# Acceptability of the interRAI Check-Up Self-Report Comprehensive Geriatric Assessment (CGA) Tool:

Evaluating Check-Up Acceptability in Assessing Care Needs of Older Adults with Human Immunodeficiency Virus (HIV) in Kampala District of Uganda

by

Brittany Kroetsch

A thesis

presented to the University of Waterloo

in fulfillment of the

thesis requirement for the degree of

Master of Science

in

Public Health and Health Systems

Waterloo, Ontario, Canada, 2022

© Brittany Kroetsch 2022

# **AUTHOUR'S DECLARATION**

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

## **ABSTRACT**

# **Background**

The Ugandan healthcare system is ill-equipped to manage the emerging medical and social needs of its aging population. With the high burden of human immunodeficiency virus (HIV), food insecurity, and the erosion of support systems, older adults are limited in their ability to maintain physical and emotional health and well-being. High levels of impairment in activities of daily living, cognition, and frailty associated with HIV coupled with increased multimorbidity for aging Ugandans calls for the revision of healthcare policies and evidence-informed practice.

## **Objectives**

This thesis aimed to estimate the association between HIV status and (i) activities of daily living, (ii) cognitive function, (iii) health stability, and (iv) clinical frailty in older persons living in Kampala, Uganda using the interRAI Check-Up self-report assessment instrument. Additionally, this thesis aimed to (v) evaluate assessment acceptability to inform healthcare system planning and care practices.

#### Methods

A mixed methods design was employed. In Phase One, HIV-positive and negative older adults aged  $\geq 60$  years were assessed using the interRAI Check-Up self-report in the Nakawa division of Kampala. Patient characteristics were summarized with descriptive statistics, and a logistic regression analysis was used to identify differences in activities of daily living, cognitive function, health stability, and frailty of older persons in the study. In Phase Two, key informant interviews with service providers at the Reach Out Mbuya Community Health Initiative were held to characterize the acceptability of the Check-Up in the Ugandan setting and to explore perceptions of its use.

### **Results**

In Phase One, 130 Check-Up assessments were obtained for older persons in the community. HIV status was found to not be statistically significantly associated with the outcomes of interest and age was found to be positively associated with outcome scores for activities of daily living, cognitive performance, and frailty. However, age was not found to be associated with health

stability. In Phase Two, 12 interviews were held with service providers at the Reach Out Mbuya Community Health Initiative. The Check-Up was found to be acceptable for use in the Ugandan setting, with minor gaps identified for coverage of economic stability, food security, living arrangement, and the physical environment. Further, challenges with languages offered, the technology required, and length of time to complete was discussed.

## **Discussion**

Findings of age-related associations for activities of daily living, cognitive performance, and frailty were conclusive with expectations for the trajectory of health throughout the aging process. Similarities across HIV-positive and negative participants are attributed to participant age, low study sample size, viral suppression, and healthcare service utilization. For Check-Up use in the Ugandan setting, several recommendations are made to address identified gaps including question modifications, further translations, provision of additional tablets, and granted permissions to RAIsoft. Next, capacity training for Check-Up use by service providers is introduced, including the need for sensitization of gender differences and appropriate structuring of assessors in the field. Lastly, a theoretical framework assessment revealed barriers in the ability of the Theoretical Framework of Acceptability to identify key gender and socio-cultural differences in intervention recipients and deliverers.

# **Implications**

This thesis provided important information for describing the needs of aging Ugandans and insight into how a standardized instrument can help to support the development of a geriatric-friendly healthcare system across the nation. This was an important step in establishing an interRAI community of practice in East Africa.

## **ACKNOWLEDGEMENTS**

I would like to first thank my present and future supervisor, Dr. George Heckman, for your tremendous wealth of knowledge and kindness. Thank you for always believing in me and for helping to make what was a seemingly impossible master's thesis project become a reality. I am sincerely grateful for all the opportunities you have provided for me, and I am excited to see what the next four years will bring. I would also like to extend my appreciation to the members of my committee: Dr. Warren Dodd and Dr. John Hirdes. Warren, thank you for your real-world knowledge in international research and for consistently advocating for our partners in Uganda. John, thank you for your expertise and guidance, and for challenging me in areas to help build my confidence.

I would also like to extend my sincerest gratitude to Emmanuel Sendaula and his team at the Reach Out Mbuya Community Health Initiative. Thank you for making the partnership with Reach Out possible, and for your continuous hard work and dedication to this project. I am eternally grateful for the opportunities that Reach Out has provided to me, and I am looking forward to continuing our collaborations in the years to come. I would also like to thank the following University of Waterloo and McMaster University Professors: Dr. Mark Dolson, Dr. Susan Elliot, and Dr. Aaron Jones. Mark, thank you for your kindness, unwavering support, and for instilling confidence in my pursuit of graduate studies. Susan, thank you for sharing your expertise in cross-cultural research, for your guidance, and for never allowing me to feel defeated when things did not go as planned. Aaron, thank you for your advice, and ongoing support with statistical analysis procedures.

I am also eternally grateful for my friends and colleagues in the School of Public Health Sciences who have supported me along the way. Lillia Louis, thank you for your support with various research activities for this project. Luke Turcotte, thank you for your kindness and assistance with incorporating the Clinical Frailty Scale into my dataset. A special thank you to my best friend, Megan Dol, who has always believed in me and pushed me through the harder days when I did not believe in myself. I would also like to thank my parents, Brian and Theresa Kroetsch, and my grandparents, Reg and Betty Goral, who have always been my number one supporters. Finally, I would like to thank my partner, Noah, for always supporting me and never letting me take myself too seriously, and my puppy, Theo, for always being a light at the end of a challenging day.

# **DEDICATION**

I would like to dedicate this thesis to my friends and colleagues at the Reach Out Mbuya Community Health Initiative.

