprehension or language, orientation and trail making.

The study describes HCW's perceptions of the tool and its feasibility for use at PHC level by different cadres of health professionals, including counsellors working across all levels of care (primary, secondary and tertiary levels of care.

1.4 Outline of this report

This study is presented in 5 chapters:

Chapter 1: Introduction

http://etd.uwc.ac.za/

This chapter introduces the study. The background and focus of the study is detailed in this chapter.

Chapter 2: Literature Review

This chapter discuss the literature reviewed, current assessments used and the development of the QPNST.

Chapter 3: Methodology

This chapter describes the research methodology used as well as the data collection and analysis procedures including ethical consideration and limitations of the study.

Chapter 4: Results

The results of this study are discussed in this chapter.

Chapter 5: Discussion

This chapter discusses the key findings together with findings from the literature, summarises the key findings and suggests recommendations based on the findings.

UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

CHAPTER 2

LITERATURE REVIEW

2.1 Prevalence of HAND

Despite SSA having the highest prevalence of HIV/AIDS, HAND continues to be largely an under researched area, whilst being a substantial source of morbidity in adults (Yusuf *et al.*, 2017).

High rates of HAND are still reported, despite ART reducing the morbidity and mortality associated with HIV infection (Heaton *et al.*, 2011). A review of the literature focusing on the nature, extent and diagnosis of HAND, highlighted that despite effective ART and improved survival rates, the high prevalence and adverse functional impact of HAND continue to be a significant public health issue (Woods *et al.*, 2009). Detecting HAND early in children and adolescents, may therefore improve the functioning and quality of life for HIV-infected individuals.

"The Essential Package for young children affected by HIV", a framework developed for action to support service delivery, was developed following a review of 56 studies focusing on young HIV-infected children aged 8 years and younger. A total of 91% (51/56) of those studies, recorded cognitive deficits (Sherr, Clucas and Jahn, 2011).

Between April and May 2010 in Manhica District, a high HIV prevalence area in Mozambique, 140 children younger than 15 years were recruited to participate in a study focused on evaluating the clinical, nutritional and neurodevelopmental status of HIV-infected children. Within this cohort, 139/140 participants were considered vertically HIV-infected. Results indicated that malnutrition and developmental delay were highly prevalent among this population, with 68% being undernourished (severely stunted) and 44% (42/95 evaluated children) who failed to pass the psychomotor development test (Pedrini *et al.*, 2015).

A review of published studies conducted in SSA (Central and Eastern Africa) with children younger than 15 years, noted that there was consistent delay in motor development across all ages and considerably compromised sensory motor skills. Moderate delay in mental development at 18 months was also indicated (Abubakar *et al.*, 2008).

Similarly, although with adults, the commissioned CNS HIV Antiretroviral Therapy Effects Research (CHARTER) study, examined 1555 patients from university HIV treatment centres

http://etd.uwc.ac.za/

across the United States by applying a battery of standard neuropsychological evaluations. The results from the CHARTER study identified neuropsychological impairment (NP) in 52 % (814/1555) of patients (Heaton *et al.*, 2010).

2.2 Defining HAND

A group of clinicians tasked by the National Institute of Mental Health and the National Institute of Neurological Diseases and Stroke redefined the criteria to classify HAND (Antinori *et al.*, 2007). According to this criteria, HAND includes 3 subtypes in adults namely Asymptomatic Neurocognitive Impairment (ANI), Mild Neurocognitive Disorder (MND) and HIV Associated Dementia (HAD) based on the extent of neurocognitive status and interference in everyday functioning (Antinori *et al.*, 2007). The criteria were developed when the clinicians met in Frascati; hence it is referred to as the Frascati criteria (Table 1).

Table 1: Summarised Frascati criteria:

The Frascati criteria (summarised)				
HAND Subtype	**Neurocognitive Impairment**	**Everyday Functioning**	**Presence of Delirium/Dementia**	**Presence of preexisting cause for ANI/MND/HAD**
ANI	1 SD below age Impairment involving 2 cognitive domains	Does not interfere with everyday functioning	Does not meet criteria for delirium or dementia	No pre-existing cause for ANI
MND	1 SD below age Impairment involving 2 cognitive domains	Mild impairment in everyday functioning	Does not meet criteria for delirium or dementia	No pre-existing cause for MND
HAD	2 SD below age Impairment involving 2 cognitive domains	Marked interference in everyday functioning	Does not meet criteria for delirium or dementia	No pre-existing Cause for MND
• SD: standard deviation below age-education-appropriate norms - Neurocognitive testing should include at least 5 cognitive domains including				

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

verbal/language, attention/working memory, abstraction/executive, memory (learning and recall), speed of information processing, sensory-perceptual and motor skills
(Antinori *et al.*, 2007)

A recent systemic review to gain knowledge to steer clinical intervention and improve cognitive outcomes in perinatally HIV-infected children and adolescents found that the children presented with impairments in executive functioning and processing speed (Phillips *et al.*, 2016). Results from this study reflected greater impairment (ranked largest to smallest effect size) in working memory, processing speed, executive function and visual memory in perinatally HIV-infected children compared to HIV-uninfected and –unexposed controls, signifying working memory as the most prominent domain and executive functioning the least prominent (Phillips *et al.*, 2016).

Similarly, when reviewing the literature on developmental outcomes in perinatally HIV-infected children, the cognitive domains of executive functioning including processing speed, memory and attention, visual-spatial ability, visual memory and planning and reasoning were impaired (Laughton *et al.*, 2013). Children with HIV may have special education needs and are at risk of cognitive and behavioural challenges and face the prospect of cognitive delay on some domains of functioning. This evidence emphasises the need for international agreed upon screening tools to assist in gaining more knowledge on the developmental challenges, and to guide clinical intervention (Sherr *et al.,* 2014). In this systematic review conducted by Sherr et al., (2014), most of the included studies (17/21, 81%) reported various forms of cognitive delay for HIV-infected children compared to HIV exposed un-infected or HIV un-infected un-exposed controls with some domains being more affected than others, and domains of language and executive functioning presenting with mixed evidence (Sherr *et al.*, 2014). Overall, the existing literature suggests that early identification of needs may assist in correct follow-up and intervention at home and in the school environment. Furthermore, it may alleviate any social isolation and school performance.

2.3 Impact and associated problems among children with neurocognitive deficits associated with HIV

HIV infection impairs the development and growth of an immature CNS (Van Rie *et al.,* 2007). CNS involvement presents as HIV encephalopathy with developmental delay or loss of developmental milestones (e.g. motor, mental and expressive language) (Van Rie *et al.*, 2007). Perinatally HIV-infected children who perform poorly in general cognitive tests,

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

processing speed and visual-spatial tasks are at much higher risk for psychiatric and mental health problems (Laughton *et al.*, 2013).

A study conducted among HIV-infected children aged 8-15 years in Kenya, administered the Kaufmann Assessment Battery for Children-Second Edition to assess cognitive difficulties and the Home Education and Peers, Drugs and alcohol, Suicidality, Emotions, Behaviour and Thought Disturbance and Discharge Resources for evaluating psychosocial issues to determine neurocognitive function and evaluating its relationship with psychosocial risk factors (Musindo *et al.*, 2018). The study results indicated a prevalence of major neurocognitive disorder (MND) in 60% of participants and the following psychosocial risk factors of MND: area of education (41, 1%), activities and peers (20%) and emotionality and behaviour (thought disturbance). Results indicate that these problems can impact on a child's daily functioning within their school and home environments, thereby impacting on their mental health and well-being.

A recent South African study explored the relationship between the home environment, caregiver factors and the neurocognitive function among 152 perinatally HIV-infected pre-school and school-age children living in a resource restraint community (Lentoor, 2019). Study findings indicate that the amount of stimulation a child receives has an impact on their sub-neurocognitive domain of verbal neurocognitive functioning. Other factors including family structure (including living with a biological caregiver), lack of resources for stimulation and lower education levels of caregivers were found to be associated with higher risk of poorer neurocognitive functioning (Lentoor, 2019). The study clearly indicated that a child's home environment in their early developmental years has an impact on the child's neurocognitive functioning, highlighting the need for early psychosocial intervention (Lentoor, 2019). This highlights that a child's neurocognitive development is not only linked to HIV infection, but is also compounded by external factors like the environment in which a child is raised.

The recent CHAKA (Mental health among HIV-infected Children and Adolescents in Kampala and Masaka, Uganda) study, found that children and adolescents with HIV presenting with enuresis and encopresis psychiatric co-morbidity, which included externalising and internalising disorders with the prevalence of enuresis or encopresis in this group was 10% and they presented with a risk of 18.7% for co-occurring externalising disorder and 36.4% for internalising disorder (Mpango *et al.*, 2019). In this study, externalising and internalising disorders were diagnosed following the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) criteria. Externalising disorders included Attention Deficit Hyperactivity Disorder ADHD), Oppositional Defiant Disorder (ODD),

http://etd.uwc.ac.za/

Conduct Disorder and Callous unemotional. Internalising disorders include Generalised Anxiety disorder, Specific Phobia disorder, Panic disorder, Post-traumatic Stress disorder (PTSD), Major Depressive Episode (MDE and dysthymia) (Mpango *et al.*, 2019). Despite this study not being linked to neurocognitive disorders, it still highlights that HIV-infected children are at risk of mental illness.

A review of studies suggests that HIV-infected children show specific mental health problems such as anxiety, depression, externalising and internalising behaviours and post-traumatic stress disorder (Sherr, Clucas and Jahn, 2011). Screening for these specific deficits among HIV-infected children is therefore important as it can assist in improving their health-related quality of life (e.g. ability to perform daily tasks at home or at school).

Executive functioning is needed to live productive and functional lives enabling an individual to make sense of and interpret the environment with which they engage on a daily basis, bearing in mind that the environment a child is reared in contributes to their physical and mental development. Thus, early identification of delays is vital to assist and provide appropriate support and intervention to HIV-infected children and their parents. Earlier detection of deficits can create environments where children can receive early and appropriate intervention, lessening the impact on their scholastic and functional ability during their schooling, adolescence and through to their adulthood years.

2.4 A reflection on current assessment tools used to assess HAND

UNIVERSITY of the
WESTERN CAPE

Assessments methods such as neuropsychological assessments are important tools to use to "diagnose and categorize the effects of HIV on the central nervous system" (Vally, 2011).

A shortage of resources and lack of validated assessment tools in LMICs where neuro-behavioural assessments are rarely performed leads to missed opportunities for timely initiation of ART and other strategies for prevention and care of HIV-associated neurocognitive impairment (Van Rie *et al.*, 2007). To identify early warning signs of HIV-associated CNS disorders and to allow neurodevelopmental assessments into paediatric HIV care and treatment programmes, the validation and standardisation of assessment tools is essential (Van Rie *et al.*, 2007).

The international HIV Dementia Scale (IHDS) was adapted with 2 minor modifications in order to be administered with perinatally HIV-infected adolescents aged 9-12 years, from community health clinics across Cape Town in the Cape Town Adolescent Antiretroviral (CTAAC) Cohort to evaluate the performance of the adapted version in the adolescents (Phillips *et al.*, 2019b). The adapted version of the IHDS, the Youth IHDS detected major

http://etd.uwc.ac.za/

neurocognitive disorder (ND) in 3% (n=8) of the cohort, with 39% (n=96) with minor ND, and the remaining 58% (n=144) with no ND (Phillips *et al.*, 2019b). The proportion of major and minor ND were slightly lower when compared to ND found in a previous smaller cohort (24), which could be compared to the CTAAC sample. This comparison between the CTAAC sample and the smaller sample highlighted that subtle forms of minor ND may be undetected and hence a validated screening tool that can detect all forms of impairment was recommended (Phillips *et al.*, 2019b).

A systematic review conducted between 2008-2013 suggests that early childhood development and stimulation is relevant to HIV-infected young children and that there is a need for internationally validated and agreed measures (Sherr *et al.*, 2014). Assessment tools used to screen for HIV cognitive difficulties include the Mini-Mental State Examination (MMSE), the HIV Dementia Scale, the International HIV Dementia Scale (IHDS) and the Montreal Cognitive Assessment (MOCA) (Vally, 2011). However, according to Vally (2011), the MMSE is not ideal for the assessment of HAND and milder forms cannot be reliably detected, and age, education and cultural background appear to impact on its psychometric validity. Despite the IHDS having been recommended as an appropriate screening tool for neurocognitive disorders in primary care settings as it is brief, its suitability for the South African context still needs to be validated (Vally, 2011). A major concern in this area is that all of the above-mentioned tools have been developed for adults in high-income settings, and the HIV Dementia Scale and the MOCA are still being used within our setting during assessments for children. Validation of HAND tools used in the South African paediatric clinical setting is needed as culturally our communities are diverse and exposure to certain terminology might not be applicable or used within our context.

Fewer well-developed measures are available for school-aged children due to challenges in measurement approaches in multilingual children in South Africa (Kammerer, Isquith and Lundy, 2013). Developing a new instrument or whether existing measures can be adapted to make it more culturally suitable is also questioned (Kammerer, Isquith and Lundy, 2013). Adapting existing measures would allow for a comparison with other tools thereby saving time and costs. Effective and low-cost tools which can be applied quickly might aid in streamlining the activities of HCW's in overburdened PHC settings. Current assessments are expensive and due to resource constraints at PHC level, accessing multiple international measures and screeners may not be feasible. A low cost locally developed tool may be more appropriate for our public sector healthcare setting. However, it needs to be determined what may be the best option i.e. direct or indirect assessment methods, comprehensive measures, screeners, or domain-specific measures (Kammerer, Lisquith and Lundy, 2013). Recent studies rely on a combination of assessment approaches, including both direct and

http://etd.uwc.ac.za/

indirect methods covering overlapping domains for convergent validity while also covering unique domains for comprehensiveness (Kammerer, Isquith and Lundy, 2013).

The Kaufmann Assessment Battery for Children (KABC), which was developed in the United States, ability to detect cognitive impairment caused by HIV across cultures in children aged 2-18 years was investigated (Van Wyhe *et al.*, 2017). The study included a systematic review of nine studies (eight from African countries, one from the United Kingdom) and found that the KABC successfully detected cognitive impairment in HIV-infected children, including children who are ART naive or who are clinically stable, receiving ART (Van Wyhe *et al.*, 2017). However, study results indicated that the use of the KABC in Uganda can be justified as it was validated for Uganda, but its use in other regions must still be investigated. The KABC may therefore not be sensitive enough to detect cognitive deficits in HIV-infected children and adolescents living in other areas such as South Africa.

The utility of the MOCA was determined in a prospective observational study of HIV-1 infected adults older than 17 years and clinically naive (Hasbun, 2012). The study concluded that the MOCA is a quick, quantitative tool that can be used to screen for neurocognitive impairment in HIV-infected patients with high sensitivity. According to Hasbun et al., (2012), HIV-positive patients with a MOCA score of <26 should be referred for further neuropsychological testing to assess cognitive impairment. When reflecting on the components assessed in the MOCA, one of the first observations is that it uses terminology such as “velvet”, which may not be necessarily used in the everyday language of South African children. Exposure to alphabet letters such as the letters used in the MOCA, prior to age 8 within the South African context is also questionable.

In a Western Cape based study, 65 adults were screened for HAD by community-based health care workers. The IHDS was used to screen the participants and 80% of participants were found to screen positive for HAD. Individuals scored worse on the motor and psycho motor subtests which highlighted the need for more regular and routine screening for HAD (Robbins *et al.*, 2011).

A comparative study between five brief screening tools for HAND in the USA and South Africa highlighted that screening for HAND is important to improve clinical outcomes. The study focused on comparing the diagnostic sensitivity and specificity of the Mini-mental state examination, IHDS, MOCA, Simioni symptom questionnaire and the cognitive assessment tool-rapid version (CAT-rapid) to a gold standard neuropsychological battery (Joska *et al.*, 2016). The CAT-rapid had a good sensitivity (94%) and weak specificity (52%), the IHDS showed fair sensitivity (68%) and good specificity (86%), however, no tool was adequate in screening for HAND (Joska *et al.*, 2016). The authors in this study indicate that these tools

http://etd.uwc.ac.za/

could result in false-positive results, and thus lead to patients without HAND also being referred for full neurocognitive assessments which can put a strain on the already pressured South African public-sector health care system (Joska *et al.*,2016).

In a review of six studies that focused on the degree of motor, cognitive, language and social-emotional impairment related to HIV-infection in children living in SSA, the authors found that various instruments which were not standardised for the local context were applied in these studies, and stated that the "insufficiently sensitive measurement tools" could "mask true level of group differences" (Abubakar *et al.*, 2008).

Currently in routine practice in South Africa, if there are any concerns regarding a child's cognitive functioning, a full neuropsychological battery is used to assess for these deficits. However, all of the above tools are not feasible or practical to use at PHC level because of cost, time constraints, high patient numbers and low human resources (Van Rie *et al.*, 2007) Hence, there is a need for the development of a brief low cost tool to screen for HAND.

UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

2.5 Challenges of screening tools in detection of HAND in children

During the period February 2011 to January 2012, The Mind Exchange program, a working group established by the National Institute of Mental Health and the National Institute of Neurological Diseases and Stroke was tasked to review definitional criteria for HAND. The Mind Exchange program identified and discussed 14 key questions that focused on screening, diagnosis, monitoring, treatment interventions and prevention of HAND in HIV-infected people of all ages (Antinori *et al.*, 2013). It determined that in terms of screening, although many paper based and computerised tools exist, none can be used across all settings with the choice of the tool being determined by the availability of a trained clinician, the cost and financial implications and the characteristics of the populations being tested. It also stated that according to their research of published criteria, a comprehensive neuropsychological (NP) evaluation is the accepted standard for the evaluation of HAND. It was highlighted that neuropsychological testing should include the following neurocognitive domains: verbal or language, attention or working memory, abstraction or education function, learning or recall, speed of information processing and motor skills. The Mind Exchange program concluded: "In brief, there is no standard and validated, easy-to-perform test to screen for minor neurocognitive disorders applicable in all HIV-infected patients" (Antinori *et al.*, 2013). After reviewing the literature on available and utilised screening tools, it appears that there are no or very few appropriate or relevant tools that can be applied within the South African context.

UNIVERSITY of the
WESTERN CAPE

Despite the availability of a variety of screening tools, none of the tools focuses specifically on the neurocognitive deficits experienced by HIV-infected children. Many of the tools used are still broad and although they do focus on some of the executive deficits, they fail to account for all the neurocognitive deficits caused by HIV. Tools developed to test adults are still being applied to children. This may not be just or fair towards the assessment of a child. The terminologies used in the available tools are questionable as some of the terms used in current tools are not used during everyday language of younger South African children. Therefore, it would be recommended that one tool be developed which can be applied and takes into consideration the context and environment in which South African children are reared. The literature also highlights the gap of not having a gold standard tool, as well as recommending the development of such a tool.

http://etd.uwc.ac.za/

2.6 Current progress towards development of a screening tool

A review of publications from 2008-2013 focused on cognitive delay in HIV-infected children suggests routine and regular cognitive monitoring from an early age is needed to ensure appropriate intervention according to their needs (Sherr *et al.*, 2014). The authors of this review also indicate that well validated scales and agreed measures are overdue (Sherr *et al.*, 2014).

Due to the lack of available and locally "adaptable, simple, sensitive and rapid" screening tools in South Africa, the Red Cross War Memorial Children's Hospital developed a tool for rapid screening of moderate to severe developmental delays for children aged 9-36 months (Boyede, Eley and Donald, 2016). The sensitivity of this tool was 78% and found to be adequate for screening of moderate to severe developmental delays in HIV-infected children (Boyede, Eley and Donald, 2016). However, the Red Cross War Memorial Children's Screening tool was developed for children under 3 years of age and does not cover all the cognitive domains affected by HIV. Therefore it was important to develop a screening tool that covers all cognitive domains affected by HIV to ensure a more comprehensive assessment of a child's HAND deficits.