# TABLE OF CONTENTS

AUTHOUR'S DECLARATION	ii
ABSTRACT	iii
ACKNOWLEDGEMENTS	
DEDICATION	vi
LIST OF FIGURES	
LIST OF TABLES	XI
LIST OF ABBREVIATIONS	xii
QUOTATION	xiv
CHAPTER 1: INTRODUCTION	1
1.1 Positionality Statement	2
CHAPTER 2: LITERATURE REVIEW	4
2.1 Aging in Uganda	4
2.2 HIV in Uganda	5 
2.3 interRAI	7
CHAPTER 3: METHODS	11
3.1 Aims and Objectives	11
3.2 Research Questions and Hypotheses	11
3.3 Research Design	
3.3.1 Ethical Considerations	
3.4 Phase One: Check-Up Instrument	
3.4.1 Research Approach	
3.4.2 Sampling and Recruitment 3.4.3 Data Sources and Procedures	
3.4.4 Independent Variables	
3.4.5 Outcome Variables	
3.4.6 Statistical Analysis	
3.4.7 Missing Data	
3.5 Phase Two: Interviews	35
3.5.1 Research Approach	
3.5.2 Sampling and Recruitment	
3.5.3 Data Sources and Procedures	
3.5.4 Data Analysis	
CHAPTER 4: RESULTS	30
4.1 Phase 1: Check-Up Instrument	30

4.1.1 Patient Characteristics	
4.1.2 Assessment Data	31
4.2 Phase 2: Interviews	
4.2.1 Service Provider Characteristics	
4.2.2 Affective Attitude	
4.2.4 Ethicality	
4.2.5 Intervention Coherence	
4.2.6 Opportunity Costs	
4.2.7 Perceived Effectiveness 4.2.8 Self-Efficacy	
4.2.9 Additional Findings	
CHAPTER 5: DISCUSSION	
5.1 Phase One: Check-Up Instrument	
5.1.1 Health Status of Older Persons	60
5.1.2 HIV Status Similarities	
5.1.3 Age-Related Associations	
5.2 Phase Two: Interviews	
5.2.1 General Acceptability	
5.2.2 Recommendations	
5.2.4 Framework Appropriateness.	
CHAPTER 6: CONCLUSION	78
6.1 Summary of Main Findings	78
6.2 Strengths and Limitations	79
6.2.1 Strengths	
6.2.2 Limitations	79
6.3 Implications	82
6.4 Recommendations	82
REFERENCES	85
APPENDICES	105
Appendix A: Phase One Recruitment and Consent Materials	105
Appendix B: interRAI Self-Report Check-Up Summary Report	149
Appendix C: Phase One Sample Size Considerations	
Appendix D: Figures and Tables for Exploratory Data Analyses	
Appendix E: Statistical Analysis Models	
Appendix F: Phase Two Recruitment and Consent Materials	
Appendix G: Interview Guide	
Appendix H: Theoretical Framework of Acceptability Constructs	
Appendix I: Phase Two Sample Size Considerations	174 175
A CORONIX AT RADICALA DRACABLE LABORES	i / •

GLOSSARY1	79

# LIST OF FIGURES

Figure 1: Scatter Plot for ADLSF vs Age	33
Figure 2: Scatter Plot for CPS2 vs Age	35
Figure 3: Scatter Plot for CHESS vs Age	37
Figure 4: Scatter Plot for CFS2 vs Age	39
Figure 5: ADLSF Frequency Distribution	152
Figure 6: CPS2 Frequency Distribution	152
Figure 7: CHESS Frequency Distribution	153
Figure 8: CFS2 Frequency Distribution	153

# LIST OF TABLES

Table 1: Participant Characteristics	30
Table 2: ADLSF Frequencies	31
Table 3: Odds Ratio Estimates for ADLSF Regressed on HIV and Age	33
Table 4: CPS2 Frequencies	34
Table 5: Odds Ratio Estimates for CPS2 Regressed on HIV and Age	36
Table 6: CHESS Frequencies	36
Table 7: CFS2 Frequencies	38
Table 8: Odds Ratio Estimates for CFS2 Regressed on HIV and Age	40
Table 9: Service Provider Characteristics	41
Table 10: Exploratory Data Analyses of ADLSF – Likelihood Ratio	154
Table 11: Joint Tests for ADLSF Regressed on HIV, Age, and HIV*Age	154
Table 12: Exploratory Data Analyses of CPS2 – Likelihood Ratio	154
Table 13: Joint Tests for CPS2 Regressed on HIV, Age, and HIV*Age	154
Table 14: Exploratory Data Analyses of CHESS – Likelihood Ratio	154
Table 15: Exploratory Data Analyses of CFS2 – Likelihood Ratio	155
Table 16: Joint Tests for CFS2 Regressed on HIV, Age, and HIV*Age	155

## LIST OF ABBREVIATIONS

ADD Tobacco and Alcohol Use Clinical Assessment Protocol

ADL Activities of Daily Living

ADLH Activities of Daily Living Hierarchy

ADLSF Activities of Daily Living Short Form

AIDS Acquired Immunodeficiency Syndrome

ART Antiretroviral Therapy

AUA Assessment Urgency Algorithm

BADL Basic Activities of Daily Living

CAP Clinical Assessment Protocol

CARDIO Cardio-respiratory Clinical Assessment Protocol

CFS Clinical Frailty Scale

CFS2 Clinical Frailty Scale Version 2.0

CGA Comprehensive Geriatric Assessment

Check-Up Self-Report

CHESS Changes in Health, End-Stage Disease, Signs, and Symptoms

CI Confidence Interval

COGNIT Cognitive Loss Clinical Assessment Protocol

COMM Communication Scale

COMMUN Communication Clinical Assessment Protocol

CPS Cognitive Performance Scale

CPS2 Cognitive Performance Scale Version 2.0

DEHYD Dehydration Clinical Assessment Protocol

DF Degrees of Freedom

DIVERT Detections of Indicators and Vulnerabilities for Emergency Room Trips

EDA Exploratory Data Analysis

HAALSI Health and Aging in Africa: A Longitudinal Study of an INDEPTH

Community in South Africa

HAND HIV-Associated Neurocognitive Disorder

HBC Home-Based Care

HIV Human Immunodeficiency Virus

IADL Instrumental Activities of Daily Living

IADLCH Instrumental Activities of Daily Living Capacity Hierarchy

IT Information Technology

MCC Major Comorbidity Count

PACTIV Physical Activities Promotion Clinical Assessment Protocol

RAI-HC Resident Assessment Instrument – Home Care

Reach Out Reach Out Mbuya Community Health Initiative

ROTOM Reach One Touch One Ministries

SD Standard Deviation

SOCFUNC Social Relationships Clinical Assessment Protocol

SRI Self-Reliance Index

SR Mood Self-Rated Mood

TFA Theoretical Framework of Acceptability

UPHIA Uganda Population-Based HIV Impact Assessment

URIN Urinary Incontinence Clinical Assessment Protocol

VPR Vulnerable Persons Risk

"We thank God for the assessment we have been doing because it has opened our eyes"					
-	Anonymous Inte	rview Participant			

## **CHAPTER 1: INTRODUCTION**

The evaluation of healthcare intervention acceptability is critical for its implementation, particularly in cultural contexts which are new to it. Across the African continent, current gaps in healthcare service provision require innovative low-cost solutions to develop a more senior-friendly system of care for the growing number of older persons. For aging Ugandans, the current healthcare system is ill-equipped to manage emerging medical and social needs, due to insufficient funds, healthcare resources, governance structures, and relevant health information systems. These challenges are also further complexed by high levels of human immunodeficiency virus (HIV), food insecurity, inadequate support, and economic disparity across the nation. Arkedly, the interRAI Check-Up self-report assessment instrument (Check-Up) has been posed as a promising intervention to address the current healthcare system needs of community-dwelling older adults in this setting. However, the acceptability of this tool in the Ugandan context has yet to be investigated.

The Theoretical Framework of Acceptability defines acceptability as a reflection of the extent to which recipients and providers of an intervention consider it to be appropriate, based on their experienced or projected responses to its implementation.<sup>8</sup> With various healthcare delivery procedures and interacting components, it is key to assess the acceptability of an intervention at the design, evaluation, and execution stages using these perspectives.<sup>8,9</sup> Notably, the successful implementation of effective healthcare interventions relies heavily on the assessment of acceptability for both recipients and deliverers.<sup>8,10,11</sup> For Check-Up intervention recipients, several factors have implications for acceptability, including relative content, quality of care received, as well as contextual factors.<sup>8</sup> If a recipient considers the intervention acceptable, they are more likely to adhere to treatment guidelines and subsequently experience increased benefits from enhanced clinical outcomes.<sup>8,12,13</sup> For Check-Up intervention deliverers, the consideration of the tool as having low acceptability can lead to poor delivery methods with subsequent impacts on intervention effectiveness.<sup>8,14,15</sup>

To address the factors outlined above, this thesis aimed to assess the acceptability of the Check-Up intervention in the Ugandan setting. As such, the structure of this thesis is as follows. The literature review will begin with discussing aging in Uganda and the impact of HIV, followed by aging with HIV across the nation. The usefulness of geriatric assessment tools will then be discussed. The importance of interRAI comprehensive geriatric assessment systems is

highlighted, with a particular focus on the interRAI Check-Up self-report instrument that was designed for community-dwelling older adults. The subsequent chapter will introduce the research rationale and aims, followed by the methods for assessing the acceptability of the Check-Up. The results section will then summarize Check-Up outcome data as well as service provider perspectives on the assessment, followed by a discussion of the findings from this section. The final chapter will summarize the main project findings, highlight the strengths and limitations of this thesis, as well as outline the implications and recommendations for research and practice.

# 1.1 Positionality Statement

My personal identity, previous experiences, and socio-cultural biases have shaped the way I engaged with this research as well as my process for implementation and analysis. Before delving further into this thesis, it is important to acknowledge my positionality as a researcher in relation to this content. I began my post-secondary education at the University of Waterloo where I obtained my undergraduate degree in Honours Health Studies with a minor in Gerontology in 2019. Following my graduation, I spent four months volunteering at the Reach Out Mbuya Community Health Initiative, a non-governmental organization in Kampala, Uganda. At this organization, I supported activities aimed at improving the quality of life of those living with and affected by HIV in the community setting. Upon my return, I then went on to complete a Bachelor of Science Post-Degree on the Ethnography of HIV in the School of Public Health and Health Systems in 2019.

Prior to starting this thesis, I also spent time working as a research assistant for the Better Targeting, Better Outcomes for Frail Elderly Patients (BABEL) research project at the University of Waterloo. BABEL was a clinical trial that aimed to improve advanced care planning practices for older persons in Canadian long-term care facilities. It was in this position that I was introduced to my current supervisor, Dr. George Heckman, who was the primary investigator for the BABEL project in Ontario. Through these experiences, I obtained both theoretical and first-hand knowledge on the impacts of aging, as well as infectious and non-communicable disease burdens on both the Canadian and East African older adult populations. It was from this that I began thinking critically about the impact of HIV on older persons in Uganda, as well as its implications for care planning practices across the nation. This, in addition

to the relationships I developed with key stakeholders at the Reach Out Mbuya Community Health Initiative, was the major driving force for my enrollment into the Master of Science program at the University of Waterloo.

Before embarking on this academic journey, I lacked prior research experience in global health and had limited experience with qualitative research methodology. As a novice global health researcher when I began the Public Health and Health Systems program, I was privileged to be supervised and mentored by Dr. George Heckman and to be advised by my committee members Dr. Warren Dodd and Dr. John Hirdes. My age, ethnicity, gender, socio-economic status, and language skills also impacted my approach and interactions I held with research personnel and study participants. As a twenty-four-year-old Canadian Caucasian female, with a higher-level university education, I am cognizant of the privileges I hold due to my location and social identity. I also recognize my inherent subjectivities and limitations as I navigate working with vulnerable populations in Uganda, a nation in which the culture and current gender norms are remarkably different from my own.

Further, as a non-Indigenous settler living and working in the Waterloo Region, this introduces an additional element to my positionality as a global health researcher. I acknowledge that my work is on the traditional land of the Haudenosaunee, Anishinaabe, and Neutral peoples. This land is situated on the Haldimand Tract, land which was promised to the Six Nations that includes six miles on either side of the Grand River. Thus, the opportunities I encountered through the University of Waterloo were only available to me because of the harm inflicted upon Indigenous populations. From this, I also recognize how I continue to participate in and benefit from systems that actively restrict, harm, and undermine Indigenous peoples.

All the factors discussed above influenced my interpretation of data, as well as my formulation of study findings for both phases of this thesis. Thus, I am incredibly grateful to my friends and colleagues at the Reach Out Mbuya Community Health Initiative, for welcoming me into this partnership and educating me on the challenges their community faces. I am extremely thankful for the opportunities and guidance these individuals have provided me, and for the trust and confidence they instilled in me to support a community-driven project with one of the vulnerable populations they serve.