2.7 Process of developing a quick paediatric neurocognitive screen tool (QPNST)

According to Robbins et.al., (2011), there is an urgent need for screening tools that are culturally appropriate and sensitive for the South African context (Robbins *et al.*, 2011)

Whilst several validated assessment tools for children in high-income countries exist, these may not be applicable to paediatric populations in LMICs (Kammerer, Isquith and Lundy, 2013). The scarcity of assessment instruments that have been developed, standardised and validated for each purpose (e.g. cognitive, executive function, socio-emotional) and country has impeded and complicated the assessment of HAND in children from Africa (Kammerer, Isquith and Lundy, 2013). The efficacy and utility of limited intervention resources will be improved through early intervention by measuring the impact of biological and environmental interventions on later development (Kammerer, Isquith and Lundy, 2013).

The development of the Quick Paediatric Neurocognitive Screening tool (QPNST) in 2014 was derived from collaboration between the Lentegeur Child and Adolescent unit and Michael Mpogwana Community Health centre's (CHC's) ARV unit, situated in Khayelitsha. The need for a paediatric screening tool was identified through engagement with the medical and counselling staff that highlighted that the paediatric population and adolescents are

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

presenting with neurocognitive deficits whilst attending therapeutic support groups at the Community Health Centre (CHC). The researcher was then asked to design a tool which will assist with screening. Input and feedback were provided by the two child psychiatrists and fellow colleagues from the MDT throughout the development of the tool which contributed to the development of the screening tool in its current form. The child psychiatrists actively gave input into and assisted with collation of the equipment, specifically the toys included in the tool. Generally when a need is identified for a new assessment tool, the process of development includes drawing up of several drafts in collaboration with other HCW's, then conducting a validation study (Slade, Thornicroft and Glover, 1999).

This QPNST was presented at an HIV Symposium hosted by Lentegeur CAMHS, at the International Association for Child and Adolescent Psychiatry and Allied Professions (IACAPAP) conference (IACAPAP, 2014) and various other platforms. Feedback from these forums was obtained which highlighted the need for such a tool as well as the uniqueness as there is a lack of a gold standard tool. The tool was distributed at the symposium which was attended by the various health professionals working across all levels in the field of HIV.

The QPNST (Appendix 1) consists of a kit which includes an information sheet, score guide, marking sheet, toys and worksheets to be used by the child being assessed. It consists of nine subtests to screen for the specific cognitive domains. The domains assessed are: Fine motor, visuo-spatial, spatial relations, auditory memory, visual memory, visual-motor, comprehension or language, orientation and trail making. The tasks designed were guided by age-appropriate developmental norms expected among 5 to 10 year-olds. No specific guide in tool development was followed, hence when the author was asked for the tool by clinicians who attended the symposium, it was made clear that the tool has not been validated and cannot be used for any diagnosis. The QPNST in its current form has not been validated or standardised and therefore limits the implementation of the tool with current HIV-infected children. Although it was developed and guided by age-appropriate norms, the QPNST must be validated to determine and ensure that the tasks used to measure the different cognitive domains do in fact measure the specific domain to indicate the presence of HAND and that the tasks are appropriate for HIV-infected children across the age group of 5-10 years. As the QPNST was not validated the researcher needs to ensure content validity which can be determined through a large quantitative survey, prior to validation of the tool. Total score is out of 30, and is called the total composite HAND score. The cut-off is 13/30. The patients who score 13 and below, must be referred to the relevant health professional to conduct a comprehensive assessment. Although the patient may score more than 13/30, there may be specific areas of difficulty and dependent on those difficulties, they must also be referred to the relevant health professional for assessment and/or intervention. Currently

http://etd.uwc.ac.za/

no study to date has assessed the feasibility of the QPNST for use in a South African PHC setting.

A lack of standardised and validated tools can negatively impact the care and intervention of children and adolescents living with HAND (Van Rie *et al.*, 2007). Due to the paucity of a gold standard tool to detect HAND in children and adolescents, the QPNST was developed to address this gap. Despite the availability of adult tools used to screen and assess children and adolescents, the QPNST was specifically developed to work towards developing a comprehensive, child-friendly and culturally appropriate tool for the South African context which could be validated should preliminary evidence suggest that the tool is feasible to implement in a clinical setting.

http://etd.uwc.ac.za/

Chapter 3

RESEARCH DESIGN AND METHODOLOGY

3.1 Aim

This study aimed to explore perceptions of the feasibility of the QPNST for HAND screening among perinatally HIV-infected children aged 5-10 years in a routine PHC setting.

3.2 Purpose

The purpose of the study was to obtain feedback regarding the feasibility of the QPNST from HCW's who work or have worked in the PHC setting and across other levels of care in the clinical field.

Feedback gained in this study could be used to:

a) Refine the QPNST to make it more appropriate and user friendly to the extent that it can be piloted with a cohort of perinatally HIV-infected children aged 5-10 years.
b) To assist in indicating if it would be appropriate to validate the QPNST against a gold standard cognitive screening tool.

3.3 Framework for assessing feasibility:

UNIVERSITY of the
WESTERN CAPE

In a study conducted by Slade, Thornicroft and Glover (1999), the authors proposed a definition and characteristics of feasibility for outcome measures used in the field of mental health. The study was conducted by reviewing literature which focused on the measurement of feasibility of outcome measures and a systematic review of patient-based outcome measures. The authors cited the definitions from the surveys and reviews to be inadequate and proposed a new definition of feasibility of an assessment. They defined feasibility of an assessment within a clinical environment as the extent to which an assessment is suitable for use on a "routine, sustainable and meaningful basis" for a "specific purpose" and in a "specific manner"(Slade, Thornicroft and Glover, 1999: p. 245). The authors proposed the following characteristics of feasibility (with aspects to consider), which may improve the feasibility of outcome measures. These characteristics form part of a checklist which can be used to investigate whether an assessment is feasible (Slade, Thornicroft and Glover, 1999):

- Brief (short and easy to use)

http://etd.uwc.ac.za/

- Simplicity (no need for formal training, short manual easy to understand instructions, the meanings of the rating is clear no special non-clinical knowledge required)
- Relevance (accords with clinical judgement, no jargon)
- Acceptable (acceptable to professions, flexible administration)
- Available (free, can be photocopied)
- Valuable (low data entry overhead, meaningful feedback)

For this study, the author explored whether some of these characteristics of feasibility applies to the QPNST when reviewing feedback from participants in the study.

3.4 Research question

Is the QPNST tool feasible for implementation in routine PHC settings?

3.5 Objectives

3.5.1 To explore HCW's perceptions of the tools structure and layout.

3.5.2 To explore the perception of the age-appropriateness of the tool with regards to language and for the task that need to be completed

3.5.3 To explore perception on the use of the tool by specific HCW cadres

3.5.4 To explore the perceptions on the ability to integrate the QPNST within existing guidelines and low resource environment

3.5.5 To explore how aspects of the QPNST can be improved upon from the perspective of HCW's

3.6 Study Design

The study employed an exploratory qualitative study design to describe HCW's perception of the feasibility of using the QPNST through conducting a training workshop and follow-up focus group discussions (FGDs). Qualitative research aims for researchers to be able to interpret and make better sense of the 'experiences, meanings and views' of participants when studying social problems in their own contexts (Pope and Mays, 1995).

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

This study design enabled the exploration of the objectives in this study as it allows for gaining insight and feedback on HCW's understanding and view of the QPNST and how it can be improved upon for future use.

3.7 Study Setting

The study was conducted at Lentegeur Child and Adolescent Unit (LGH CAMHS) situated at Lentegeur Psychiatric Hospital in the Western Cape. This unit was selected as it delivers child and adolescent mental health services to children and adolescents, particularly those referred from neighbouring high density peri-urban communities such as Khayelitsha and Mitchell's Plain. Perinatally HIV-infected children form part of the patient population this unit serves. The out-patient multidisciplinary team consists of 22 members who see an average number of 250-300 patients a month who come for an average 1-2 visits a month. In the year 2003 an estimated 1400-1650 HIV-infected children were born in the Western Cape Province (Eley, 2006).

HCW's from various disciplines (e.g. medical, psychiatry, occupational therapy, psychology, nursing, social work, creative arts therapies) work within the unit. They not only provide services at the unit, but are also responsible for conducting outreach work and liaison and training to HCW's working at PHC level.

These HCW's regularly refer children to LGH CMHS for assessment and intervention. Regular meetings occur between the HCW's from tertiary and primary level to discuss service developments, training, follow-up of clinical cases and for advocacy of the rights of children and adolescents across all public health sectors.

UNIVERSITY of the WESTERN CAPE

3.8 Study participants

Our sampling frame constituted of HCW's working in paediatric mental health services within tertiary and primary healthcare facilities, and who refer patients to the LGH CAMHS unit. The participants included HCW's from various disciplines and levels including medical, general and child psychiatry, occupational therapy, psychology, nursing, clinical social work and drama therapy. This diverse group of HCW's from different backgrounds and training was included as it facilitates different views and perspectives within the FGDs (Kitzinger, 1995).

The HCW's were appropriate participants as they provide assessment, treatment and intervention to children and adolescents presenting with psychiatric illnesses including HIV-positive children. Buy-in and feedback regarding the feasibility of the QPNST from the

http://etd.uwc.ac.za/

HCW's is important as they would be responsible for implementation of the tool in clinical practice.

3.9 Sampling procedure and selection criteria

This study utilised purposive sampling. In purposive sampling, the experiences and characteristics of the participants enables the researcher to conduct a more detailed investigation of the research topic as they can relate and are more knowledgeable on the topic of study (Mays and Pope, 1995).

Participants were purposefully selected from 3 PHC facilities and 1 tertiary facility. Participants were recruited at the weekly academic meetings as well as during outreach meetings in the PHC setting. This approach was relevant to this study as the participants work with children and adolescents and receive referrals of HIV infected individuals.

Inclusion criteria:

- HCW's working within the PHC or tertiary child and adolescent mental health setting
- HCW's working with HIV infected children and adolescents and their families
- HCW's who refer to LGH for further assessment and intervention

Exclusion criteria:

- HCW's with no work experience with HIV infected children and adolescents
- No mental health (psychiatry experience) was excluded from the study.

UNIVERSITY of the
WESTERN CAPE

3.10 Sample Size

HCW'S from different cadres working in Child and Adolescent Mental Health from Khayelitsha and Mitchell's Plain sub-districts and LGH CAMHS were approached to participate in the study and the training session on the QPNST. These invited HCW's consisted of a group of HCW's who works only at community level and other HCW's working at both community and tertiary level. The total amount of HCW's invited to the training session and the study amounted to 30 HCW's.

From the total of 30 HCW's who were invited only 25 HCW's attended the training session that formed part of the academic programme at LGH CAMHS. Out of the 25 HCW's who attended the training 20 consented to form part of the study, with 5 refusing to be part of the study. The other 5 participants who did not attend the training, and therefore did not form part of the study, excused themselves due to work requirements and high workloads in their respective work environments. Overall 20 HCW's agreed to participate in the study.

http://etd.uwc.ac.za/

3 FGD's were conducted with the HCW's. The configuration of the FGDs was as follows:

FGD 1: N=13, 2 male participants, 11 female participants. All participants have PHC and Tertiary work experience in the field of working with children and adolescents. The participants consisted of 2 Child Psychiatry registrars, 1 Social worker, 2 Medical officers, 1 Child Psychiatrist, 1 Occupational Therapy Technician, 1 Occupational Therapist, 3 Professional Advanced Psychiatry speciality nurses and 2 Professional nurses.

FGD 2: N=5, 1 Male participant, 4 female participants, 4 have PHC and Tertiary work experience in the field of working with children and adolescents. The participants consisted of 1 Clinical Social worker, 2 Clinical Psychologists, 1 Occupational Therapist, 1 Drama Therapist.

FGD 3: N=2, 2 female participants. Both participants have PHC and Tertiary work experience in the field of working with children and adolescents. The participants consisted of 1 Advanced Psychiatric nurse and 1 Professional nurse.

3.11 Data collection

Data were collected via FGDs in order to gain a broad understanding of participants' views and perceptions of the QPNST. Communication and interaction in the FGDs between participants encourages debate, reflection and asking of questions on each other's experiences and knowledge (Kitzinger, 1995). The use of FGDs allowed for engagement through the use of questions to gain feedback from participants on their thoughts and experiences. It also allowed for more probing questions which could be answered and participants can explore more on certain topics by reflecting on other participants' feedback.

Data collection was scheduled to take place in May 2019 over a two-week period, however it was extended to June 2019 due to some HCW's not being able to attend the training or not being able to slot into the scheduled FGDs. The researcher recruited ten participants for each FGD divided into the PHC group and the tertiary group. HCW's were going to be divided into a specific focus group according to their work experience (PHC or tertiary work experience). However, due to factors such as time constraints, work shifts and schedules as well as work load, the HCW's attended the FGDs according which time slot suited those best. This resulted in groups with a mix of PHC and tertiary level staff. However, the mixed groups did not have a negative impact and participants were still able to generate good discussion points. Participants working in both tertiary and primary level reflected on their experiences of working at both levels. A third FGD was held to accommodate HCW's who were unable to attend the two FGDs which was scheduled by the researcher.

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

Although a training workshop was conducted by the researcher, an Occupational Therapist from the unit, it did not form part of this research study as it formed part of the weekly academic programme of the Lentegeur Child and Adolescent Mental Health unit (LGH CAMHS). Participants attending the training were invited to participate in a one- hour FGD, a week after the training at the LGH CAMHS. The training included a power-point presentation focused on the background, purpose and development of the QPNST. Participants were divided into smaller groups providing those with the opportunity to interact and engage with the QPNST and the equipment used therein. This allowed for reflection and interrogation with their peers. Each participant was provided with a copy of the QPNST which they then could peruse in the week leading up to the focus groups. Participants did not use the QPNST in clinical practice and their feedback was based on the training they received 1 week prior to the FGDs.

The researcher developed an interview guide for the FGDs. The guide consisted of broad topic (open-ended) questions. Examples of more probing or specific questions (Appendix 2: Outline of FGDs) were also provided for each broad topic as part of a hand-out, to assist the interviewer during the FGD. The researcher used the feedback and questions received at the different platforms, meetings, conference and symposium where the QPNST was previously presented, to inform the questions included in the interview guide. This then aided as reminders and provided the interviewer with specific questions if unsure. Broad topics included general perception of the tool, determining if the tool would be useful to HCW's and patients, applicability of the tool in the PHC context or other levels of care and settings, ease of use of the tool, difficulties that might be experienced in the application of the tool, language and activities used to screen, possible challenges, effectiveness of the tool, recommendations or changes and other methods of using the tool.

All the questions were able to be asked, but at times participants needed prompting when necessary. The researcher recruited two interviewers and two note takers. Each interviewer and note taker was allocated 1 FGD respectively. One interviewer and 1 note taker subsequently conducted 2 FGDs as a third FGD needed to be conducted to accommodate nursing staff who were unable to meet the time slots of both FGDs which was originally planned. The interviewers then made use of the prompting questions as per the hand-out guide, provided by the researcher. Both interviewers were female Occupational Therapists who work at Lentegeur Psychiatric Hospital. The interviewers were chosen as they regularly facilitate groups with individuals of varying age groups (adolescents and adults) in the clinical setting. Their group work experience enabled them to probe with open and closed ended questions according to the responses of participants. The interviewers and the note takers attended the training to understand the tool and to gain knowledge of the topic when

http://etd.uwc.ac.za/

asking questions or taking notes. The researcher felt that by not conducting the FGDs herself, the participants may participate more fully in the discussion and feel more comfortable and not feel pressurised to only give positive feedback.

The researcher developed a demographic questionnaire (see Appendix 3: Demographic Questionnaire) which was completed at the training and submitted to the researcher at the FGDs. The questionnaire sought to collect basic information regarding the HCWs job title, department in which they work, work experience (tertiary, district), patient population (adults, paediatrics), mental health work experience or psychiatry work experience.

3.12 Study procedures

The researcher coordinated dates for both the training session and the follow-up FGDs as part of the academic programme at LGH CAMHS. The gym area at LGH CAMHS was identified as the space to facilitate the FGDs. Three FGDs were conducted of which 2 took place in the gym, and the third FGD took place in a smaller therapy room for privacy.

The researcher met the interviewers 3 days prior to the FGD's to discuss the outline, questions and FGD process. The room was prepared prior to the group where the researcher ensured that the chairs and table were properly positioned (i.e. chairs were put in a circle to facilitate discussion and ensure that all participants and interviewers could see each other. Refreshments were provided prior to the start of the FGD. The researcher welcomed all participants, introduced the interviewers and note takers. All participants also had an opportunity to introduce themselves. The researcher then explained to the group about confidentiality, their right to withdraw and the FGD confidentiality binding form that was provided to participants at the end of the previous week's training session. The purpose of the digital voice-recorder was explained and the recorder was put in the middle of the group. The researcher emphasised the purpose of the study and gave an opportunity to clarify any questions from participants. The structure and process of the FGD was explained to the group with the FGD interviewer taking over afterwards.

The interviewer then proceeded with an ice-breaker activity to make them feel comfortable and relaxed. By creating this atmosphere, the researcher aimed to create a space for participants to feel free to give feedback without feeling under pressure or the need to hold back on e.g. negative feedback of the tool. The interviewer continued the session by asking the open-ended questions, followed by a refreshment break mid-way through the session, and then the final set questions, points for clarification, questions from participants and summary of the session. The interviewer closed the FGD by thanking all participants for their

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

participation in the study and ensured the collection of all signed consent and confidentiality binding forms.

The researcher met with the note takers after the FGDs to discuss and review observations and notes made from the FGDs. The meeting with the note takers took place 1 week after the FGDs at LGH CAMHS unit. The note takers took responsibility to take notes on the non-verbal content, facilitation style, main points of discussion and dynamics within the group. Note takers have extensive experience and clinical qualifications in group facilitation with adults. The researcher and note takers compared and discussed the observations made during the FGDs. This allowed the researcher to get a different perspective from the FGDs as results and feedback can be interpreted differently, encouraging greater objectivity of the results.

The language used was English and very little jargon was used. Although participants attended the training 1 week before the FGD, asked questions throughout and at the end of the training, as well as being provided a hand-out with the actual tool to scrutinise during the week prior to the FGD, participants still had clarifying questions about the tool or would forget the purpose, flow or scoring of activities. The interviewers were able to answer and reflect as they also attended the training. A contributing factor for various HCW's asking clarifying questions can be attributed to the fact that they have not all been trained in assessment and screening tools during their training and they don't conduct formal screening or assessments on a daily basis.

UNIVERSITY of the
WESTERN CAPE

3.13 Data Analysis

A thematic analysis approach was used to analyse the data. Thematic analysis is a method that can be used to identify, analyse, organise, describe and report themes found within a data set (Braun and Clarke, 2006). The themes then allow for interpretation and give meaning to data. The FGDs were transcribed word for word by a certified translation company. After receiving the transcriptions, the researcher conducted a quality check on transcripts and filled any gaps.

The transcriptions were read a few times and coded for themes (See Appendix 4). The researcher met with both note takers to review the notes and discuss the codes and identify themes. The researcher first printed the transcripts and thereafter manually coded the transcripts on the side of the paper. Broad categories were also identified. Phrases and words that occurred in the categories were also identified and assigned a code. These identified categories were used for interpretation. The descriptive data was then entered into an electronic version using Open Code version 4.0 and categorized into themes emerging

http://etd.uwc.ac.za/

from the analysis. The transcripts were then read and re-read to identify emerging themes. Mnemonic coding was used for quick and easy reference to the themes.

3.14 Validity and trustworthiness

Rigour in qualitative research can be ensured through the systematic research design, data collection, interpretation and collection (Mays and Pope, 2000).Triangulation is one of the procedures that contribute to ensure validity in qualitative research. The researcher applied source triangulation which ensured validity through searching and comparing the results from multiple sources (Creswell and Miller, 2000). This was done by meeting with the note takers to discuss findings to ensure that coding and interpretations are accurate. Quotes were included in the write up to demonstrate and verify findings. This study included HCW's from different disciplines and levels. The various disciplines embody their own disciplines' philosophies, models and intervention approaches.

The researcher ensured credibility by having the transcription of the FGDs done verbatim by a reputable translation company. Credibility signifies the trustworthiness of the results (Tracy, 2010). Note takers took responsibility for taking notes during the FGDs to record details of non-verbal behaviour e.g. body language that was not captured on the digital voice recorder. Facilitators (interviewers) of the FGDs applied member checking throughout by reiterating, clarifying and validating participants' responses and feedback during the sessions. This was done to assist in validating the accuracy in understanding the participants' perceptions of the tool.