## **CHAPTER 2: LITERATURE REVIEW**

# 2.1 Aging in Uganda

In recent years, human life expectancy has greatly increased globally, with much of this progression owed to low-income nations, such as Uganda.<sup>3</sup> Due to a significant reduction in childhood and adult mortality, the Ugandan population is aging.<sup>1,3,4,16</sup> In 2017, life expectancy reached 63 years in Uganda, surpassing the mean of 60 across African nations South of the Sahara.<sup>1,3,4,16</sup> Further, in the Status of Older Persons report for the 2014 Census, it was found that the average life expectancy at 60 years was 19.5 years, with females expected to live longer (21.7 years) in comparison to males (17.3 years).<sup>17</sup> Despite the Ugandan population still being largely comprised of young people, the absolute number of persons over 60 has steadily risen, and now constitutes over 4% of the total population.<sup>3,18</sup> Notably, between 1991 and 2014, Uganda's older adult population aged 60 or above nearly doubled from 840,000 to 1,430,577.<sup>17</sup> However, a pre-existing lack of resources and formal structures to support older persons in Uganda is further compounded by this onset of rapid population aging.<sup>2</sup>

The Ministry of Gender, Labour, and Social Development has recognized that the older adult population remains among the most vulnerable groups across the nation. <sup>17</sup> Notably, the greatest proportions of older persons engage in work that is insufficient to provide regular and stable income, they are highly vulnerable to disability and disease, and experience significant additional strain through caregiving practices for grandchildren. <sup>17</sup> The Ugandan healthcare system is also ill-equipped to manage the emerging medical and social needs of its aging population, due to insufficient funds, healthcare resources, governance structures, and relevant health information systems. <sup>1,2</sup> In efforts to address financial challenges and help older persons in Uganda to live more fulfilled and dignified lives, the Ugandan Government introduced a Senior Citizen's Grant in 2010 across the nation. <sup>17</sup> While benefits have been observed in beneficiaries receiving this grant, it was only made available for 15 of 112 districts in Uganda, and was set at 25,000 UGX, which is approximately 8.50 CAD per month. <sup>17,19</sup>

Next, population aging also comes with a variety of health challenges, usually following a negative trajectory toward chronic disease, multimorbidity, and frailty.<sup>20</sup> In addition to the expected rise in chronic disease that accompanies aging, challenges specific to the Ugandan experience include a high burden of HIV, food insecurity, and the erosion of family and social

support systems.<sup>2–6</sup> Resulting from rural-urban migration and high unemployment rates, these factors have limited the capacity of older adults to maintain physical and emotional health and well-being.<sup>2–6</sup> To slow the trajectory of this decline, comprehensive monitoring of older persons through health assessment, early identification, and timely intervention of healthcare services is required.<sup>20,21</sup> Unfortunately, however, while few studies have been conducted, there is consensus in the literature that healthcare systems in low-income countries often fail to meet the needs of their older adults, owing to limited access to care and an overall lack of responsiveness to patient needs.<sup>6,22</sup> Thus, with the growing HIV prevalence in older persons in a resource-constrained context such as Uganda, the impact of population aging must be addressed.<sup>3,6,22,23</sup>

## 2.2 HIV in Uganda

HIV is a major contributor to morbidity and mortality worldwide. HIV is a sexually transmitted and blood-borne infection that interferes with the body's normal immune response. Through the progressive destruction of CD4 T lymphocytes, a specialized white blood cell in the body, HIV suppresses the immune system, increasing the risk of developing acquired immunodeficiency syndrome (AIDS). Characterized by profound immunosuppression, AIDS is defined by the development of certain cancerous tumors, opportunistic infections, wasting, and degeneration of the central nervous system. AIDS, the first effective treatment for HIV infection emerged. While there is no effective cure for HIV, the discovery of azidothymidine, an antiretroviral drug developed in 1964, was shown to successfully suppress HIV replication, reducing associated death and opportunistic infections. As a result, in 1987, azidothymidine became the first drug to gain approval for treating HIV/AIDS from the U.S. Food and Drug Administration, paving the way for upscaled research and development of antiretroviral drug therapies in the years to follow.

While treatment is largely well tolerated, antiretroviral therapy (ART) success requires lifelong drug adherence, accompanied by both short and long-term toxic effects. This, coupled with challenges related to HIV prevention, testing, and treatment accessibility, further limits the capacity of the Ugandan population to age well and with dignity. For example, reports have shown that as a result of high levels of stigma and inadequate HIV testing services, there is difficulty in estimating the true proportion of older adults living with HIV, which may also be

reflected in self-reported HIV disease statuses.<sup>32</sup> Notably, diagnosis is a major challenge, and linking persons to appropriate care who are unaware of their status remains a critical priority.<sup>33</sup>

The current impact of HIV is still of grave concern across Uganda. In comparison to developed nations where HIV is on the decline, most African countries have experienced a rise or stagnation in rates. <sup>24</sup> Despite the successful reduction in the prevalence of HIV/AIDS in Uganda over the past few decades, it has been reported that HIV prevalence has recently stagnated between 6.1% and 6.5% and is on the rise in certain areas of the nation. <sup>34</sup> Further, while there has been notable progress towards targets set by the Joint United Nations Programme on HIV/AIDS in Uganda, HIV continues to cause a significant disease burden across the nation, disproportionately impacting older persons. <sup>33</sup> In the final report for the Uganda Population-Based HIV Impact Assessment (UPHIA) for 2016 – 2017, the annual incidence of HIV among persons aged 15 – 64 was reported to be 0.40%: 0.35% among males and 0.46% among females. <sup>33</sup> This corresponded to roughly 73,000 new cases of HIV infection from 2016 – 2017. <sup>33</sup>

## 2.2.1 HIV in Older Adulthood

HIV among older persons is becoming more prominent in Uganda.<sup>32</sup> There are two major pathways for HIV in older adulthood; the contraction of new infections among older persons, and aging with HIV.<sup>32</sup> Since the emergence of ARTs for treating HIV occurred in 1987, the latter of the two has become significantly more common.<sup>28,32,35,36</sup> With population aging and successful HIV drug therapies, people are living longer with HIV.<sup>37</sup> From 1995 − 2013, the global HIV prevalence in older persons aged ≥50 years has increased by more than two-fold.<sup>36</sup> Notably, the highest burden of HIV in older adults has been found to reside in African Regions South of the Sahara, with an HIV prevalence of approximately 2.5 million in 2013.<sup>36</sup>

From 2016 - 2017, the UPHIA reported the annual prevalence of HIV among older persons in Uganda aged 60 - 64 to be 6.2%. As well, there was a positive correlation between the age of participants and the overall burden of infection reported. This report was the first to include HIV prevalence estimates for those aged 50 - 64 at a national level. HIV however, factors such as HIV-targeted discrimination and stigma may have resulted in underestimated HIV prevalence estimates for this population. This further highlights the need for upscaled research on older adults with HIV across Ugandan regions.

The interaction and subsequent complications of aging and HIV are of immense priority. With the improved access and adherence to ARTs enabling increased survival for persons living with the disease, HIV has been re-characterized as a chronic condition, resulting in a high disease burden among the older adult population. This transformation of HIV and its subsequent impacts on the elderly is considered an international "hidden epidemic". As persons living with HIV continue to age, their risk of developing additional chronic health conditions steadily rises, with several implications for disease and care requirements. Even with the effective implementation of ARTs, compared to HIV-negative persons, older populations living with HIV experience higher rates of morbidity and mortality.

Markedly, HIV-positive persons adhering to ARTs experience an early onset of agerelated complications, including impaired activities of daily living, 42–44 cognitive decline, 45 frailty, 46 falls, 47 and fractures. 48,49 As a result, the focus of HIV care planning has recently shifted from the management of AIDS-related complications to chronic comorbidities in what is an increasingly more complex aging population. With a rapidly aging population, the aforementioned factors pose unique challenges for Ugandan older adults, of which the state of scientific knowledge is considerably lacking. Thus, as the absolute number of individuals living into older age with HIV and other chronic conditions continues to rise, this calls for a substantial revision of health policy and evidence-informed practice. 35

## 2.3 interRAI

The use of geriatric assessment instruments is a pivotal strategy for addressing health system challenges resulting from population aging. <sup>20,50–52</sup> In the current healthcare system, older persons often complete standalone health assessments, fueling individual-level assessment burden while lacking the benefit of comparable longitudinal data. <sup>20,51</sup> In response, as traditional standalone medical surveys are often not enough to evaluate older persons with multiple comorbidities, geriatric assessment was developed. <sup>53,54</sup> For example, the interRAI suite of comprehensive assessment systems has helped to fill this gap, offering tools that encompass mental, social, and psychological health, environmental factors, as well as functional status to describe the health of older persons. <sup>54</sup> Markedly, the interRAI family of assessment instruments was created for use across a range of vulnerable populations. <sup>55–57</sup>

interRAI is a non-profit collaborative research network that is committed to improving care practices across healthcare settings through the development and implementation of assessment and screening systems. 7,20,58,59 This network maintains high-quality standards and aims to uphold evidence-informed policy and clinical practice to improve the quality of care for vulnerable populations including persons living with disability and those who are medically complex. Since 1990, interRAI has worked to design comprehensive assessment systems catered to healthcare setting specificity, and in 2006, released an integrated suite of assessment tools that covered all major sectors focused on care for older persons. This represents a comprehensive interoperable system of approaches for home care, assisted living, supportive housing, palliative care, acute care, persons living with intellectual disabilities, mental health, and psychiatry. Notably, within this system, interRAI comprehensive geriatric assessment (CGA) instruments have undergone extensive reliability and validity testing. 55,60–67

To best understand population-level needs and support the development of a senior-friendly system of care, standardization across healthcare settings is required. Thus, in response to presented gaps in the current healthcare system, the interRAI model for the development of geriatric assessment instruments was designed to create an integrated health information system that could provide longitudinal medical records and follow older persons across care settings. 7,55,56,68,69 Fundamentally, these tools are affordable and easy to administer, without sacrificing the clinical relevance of the information gathered, and allow for data to be collected at one-time point, but to be used by multiple stakeholders and for multiple purposes. 70,71 Overall, the concept of the interRAI approach is that the information derived which is used to support the patient can also be used to support the system. This information can be used in several ways, starting with care planning at the individual level.

First, these tools allow clinicians to identify individual patient needs, and enable the provision of suitable interventions to improve health outcomes. <sup>67,72</sup> Through the information gathered on the assessment, individual-level risk algorithms, outcome scales, and condition flags are calculated, which can inform care planning decisions. <sup>73,74</sup> Notably, the use of multi-domain CGA instruments has been shown to effectively assist in the identification of cognitive and functional ability in older persons, as well as assist in the facilitation of appropriate care. <sup>67,75,76</sup> Second, these functions can support care planning more broadly, and be aggregated at the population level to inform policy. <sup>67</sup> Through the use of secondary data, service providers and

policymakers can identify population needs, allocate resources, and monitor the quality of care delivered across multiple healthcare settings.<sup>56,77–81</sup> These various applications are important to note, as they set interRAI apart from more traditional geriatric surveys and assessment systems.

The suite of interRAI CGA systems for older persons is also a valuable resource that can inform clinical decision-making in low-income nations, most promising is that of the interRAI Check-Up self-report.<sup>7</sup> The interRAI Check-Up is a standardized CGA that is based on established and validated interRAI tools.<sup>7,67,69</sup> While the majority of interRAIs assessment systems were developed specifically for use by health professionals, the Check-Up differs in that it was designed to be administered by lay assessors or self-administered by patients. Further, in contrast to conventional surveys, the Check-Up is also designed to provide clinically actionable information. Specifically, this instrument was developed to address the care requirements of community-dwelling older adults and aims to identify individual patient needs for further support, care, intervention, or assessment.<sup>67</sup>

As is the case with other interRAI assessment instruments, the Check-Up has embedded measurement scales and algorithms which can be used to assess the clinical status of an individual and support decision-making. For example, the Check-Up includes clinical scales which measure activities of daily living, cognitive impairment, falls, and pain, as well as scales that help to predict hospitalization and mortality. Further, the instrument also has embedded Clinical Assessment Protocols (CAPs); specific care planning tools which use assessment responses and algorithms to support individual-level care planning continuity. Importantly, reliability and validity of the tool were also established in both Canada and South Africa. Africa. 20,67

While clinician-administered geriatric assessment is more widely used across healthcare settings, this is problematic in low-income nations, due to high facilitation costs and a lack of health human resources. <sup>20</sup> In countries such as Uganda, simple low-cost solutions are required to deliver high-quality care to the emerging number of older adults. <sup>67,87</sup> Thus, the availability of the Check-Up self-report has created a unique opportunity for this tool to be used in the Ugandan setting through administration by lay community health workers as well as self-administration by literate older adults. <sup>67</sup> The established reliability and validity of the tool in the community setting further points to the potential for implementation of the Check-Up in this cultural context. <sup>20,67</sup> Therefore, with identified healthcare system challenges faced in Uganda, the use of the Check-

Up as a clinical assessment system in geriatric care may help to address individual-level health challenges. Further, this information may be pooled at the organizational level to form the basis of a preliminary care system for older persons across the country, which has been historically lacking.<sup>1</sup>

#### **CHAPTER 3: METHODS**

## 3.1 Aims and Objectives

The aims of this thesis were to identify potential differences in care planning requirements across older persons in urban areas of central Uganda using the standardized interRAI Check-Up instrument and to determine the acceptability of the Check-Up in this setting. Specifically, within the Kampala district, this thesis aimed to:

- characterize the sociodemographic, clinical, neuropsychiatric, and functional characteristics of older persons living with and without HIV;
- estimate the association between HIV status and (i) one primary outcome; activities of daily living, and (ii) three secondary outcomes; cognitive function, health stability, and frailty in older persons;
- identify specific care needs of older adults living with HIV; and
- determine the acceptability and perceptions of using the standardized Check-Up instrument for assessment and care planning for older persons living in central Uganda.