UNIVERSITY of the
WESTERN CAPE

3.15 Ethical Considerations

The study protocol was approved by the Research and Ethics Committee of the University of the Western Cape (BM17/10/18). The researcher then requested permission from the Western Cape Department of Health and the Lentegeur Psychiatric Hospital Ethics Committee to conduct the study at the Lentegeur Child and Adolescent Mental Health Unit (LGH CAMHS).

Once all approvals were obtained, the researcher provided interested participants with information letters outlining the purpose and intent of the study (See Appendix 5: Participant Information Letter). The information forms, consent forms and FGD confidentiality binding forms were explained and handed out at the academic training session and participants who were willing to participate, submitted these forms to the researcher at the FGDs. This allowed participants to read through the information and content during the week thereafter

http://etd.uwc.ac.za/

to allow them to make well informed decisions to partake or not partake in the study. Participants were informed on the information sheet that should they experience any discomfort or distress during the sessions, they would be immediately supported by the researcher and a necessary referral would be made to a suitable professional for further intervention and support. Information sheets highlighted the use of a digital voice recorder during the FGDs. Participants were informed that their participation is voluntary and they were free to withdraw from the study at any stage.

Participants were provided with consent forms to sign once they decided to participate in the study (see Appendix 6: Consent Form). Participants were provided with refreshments.

The researcher ensured confidentiality and provided the participants with a FGD confidentiality binding forms to sign (See Appendix 7: Participant Confidentiality Binding Form). Each participant was allocated a unique ID which was also applied during the coding process.

No names were used during the transcriptions which were anonymous. Once all transcriptions were completed the voice recordings were deleted from the digital recorders. Consent Forms and binding forms were stored in a locked cupboard at the researchers LGH office. The information was stored in an electronic folder on a password protected PC.

3.16 Study limitations

Through the use of FGDs the study may be limited in not getting more detailed and in-depth reflections from the individual participants as the discussions flowed in the direction of other participants as they gave feedback. Participants may have been hesitant to oppose the views of others in the group.

Another limitation is that the researcher was unsuccessful in recruiting sufficient number of HCW's who have not been formally trained and who only work at PHC level. Only one non-formally trained HCW attended. One of the FGDs had only two participants which may have limited the breadth of the discussion.

The participants were heterogeneous and diverse in their specific clinical background, discipline, years of experience and training which they may have received. Depending on their exposure or lack thereof and knowledge about mental health, HIV and the impact it may have on cognitive functioning, their responses may be limited to the possible use and impact the development of the tool may have.

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

The participants are representative of different disciplines and backgrounds and their approach and philosophies may differ. Some HCW's for example the social workers, nurses and drama therapists do not conduct cognitive assessments in their scope of practice. Their knowledge and understanding in the manner in which the cognitive assessments are done and approached may be limited and influence their understanding of the tool and its implementation. The 1 training workshop prior to the FGD on the QPNST may not have been sufficient for HCW's who do not have much experience or training in cognitive screening thus impacting their responses.

However, their contribution is still valuable as it provides the researcher with a greater understanding regarding the approach and level of understanding of HCW's who do not have a background in conducting cognitive assessments as the knowledge gained can inform future revisions to the QPNST. The researcher first printed the transcripts and thereafter manually coded the transcripts on the side of the paper. Although the researcher met with the note takers to discuss and reflect the codes, with only the researcher doing the coding, it may have resulted in the researcher emphasizing specific themes and not identifying themes from a broader or other perspective. The framework by Slade *et.al* (1999), used to measure feasibility of outcome measures, which the researcher used as a guide to reflect on the QPNST's feasibility, needed to be adapted to reflect nuances in the setting. The measure of being relevant (using terminology that is familiar), included in the framework does not include equipment (Slade, Thornicroft and Glover, 1999). The researcher needed to adapt the framework and included equipment as participants highlighted equipment that is familiar as a measure indicating that it fits the description of being relevant. Task shifting and task sharing was another feature that is not included the framework, but was included by the researcher as it embodies brevity, acceptability, relevance, availability, valuable and simplicity. These measures enable task shifting and task sharing as participants highlighted that different health care professionals can use it and they perceive it as valuable.

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

CHAPTER 4

RESULTS

This study aimed to explore perceptions of the feasibility of the QPNST for HAND screening among perinatally HIV-infected children aged 5-10 years in a routine PHC setting.

This chapter presents the main findings of the study. The main characteristics of the participants followed by descriptions of how HCW's perceived the tool are described. The key themes that emerged include:

1. Creative nature of the QPNST
2. Ease of implementation into routine health and non-health services
3. Context sensitive nature of the tool
4. Recommendations to the functional composition of the QPNST

4.1 Demographic characteristics of participants

The characteristics of attendees by discipline are shown in table 1.

More females (n=17) than males (n=3) participated in the FGD's. The number of years of professional health service experience varied for each participant: it ranged from 3 months to 28 years of experience in the tertiary setting and 1 year to 11 years in the district (PHC) setting. Years of experience of participants working in mental health or psychiatry ranged from 3 months to 28 years. All participants had work experience in both the adult and paediatric patient populations.

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

4.2 Overview of key themes:

Feedback generated from the FGD's was varied but several themes were common across the groups. The key themes emerging from the discussions included:

1. Creative nature of the QPNST
2. Ease of implementation into routine health and non-health services
3. Context sensitive nature of the tool
4. Recommendations to the functional composition of the QPNST

Each theme consists of sub-themes (Table 2) and will be discussed in further detail below. Participants' feedback is detailed through quotes relating to the themes and sub-themes below.

Table 2: Themes and Sub-themes:

Themes	Sub-themes
Creative nature of the QPNST	Playfulness
Ease of implementation into routine health and non-health services	Accessibility to all cadres of HCW Complementary to current screenings and assessment processes Facilitates referrals and identification of at risk children
Context Sensitive	Context applicability and cultural relevance
Recommendations to the functional composition of the QPNST	Orientation task Comprehension/Language task Trail making task Instruction guide and Tool layout Completion time Equipment alternatives/replacement and maintenance availability General feedback on activities in QPNST

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

4.3 Creative nature of the QPNST

Participants expressed their views on the colourful and playful nature of the QPNST. These views are described below:

4.3.1 Playfulness

Some participants highlighted that the QPNST does not feel like a test or look like a test and children may even think that they are playing whilst the test is being conducted with them.

"It's a very plain tool, so when you asses a child, you don't want them to think okay, we are doing a test, and this is exactly what this feels like. It doesn't look like a test. So the child will be thinking oh, we're just playing around. So, I like that aspect of that". (Occupational Therapist, female)

The fun and appealing nature of the QPNST which is attractive to children, without them realising that they are being screened for deficits was expressed by participants. Various participants reflected that the children could relate very easily with the QPNST as it is colourful, hands-on, child-friendly and easy to understand.

Figure 2: Picture of toys in the QPNST

"Just in terms of general, I agree, user-friendly, and also the bag of toys is quite appealing. I like the colourful, hands-on approach". (Child Psychiatry registrar, male)

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

Many participants described the toys as appealing and felt that children will identify with the toys used in the QPNST. (See Figure 2)

"I think the tool is child-friendly and it is also user friendly, I like the toys that are there and those beads and those animals and blocks. I think it's going to be a tool, a screening tool that will be easy to use, and also children will also be able to identify with the tool, and will be able to use it". (Professional advanced speciality nurse: (psychiatry), Female)

One participant suggested the QPNST can be used as a playful method to conduct a Mental State Exam (MSE).

"Can I also just say I don't know if you could use it like that, but I think it would be nice to engage with the child and kind of do the MSE, like in a playful way? So testing a few things, because sometimes you know, what do you talk about? So, I think that's the benefit". (Child Psychiatrist, female)

4.4 Ease of implementation into routine health and non-health services

The ability of the QPNST to be used by varied types of professions involved with children from clinical to non-clinical and how it can benefit the system was commonly expressed.

4.4.1 Accessibility to all cadres of HCW's

Participants shared that they felt the tool was applicable for all healthcare professionals:

"But in general, it's very user friendly. It can be used by anyone, irrespective of whether you are a specialist or a generalist, or you are just a novice, but the tool is useable ". (Professional advanced speciality nurse (psychiatry), female)

"A large bulk of healthcare is provided by home-based carers, so community based healthcare workers, and they would be able to…….. It's very useful because again, they are the ones who visit the families. They would be able to take the tool with them on their home visits, would be able to very quickly administer the tool, and then be able to get help or access the services for the child". (Clinical psychologist, female)

Another participant highlighted how the QPNST could be used outside healthcare facilities (i.e. the education sector) as a point of entry into the clinic. Specifically referring to how teachers can use it as well. Furthermore, several participants highlighted how teachers, including caregivers would be able to administer the tool.

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

"It's also very helpful, for example, I could see how a teacher would be able to use this as well. That could be the entry point into accessing help at clinic level". (Clinical psychologist, female)

"So, if you do it like that, you'd be able to roll it out to teachers, to caregivers of every level". (Clinical social worker, male)

Task shifting was identified as a measure of equipping HCW's with a tool they can use to screen.

"I also think that just in terms of, if we are thinking about task shifting and task sharing, which is the way that the department seems to be moving, I think a tool like this is very helpful in that way, because it allows different professions and different levels of professions who work in the primary healthcare setting, which is the first port of call into healthcare, it provides those professionals with a tool that they can use to assess, and anyone can use it". (Clinical psychologist, female)

4.4.2 Complementary to current screenings and assessment processes

Various clinicians highlighted how the QPNST can complement and support current assessments that are being used in clinical practice and how through this process it will aid in the referral of patients.

One participant stated how the availability of a tool such as the QPNST can assist her when doing clinical interviews with patients.

"Yesterday I saw a child in the HIV study, we were doing psychiatry where I wished I had something that evaluates some of his cognitive abilities, because already I could sense, I don't know if there is a problem here, but I can't say whether, how, just on the clinical aspect. But I couldn't quantify it, just from doing a clinical interview in terms of what is wrong, and I thought this would have been nice to see. Yes, he wasn't a child; he was 12, or 13 soon. So ... I thought that would have been nice, just to give some composite idea of this." (Child psychiatrist, female)

Some participants articulated that the QPNST is helpful because it can be done by non specialist health workers and can give an indication if further assessment is needed, thus reducing waiting times at referral levels.

"Because other professions can then also do it. That is the beauty of it, because with the more in-depth assessments, there are only a few professions that can do it, which causes

http://etd.uwc.ac.za/

the waiting list in the first place. So now other professions can screen and not waste the time of the people or if I don't know if waste of time is the right word, but not clog the system up further by making the waiting list longer for kids that may or may not need further assessment". (Clinical social worker, male)

During the discourse, participants compared the QPNST to standardised tools currently used in their daily clinical practice to assess or screen for cognitive challenges or difficulties children might be experiencing such as the SAIS (South African Individual Scale). The SAIS is an intelligence scale which is administered individually. The QPNST was described as less expensive compared to the SAIS which is a larger assessment tool. Participants expressed that it would be good to have the QPNST available in the clinics as clinicians do not have assessment tools at that level and that it may be more affordable.

Some participants described that children with difficulties are picked up later and would constantly repeat classes due to lack of screening tools. One participant stated that the tool can assist with management of scarce resources, as children are often referred for large assessments and amid long waiting lists. Participants indicated that this tool could assist in assessing which children to prioritise for further assessment and intervention.

"So, also to manage resources, in not every child gets them, or the SAIS.....this would help to kind of look at exactly who really needs it..." (Drama therapist, female)

"They're not expensive. That is nice, because for those of us who have worked in the clinics, you don't get a SAIS in the clinics. You don't have assessment tools in the clinics". (Clinical psychologist, female)

"I think for me it would also be useful, because we often get lots of referrals for younger children to do a SAIS. So what would be useful is to do this as a screen to see whether the SAIS is the best or appropriate assessment to use. Or whether there is another tool we should be using, if a child needs a more comprehensive assessment". (Clinical psychologist, female)

4.4.3 Facilitates referrals and identification of at risk children

Participants expressed their thoughts on how the QPNST can be used as a basis for referral and further support.

"If they then have this screening tool, use the screening tool, at least they will refer appropriately. They will make appropriate referrals, because they just refer anything". (Professional advance speciality nurse (psychiatry), male)

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

One participant affirmed this by saying the access to the psychiatric registrar may improve as well with this referral process.

Participants questioned the referral process after administration of the tool. They queried whether they must be referred to the school psychologist or OT at the clinic and questioned whether they will be trained in the tool.

"…….I was just wondering, when you finally assess, do you then with the referral say what, which area, and then who do you refer to? Because there isn't always like back up in the clinics. Is it the school psychologist, to alert them, OT at the clinic, and then will they kind of also be trained in this?" (Child Psychiatry Registrar, female)

Participants highlighted that the tool provides a method for children with difficulties to be identified.

"I think one of the things we struggle with is children with any potential difficulties not being identified. For me it is a way to identify some children who might have challenges". (Child Psychiatrist, female)

".....The tool allows for easier identification of the needs of the child and justification of the need for referral for further assessment and intervention." (Professional advanced speciality (psychiatry) nurse, female)

One participant identified that the tool would assist in discerning between whether the child has a cognitive or an emotional difficulty.

"For me, it would really be about being able to understand whether this is a neurocognitive difficulty or an emotional difficulty. It would at least give me an indication which sometimes can take a long time to establish." (Drama therapist, female)

4.5 Context applicability and cultural relevance

The different contexts and settings where the tool may be used were highlighted by various participants and how relevant it is for children to relate to.

Below is some feedback received from participants.

"First of all, it's appropriate for South Africa, and especially from the rural point of view. In rural areas it can fit, because they don't have those fancy things, so they will be able to identify some of this. They can relate to some of the objects that are in the tool". (Professional advanced speciality nurse (psychiatry), male)

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

The QPNST's ability to be used in resource limited settings was also highlighted.

"And you can use it in any setting. So even if you have a clinic that doesn't have resources, so that is what I found amazing about it". (Drama Therapist, female)

"I think maybe just from my side; my impression is that the tool is very sensitive to the culture and the context in which we work". I think I use the SAIS the most and I think if I just think about some of the items on the SAIS in terms of vocabulary, its terms that our children wouldn't be familiar with, and they often struggle with. So the nice thing about this tool is that it's sensitive to that. It's items that our children are familiar with". (Clinical psychologist, female)

Participants expressed how the tool can be useful in different settings and compared it to its possible friendliness for the adult sector. One of the participants described her experience working in an adult male environment and how difficult it was to conduct neuropsychological assessments or assessments to determine intellectual functioning due to no levels of literacy. The participant She compared it to the MOCA (Montreal Cognitive Assessment), an assessment used to determine cognitive functioning. The participant compared the practicality and appropriateness of the tasks in the QPNST to the tasks in the MOCA.

A question around translation of the tool was raised by one of the participants.

"My question is will the test be in different languages? So, say for instance you go into the community, let's say in Eastern Cape, the majority speaks isiXhosa and so will the tool be available in isiXhosa?" (Professional advanced speciality nurse (psychiatry), female)

UNIVERSITY of the
WESTERN CAPE

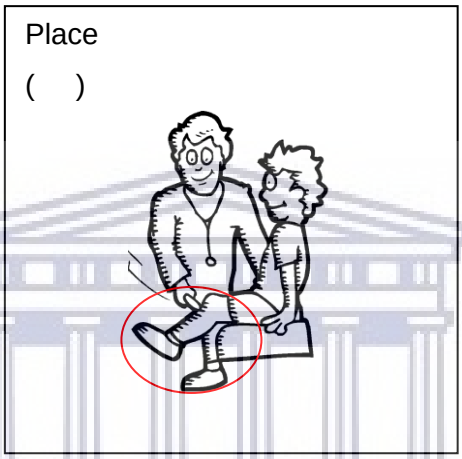
http://etd.uwc.ac.za/

4.6. Recommendations to the functional composition of the QPNST

In all FGDs, participants expressed their views on the activities and the layout of the tools, and provided suggestions to improve the tool.

4.6.1 Orientation task of the tool

Some participants expressed their observations on the expected outcomes for each activity within the QPNST.



"Can you tell me where are you now"

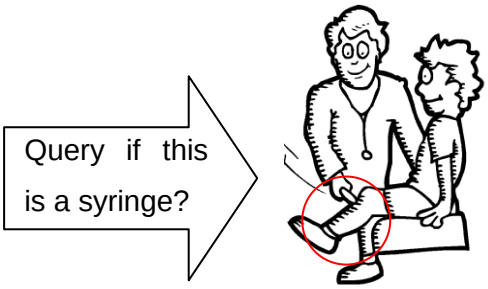
The orientation task of the QPNST consists of 3 components Night/day, Time and Place. The component focused on Place requires the child to answer the question *"Can you tell me where you are now?"* by looking at the picture above. One of the participants expressed that although he can see that it is a stethoscope (circled in red in picture above); he still questioned whether a child would be able to see it.

"Maybe we can consider putting another picture which can be recognised almost by any child, because I see there is a stethoscope, but it may just look like a zip or whatever if you look at this picture. The child might not understand what the person is doing. It may look like hitting, you see?" (Professional advanced speciality nurse (psychiatry), male)

He went on to state that it may look like a zip and that the child might not know. He did ask for re consideration to be given to the same picture as he questioned whether a child from a rural area would be able to identify that it is a doctor with a patient in the picture.

Another participant also queried the expectation of the child being screened and how the child will be able to distinguish between objects in the picture below.

UNIVERSITY of the WESTERN CAPE
http://etd.uwc.ac.za/



"Then also the place, do you want them to say they are in hospital? Do you want them to say that they are in…? Also, are they going to know that this picture is I in hospital? Is this a syringe or maybe you now, just a house with a cross on, to indicate that this is a hospital"? (Drama therapist, female)

In addition to the above, giving the child an opportunity to choose between boy, girl or an adult person in the above picture was recommended.

"Maybe you can put a picture there that the child can identify. Maybe you have a boy, girl, a young person, older person, then you can see okay, he is related and so on, he is this. Or else, yes, it can be boy or girl, adult person, so that he can choose which one he is or she is. Yes, I think that is appropriate, then it would speak to that person, or relation to that person". (Professional advanced speciality nurse (psychiatry), male)

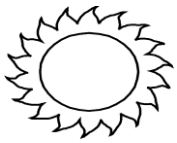
One participant raised a concern about gender identity.

"But to just add a little twist to that thing. Then there is gender ID or gender neutral. If we can just take that into account. At least they choose something". (Child Psychiatrist, female)

Some participants compared the "Night/day" and "Time" components of the orientation activity. See below picture for the components which the participants compared.

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

Orientation Materials: None Instructions: "Is it day or night?" "What day is it today?" "Can you tell me where you are now?"	Night/day ( ) 	Time ( ) 

"I also think the second picture; it's confusing, because the first picture says day and night hey? So that's already time of day. The second, you have a rainy day and then you have the sun, because you say what day is it today? Maybe what's the weather or something like that, because of the picture?" (Professional advanced speciality nurse (psychiatry), female)

4.6.2 Comprehension and Language task of the tool

Some participants questioned the third story card (mom playing with the baby boy) in the comprehension/language task. See picture below:

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

Comprehension/ Language Materials: 3 picture cards in the kit Instructions: (take out the first picture card) "Look at this picture. What is happening in this picture?" *Repeat for picture 2 and 3	 ( ) ( ) ( )

UNIVERSITY of the
WESTERN CAPE

"One other thing, the social message, language and comprehension, the first child I think is fine, the child can see that….. The second one is playing with the ball. Then you go to the third one. Maybe that is the mommy and the child, but I can't really figure out what is going on there. So if you think of the child, and also the difficulty, because, okay, yes, the mother and the child…What is this next to him? Is it playtime? So, it's a bit confusing". (Professional advanced speciality nurse (psychiatry), male)

One participant stated that the child may not understand what the person is doing and it might look like the child is being spanked (male nurse).

Another possible challenge of the tool in its current form in terms of its accommodation of children with special needs was highlighted. Making adaptations to the tool and how it is used for children with special needs was alluded to. Examples given included the cards used in the comprehension/language task (depicted in picture above) which may prove difficult for a child with a visual impairment as the current pictures are printed in black and white and not

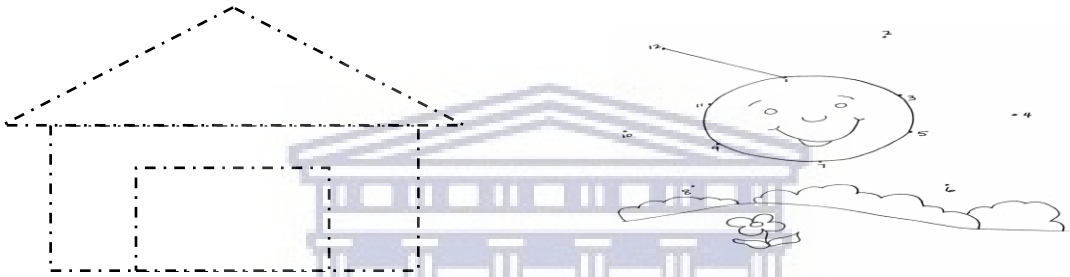
http://etd.uwc.ac.za/

in colour. A request was made to consider replacing the task or restructuring the task, as well as considering the support of a translator when needed.

"So, I'm just thinking how that might be challenging if a child does have, for example, some of the things like the cards maybe, if they have partial visual impairment, then it might be a bit challenging for them So maybe other ways of, or replace that task, or to structure it in a different way." (Occupational therapist, female)

4.6.3 Trail making task

A third task which participants provided feedback on was the trail making task. It was questioned whether the sun is easier to draw than the house.



"Actually, on that, but I mean, this is really not my area of expertise, but when I looked at that, the sun looked a lot easier to draw than the house. I was kind of thinking which would be easier for me, the sun or the house". (Drama Therapist, female)

UNIVERSITY of the
WESTERN CAPE

4.6.4 Instruction guide & Tool Layout

The structure of the screening tool and order of activities within the tool was extensively discussed by participants. Providing context was highlighted as important. Suggestions included providing more details on: why the tool was developed, purpose of the tool. A key suggestion was to incorporate a rationale and step-by-step description to guide clinicians on how to correctly conduct the screening, activity completion and expectations for each activity.

"A kind of rationale of why this is important, and then get peoples thoughts, like a very short reference list, if they want to go and see more". (Drama therapist, female)

Participants indicated a need for more details to be included such as "what kind of child we use it for, what would be the indicators" and "what to use it for".

http://etd.uwc.ac.za/

Many participants expressed their views on ensuring that a standard and step-by-step instruction guide is provided to assessors when attending training on the tool.

One participant suggested how demonstration through video's can be more effective.

"In terms of training, we can maybe make ....., say for instance a video, showing how to do it. I think many people grasp it much easier when they see someone physically doing it, than reading it". (Occupational therapist, female)

Participants expressed their concern regarding the equipment and ensuring that the tool is standardised.

"*Especially if you standardise it. So, if you are testing and it's standardised to this kit, those parameters must just be put in. This is what's important, because this is what we standardise it for, with the list, because then you can just take that and again, go and buy that stuff, or the kit, if you need it".* (Clinical social worker, male)

Participants recommended that despite the information already being simple, the information needs to be explained such as the outcomes, measurements even "simpler".

"Just one more thing, just a suggestion also, with your instructions in the exact same vein, I would give the instructions on what needs to happen in the activity, and then add the wording afterwards, so that the person who is looking at the instrument doesn't have to extrapolate from the question, what he needs to do. So, like the recall, so it says materials, container with toys in it, and then the instructions are, remember this box, what is in it, which is the wording you will use with the patient"? (Clinical social worker, male)

Participants highlighted that the interpretation of the scores could be more simplified. Simplifying the interpretation of the scores without having to give context was another example shared by participants that could be more simplified.

4.6.5 Completion time

Participants had various questions and concerns on the concept of time and how it influences and may impact on conducting and completing the QPNST.

Some participants discussed whether or not children must be given a time limit within which to complete the screen and others felt that a time must be given to the assessor to gauge how long it should take to complete the screening.

"I wouldn't put a time limit…..like you say its anxiety provoking". (Medical Officer, female)

http://etd.uwc.ac.za/

"Maybe you could just, after experience, kind of see how long it takes for an average child to complete the test, and then you can mention that to whoever is going to do the test. Let's say it takes about on average half an hour, then maybe if the parent knows it lasts more than an hour, then you can maybe decide to split it in two. I don't know, but yes, maybe just give a gauge on what to expect in terms of time". (Child Psychiatry Registrar, male)

Recording the time for completion was highlighted during the discussion.

"So I think what would be of value is doing it the way it is, but then recording how much time it took each child maybe to complete that section, maybe just how many minutes, so you get a sense of what the child needs". (Occupational therapist, female)

4.6.6 Equipment alternatives/replacement and maintenance availability

Participants cited the ease or difficulty with which equipment can be replaced or repaired and made suggestions towards ensuring durability of some of the equipment.

One participant made a suggestion to ensure durability of the small cards used in the tool.

"……, I'm only thinking of it now, maybe if the small cards with the emotions could be laminated. Just in terms of carrying it around and not replacing it as often, so that it would be a bit more…." (Occupational therapist, female)

Participants reflected on the equipment used in the tool. They raised questions on whether the equipment such as the blocks and beads used to screen would be easy to replace.

"So, we can think about how we are going to use those, and how easy is it to replace the blocks, because I think the plain ones may be hard to find, compared to the others ". (Child psychiatrist, female)

The question of replacing the equipment and who should be responsible when it becomes lost was also noted.

"So, you lose the beads or whatever, then the clinic could easily replace that. But at the end of the day, it should be the responsibility of the clinic who has it, to maintain the box, and keep it". (Child psychiatry registrar, female)

The effortlessness in transporting the tool in addition to the equipment not being too expensive to replace was expressed.

"Then the other nice thing about it is that it's transportable. You can easily transport it, and the items can be easily replaced if you lose them". (Clinical Psychologist, female)

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

The cost of replacement of equipment in the QPNST was highlighted.

"If you lose a part ...it's not going to cost you thousands of Rands to replace...." (Clinical Psychologist, female)

4.6.7 General feedback on activities in the QPNST:

One participant suggested a warm-up activity.

"I was thinking earlier, and ignore me if I'm talking nonsense, but it might be great to have a kind of warm-up activity, or a suggestion of a warm-up activity. Like, whatever might be age appropriate, to do before you start the actual assessment". (Drama therapist, female)

Participants questioned the blocks included in the kit and indicated that having numbers on the blocks or not may lead to confusion.

"Some of the blocks that were in the tools have got numbers and letters, and I think it might be of value maybe just to think about whether we need to get plain blocks or not, without the numbers, or if we are going to use the ones with numbers and colours, and also use those to see if the kids know colours or numbers." (Child psychiatrist, female)

One participant expressed that the QPNST covers a large number of components.

"In terms of activities, I found that even though it was short and brief, it still covers quite a vast factor of components". It assesses a very different..., various components. So, it gives you quite a nice overview of a child's function, even though it's so quick". (Clinical Psychologist, female)

UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

CHAPTER 5

DISCUSSION

5.1 Summary of results

This study aimed to explore HCW's perceptions of the feasibility of the QPNST for HAND screening among perinatally HIV-infected children aged 5-10 years in a routine PHC setting. The findings of this study indicate that with the lack of available neurocognitive screening tools, HCW's perceive the QPNST to be child-friendly and culturally appropriate. Participants found that the tool could be readily applied in a PHC setting by different cadres of HCW's, including education professionals, with minimal specialised training in mental health or in cognitive screening or assessment of younger children. Previous studies have found that factors including reduced time, cost and simplicity of administration have been identified as advantages of paediatric screening instruments (Kammerer, Isquith and Lundy, 2013). The current study results correspond with these features as the QPNST has been described as quick and easy to implement, with HCW's indicating that it could complement current standardised screening and assessment tools used in clinical practice. Suggestions to improve the tool included strategies to standardise format and layout. The majority of the participants expressed the importance for adequate training on the tool.

The importance of screening to assist in the identification of children at risk of developmental problems, despite the lack of internationally validated tools was highlighted by the South African HIV Clinician Society (Nassen *et.al,* 2014). This may be one of the first quick screening tools for HAND to be tested in South Africa for children aged 5-10 years and the results of this study provide important insights for the further development and scale up of the tool in routine practice.

5.2 A reflection on mental health tool feasibility

The six different characteristics proposed to measure feasibility of mental health screening tools are brief, simple, relevant, acceptable, available and valuable (Slade, Thornicroft and Glover, 1999). Below the findings of the study are contrasted with each characteristic used to measure feasibility as proposed by Slade, Thornicroft and Glover (1999).

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

5.2.1 Brief (looks short, easy to use)

A common theme of the QPNST being user-friendly and described as "perfect" for the PHC setting and its appropriateness for community level was emphasized throughout the FGD's. The IHDS is a brief screening tool that has been recommended to screen for neurocognitive deficits (2-3 minutes implementation), but its suitability to the South African context still needs to be validated (Vally, 2011). Compared to the IHDS, responses reflect the QPNST is more suitable to the PHC setting as the items are more relatable, relevant and known to the individual being screened.

The QPNST was described as short in length and quick to administer and easy whilst covering many components and providing a good overview of a child's functioning. These qualities are affirmed in the literature that recommends that simple HAND tools which can be quickly administered must still reflect the characteristics of HAND (Bloch *et al.*, 2016). The current gold standard used to detect neurocognitive deficits is extensive and lengthy neuropsychological batteries, making it impractical for use in clinic settings (Janssen *et al.*, 2015). The simplicity, brevity and free availability of the QPNST are appealing features that can contribute to HCW's feeling less overburdened. This is a positive feature as neurocognitive batteries are not feasible in LMICs due to their length, expensive costs and overburdened health systems (Phillips *et al.*, 2019a).

When screening younger children, it is important for HCW's to be mindful that time-consuming and complex tools can cause fatigue in children and may be impractical to implement, taking into account parents work schedules and time available for follow-up appointments (Kammerer, Isquith and Lundy, 2013). With time being an important factor as it can influence a child's performance in a test, participants' description of the QPNST being short, brief and easy appears to be a positive attribute that combats time constraints. However, only with the implementation of the QPNST across various settings a more accurate indication of the duration of the test will be gained as there may be other environmental or child related factors impacting on time required to complete the test.

Lower cadre staff may find tools which are lengthy and complex to administer, challenging and impractical to implement in busy clinic settings (Boyede, Eley and Donald, 2016). Conducting neuropsychological batteries is time consuming, varying between 1-2 hours depending on their length (Singh, 2009). Compared to these tools, HCWs opinion is that less time is required to screen a patient and easier to implement, although it will have to be tested on children in order to confirm this. Time efficiency, convenience and practicality

http://etd.uwc.ac.za/

were some of the positive features highlighted by community care workers when they investigated the clinical utility of a mHealth developmental screening tool with families with children affected or infected by HIV (van der Merwe *et al.*, 2019). The results indicate that these features are reflected in the QPNST as it provides a quick measure to determine if comprehensive assessment is needed, assisting in resource management and the management of a waiting list. All of which can be beneficial to all levels of care. Studies have found that brief screening tools can address barriers of long waiting times due to waiting for specific service providers resulting in appropriate specialist assessment and intervention (Bloch *et al.*, 2016).

5.2.2 Simplicity (no training required, meanings of ratings is clear)

Simplicity is another characteristic to determine feasibility of a mental health screening tool (Slade, Thornicroft and Glover, 1999). Participants found the QPNST is simple to use. Nurses and clinical psychologists who have experience working with home based carers (HBC's) reflected that the QPNST is *"simple enough"* for the HBC's to *"be able to utilise"* when conducting home visits. Social workers shared that despite their lack of specialised training in psychiatry that they would be able to use it. It has been recommended that screening tests used to detect mental health disorders should be quick and easy to administer and interpret (Kagee *et al.*, 2013). According to Bhana *et al.,* (2019), detection of mental health disorders can be facilitated by short and easy screening (Bhana *et al.*, 2019). Our findings indicate that the QPNST is in alignment with recommendations for local mental health screening tools.

UNIVERSITY of the
WESTERN CAPE

Although the results indicate that the QPNST is simple, it was more the professional staff who appeared to find it simpler to use, compared to staff with limited clinical training requesting more detailed instruction and guidance. Experienced HCW's highlighted the importance of simplifying the scoring system for lay HCW's. This is an important fact to be aware of as it is indicative of the training needed for non-professional staff. The importance of training and psycho-education of lay HCW's was highlighted in the PRIME Policy Brief 3 which looked at human resources in mental health and how it can lead to early detection and improved intervention (Kakuma *et al.*, 2011). Enhancements of the tool suggested by participants include having a formal, standard step by step layout, supported by an instructional video to provide practical hands-on demonstration with the scoring included. Together, these findings underscore the importance of intense and ongoing training, supervision and support of HCW's, particularly lay HCW's in the implementation, roll-out and scoring of the QPNST. Content of the training should include details on what kind of child the QPNST is used for, indicators, scoring and components assessed as suggested in

http://etd.uwc.ac.za/

the FGDs. This can be beneficial as HCW's will learn more about HIV and cognitive development.

5.2.3 Relevant (accords with clinical judgment, no jargon)

The characteristic of relevance refers to terminology being "normal", relevant and familiar to the patient and staff (Slade, Thornicroft and Glover, 1999).

Participants' backgrounds in terms of exposure to different socio-economic, rural and urban areas, encouraged a dialogue on the "vocabulary" and task content used by comparing the QPNST to bigger assessment tools currently used in practice. Participants expressed that they have found that terminology used in the larger tools is not appropriate as children find it difficult to identify with, as opposed to terms used in the QPNST that they found appropriate and sensitive to the South African context and culture. Age, education and culture have been indicated as factors that affect other cognitive screening tools, including the MMSE (Tombaugh and McIntyre, 1992). The MOCA, a test currently used to screen for neurocognitive impairments in HIV-infected patients, uses less familiar terminology including camel and rhinoceros in the language component (Vally, 2011). Velvet, another term used in the MOCA, is also not used on a daily basis in the South African context. However, as most tests have been developed and standardised for higher income countries, emphasis have been put on importance of choosing more appropriate tests for the local context (Kammerer, Isquith and Lundy, 2013). This study results partly support this as participants felt the QPNST is more sensitive to our context; therefore, children would more easily identify and know it as it is familiar to them. However, this feedback is limited as this study did not include testing of the tool on children and can only be substantiated when feedback and insight is gained from children who have undergone testing on the QPNST. The discussions generated detailed feedback and recommendations from participants.

Although equipment is not one of the characteristics of relevance used to measure feasibility, participants expressed how children can relate to some of the objects used in the QPNST. Specifically referring to rural areas where access to elaborate equipment is difficult. This could help for the tool to feel less "foreign" and give children a sense of confidence and proficiency in their ability to identify objects, opposed to possibly feeling like a failure when they are not able to identify unknown objects. Materials used in tests are best if the child is familiar and able to recognize those materials (Kammerer, Isquith and Lundy, 2013). Some participants substantiated these findings by indicating that they come from rural areas, giving them a better perspective in identifying whether or not the equipment and vocabulary is

http://etd.uwc.ac.za/

appropriate for their context. This makes the QPNST fairer in terms of expectations of responses as the equipment and vocabulary used are familiar to their context and known to the child. These terms are used in their everyday living environments indicating that as HCW's, they are able to relate to the content, terminology and equipment in the QPNST.

5.2.4 Acceptable (acceptable to professions, flexible administration)

This characteristic refers to staff and patients' acceptance of the assessment (Slade, Thornicroft and Glover, 1999). For staff, the assessment should not duplicate information gathered and for patients the assessment should still be probing but not obtrusive and the administration should be flexible**.** Lay and experienced staff was unanimously accepting of the QPNST as they highlighted the contribution it brings in assisting and complementing other current assessments and interviews.

The study indicates HCW's finding the QPNST appealing, user-friendly with colourful toys, therefore children may perceive it as playing instead of being screened or "tested" for deficits**.** Play has been identified as a fundamental part of childhood which also facilitates learning which is evident in preschool and educational settings (Lynch and Moore, 2016). If play is what children do daily, engaging in the QPNST may thus not be as intimidating to the child being screened; making it less obtrusive, whilst still gaining an indication of the child's cognitive functioning. Conducting clinical interviews with children and adolescents who may have experienced trauma and challenges in life, to determine a child's functioning or their mental state can sometimes be quite difficult, resulting in therapists needing to use their own creativity. Younger children need time to trust unfamiliar adults and teenagers may be anxious of being judged requiring HCW's to use different methods of communication to gaining information instead of just talking (Rey and Martin, 2013). The user-friendly characteristics enable children to easily identify with the QPNST, resulting in it being more age appropriate for children. This study highlighted how the QPNST through a more playful approach provides flexibility when gathering information similar or identical to the components included in other assessment processes such as the MSE.

Although participants indicated that the child being screened may experience more a sense of play, whilst being screened, it does not give a true reflection from the patient's perspective as this study did not include a process of implementation and evaluation of the QPNST.

The participants' feedback was broad and unanimous on the user-friendliness of the QPNST to different cadres of HCW's across different levels, including the PHC and community setting. This may be attributed to participants being from different professions and backgrounds, ranging in various skills levels and training. Participants reflected on their own

http://etd.uwc.ac.za/

experience of working in a MDT at community level, how other community based workers and various levels of HCWs will be able to use the tool. It has been recommended that integrated PHC systems should develop and test approaches that use CHW's for detection of psychiatric disorders (Kagee *et al.*, 2013). Effective delivery of mental health services, including diagnosis and treatment in PHC context have been demonstrated, by ensuring the development of non-specialist HCW's through training and supervision (Kakuma *et al.*, 2011). This non-specialist HCW's includes nurses, social workers, occupational therapists and family physicians. HCW's representing these non-specialist cadre groupings were present in the FGDs and indicated that they would be able to implement the tool, affirming how they can contribute to effective mental health service delivery at PHC level. Depending on the different HCW's training and exposure to working at different levels, areas and possibly provinces, it may influence their response to the tool. For example, HCW's working in or who have had experience working in resource poor settings may find the tool more valuable compared to HCW's who have worked or are working in more resource privileged environments.

The HCW's feedback stemmed from factors including their own experiences of lack of training and lack of availability of assessment resources at PHC level. These factors possibly influenced their responses as it would allow them access to a screening tool as a resource and equipping them with knowledge and insight, giving them a sense of empowerment, contributing to their receptiveness and openness to accept the QPNST. This can broaden the skill and knowledge level of more HCW's in the field of HIV, cognitive impairment and its link to psychiatry. It has been proven that non-specialist HCW's who have been trained by neuropsychologists have been able to conduct HAND screening in a 20-minute computerised CogState battery against a gold standard tool (Bloch *et al.*, 2016). Despite the QPNSTS not being a computerised tool, the study results correlate with feedback received from participants that it is possible for various professionals across different levels to be able to use the tool.

Participants indicated how home based care workers and social workers working in the community can use the tool to screen within a child's home environment. This approach was affirmed in a study where community care workers participated in a screening programme by using a mHealth (mobile health) tool in the home environment of parents and children, and reported feeling more knowledgeable about development and the importance thereof (van der Merwe *et al.*, 2019).

The acceptability of the QPNST to different HCW cadres can enable task shifting and task sharing as participants highlighted during discussions. Although task shifting and task

http://etd.uwc.ac.za/

sharing does not form part of the characteristics used to measure feasibility, it is an important consequence to their receptivity to the tool. Strategically, task shifting provides opportunity to address staff shortages (human resources) in HIV care and treatment offering high quality and cost effective care (Callaghan, Ford and Schneider, 2010). By having the QPNST available and being trained in implementing the tool, it can assist in alleviating the pressure experienced by specialists and can lead to a more efficient and cost-effective service delivery. However, some HCW's may need training and supervisory support for an extensive period to ensure they are fully equipped to implement the QPNST and to make appropriate referrals as needed. This is supported in the literature which indicated that an increase in the number of human resources, structured support and training were among a few other conditions which needs to be met for task-shifting to be perceived as feasible in LMICs among primary care service providers (Mendenhall *et al.*, 2014). Furthermore, several participants highlighted how teachers, including caregivers would be able to administer the tool, broadening the reach of the tool.