# 3.2 Research Questions and Hypotheses

## 3.2.1 Phase One

 How do older adults aged ≥ 60 years with a positive HIV status differ from older adults with a negative HIV status in their activities of daily living, cognitive function, health stability, and frailty in the Kampala district of central Uganda?

 $H_0$ : older adults with a positive HIV status *do not* differ from older adults with a negative HIV status in their activities of daily living, cognitive function, health stability, and frailty in the Kampala district.

 $H_1$ : older adults with a positive HIV status do differ from older adults with a negative HIV status in their activities of daily living, cognitive function, health stability, and frailty in the Kampala district.

## 3.2.2 Phase Two

• Is the use of a standardized CGA tool acceptable to inform clinical care practices at an individual and system level in the Kampala district of central Uganda?

## 3.3 Research Design

This thesis employed a mixed methods approach with a sequential explanatory design. Namely, quantitative assessments and semi-structured interviews were used to answer the research questions of interest. In Phase One, the Check-Up instrument was administered in communities within the Nakawa division of Kampala district to capture quantitative information for older persons living with and without HIV. In Phase Two, key informant interviews were held with service providers involved in patient care and assessment implementation at the Reach Out Mbuya Community Health Initiative (Reach Out) to characterize the acceptability of the Check-Up in this setting.

## 3.3.1 Ethical Considerations

Protection of the rights and welfare of participants

This research protocol obtained clearance from (i) the University of Waterloo Ethics Review Committee (#43401), (ii) the Clarke International University Research Ethics Committee in Uganda (#2022-338), and (iii) the Uganda National Council for Science and Technology (#HS2229ES). Implementation clearance was also granted from the management of Reach Out. Informed consent to participate was obtained and documented from study participants for both Phase One and Phase Two of the project.

## 3.3.2 Reach Out Partnership

This study was conducted in partnership with the Reach Out Mbuya Community Health Initiative. In central Uganda, Reach Out is a community-based non-governmental organization that aims to reduce the spread of HIV and improve the quality of life of those in the communities they serve. <sup>2,89–91</sup> In efforts to address the AIDS scourge in slum communities, Reach Out was founded in 2001 by a physician as a project under the Catholic Parish of Our Lady of Africa Church in Mbuya, Kampala. <sup>92</sup> Since then, Reach Out has continued to experience rapid growth, and now serves over 7,000 clients across six districts. <sup>91</sup> Across this large catchment area, Reach Out operates several satellite clinics to provide comprehensive HIV and ART services to the communities they serve. <sup>2,90</sup>

Parishes in Kampala with satellite clinics include Mbuya, Banda, and Kinawataka, as well as multiple mobile outreaches and public-private partnerships across the district.<sup>2,90</sup>

Intending to curb the spread of HIV among the less privileged members of the community, Reach Out's approach helps them support more vulnerable populations, reduce transmission, and enable those already living with HIV to live responsible and dignified lives. <sup>91</sup> Through employing a holistic model of care, Reach Out supports persons living with HIV by addressing their social, emotional, medical, and economic needs while caring for the mind, body, family, and community. <sup>91</sup> This person-centred approach to care relies heavily on community-based outreach and ownership. <sup>91</sup>

#### **Home-Based Care**

Reach Out's framework for providing holistic care to the communities they serve is supported heavily by their Home-Based Care (HBC) team. This team is composed of a network of community health workers who help to bridge gaps in service provision for vulnerable populations. Conducting home visits for persons in the community is considered a best practice at the organization.<sup>93</sup> These visits are categorized as routine and targeted, where targeted visits by community health workers are completed in response to critical issues with client treatment, including high viral load, missed appointments, and poor drug adherence.<sup>93</sup> Notably, in 2021, Reach Out conducted a total of 7,328 visits to the community, including 4,503 targeted visits and 2,825 routine visits.<sup>93</sup>

# **Grandmothers' Project**

Reach Out has been supporting the care of older persons in the community at satellite sites and via their HBC team through their community-based arm. Markedly, the organization operates a comprehensive program for grandmothers in the community who have been impacted by HIV, known as the Grandmothers' Project. This program aims to improve the well-being of grandmothers and their households in Luweero district and Kampala district. Markably, this project offers medical outreach and home visits to older adults in neighbouring communities, weekly clinics with access to free healthcare, as well as HIV testing and counselling services integrated into general care. Markably of the community of the communities are supported by the community of the comm

Since the beginning of the AIDS crisis in Uganda, a large number of older persons have been significantly impacted by HIV. 97 Notably, the Reach Out community has identified information and care gaps related to the assessment and care provided to over 1,000 HIV-

positive older persons that they serve within the community.<sup>2,89,90</sup> As well, the majority of grandmothers in this setting also function as primary caretakers for their grandchildren, stemming from AIDS-related deaths of their children.<sup>97</sup> As a result, aging grandmothers are often overwhelmed and require an increasing amount of support.<sup>98</sup>

Since 2012, Reach Out has supported more than 1,000 grandmothers as caretakers of young mothers and vulnerable children. Specifically, they provide support with nutrition, economic empowerment, primary medical care, as well as social and psychological development. Specifically, in the Annual Report for 2020, it was reported that 1,501 medical consultations occurred, 78 grandmothers received home-based care, 103 underwent screening for cervical cancer, and 10 received shelter through the program. In addition to this, 24 teenage mothers under the care of grandmothers received sewing machines, 57 beneficiaries received food support, and 5 pit latrines were constructed.

# **Partnership Formation**

My collaboration with Reach Out was made possible through a four-month volunteer placement I completed at the Mbuya parish site in 2019. During my time at the organization, I established and maintained strong professional relationships with Reach Out stakeholders. Through this partnership, organizational-level approval was received, and on-the-ground research activities were led by a team in Kampala. These activities included:

- assistance in the navigation of ethical approval processes from the Clarke International University Research Ethics Committee in Uganda, and the Uganda National Council for Science and Technology;
- facilitation of stakeholder connections for training, assessment implementation, and interview processes;
- reception and dispersion of mobile tablets for data collection activities;
- uploading of Check-Up assessments to a secure platform for data extraction and analysis; and
- consultation of patient charts and service providers for addressing missing data queries.