5.2.5 Available (free, can be photocopied)

Availability refers to the assessment being free, easily accessible and able to be photocopied (Slade, Thornicroft and Glover, 1999). The study indicates HCW's views that the QPNST is less expensive than other assessment tools used in clinical practice. With the HCW's expressing that the equipment of the QPNST is cheap, easy to replace and easily transportable, its affordability and versatility for resource limited areas was emphasized. Expensive materials are used to implement neuropsychological assessments in LMICs (Phillips *et al.*, 2019a). Lack of resources and financial limitations are key challenges that impede accessibility and detection of mental health problems among children (Esponda *et al.*, 2020). High cost is associated with purchasing western-based tools and their administration forms (Kammerer, Isquith and Lundy, 2013). An example of a tool used to describe this was the SAIS, which HCW's in this study stated is not available at PHC level, due to its high costs. With the lack of resources, limited finance and high costs of screening tools, the QPNST appears more affordable as it is low cost and can be photocopied for future use and dissemination. Although, the basic equipment of the toys need to be purchased by the clinicians using the tool, the toys are cheap and easily accessible as these can be bought locally. Overall, the affordability of QPNST appears to be an attractive feature for HCW's in routine PHC settings.

5.2.6 Valuable (low data entry overhead, meaningful feedback)

For an assessment to be deemed valuable for staff and patients, its results should be more

http://etd.uwc.ac.za/

comprehensive and detailed than previously (Slade, Thornicroft and Glover, 1999). The study results reflected participants' perceptions of the QPNST providing a tangible method contributing to detecting difficulties in the absence of available assessment tools at PHC level which will also facilitate more appropriate referrals. In addition the literature highlights that early detection of the HIV at risk child can capitalize on the effectiveness and use of intervention resources (Kammerer, Isquith and Lundy, 2013). It was evident from the results, that the QPNST was compared to other standardised tools currently used in clinical practice, including the SAIS. A lack of resources (tools) were identified as barriers for PHC staff to recognise and diagnose mental health problems (O'Brien *et al.*, 2016). Participants emphasized using the QPNST as a first step to screen prior to conducting a more comprehensive assessment. In daily clinical practice, children are identified to be assessed with very specific screening tools and put on a waiting list. Barriers to referrals from PHC practitioners to specialist service, included waiting times, lack of providers and available resources (O'Brien *et al.*, 2016). Evidence suggests that the longer a HIV-related neurocognitive impairment remains undetected, it can lead to negatively impacting on successful attainment in the socio-economic and occupational spheres of their lives (Phillips *et al.*, 2019a). The QPNST can contribute to facilitating referral enabling access to services. Early diagnosis was identified amongst other factors that can be facilitated through improved referral pathways (Pedrini *et al.*, 2015). Whilst this speaks to early diagnosis and start of ART for HIV-infected children and not specifically diagnosis of cognitive deficits, the latter cannot be addressed if a child has not been diagnosed, hence improvement of referral pathways can assist in earlier detection and decreased waiting times.

Although the QPNST can assist in referrals, a key question was raised in the FGD's querying the referral pathway which CHWS can follow once the screen has been completed. Currently there is no referral guide in the QPNST. This is an area that can be improved upon through the addition of a referral guide/protocol detailing where and to which profession children must be referred when deficits are identified. Through monitoring and evaluation, the true value of the QPNST can only be determined after a long period of implementation (more than 1 year) where the outcome of referrals, diagnosis and intervention can be quantified and justified.

Participant's reflected on how the QPNST can support and complement current assessment practices. Screening tools that have been used to assess HIV-related cognitive deficits include the MMSE, the HIV Dementia scale and the IHDS (Vally, 2011). These scales have been developed for the adult population, opposed to the QPNST which was specifically designed for children. The IHDS, MOCA and the cognitive assessment tool-rapid version

http://etd.uwc.ac.za/

(CAT-rapid) was not found to be adequate in screening for HAND with a recommendation that a full neurocognitive assessment be completed (Joska *et al.*, 2016). The MMSE similar to the QPSNT is brief to administer but has poor sensitivity and specificity to detect HAND (Hasbun, 2012).The QPNST can overcome this challenge as it includes components that screen for HAND and will take much less time to conduct than a neuropsychological battery and can be used to complement the current screenings once validated.

The y-IHDS which was adapted from the IHDS was able to detect major and minor ND in perinatally HIV-infected children, but when the results was compared to a smaller sample, it did highlight that the y-IHDS may not be able to detect subtle forms of ND (Phillips *et al.*, 2019b). The y-IHDS is also brief and inexpensive to administer, similar to the QPNST as it takes 5-10 minutes to administer. However the y-IHDS has been modified from the adult version of the IHDS and can be implemented with children aged 9 years and older into adolescence whereas the QPNST aims to detect all forms of HAND and is geared towards children aged 5-10 years, which can facilitate earlier detection and intervention prior to age 9.

Another tool which was developed to screen for developmental delay in HIV-infected children is the Red Cross War Memorial Children's Screening Tool for children aged 9-36 months was found to be sensitive to detecting developmental delay. (Boyede, Eley and Donald, 2016). Compared to the QPNST, the Red Cross War Memorial Children's Screening tool is brief, simple and can be implemented by lay HCW's. Despite the tool's sensitivity to detect developmental delay, children will still need to receive a full developmental assessment as it does not cover all cognitive domains affected by HIV, as opposed to the QPNST which aims to screen for all forms of HAND.

UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

CHAPTER 6

CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

Findings from this study indicate that the QPNST is feasible to implement in routine PHC settings. Results indicate that this tool is age-appropriate and has the potential to be used by various HCW's and can readily complement current screening processes within routine services. More importantly, this tool was favoured by HCW's for being brief, context specific and affordable. Implementing the QPNST will equip HCW's with a tangible resource which is child-friendly allowing different cadres of HCW's across different levels of care to screen for HAND leading to earlier detection and positively contribute to alleviate pressure and burden on the health system and HCW's. Although the QPNST must still be validated, it does show potential to be a screening tool that can enhance detection of HAND and thereby become a valuable resource in the field of public health prevention and promotion.

6.2 Recommendations

Based on the results of the study the following recommendations for further research, training and policy and practice are made.

6.2.1 Further research

UNIVERSITY of the
WESTERN CAPE

Further research is recommended to conduct qualitative studies with stakeholders, ensuring a broader group and larger sample in order to gain broader and more comprehensive feedback. This should include qualitative studies with CHW's (not necessarily professionally trained), CCW's and counsellor's working in the community which include CHC's and home visits. Although this study included HCW's from different disciplines and background, no counsellors participated in the study and it would be valuable to gain feedback from their perspective and experience. Training to use the tool should be conducted and feedback can be obtained via in-depth interviews (IDI) and/or FGDs. IDI's will allow for more in-depth reflection and questioning of participants.

Qualitative research with other stakeholders outside of the Health Department is recommended such as Educators and Social development service providers (social workers) to determine their perception of the QPNST after receiving training would be valuable.

http://etd.uwc.ac.za/

To conduct a study with children themselves via cognitive interviews using the QPNST to assess understanding. IDIs can be held with parents to determine difficulties that their HIV-infected child may be experiencing in the home environment as it may complement or inform information generated from the QPNST. To translate the QPNST into Afrikaans and Xhosa and conduct cognitive interviews to determine if children understand the tool. Using the results with the feedback gained in this study and other stakeholder feedback to refine the QPNST before engaging in a larger study (e.g. quantitative psychometric evaluation assessing the reliability and validity (content, construct, known-group) of the QPNST).

6.2.2 Policy and practice

It is recommended that an integrative approach to screening and protocols for screening during regular and routine visits in CHC's and as part of home visits to be incorporated into daily practice. Clear guidelines and protocols should be developed for referral and further management. Policy guidelines must be developed to include mental health and HIV training for community based services in order to broaden the scope for screening which can facilitate task shifting and task sharing. It would be important for policy makers to include all relevant stakeholders and ensure participatory process.

Training of nurses and HCW's (including social workers, HBC's, CCW's) who have no specialised training in HIV and mental health, specifically focused on children and adolescents is an important component to empower HCW's. This includes developmental delay and cognitive development. Nurses and HCW's (including social workers, HBC's, community care workers) need to be equipped with screening and assessment tools which are short easy and quick to administer with children and adolescents. These tests should be available for the MDT to use and not only dependent on one or two disciplines.

Training sessions and provide regular support and supervision should be conducted to guide intervention and support to children and adolescents. This will assist in decreasing waiting lists for an already overburdened health system.

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

References

Abubakar, A., Van Baar, A., Van De Vijver, F., Holding, P. Newton, C. (2008) 'Paediatric HIV and neurodevelopment in sub-Saharan Africa: a systematic review', *Tropical Medicine & International Health*, 13(7), pp. 880–887. doi: 10.1111/j.1365-3156.2008.02079.x.

Antinori, A,. Arendt, G,. Becker, J,. Brew, B., Byrd, D., Cherner, M., Clifford, D., Cinque, P., Epstein, L,. Goodkin, K,. Gisslen, M,. Grant, I,. Heaton, R,. Joseph, J,. Marder, K,. Marra, C,. McArthur, J,. Nunn, M,. Price, R,. Pulliam, L,. Robertson, K,. Sacktor, N,. Valcour, V,. Wojna, V. (2007) 'Updated research nosology for HIV-associated neurocognitive disorders', *Neurology*, 69(18), pp. 1789–1799. doi: 10.1212/01.WNL.0000287431.88658.8b.

Antinori, A., Arendt, G., Grant, I., Letendre, S., Muñoz-Moreno, J., Eggers, C., Brew, B., Brouillette, M., Bernal-Cano, F., Carvalhal, A., Christo, P., Cinque, P., Cysique, L., Ellis, R., Everall, I., Gasnault, J., Husstedt, I., Korten, V., Machala, L., Obermann, M., Ouakinin, S., Podzamczer, D., Portegies, P., Rackstraw, S., Rourke, S., Sherr, L., Streinu-Cerce, I., A., Winston, A., Wojna, V., Y., Azdanpannah, Y., Arbess, G., Baril, J., Begovac, J., Bergin, C., Bonfant,i P., Bonora, S., Brinkman, K., Canestri, A., Cholewinska-Szymanska, G., Chowers, M., Cooney, J. Corti, M., Doherty, C., Elbirt, D., Esser, S., Florence, E., Force, G., Gill, J., Goffard, J., Harrer, T., Li, P., Van De Kerckhove, L., Knecht, G., Matsushita, S., Matulionyte, R., McConkey, S., Mouglignier, A., Oka, S., Penalva, A., Riesenberg, K., Sambatakou, H., Tozzi, V., Vassallo, M., Wetterberg, P., Drapato, A'Assessment, Diagnosis, and Treatment of HIV-Associated Neurocognitive Disorder: A Consensus Report of the Mind Exchange Program', *Clinical Infectious Diseases*, 56(7), pp. 1004–1017. doi: 10.1093/cid/cis975.

Bhana, A., Mntambo, N., Gigaba, S., Luvuno, Z., Grant, M., Ackerman, D., Ntswe, E., Nomathemba, M., Petersen, I. (2019) 'Validation of a brief mental health screening tool for common mental disorders in primary healthcare', *South African Medical Journal*, 109(4), pp. 278–283. doi: 10.7196/SAMJ.2019.v109i4.13664.

Bloch, M., Kamminga, J., Jayewardene, A., Bailey, M., Carberry, A., Vincent, T., Quan, D., Maruff, P., Brew, B., Cysique L. (2016) 'A Screening Strategy for HIV-Associated Neurocognitive Disorders That Accurately Identifies Patients Requiring Neurological Review', *Clinical Infectious Diseases*, 63(5), pp. 687–693. doi: 10.1093/cid/ciw399.

Booi, T,. Moos, A,. Nassen, R. (2014) *'The development of a screening tool to detect HIV associated neurocognitive deficits among perinatally infected HIV positive South African Children'*,11-15 August 2014 presented at 21st World Congress of the International

http://etd.uwc.ac.za/

Association for Child and Adolescent Psychiatry and Allied Health Professions hosted by the South African Association for Child and Adolescent Psychiatry and Allied Health Professions (SACAPAP) in Durban South Africa.

Boyede, G., Eley, B. and Donald, K. (2016) 'Preliminary Validation of a New Developmental Screening Tool for Neurodevelopmental Delay in HIV-Infected South African Children', *Journal of Child Neurology*, 31(2), pp. 145–152. doi: 10.1177/0883073815585351.

Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, 3(2), pp. 77–101. doi: 10.1191/1478088706qp063oa.

Callaghan, M., Ford, N. and Schneider, H. (2010) 'A systematic review of task- shifting for HIV treatment and care in Africa', *Human Resources for Health*, 8. doi: 10.1186/1478-4491-8-8.

Clifford, D. B. and Ances, B. M. (2013) 'HIV-associated neurocognitive disorder', *lancet Infectious Diseases*, 13(November), pp. 976–986. doi: 10.1016/S1473-3099(13)70269-X.

Creswell, J. W. and Miller, D. L. (2000) 'Determining Validity in Qualitative Inquiry', *Theory Into Practice*, 39(3), pp. 124–130. doi: 10.1207/s15430421tip3903_2.

Eley, B. (2006) 'Addressing the paediatric HIV epidemic: a perspective from the Western Cape Region of South Africa' *Transactions of The Royal Society of Tropical Medicine and Hygiene*,Volume 100, Issue 1, January 2006, Pages 19–23, https://doi.org/10.1016/j.trstmh.2005.04.015

Esponda,G., Hartman, S., Qureshi, O., Sadler, E., Cohen, A., Kakuma, R. (2020) 'Barriers and facilitators of mental health programmes in primary care in low-income and middle-income countries', *The Lancet Psychiatry*. Elsevier Ltd, 7(1), pp. 78–92. doi: 10.1016/S2215-0366(19)30125-7.

Flisher, A,. Dawes, A,. Kafaar, Z,. Lund, C,. Sorsdahl, K,. Myers, B., Thom, R,. Seedat, S. (2012) 'Child and adolescent mental health in South Africa', *Journal of Child & Adolescent Mental Health*, 24(2), pp. 149–161. doi: 10.2989/17280583.2012.735505.

Hasbun, R. (2012) 'Screening for Neurocognitive Impairment in HIV Individuals: The Utility of the Montreal Cognitive Assessment Test', *Journal of AIDS & Clinical Research*, 03(10), pp. 3–5. doi: 10.4172/2155-6113.1000186.

Heaton, R., Clifford, D., Franklin, D., Woods, S., Ake, C., Vaida, F., Ellis, R., Letendre, S., Marcotte, T., Atkinson, J., Rivera-Mindt, M., Vigil, O., Taylor, M., Collier, A., Marra, C., Gelman, B., McArthur. J., Morgello, S., Simpson, D., McCutchan, J., Abramson, I., Gamst, A., Fennema-Notestine, C., Jernigan, T., Wong JGrant I. (2010) 'HIV-associated

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

neurocognitive disorders persist in the era of potent antiretroviral therapy: Charter Study', *Neurology*, 75(23), pp. 2087–2096. doi: 10.1212/WNL.0b013e318200d727.

Heaton, R., Clifford, D., Franklin, D., Woods, S., Ake, C., Vaida, F., Ellis, R., Letendre, S., Marcotte, T., Atkinson, J., Rivera-Mindt, M., Vigil, O., Taylor, M., Collier, A., Marra, C., Gelman, B., McArthur. J., Morgello, S., Simpson, D., McCutchan, J., Abramson, I., Gamst, A., Fennema-Notestine, C., Jernigan, T., Wong JGrant I (2011) 'HIV-associated neurocognitive disorders before and during the era of combination antiretroviral therapy: Differences in rates, nature, and predictors', *Journal of NeuroVirology*, 17(1), pp. 3–16. doi: 10.1007/s13365-010-0006-1.

Janssen, M., Bosch, M., Koopmans, P., Kessels, R. (2015) 'Validity of the Montreal Cognitive Assessment and the HIV Dementia Scale in the assessment of cognitive impairment in HIV-1 infected patients', *Journal of NeuroVirology*, 21(4), pp. 383–390. doi: 10.1007/s13365-015-0324-4.

Joska, J., Witten, J., Thomas, K., Robertson, C., Casson-Crook, M., Roosa, H., Creighton, J., Lyons, J., McArthur, J., Sacktor, N. (2016) 'A Comparison of Five Brief Screening Tools for HIV-Associated Neurocognitive Disorders in the USA and South Africa', *AIDS and Behavior*, 20(8), pp. 1621–1631. doi: 10.1007/s10461-016-1316-y.

Kagee, A., Tsai, A., Lund, C., Tomlinson, M. (2013) 'Screening for common mental disorders in low resource settings: Reasons for caution and a way forward', *International Health*, 5(1), pp. 11–14. doi: 10.1093/inthealth/ihs004.

Kakuma, R., Minas, H., Van Ginneken, N., Dal Poz, M., Desiraju, K., Morris, J., Saxena, S., Scheffler, R. (2011) 'Human resources for mental health care: current situation and strategies for action', *The Lancet*, 378(9803), pp. 1654–1663. doi: 10.1016/S0140-6736(11)61093-3.

Kammerer, B., Isquith, P. K. and Lundy, S. (2013) *Neuropsychology of Children in Africa*. Edited by M. J. Boivin and B. Giordani. New York, NY: Springer New York. doi: 10.1007/978-1-4614-6834-9.

Kitzinger, J. (1995) 'Qualitative Research: Introducing focus groups', *BMJ*, 311(7000), pp. 299–302. doi: 10.1136/bmj.311.7000.299.

Laughton, B., Cornell, M., Boivin, M., Van Rie, A. (2013) 'Neurodevelopment in perinatally HIV-infected children: a concern for adolescence', *Journal of the International AIDS Society*, 16(1), p. 18603. doi: 10.7448/IAS.16.1.18603.

Lentoor, A. G. (2019) 'The association of home environment and caregiver factors with

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

neurocognitive function in pre-school- and school-aged perinatally acquired HIV-positive children on cART in South Africa', *Frontiers in Pediatrics*, 7(MAR), pp. 1–8. doi: 10.3389/fped.2019.00077.

Lynch, H. and Moore, A. (2016) 'Play as an occupation in occupational therapy', *British Journal of Occupational Therapy*, 79(9), pp. 519–520. doi: 10.1177/0308022616664540.

Mays, N. and Pope, C. (1995) 'Qualitative Research: Rigour and qualitative research', *BMJ*, 311(6997), pp. 109–112. doi: 10.1136/bmj.311.6997.109.

Mays, N. and Pope, C. (2000) 'Qualitative research in health care: Assessing quality in qualitative research', *British Medical Journal*, 320(7226), pp. 50–52. doi: 10.1136/bmj.320.7226.50.

Mendenhall, E., De Silva, M., Hanlon, C., Petersen, I., Shidhaye, R., Jordans, M., Luitel, N., Ssebunnya, J., Fekadu, A., Patel, V., Tomlinson, M., Lund, C. (2014) 'Acceptability and feasibility of using non-specialist health workers to deliver mental health care: Stakeholder perceptions from the PRIME district sites in Ethiopia, India, Nepal, South Africa, and Uganda', *Social Science & Medicine*. Elsevier Ltd, 118(C), pp. 33–42. doi: 10.1016/j.socscimed.2014.07.057.

Mpango, R., Rukundo, G., Muyingo, S., Gadow, K., Patel, V., Kinyanda, E. (2019) 'Prevalence, correlates for early neurological disorders and association with functioning among children and adolescents with HIV/AIDS in Uganda', *BMC Psychiatry*. BMC Psychiatry, 19(1), pp. 1–7. doi: 10.1186/s12888-019-2023-9.

Musindo, O., Bangirana, P., Kigamwa, P., Okoth, R., Kumar, M. (2018) 'Neurocognitive functioning of HIV positive children attending the comprehensive care clinic at Kenyatta national hospital: exploring neurocognitive deficits and psychosocial risk factors', *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*. Taylor & Francis, 30(5), pp. 618–622. doi: 10.1080/09540121.2018.1426829.Nassen, R., Donald, K., Walker, K., Paruk, S., Vujovic, M., Duncan, W., Laughton, B. and Moos, B. (2014) 'Management of mental health disorders and central nervous system sequelae in HIV-positive children and adolescents', *Southern African Journal of HIV Medicine*, 15(3), p. 81. doi: 10.7196/sajhivmed.1091.

O'Brien, D., Harvey, K., Howse, J., Reardon, T., Creswell, C. (2016) 'Barriers to managing child and adolescent mental health problems: a systematic review of primary care practitioners' perceptions', *British Journal of General Practice*, 66(651), pp. e693–e707. doi: 10.3399/bjgp16X687061.

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

Pedrini, M., Moraleda, C., Macete, E., Gondo, K., Brabin, B., Menéndez, C. (2015) 'Clinical, nutritional and immunological characteristics of HIV-infected children in an area of high HIV prevalence', *Journal of Tropical Pediatrics*, 61(4), pp. 286–294. doi: 10.1093/tropej/fmv038.

Phillips, N., Thomas, K., Myer, L., Sacktor, N., Zar, H., Stein, D., Hoare, J. (2016) 'HIV-Associated Cognitive Impairment in Perinatally Infected Children: A Meta-analysis', *Pediatrics*, 138(5), p. e20160893. doi: 10.1542/peds.2016-0893.

Phillips, N., Thomas. K., Myer, L.,Sacktor, N., Zar, H., Stein, D., Hoare, J(2019a) 'Screening for HIV-associated neurocognitive disorders in perinatally infected adolescents: Youth-International HIV Dementia Scale validation', *Aids*, 33(5), pp. 815–824. doi: 10.1097/QAD.0000000000002144.

Phillips, N., Amos, T., Kuo, C., Hoare, J., Ipser, J., Thomas, K., Stein, D. (2019b) 'Screening for HIV-associated neurocognitive disorders in perinatally infected adolescents: Youth-International HIV Dementia Scale validation', *Aids*, 33(5), pp. 815–824. doi: 10.1097/QAD.0000000000002144.

Pope, C. and Mays, N. (1995) 'Qualitative Research: Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research', *BMJ*, 311(6996), pp. 42–45. doi: 10.1136/bmj.311.6996.42.

Rey, J. M. and Martin, A. (eds) (2013) *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions.

Robbins, R., Remien, R., Mellins, C., Joska, J., Stein, D. (2011) 'Screening for HIV-associated dementia in South Africa: Potentials and pitfalls of task-shifting', *AIDS Patient Care and STDs*, 25(10), pp. 587–593. doi: 10.1089/apc.2011.0154.

Saxena, S., Thornicroft, G., Knapp, M., Whiteford, H. (2007) 'Resources for mental health: scarcity, inequity, and inefficiency', *The Lancet*, 370(9590), pp. 878–889. doi: 10.1016/S0140-6736(07)61239-2.

Sherr, L., Croome, N., Parra Castaneda, K., Bradshaw, K., Herrero Romero, R. (2014) 'Developmental challenges in HIV infected children—An updated systematic review', *Children and Youth Services Review*. Elsevier Ltd, 45, pp. 74–89. doi: 10.1016/j.childyouth.2014.03.040.

Sherr, L., Clucas, C. and Jahn, N. (2011) 'Distinct disadvantage: A review of children under

UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

8 and the HIV/AIDS epidemic', *Toronto, Ontario: The* …. doi: doi=10.1.1.259.6460.

Sherr, L., Clucas, C. and Jahn, N. (2011) *THE ESSENTIAL PACKAGE: Distinct Disadvantage : A Review of Children Under 8 and the HIV / AIDS Epidemic Table of Contents*.

Singh, D. (2009) 'Neurocognitive impairment in PLWHA: Clinical features and assessment', *Southern African Journal of HIV Medicine*, (35), pp. 30–34. doi: 10.4102/sajhivmed.v10i3.280.

Slade, M., Thornicroft, G. and Glover, G. (1999) 'The feasibility of routine outcome measures in mental health', *Social Psychiatry and Psychiatric Epidemiology*, 34(5), pp. 243–249. doi: 10.1007/s001270050139.

Tombaugh, T. N. and McIntyre, N. J. (1992) 'The mini-mental state examination: a comprehensive review.', *Journal of the American Geriatrics Society*, 40(9), pp. 922–35. doi: 10.1111/j.1532-5415.1992.tb01992.x.

Tracy, S. J. (2010) 'Qualitative Quality: Eight "Big-Tent" Criteria for Excellent Qualitative Research', *Qualitative Inquiry*, 16(10), pp. 837–851. doi: 10.1177/1077800410383121.

UNAIDS: Joint United Nations Programme on HIV/AIDS (2019a) *GLOBAL AIDS UPDATE 2019*, *C0MMUNITIES AT THE CENTRE*. Bristol University Press. doi: 10.2307/j.ctt1t898kc.12.

UNAIDS: Joint United Nations Programme on HIV/AIDS (2019b) 'UNAIDS data 2019', pp. 1–471.

van der Merwe, M., Mosca, R., Swanepoel, D., Glascoe, F., van der Linde, J. (2019) 'Early detection of developmental delays in vulnerable children by community care workers using an mHealth tool', *Early Child Development and Care*. Taylor & Francis, 189(5), pp. 855–866. doi: 10.1080/03004430.2018.1480481.

van Rie, A., Harrington, P., Dow, A., Robertson, K., (2007) 'Neurologic and neurodevelopmental manifestations of pediatric HIV/AIDS: A global perspective', *European Journal of Paediatric Neurology*, 11(1), pp. 1–9. doi: 10.1016/j.ejpn.2006.10.006.

Van Wyhe, K., Van De Water, T., Boivin, M.,Cotton, M.,Thomas K(2017) 'Cross-cultural assessment of HIV-associated cognitive impairment using the Kaufman assessment battery for children: A systematic review', *Journal of the International AIDS Society*. Taylor & Francis, 20(1), pp. 1–11. doi: 10.7448/IAS.20.1.21412.

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

Vally, Z. (2011) 'HIV-associated neurocognitive disorders', *South African Journal of Psychiatry*, 17(4), p. 4. doi: 10.4102/sajpsychiatry.v17i4.294.

Woods, S., Moore, D., Weber, E., Grant, I. (2009) 'Cognitive Neuropsychology of HIV-Associated Neurocognitive Disorders', (19), pp. 152–168. doi: 10.1007/s11065-009-9102-5.

Woollett, N., Cluver, L., Bandeira, M., Brahmbhatt, H. (2017) 'Identifying risks for mental health problems in HIV positive adolescents accessing HIV treatment in Johannesburg', *Journal of Child and Adolescent Mental Health*, 29(1), pp. 11–26. doi: 10.2989/17280583.2017.1283320.

Yusuf, A., Hassan, A., Mamman, A., Muktar, H., Suleiman, A., Baiyewu, O. (2017) 'Prevalence of HIV-Associated Neurocognitive Disorder (HAND) among Patients Attending a Tertiary Health Facility in Northern Nigeria', *Journal of the International Association of Providers of AIDS Care*, 16(1), pp. 48–55. doi: 10.1177/2325957414553839.

UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

Appendix 1

Quick Paediatric Neurocognitive Screening Tool (QPNST)

SOP and information sheet for QPNST

Contents:

1. Information about the kit (equipment and screening tool) p.2
2. Description of the tool p.3
3. Implementation and scoring guide p.5
4. Marking Sheet p.7

UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

1. **Information about the kit (equipment and screening tool):**

Kit

The following materials are included in the QPNST:

- Description of the tool
- Implementation and scoring guide
- Marking sheet
- Equipment includes the following:
  - 10 large beads
  - 10 small beads
  - 2 pieces of string
  - 6 square wooden blocks
  - 1 rectangular wooden block
  - Container with a toy cow; car and little ball in it
  - 3 picture cards
  - Sheet A; B1; B2; C and D
- For child's use: copies of Sheet A; B1; B2; C and D.

UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

2. Description of the tool:

The tool consists of a kit which includes an information sheet, score guide, marking sheet, toys and worksheets to be used by the child being assessed.

The test consists of 9 subtests to screen for the specific cognitive domains which are screened for. Total score is out of 30, and is called the total composite HAND score. The cut-off is 13/30. The patients who scores 13 and below, need to be referred to the relevant health professional to conduct a comprehensive assessment. Although the patient may score more than 13/30, there may be specific areas of difficulty and dependent on those difficulties, they must also be referred to the relevant health professional for assessment and/or intervention.

Below is a description of the test:

Subtest	Description of test	Score	Materials used
1. Fine Motor	Tested by the threading of big and small beads	2	Colourful big beads Colourful small beads Thread
2. Visuo –spatial	Block building of specific patterns which need to be copied	4	Square Building blocks
3. Spatial relations	Specific instructions to be followed regarding moving own body in position in space	3	Patients chair which they are sitting on
4. Auditory Memory	Assessor naming three daily objects which need to be recalled later in the screen	3	Nothing
5. Visual Memory	Actual toys which the assessor shows to the patient. The patient	3	Toy cow Toy car

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/
Anbrenthia Moos, 9605838, UWC, SOPH, Mini Thesis

	need to recall this objects later in the screen		Toy ball
6. Visual Motor	The patient need to copy specific geometric forms	6	Page with examples of geometric shapes. Pencil
7. Comprehension/Language	Patient need to describe what is 3 different picture cards	3	3 different picture cards
8. Orientation	Patient need to identify, day/night, rain/sunshine & place	3	Nothing
9. Trail making	Patient need to connect the dots of the house if they have not been exposed to numbers or patient need to complete a sun which have numbers to connect for children who have been exposed to number concepts.	3	2 trails: A house without numbers & a sun with numbers

UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

3. <u>Implementation and scoring guide:</u>

1. Fine motor
   - Must assess the ability to thread all 10 beads (large and small)
   - A child gets a point if all the beads are threaded
   - Note if the child has difficulty threading the beads (slow threading; difficulty grasping the beads)
   - If the child cannot complete the task, no points are awarded
2. Attention/Sequence/Memory/Visual Spatial
   - The child gets a point for constructing each block pattern correctly
   - No points scored if there's a missing block in the structure or if the block is placed in the wrong position
   - An extra pattern can be scored at block pattern 2 if there is a clear large and small space in its correct position
3. Spatial relations
   - The assessor to give the instruction only (no verbal or visual cues allowed)
   - One point awarded if child is correct
4. Auditory memory
   - Words to be stated slowly and clearly
   - Only state once
   - Recall done later in the test
5. Visual-Motor
   - Instructions as stated
   - One point awarded for each correct pattern
   - Exceptions: A point can still be awarded if the circle is slightly oval in shape
     The triangle lines do not have to be perfectly straight but it should clearly have three corners
     The child only gets a point for the square-and-circle shape if the shapes are in correct position and if the shapes are in contact.
6. Recall (auditory memory)
   - Allow the child to think
   - No hints allowed
7. Visual memory
   - Picture cards to be shown only once (3 seconds per picture)
   - Recall done later in the test
8. Comprehension and language
   - A point is awarded for each picture card if the child is able to give an appropriate description of what is happening in the picture

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

- No points are scored if the child is conveying information that is unrelated to the picture

9. Recall (Visual memory)
   - Allow the child to think
   - No hints allowed
10. Orientation
    - One point awarded for each correct answer
    - Exception: the child does not have to name the place exactly but should have an idea of where they are e.g. at hospital; at school
11. Trail making
    - Children that aren't in grade 1 yet should do the dotted house drawing
    - Children in grade 1+ should do the dot-to-dot with the numbers
    - The child should do this task without any assistance. Make sure Sheet C/D is out of view to avoid copying
    - A total of three points can be scored for each picture

Score guide

Points:

3 points awarded if the child is able to complete the picture without any errors

2 points awarded if the child makes one error i.e. if the child goes off track but is able to correct him/herself

1 point awarded if the child makes two errors but is still able to complete the task

Tips on conducting the screening and principles to remember:

UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

4. Marking sheet: QPNST

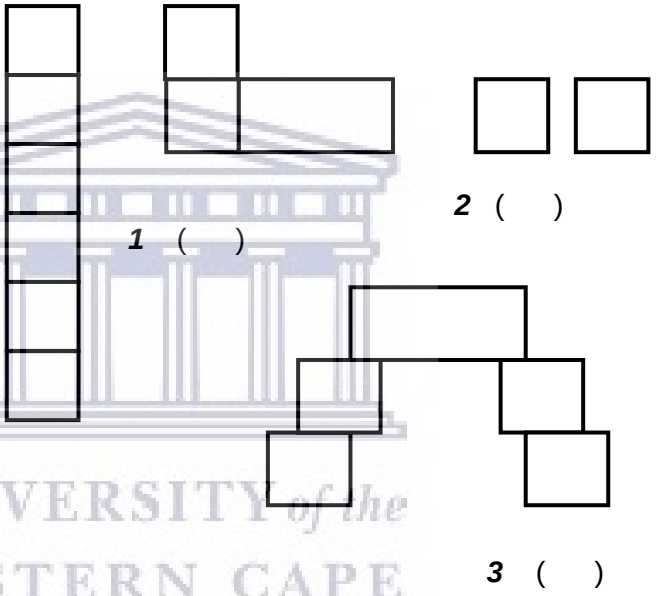
<table>
<tr><td rowspan="2">Fine Motor
Materials: string, 10 large beads; 10 small beads

Instructions:
“Take 10 big beads and put it on the string. Take 10 small beads and put it on the string”.</td><td colspan="3">Big beads

( )</td><td rowspan="2">Score

/2</td></tr>
<tr><td colspan="3">Small beads

( )
 </td></tr>
<tr><td>Attention/Sequence/Memory/
Visual Spatial
Materials: Sheet A; 6 wooden square blocks; 1 wooden rectangular block

Instructions:
“I am going to build a tower with these blocks” (demonstrate then break down).
“Can you build one like the one I did?” (child to build the first tower)
“Look at the patterns on this page” (point to patterns).
“Use the blocks to build this one” (point to the next pattern). Repeat for the pattern 3.</td><td colspan="3"> 
1 ( )
2 ( )
3 ( )</td><td>/4</td></tr>
<tr><td>Spatial relations
Materials: chair

Instructions:
(point to a chair in the room)
“Stand behind that chair. Now, sit next to the chair. Please lift both your arms up”.</td><td>Stand behind chair

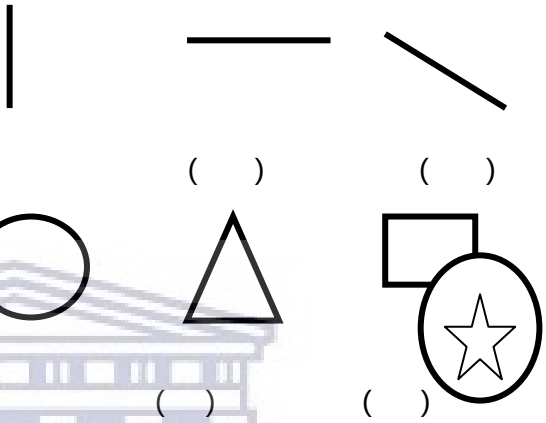
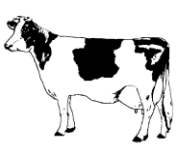
( )</td><td>Sit next to chair

( )</td><td>Lift both arms up

( )</td><td>/3</td></tr>
</table>

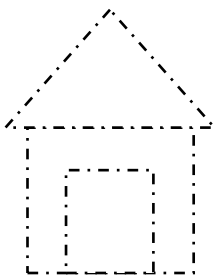
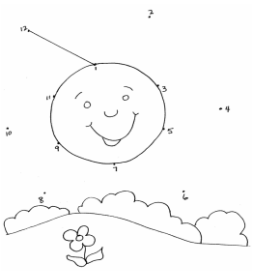
UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

Auditory Memory Materials: none Instructions: *"I am going to name three different things. Listen carefully".* *'Dog, flower, cat'*	Dog 	Flower 	Apple 	**N/A**
Visual-Motor Materials: Sharp Hb pencil; sheet B1 and B2; two sheets for the child to complete the patterns Instructions: (point to the first shape) *"Copy this shape in this block below"* (point to the relevant block on the sheet). *"Try your best".* *"Copy one shape at a time"*	 ( ) ( )	( )	( )	**/6**
Recall (Auditory memory) Materials: None Instructions: *"Remember the three things I named earlier? Can you name them?"*	Dog ( )	Flower ( )	Apple ( )	**/3**
Visual Memory Materials: container with toy cow; toy car; little ball in it Instructions: (take out the cow and show it to the child). *"Look at this, this is a cow"* (now put the cow back in the container) *repeat for the car and the ball				**N/A**

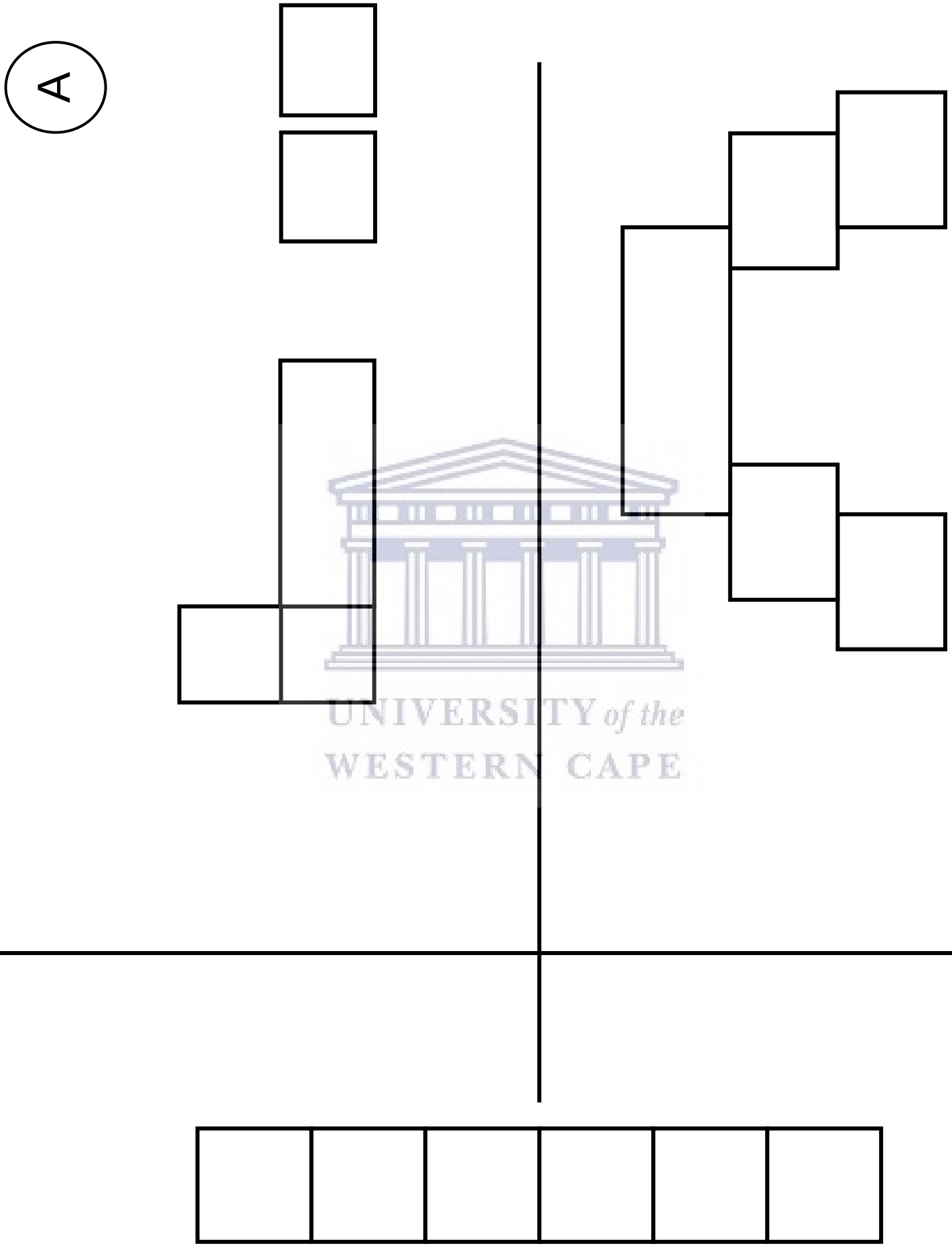
UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