# 3.4 Phase One: Check-Up Instrument

# 3.4.1 Research Approach

In the quantitative portion of the project, patients were assessed using the standardized interRAI Check-Up self-report instrument for older adults in the community. <sup>7,67,69</sup> This was used to investigate differences in one primary outcome, activities of daily living (personal hygiene, toilet use, locomotion, eating), and three secondary outcomes, cognitive function (executive function, decision-making ability, memory impairment, etc.), health stability (decision-making ability, health conditions, disease statuses, etc.), and frailty (mobility, balance, eating ability, dressing ability, etc.), respectively. <sup>100–102</sup> Due to the exploratory nature of this project and significant barriers faced by this population including caregiver burden, reduced communication ability, lower means of transportation, and high levels of distance between healthcare facilities and places of residence, a cross-sectional design was most appropriate to investigate the proposed hypothesis. <sup>103</sup>

Study inclusion and exclusion criteria were made following a review of similar cross-sectional study designs for this population, and one pre-post pilot study which utilized the interRAI Check-Up in South Africa.  $^{1,3,4,6,104}$  An age requirement of  $\geq 60$  years for participants was chosen due to the Ugandan life expectancy of 63 years, and the Ugandan adoption of the United Nations definition of older persons.  $^{4,16,105}$  This also aimed to increase study generalizability to other African contexts such as South Africa and Rwanda.  $^{106,107}$  Due to significant levels of illiteracy in this population, informed consent was obtained both verbally and in a written and/or virtual format using a signature from the participants with the capacity to provide informed consent, and from their care partners as required.  $^{4,17,104}$ 

To account for language barriers, a front translation of the Check-Up from English into Luganda, the most widely spoken Indigenous language in the Kampala district, was completed. As a quality assessment method, this was followed by a translation of the Luganda assessment back into English, a common practice in cross-cultural research, and during the integration of interRAI assessment systems in new cultural contexts. This approach minimizes semantic discrepancies between the two assessment versions, thus, ensuring the quality and accuracy of the translated tool. The completion of the translation into Luganda afforded service providers and older adults the choice to complete the Check-Up in their local language

without sacrificing assessment validity. Further, this approach also helped to promote participation while reducing the risk of reporting bias.

# 3.4.2 Sampling and Recruitment

Across each included parish in the Nakawa division of Kampala, this phase recruited a sample size of 130 study participants in May 2022. Eligible participants included permanent residents of Kampala district aged ≥ 60 years who were able to provide free and informed consent with or without the presence of a care partner. Older persons who were eligible to participate in the study were identified and recruited in the community by trained members of the Reach Out HBC team. Since Reach Out serves most of the slum communities in Kampala, they have a large pool of HIV-positive and negative clientele receiving different services. Thus, organization was made and centred to Reach Out community teams who recruited and enrolled participants in the study.

For HIV-positive participants, most older persons were recruited through existing community structures, and for HIV-negative participants, most older persons were recruited through linkages with community leaderships and other non-HIV services. Older adults without the accompaniment of a care partner who were identified as critically ill or otherwise presented substantial difficulties with communicating were excluded from the study.<sup>4</sup> In addition to administrative personnel and team leads, volunteer assessors, namely, community health workers from Reach Out's HBC team were recruited from the Mbuya, Kinawataka, and Banda parishes to complete community-based data collection. Potential participants identified in the community were briefed about the purpose of the study and recruited if they fulfilled the study selection criteria.

## 3.4.2.1 Service Provider Training

Prior to participant recruitment and Check-Up assessment procedures, service providers involved in assessment implementation were required to undergo a full-day training session. This included community health workers involved in assessment facilitation, administrative support persons such as research and information technology (IT) personnel, as well as project team leads at the organization. Service provider training was designed and implemented in early May 2022. This aimed to ensure Reach Out personnel had adequate knowledge and resources to

support study procedures effectively. Everyone in attendance was provided with a virtual and hard copy of the training agenda and supplementary documents in both English and Luganda. First, a short presentation on the background, aims, and objectives of the project were provided to attendees. Following this, a comprehensive review of the Check-Up assessment was completed to familiarize providers with questions and potential responses. Next, a review of all necessary study materials was completed. This included but was not limited to participant screening questionnaires, recruitment letters, informed consent documents, and thank you letters.

At the half-day mark, Dr. George Heckman was introduced to the team. During this time, Dr. Heckman reviewed the Check-Up outcome scales and CAPs with attendees and offered some real-life examples of how providers can use and interpret assessment results. This provided Reach Out personnel with the opportunity to ask any pertinent clinical questions and learn how to best interpret individual-level results. After Dr. Heckman completed his session components, the training focus shifted to technology. Namely, the remainder of the day was spent practicing using the tablets, including finding the proper forms, completing them, and accurately saving and uploading. Providers also practiced entering data on the Check-Up form in the Qualtrics survey platform. Specifically, questions were reviewed one by one as a group where providers entered responses based on their situations. This allowed Reach Out personnel to practice using the tool firsthand under the supervision of researchers and ask questions. Finally, throughout the training session, several gaps in service provider knowledge and areas for improvement of the Check-Up were also identified, which were recorded and explored further in qualitative interviews.

## 3.4.3 Data Sources and Procedures

To obtain a more accurate representation of older persons in urban central Uganda, data collection occurred across the three parishes in the Nakawa division of Kampala. These included Mbuya, Kinawataka, and Banda communities. Each parish supports a diverse range of older adults including men and women from various tribal groups (e.g., Bantu, Luo peoples) across the Kampala district, which allowed for a more generalizable sample. The trained members of the Reach Out HBC team were assigned from the sampled parishes in Kampala. At each assigned site, community health workers recruited eligible participants and performed data collection activities using the Check-Up in the participant's selected language. To help build trust, encourage participation, and reduce third-party interviewer bias, the assessment was offered in

both English and Luganda, and volunteer assessors who administered the Check-Up were also sourced from the community. 108

Data collection procedures involved the provision of the study recruitment letter, eligibility checklist, informed consent, Check-Up assessment, and participant thank-you letters, respectively. To help encourage participation, the study's purpose and benefits were described in detail, and assessors highlighted the information gained from the assessment which can inform patient care. In addition, participants were assured of confidentiality, and all relevant measures that were taken to accomplish this were described at a high level. Next, assessment data was collected in the Qualtrics survey platform on mobile tablets and uploaded to a secure server upon return to Reach Out facilities. While the Check-Up can be self-administered, this project utilized lay assessors in the community due to low population literacy and the need for complete data for analysis. Once data was securely uploaded, it was extracted for analysis. Namely, data was entered into the commercial-grade software offered by RAIsoft, an industry partner of interRAI, and a quality assurance review by a research volunteer was conducted to enable the identification of person-level outcomes. 111

## 3.4.4 Independent Variables

This study was comparative in nature. The independent disease variable was a positive HIV status, and the comparative variable was a negative HIV status. Patients were asked to self-report their HIV status during the Check-Up assessment, and this was confirmed through consultation with Reach Out service providers involved in patient care. Sociodemographic data and other additional variables which were also collected using the Check-Up included age, gender, living arrangement, previous healthcare service utilization, and medical diagnoses.