Comprehension/ Language Materials: 3 picture cards in the kit Instructions: (take out the first picture card) *"Look at this picture. What is happening in this picture?"* *Repeat for picture 2 and 3	 ( ) ( ) ( )	/3
Recall (Visual memory) Materials: container with the toys in it Instructions: *"Remember this box? What is in it?"*	Cow ( ) Car ( ) Ball ( )	/3
Orientation Materials: None Instructions: *"Is it day or night?"* *"What day is it today?"* *"Can you tell me where you are now?"*	Night/day ( ) Time ( ) Place ( ) 	/3
Trail making Materials: Sheet C (not in grade 1 yet); **OR** sheet D (grade 1+); A4 sheet with the relevant pattern for the child to use; Hb pencil. Instructions: (show the child Sheet C **OR** Sheet D) *"Look at this picture. I want you to connect the dots on this page* (point to the relevant A4 sheet) *so that it looks like this".*	 **OR**  ( ) ( )	/3
	Total score: /30	

UNIVERSITY of the WESTERN CAPE

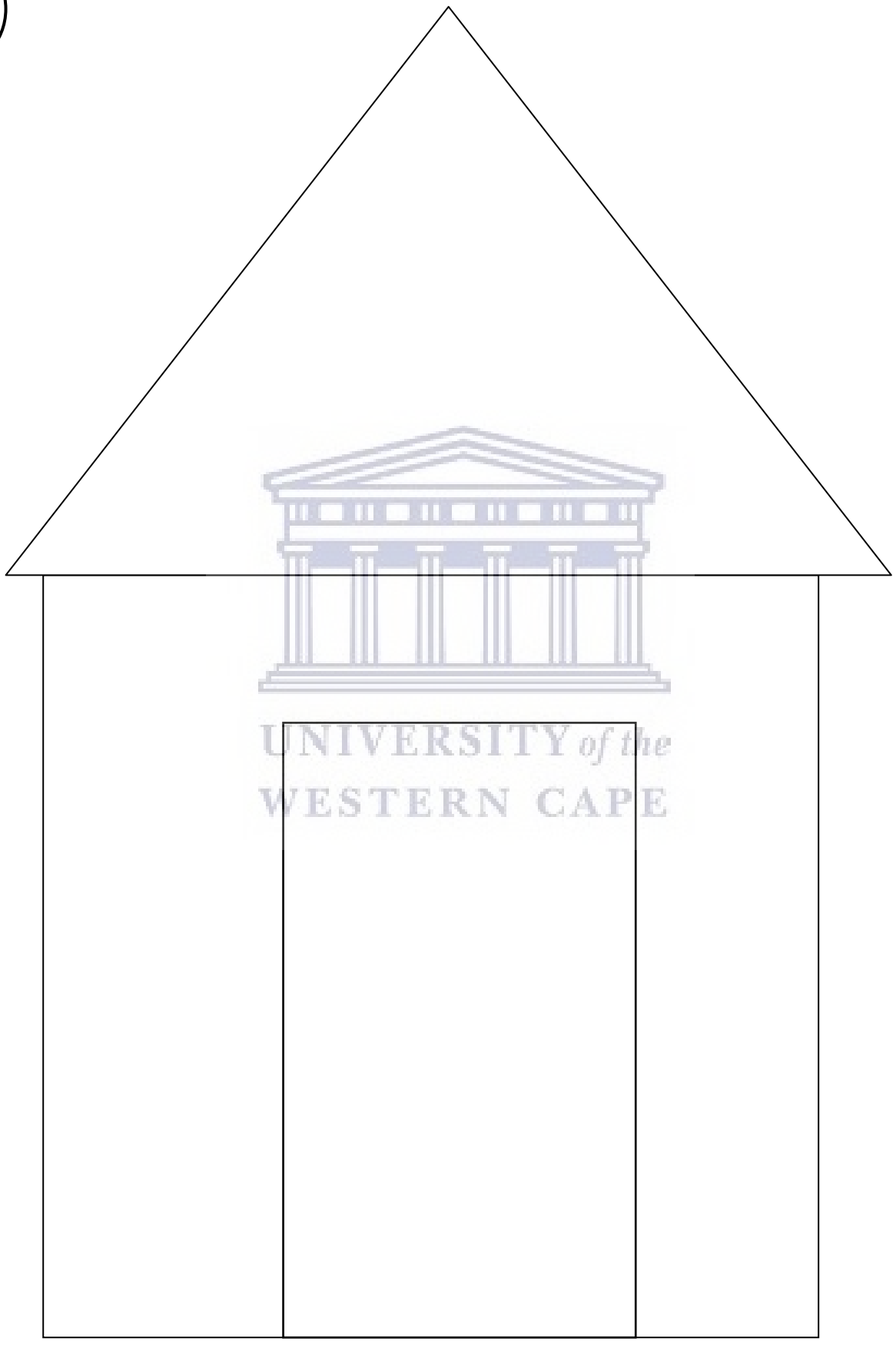
http://etd.uwc.ac.za/



UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

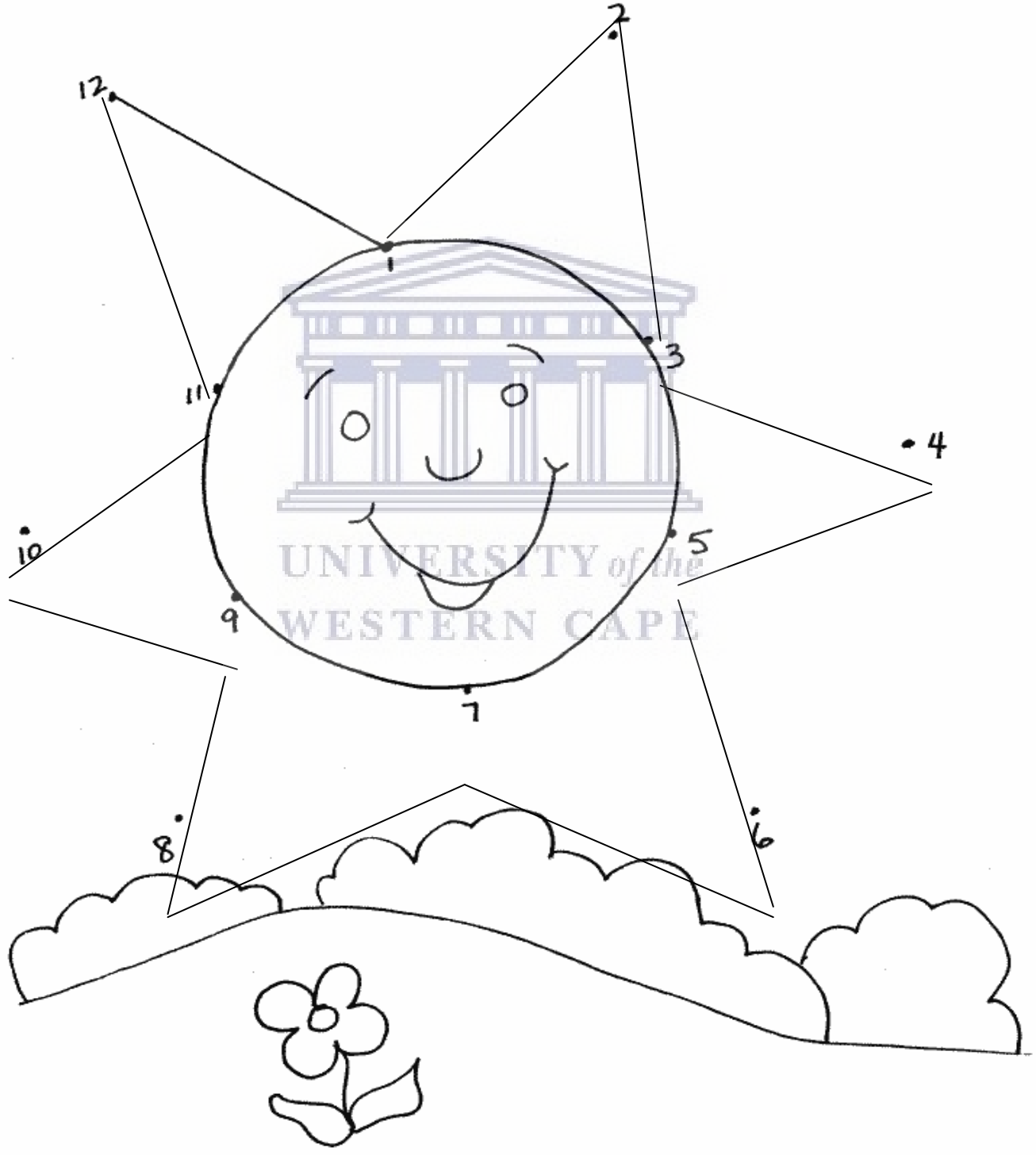
C



UNIVERSITY of the
WESTERN CAPE

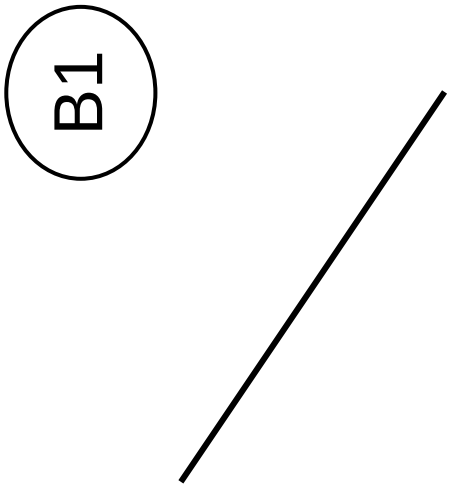
http://etd.uwc.ac.za/

D



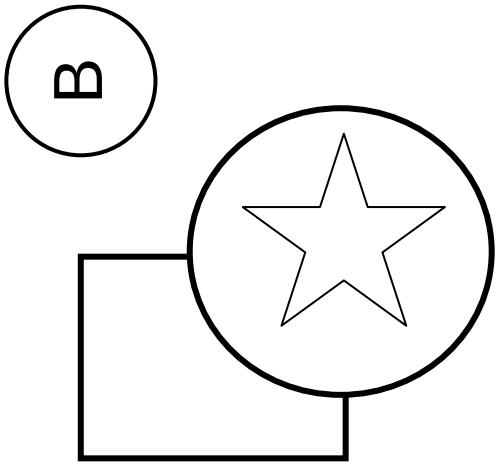
UNIVERSITY of the WESTERN CAPE

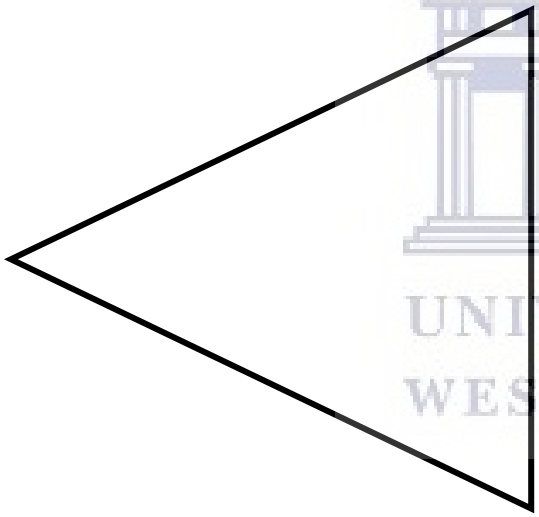
http://etd.uwc.ac.za/

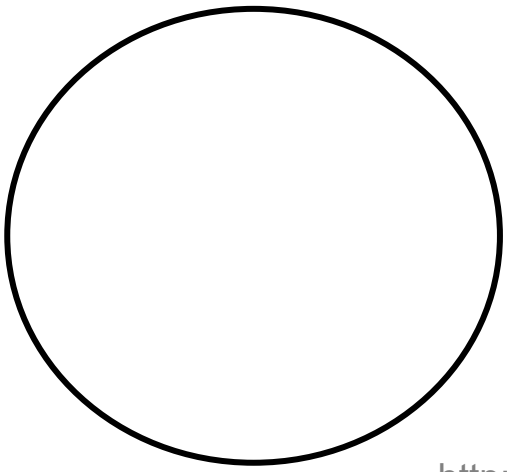


UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/







UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

Appendix 2

Outline of focus group with MDT

Aim: To determine the feasibility of the QPNST by conducting a focus group with the MDT

Participants: The MDT team

Format of Focus group:

Welcome and introductions
Ice-breaker
General discussion (guided by questions from the facilitator/researcher)
Recommendations & Closure

Welcome and introductions:

Participants will be welcomed to the training session and formal introductions will be led by the researcher. The researcher will explain the purpose of the study along with issues of confidentiality and asking participants for their consent to take part in the discussion. If participants accept, they will be provided with the consent forms to sign. Thereafter the training session will commence.

UNIVERSITY of the
WESTERN CAPE

Questions to be posed during Focus group:

The following are questions guiding the facilitator to create discussion and gain feedback from the MDT who have received training on the HAND tool:

What is your general perception of the tool/what do you think of the tool in general?
Do you think the tool would be useful to clinicians and patients? Or Families?
What is your thinking around the applicability for the tool in the PHC context ,or other levels of care:
Was it easy to use? Any difficulties experienced in applying the tool?
Was the length of time reasonable to administer the tool?
Were children able to relate to the questions, i.t.o language and toys used?
What do you think of the language and activities used to screen? Do you think these activities are suitable or reasonable?
Were there any challenges?

http://etd.uwc.ac.za/

Will you use the tool in future?

Will this tool be effective? Is it appropriate for the population it has been developed for?

What are your recommendations?

What & where else can you use this tool?

Was the training adequate that you have received? Any recommendations or adjustments?

If you could, what would you change about the tool?

Recording of session:

The session will be record by a minute taker for the duration o the focus group and an audio recording will be made with the permission of the MDT. This will done to gain a collective sense from the perspective of the MDT regarding the HAND tool.

UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

Focus group questions for interviewer (Handout)

Focus group questions

Question 1: What is your general perception of the tool/what do you think of the tool?	Probing questions if participants do not give info: What do you think of the format of the tool? What do you think about the graphics used within the tool? Do you think as it is designed it is able to pick up the deficits or difficulties? Are the activities appropriate? What do you think of the writing style, is it easily understandable, does it need to be changed?
Question 2: Do you think the tool would be useful to clinicians and patients?	Why or why not? How would it be useful? Please expand… Is there anything that would not be useful or has no purpose in the tool?
Question 3: What is your thinking around the applicability for the tool in the PHC context or other levels of care or settings?	Do you think it is feasible to implement at secondary/tertiary level? Why or why not?
Question 4:	

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

Do you think it would be easy to use? Any difficulties you think might be experienced in applying the tool?	Why of why not?
Question 5: Do you think the children will be able to relate to the questions, in terms of language and toys used?	Is using actual toys a good or a bad thing? Do you think that children can relate to the toys and activities? Are the toys appropriate for the community setting or our context? Are the toys known or unknown to the children?
Question 6: What do you think of the language and activities used to screen?	Do you think the activities are suitable and reasonable to ask the children to complete?
Question 7: What do you think could be possible challenges and will you actually use the tool should you be provided with it in the future?	
Question 8:	DO you think the tool will be able to

UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

Do you think this tool will be effective?	pick up the difficulties it aims to screen for?
Question 9: Do you have any recommendations? Anything you would add or change?	Is it appropriate for the population it has been developed for? Could you use it in any other ways?
Question 10: What & where else can you use this tool?	

UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

Appendix 3

Demographic Questionnaire

Demographic questionnaire:

Participant Professional information sheet

Date:

Instructions:

Please tick relevant boxes and add any additional information if applicable.

Name and Surname:

……

Job Title:

……

HPCSA /Relevant registration Number:

……

Department:

Social work: **Nursing**: **Medical/Psychiatry**: **Psychology:**

☐ ☐ ☐ ☐

Occupational Therapy: **Other professions (if yes, please indicate):**

☐ ☐

Work Experience:

Tertiary: ☐ **Years of experience:**

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

District: ☐ **Years of experience:**

Please tick where appropriate which patient population you have worked with:

Only Paediatric patients: ☐

Only Adult patients: ☐

Both Adult & paediatric patient population: ☐

Previous Work experience in Mental health/Psychiatry: Duration:

…..

UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

Appendix 4

Codes and Themes

Coding definitions:

Code	Definition
Task Suggestion	The activities expected to be completed to detect the deficits by the child.
Tool adaptability	Ability to use the tool and equipment in different ways /method other than its intended purpose Ability to apply equipment differently and ability to adapt to use with children according to their needs.
Equipment alternatives/replacement	The ease of difficulty with which equipment can be replaced or repaired.
Task/Tool expectation/outcome	The desired method /activity in which participants are expected to complete the task.
Need for a tool	Clinician identification of a gap or need for a screening tool to detect deficits or concerns with patients currently receiving assessment and treatment interventions by various clinicians in the health system.
Tool versatility	Ability of the tool to be applied/used in different methods, activities, settings, other expected outcomes (other than for HAND screening).
Tool layout	Structure of the screening tool and order of activities within the tool.

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

Tool outcome & referral	Defining the outcome of the tool indicating difficulties and process of referral to MDT or relevant resources for further intervention or support.
Equipment maintenance	The methods of ensuring equipment used within the tool is maintained to correct standard allowing clinicians to screen correctly. Includes a resource list of places to purchase the equipment.
Tool/Task expectations/changes	Refers to outcome expected for each activity indicating ability or inability to complete the tasks or what the task intend to screen for.
Context applicability	The various setting or context to the tool can be used in including clinic, which health are level, communities and area where child lives.
Instruction guide	Step-by-step description to guide clinicians how to correctly conduct the screening, tool use, activity completion and expectation.
MDT	The various clinicians and health care workers working across all levels in a multidisciplinary team.
Playfulness	Fun and appealing nature of the tool which is attractive to children, without them realising that they are being screened for deficit.
Accessibility	The user-friendliness of the tool to various clinicians/health workers.
Tool simplicity	Ease of use of the tool.
Appealing toys	The colourfulness and attractiveness of toys used within the tool

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

Results impacting factors	Factors impacting on the outcomes/results of children screened.
Completion time	Time needed to complete ah of the activities/overall tool.
Wish for a tool	Clinicians'' sense of needing a tool to conduct screening within their clinical area/unit.
Culturally relevant	Relevance of the tool to the culture of the screened population
Relatable objects	Equipment/toys children can identify with.
Tool safety	
Time constraints	Putting time limits on the completion of each activity/task
Simplicity	Ease of use of the tool
	Simplicity of the tasks
Standard pack	Pack with instruction guide, scoring sheets ect..The entire "kit".
Equipment availability/accessibility	How readily available are the tools
Tool value	Value or worth of the tool to clinicians an all health care workers
Varied applications	Variety of way/methods to how tool can be applied
Language applicability	Indicating whether language use within the tool is relevant to child screened and the context in which the child lives

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

Activity selection/expectation	Selection of activities used and appropriateness thereof
	What is expected outcome of activity
Human resources	Human resources (people) needed to conduct the tool and to refer for further intervention and support.
Referral resource	Resources where children can be referred to for further intervention and support.
Early detection	The availability and ability for the tool which allows/facilitate detect HAND deficits early, instead of during adolescence or adulthood.
Health worker (HW) empowerment	Empowering HW's with the training and enabling them to apply the tool (conduct the screening).
Referral	Process or person the screened child i referred to once difficulty or need is identified.
Training tool	Tool used to train health care workers on how to use the screening tool
Tool training	Training process of the tool, including instruction guide, video's tool kit etc.
Tool comparison	Comparing the tool with other screens or assessments.
Tool efficacy	Effectiveness of the tool detect HAND.
Task shifting	Process of delegation whereby tasks are moved, where appropriate, to less specialised workers
Equipment suitability	Suitability or appropriateness of equipment to test the desired comments' screened for within the tool

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

Context/Setting	Training/Education	User-friendliness	Equipment/Toys	Activities	Benefits/ Usefulness	Challenges	Implementation
M12: **Appropriate for SA; rural point of view**; **don't have fancy things.** Will be able to identify some of this...can relate to some of the objects (culturally relevant, area appropriateness, relatable objects)	M12: **Something to explain the tool,** a brief, something to explain it (instruction guide) F13: **In terms of training** maybe make a	F1: **Ease of use** (simplicity) **User friendly, useable** (accessibility) **Able to grasp** (accessibility) F12: **Child-friendly**	F1: like the toys (appealing toys) M1: **Like the colourful hands-on approach** (playfulness?) F13: Like the tools, toys (appealing	F13: **Blocks;** have to think **how** we are going **to use them, with or without colours and numbers** (Tool adaptability) M12	F1: **Children will identify** (playfulness) F13: **Wished for a tool with current HIV**	F1: **Other difficulties; cognitive disabilities, other medical conditions** (factor impacting results) Concentration difficulties (factors impacting results)	F1: **Can be used by anyone** (MDT /HCW accessible/friendly/useable) M12: Appropriate for CHC's and everything **mainly nurse driven** (MDT: Nurses)

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

M12: Orientation activity ***I*** **will child be able to identify the doctor in rural rural Eastern Cape? (?** Fairness expectation vs context?) **Suitable for South Africans and specifically rural areas**	tool with the tool for instance **a video** (instruction guide) M1: Past training as doctor not include impact HIV on cognitive..no psych experience, no paeds experience+ uncertainty=no use of tool	(playfulness) **Easy to administer** (accessibility) M1: **user friendly** (accessibility) M1: Assuming standard pack with it (simplicity/accessibility)	toys) ? how easy to **replace?** (equipment alternatives/replacement) M12: Tools are **interesting** (appealing toys) F13: Very plain tool, **child don't think doing a test,** doesn't look like test, **look like just playing**	Consider another picture (Tool/task expectation changes)	**patient to evaluate;** can sense, but cant's say, can't quantify just from interview (need for a tool) F14: **If they** are **invested** in it, **can see the value of the tool,** I think **people**	Putting a **time limit=**anxiety provoking?? (completion time?) M1: **?gauge time limit,** (completion time?) F13: **Value Time**	F14: Who is the target, every nurse, OT, physio or nurse? MDT /HCW accessible/friendly/useable) F1: With **referral say what, which area, and who do you refer to?** **school psychologist, OT at the clinic** and will they also be trained

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

	(HW /MDT education)	F14: In W Cape each clinic to have a standard pack with algorithm (simplicity/accessibility)	**around, like this aspect** (Playfulness) F14: If each clinic has a pack, they **can easily replace what is missing in** the **pack** (equipment replacement) F14: Responsibility of the **clinic to maintain the box and**		**will use it** (Tool value) F1: **Nice to engage** with the child and **kind of do the MSE, like in a playful way** (different/ varied applications)	**recording?** (completion time? **Child needing breaks** = demonstrating cognitive difficulties i.t.o tool (completion time, parent/assessment feedback)	in this? (referral) CH: (F13): **As S/W with no specialized training** in psychiatry, find the tool very appealing, working with a lot of young children (MDT accessible)

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

			replace (maintenance/equipment replacement)				
Context/Setting	**Training/Education**	**User-friendliness**	**Equipment/Toys**	**Activities**	**Benefits/** **Usefulness**	**Challenges**	**Implementation**
F1: **In clinic** would be useful (context applicability) F1: If clinician familiar with tool, won't take	F12: **Has to be explanation** for use, indicators, outcomes (instruction guide)		F14: Think forward to **easy access, might require the clinic to have the beads and blocks** and all those things (Equipment availability/accessibility?)	M1: Orientation activity: night and day activity and rain and sun and could with rain **both referring to time.**	F1: Children not being identified.. **.this is a way to identify children** who **might have challenges**	F12: Leave out beads (tool safety) F13: Wonder about beads, **might**	F12: If **CNP's have the tool** and **use it allow appropriate referral** (referral CNP's)

http://etd.uwc.ac.za/

more than an hour, therefore can be used in **clinic settings and CHC's**) (context applicability)				(Task expectation/ outcome?)	(need for tool)	**swallow them** (tool safety) M12: Time also (time constraints)	
Context/Setting	**Training/Education**	**User-friendliness**	**Equipment/Toys**	**Activities**	**Benefits/ Usefulness**	**Challenges**	**Implementation**
M12: Yes agree, **appropriate/perfect for CHC**	F12: Have to detail introductory aspect +			M12: The social message, language	F1: **Beauty of it somebod**	F1: **Time constraints for**	M1: More the **MH care workers latch on**

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

clinics mainly nurse driven F1: Useful **in clinic setting** (context applicability) F1: **Will the test be in different languages?** E.g in E Cape, majority speaks isiXhosa, so will tool be available in Xhosa (language	developed and why + aim (Tool training)			and comprehension…**the 3rd one....I can't really figure out** what is going on there… (task expectations/changes) M12: **Pictures must be clear to the assessor** (task expectations)	**y has thought there might be a problem**, because seeing children picked up much later (early detection) F1: Children repeating	**clinicians** in clinics, time may be a problem (workload vs time pressure)	and **general doctors might need training** (MDT) F1: SW: **yes, would use** tool (MDT use) F12: **Obviously would use it** and

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

applicability) F1: And? can distribute to DSD (context applicability)					classes over and over, if **picked up earlier, interventions are multi-fold** (early detection)		encourage others (MDT use)
Context/Setting	**Training/Education**	**User-friendliness**	**Equipment/Toys**	**Activities**	**Benefits/** **Usefulness**	**Challenges**	**Implementation**
CH/F13: ……5year				F1: Orientation:	F1: **Empower**		CH/F13: In terms of

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

project in M/plain for HIV+ children and adolescents **obviously during the screening at PHC clinics obviously tool would work** (context applicability)				orientate to time, person and place. This one, **orientate to time twice,** no person thing,? **Deliberate or oversight?** (task expectation) F12, M12, F1,F13: Orientation activity **Relook at the pictures and**	**s to say child has a problem** and to refer **Empowers** you to say **to refer** to teacher, psychologist.. (HW empowerment) F1: **Something can use a**		resources. ...**There going to be enough resources?** dilemma we facing...**who do we refer to, how long is it going to take before child attended to** if identified deficits? (human resources) F1: **When pick up, and screening done by a nurse, and asked if you must have a look, then you are going to have a look** (registrar)

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

				correspon ding task expectatio n i.t.o. time, person and place. (Task expectation changes)	**referral**.. Helps to show child needs extra help (HW empower ment)		(referral resource)
Context/Settin g	**Training/Educ ation**	**User-friendliness**	**Equipment/Toy s**	**Activities**	**Benefits/ Usefulnes s** F12:	**Challenges**	**Implementation**
					Appropria te referral to..where to and to whom and		

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

					will get through to the clinic.. (referral & context)		

http://etd.uwc.ac.za/

FGD 2:

? can we use and apply same feedback in two different themes?

Context/ Setting	**Training/Education**	**User-friendliness**	**Equipment/Toys**	**Activities**	**Benefits/ Usefulness**	**Challenges**	**Implementation**
F1: Use in any setting, in **clinic** with no resources (context applicability)	M1: S/W don't use lot of instruments, thus have to **explain simpler e.g. outcomes, measurements;** Measurements used excellent, but roll-out into community = people not understanding=	F1: Fabulous incredibly **user-friendly** (accessibility)	F12: **String little bit thick for smaller beads** (equipment suitability)	F12: **Activities short and brief,** still **covers vast factor of components and nice overview** (task expectation)	F13: **Quick + brief = more beneficial** (Completion time)??	F1: How long to complete activity, reasonable amount of time? (Completion time?)	M1: **S/W:** very useful to be able to use **S/W in field useful** **They will use it** (MDT)

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

	explain more (instruction guide)						
F12: Tool **sensitive to** the **culture and context** **(cultural relevance, context applicability)**	F1: **Rationale,** why important (Tool Training)	F12: Great tool **easy for children to understand** (playfulness)	F1: In pack, if look t cow, make sure have cow…be specific….enough blocks.. (equipment suitability)	M1: Instructions on what needs to happen.. add words afterwards then person don't have to extrapolate what he needs to do (instruction guide)	M1: **S/W:** very useful to be able to use (HW empowerment)	M1: ….learn everything at training …not use every day…and afterwards not entirely clear on what to do. (instruction guide/tool package)	
Context/ **Setting**	**Training/Education**	**User-friendlines**	**Equipment/Toys**	**Activities**	**Benefits/** **Usefulness**	**Challenges**	**Implementation**

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

		s					
F12: **Male admissions**… .large sample men…**no level of literacy…**any **neuro psych assessment/assesment for intellectual function …quite hard….MOCA can't even do….tool like this, useful in that setting…** (context		F12: Not long, **quick and simple** to use (simplicity)	M1: Blocks nice…colourful …,but numbers, letters and colours might interfere with actual activity (equipment suitability)	M1: Step-by step instructions (take the box, show it to the child, ask child to identify the items etc. (instruction guide)	F12: Us who worked **in clinics , don't get an SAIS, don't have assessment tools** (HW empowerment) ??	F13: C**hallenge** when **explaining results to parents** and the context and where (Tool outcome & referral)	

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

applicability) (Tool versatility)							
		F13: Very **simple, time quick and brief** = making it more beneficial **Context/** **Setting** (simplicity)	F13: Have bucket not see-through (equipment suitability)	F1: Have age appropriate warm up activity (task suggestion)	F12: **Quick, efficient** and give **indication of need for further assessment** (completion time)/ **HW empowerment**	M1: Yes, person **screening not understand all of what screening to answer parents or...** **F1:** **Say why child should go for further**	

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

						assessment&wha is it (tool outcome & referral)	
F1: NGO's, Home Based Carers...training NGO's (context applicability/MDT) F12: Aftercare centres..often more time than		F1: Age group not visible (accessibility)/ **Instruction guide?**	F12: **Attach list of places to buy toys** for replacement (equipment maintenance)?	F13: **Orientation activity: second picture confusing** ...time of day **(time)...** not have weather...we said day of the week..p**lace**: want to say in hospital...that they are	M1: **Few things like this available** (need for tool)		

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

teachers..				in....a syringe...or house with cross to indicate hospital F12: Minor or child..? (Task expectation)			
Context/ Setting	**Training/Education**	**User-friendliness**	**Equipment/Toys**	**Activities**	**Benefits/ Usefulness**	**Challenges**	**Implementation**

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

		M1: **People on ground level** not same understanding of mental health..to **simplify even more,** especially **instructions ..clear** (MDT)/ (instruction guide)	M1: Easy replaceable? **Yes,....complete description and photo...? how will be distributed..** (equipment maintenance/Instruction guide)	F1: C and D intended to draw lines? (task expectation)	M1: **If there is a** screening tool, **easier to show what was done and the** outcome on instrument **show to take to the clinic** (HW empowerment)		F12: **Think about task shifting, task sharing**, tool helpful in that way…**different levels of professionals who work in PHC setting, which 1st port of call into healthcare** (MDT/context applicability)
				F12: **Sun** looked **easier** to draw **than**	M1: **Equips profession** with **ability to**		

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

				house..but not my expertise**?** (task expectation)	**screen** for things they don't have much training in, then **allow patients to access services** they need. (HW empowerment/ service access(?))		F12: Provides professionals with a to use to assess, anyone can assess Clinics employ **counsellors, HIV counsellors, nurses with no specialist psych training could use tool, based at clinics, think smaller communities** (HW empowerment/ MDT/context applicability)

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

		F12: Challenging: Have had **children with hearing and partial visual impairment ....look at other ways, replace task e.g. the cards** or structure in a different way (Tool adaptability)		F13: With **orientation first clarify what asking, then either depending on the child's age or abilities tie in with its rainy or sunny, or days of the week** (task expectation)	M1: If know how to execute then can do basic neuro-assessment ..as opposed to not being able to do at all. (HW empowerment/ Tool versatility)		F12: Helpful, could see **teacher able to help as well…**can be **entry point to accessing help** (MDT/Context applicability)

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

		F1: that's a good one..					
		F12: Maybe **small cards with emotions ... should be laminated i.t.o carrying it around** ..**not replacing as often** (equipment alternatives/ replacemen		M1: **Minor, a single person redo pictures, drawings and single star** straight through ...would make even more accessible (tool layout)	F1: **Understanding whether neurocognitive or emotional difficulty**…would give indication…sometimes takes long to establish (Tool efficacy)		F12: Smaller communities, rural, large bulk healthcare provided by HBC & CBHCW's..would be able to use tool Tool simple enough, worked with HBC's (MDT)

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

		t)					
Context/ Setting	**Training/Education**	**User-friendliness**	**Equipment/Toys**	**Activities**	**Benefits/ Usefulness**	**Challenges**	**Implementation**
F12: Translation of tool? (Context applicability)		M			F1: **HCW's tool simple enough to utilise**, useful because they ones that visit families…**home visits, quick to administer and able to get help/access the services**		M1: If make it A, then B, able to **roll out to teachers, caregivers of every level** **Step by step..reach becomes further**

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

					for the child **(HW empowerment)/context applicability)**		(MDT)/instruction guide)
Context/ Setting	**Training/Education**	**User-friendliness**	**Equipment/Toys**	**Activities**	**Benefits/ Usefulness**	**Challenges**	**Implementation**
					F1: Often **child referred for large assessment**… to manage		M1: If standardise it...parameters must be put in.. (tool expectation)

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

					resources in not every child gets them or the **SAIS, because of waiting list and stuff…**so **this** would help to **look at exactly who needs really needs** it and if you get results who can verify them. (HW empowerment/ tool versatility)		
					M1: **Because**		

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

					other professions can then also do it that is the beauty of it, because with more in-depth assessments, are **only few professions that can do it…causes waiting list**. Now, other **professions can screen and not waste time /clog the system** by making waiting list longer for kinds that may		

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

					toolor may not need further assessment. (HW empower /MDT/tool versatility)		
					F13: ***See yourself using the tool?*** **Do have a patient, this will work well with,** especially because I don't now what's happening with		

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

					her…**it's in PHC setting so yes..** (need for tool) (context applicability)		
					F12 ***See yourself using the tool?*** **Yes** (need for tool)		
					F14: For **me would be useful,** often referrals for younger		

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

					children to do SIAS…**but useful to do this as a screen if SAIS appropriate or if another to should be used…** (tool versatility)		
					M1: Nice **versatility of it...can take instrument and can go and buy things** (tool versatility)		

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

Appendix 5

Participant Information Sheet

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 Fax: 27 21-959 2872

E-mail: soph-comm@uwc.ac.za

UNIVERSITY of the
WESTERN CAPE

INFORMATION SHEET

Project Title: A qualitative feasibility study to evaluate of use of a screening tool to detect neurocognitive deficits among perinatally HIV-infected children by primary health care workers

What is this study about?

This is a research project being conducted by Anbrenthia Moos at the University of the Western Cape. We are inviting you to participate in this research project because you are a health care practitioner with experience working in the health sector and can provide relevant and appropriate feedback regarding the development of a new tool which can potentially be used within clinical practice.

The purpose of the study:

The purpose of the study is to obtain your feedback on the Quick paediatric neurocognitive screening tool. I would like to hear from you what you think are the strengths and

http://etd.uwc.ac.za/

weaknesses of this tool, how we could improve the tool, and whether or not it would be feasible to implement in a PHC settings.

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

You will be asked to participate in a 1 day training session and a 2 hour focus group discussion which will be held at the Child and Family Unit at Lentegeur Hospital. The focus group discussion will take place 1 week after participating in the training session. Please find attached a summary of the outline of the training session as well as a summary of questions of the focus group discussion.

Would my participation in this study be kept confidential?

The researchers undertake to protect your identity and the nature of your contribution. The researcher will take the necessary steps to ensure that confidentiality is maintained at all times. Your confidentiality in this research is guaranteed. Under no circumstances will your identity be revealed. All details will be anonymous and participants will be allocated unique study identification number.

UNIVERSITY of the
WESTERN CAPE

To ensure your confidentiality all recording of the training sessions, focus group discussions and written notes to questions will be kept locked and will only be accessed by the researcher for the entire duration of the research. Password-protected computer files will be used. On completion of the research, all the records will be kept at the UWC for a period of 5 years thereafter, after which the records will be destroyed.

If we write a report or article about this research project, your identity will be protected.

This study will use focus groups therefore the extent to which your identity will remain confidential is dependent on participants' in the Focus Group maintaining confidentiality.

What are the risks of this research?

There may be some risks from participating in this research study.

http://etd.uwc.ac.za/

There may be some risks from participating in this research study. Participants may become uncomfortable or feel pressurized to speak during the Focus Group discussion; however the researcher will ensure a comfortable and relaxed atmosphere. We will nevertheless minimize such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

You will receive no direct benefits from this study. Likewise there are no costs to you for participation apart from the time you will commit to the interviews and/or discussions. This research is not designed to help you personally, however, the information and knowledge the study will generate will aid in the improvement of a tool that is culturally relevant and appropriate for the South African setting. Through these two techniques and with your active and invaluable participation, will contribute significantly as the beginning of a process of developing a culturally appropriate, valid and user friendly instrument to assess for neurocognitive deficits among HIV infected children, in the South African context.

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

Your participation in this study is totally voluntary and under no circumstances will you be compelled or forced to participate in the training sessions or focus group discussions. Participation or even withdrawal from the study while it is underway is your prerogative. You are also at liberty not to answer any questions you may deem inappropriate or are compromising your confidentiality and you may withdraw from the study at any time. Should you have any issues, subjects or situation you don't want to discuss kindly let me know.

What if I have questions?

This research is being conducted by Anbrenthia Moos, Lentegeur Psychiatric Hospital at the University of the Western Cape. If you have any questions about the research study itself, please contact If you have any questions about the research study itself, please contact Anbrenthia Moos at: cnr Highlands & .Z Berman Drive, Child and Family Unit, Lentegeur Hospital, e-mail: Anbrenthia.Moos@westerncape.gov.za

http://etd.uwc.ac.za/

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

Prof Uta Lehmann

School of Public Health

Head of Department

University of the Western Cape

Private Bag X17

Bellville 7535

soph-comm@uwc.ac.za

Prof Anthea Rhoda

Acting Dean of the Faculty of Community and Health Sciences

University of the Western Cape

Private Bag X17

Bellville 7535

chs-deansoffice@uwc.ac.za

UNIVERSITY of the
WESTERN CAPE

This research has been approved by the University of the Western Cape's Research Ethics Committee. (REFERENCE NUMBER: BM 17/10/18)

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office

New Arts Building,C-Block, Top Floor, Room 28

http://etd.uwc.ac.za/

Tel.: (021) 959 2988

E-mail: research-ethics@uwc.ac.za

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

http://etd.uwc.ac.za/

Appendix 6

Consent Form

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809, Fax: 27 21-959 2872

E-mail: soph-comm@uwc.ac.za

CONSENT FORM

Title of Research Project: A Qualitative feasibility study to evaluate of use of a screening tool to detect neurocognitive deficits among perinatally HIV-infected children by primary health care workers

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 and agree to be audio recorded during the focus group discussions. 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.

Participant's name……..

Participant's signature……..

Date……

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office

New Arts Building,

C-Block, Top Floor, Room 28

Tel.: (021) 959 2988

E-mail: research-ethics@uwc.ac.za

University of the Western Cape

Private Bag X17

Bellville 7535

http://etd.uwc.ac.za/

Appendix 7

FGD Confidentiality Form

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809, Fax: 27 21-959 2872

E-mail: soph-comm@uwc.ac.za

FOCUS GROUP CONFIDENTIALITY BINDING FORM

Title of Research Project: A Qualitative feasibility study to evaluate the use of a screening tool to detect neurocognitive deficits among perinatally HIV-infected children by primary health care workers

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 by the researchers. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits. I understand that confidentiality is dependent on participants' in the Focus Group maintaining confidentiality. I agree to be audio recorded during the Focus Group Discussion.

UNIVERSITY of the WESTERN CAPE

http://etd.uwc.ac.za/

I hereby agree to uphold the confidentiality of the discussions in the focus group by not disclosing the identity of other participants or any aspects of their contributions to members outside of the group.

Participant's name……..

Participant's signature……..

Date……

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office

New Arts Building,

C-Block, Top Floor, Room 28

University of the Western Cape

Tel.: (021) 959 2988

E-mail: research-ethics@uwc.ac.za

Private Bag X17

Bellville 7535

UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/