### 3.4.5 Outcome Variables

For this thesis, all outcome variable data was determined through completion of the assessment, and any missing data was filled in using patient medical records and service provider consultation. Specifically, one primary outcome and three secondary outcomes were analyzed, including activities of daily living, cognitive function, health stability, and frailty, respectively.

# 3.4.5.1 Primary Outcome – Activities of Daily Living

The primary outcome variable for this project was activities of daily living. Activities of daily living (ADL) is an umbrella term that is used to describe the fundamental skills needed to take care of oneself independently including eating, bathing, and mobility. 112,113 This is an indicator of an individual's functional status, whereby, limitations in ADLs can lead to a dependence on caretakers and assistive devices, and poorer quality of life. 112,114,115 Types of ADLs are further classified into basic ADLs (BADLs) and instrumental ADLs (IADLs). 112 BADLs encompass the skills needed to manage one's basic physical needs, such as eating, dressing, transferring, toileting, and personal hygiene. 112 IADLs include more comprehensive thinking and organizational skills required to live independently, such as preparing meals, managing medications, shopping, and managing finances. 112,116 By determining the extent of loss in basic and instrumental ADLs, providers can more appropriately support older persons and intervene as needed. 112,115

Early in the HIV/AIDS epidemic, the increased risk of ADL impairment was identified.<sup>39</sup> For example, in an early large-scale study conducted before widespread ART utilization, low CD4 counts and AIDS diagnoses were found to be correlated with an increased ADL dependency.<sup>39</sup> Many additional studies have also investigated this relationship following effective ART implementation. In a smaller cohort of 179 persons, both age and HIV were found to have synergistic impacts on ADLs.<sup>39,117</sup> These examples help to showcase how even with successful ART implementation, ADL impairment is significantly associated with HIV, AIDS, and low CD4 counts.<sup>39,117</sup> Thus, as ADL impairment can arise from several conditions throughout the aging process, and is associated with HIV, it was determined that the potential impact of a positive HIV status on ADLs should be explored in the Ugandan older adult population.<sup>112,118</sup>

For this thesis, ADLs among study participants were determined using the score produced by the Activities of Daily Living Short Form (ADLSF) scale in the Check-Up instrument. The ADLSF summarizes four central ADLs, namely, personal hygiene, toilet use, locomotion, and eating on a scale of 0 to 16. Specifically, a score of 0 indicates no impairment, 1-4 indicates minimal impairment, 5-8 indicates mild impairment, 9-12 indicates moderate impairment, and 13-16 indicates high impairment.

## 3.4.5.2 Secondary Outcome 1 – Cognitive Function

The first secondary outcome of this project was cognitive function. Cognitive function involves an individual's level of decision-making ability, executive function, and memory, whereby, impairments in cognition are defined by difficulty with remembering, focusing, learning, or decision-making. 101,120 The degree of cognitive impairment can range from mild to severe, whereby, mild impairment is characterized by small changes in cognitive function, and severe impairment is characterized by a loss in one's ability to live independently. While the occurrence of cognitive impairment increases with age, for most older adults, the degree of loss experienced is limited to more minor issues with memory. However, for some older persons there can be a cumulative effect on higher order mental functions. Cognitive impairment among persons living with HIV has also been commonly identified and is estimated to become increasingly more critical with population aging. 125

The transition of HIV to a chronic disease has resulted in the manifestation of HIV-associated neurocognitive disorder (HAND). A5,126 Notably, HAND has been found to impact individual-level medication adherence, unemployment rates, life expectancy, and quality of life for persons living with HIV. A5,125,127–130 Prior to the widespread use of ARTs, severe forms of HAND were more common. This included HIV-associated dementia, which was a strong predictor of frailty, functional dependence, falls, and mortality. A5,131,132 While HIV-associated dementia is less common with combination ART utilization, this is still a persistent problem across HIV-infected persons, particularly in African nations. Turns at Further, there is very limited data on the relationship between aging, cognitive impairment, and HIV across African regions.

As a result of the factors discussed above, it was determined that cognitive function was a critical outcome to assess for differences across HIV-positive and negative older adults in central Uganda. For this thesis, cognitive function among study participants was determined using the score produced by the Cognitive Performance Scale Version 2 (CPS2) in the Check-Up instrument. The CPS2 is an updated version of the Cognitive Performance Scale (CPS) that produces a score from 0 to 8 to characterize cognitive function. Namely, a score of 0-1 indicates intact performance, 2-3 indicates borderline impairment, 4-5 indicates moderate impairment, and 6-8 indicates severe to very severe impairment.

## 3.4.5.3 Secondary Outcome 2 – Health Stability

The next secondary outcome for this project was health stability. Markedly, health stability involves factors such as health conditions, disease diagnoses, weight loss, changes in ADLs, and changes in decision-making capacity. Through risk reduction, there are numerous benefits to assessing health stability and identifying an individual-level need for medical intervention, including prolonged life expectancy, improved quality of life, and reduced healthcare costs. For this reason, assessing health stability and its association with HIV status in older persons in Uganda was identified as a key measure for this project. Health stability among study participants was determined using the score produced by the Changes in Health, End-Stage Disease, Signs, and Symptoms (CHESS) scale in the Check-Up instrument.

In 2003, the CHESS scale was designed specifically to identify health stability in older populations. Since its development, this scale has been used as a risk adjustment tool to identify patients with unstable health conditions who are at risk of serious decline and adverse health outcomes, including hospitalization and mortality. Through revisions to the measure in 2018, it was also identified that the CHESS scale has implications for appropriate referrals and advanced care planning practices in older persons. Specifically, the CHESS scale calculates a score from 0 to 5 with higher scores being predictive of adverse outcomes including pain, hospitalization, and mortality. Namely, a score of 0 indicates no instability, 1 – 2 indicates minimal to low instability, and a score of 3 – 5 indicates moderate to very high instability.

## 3.4.5.4 Secondary Outcome 3 – Frailty

The final secondary outcome for this project was clinical frailty. In the relevant literature, frailty is a multidimensional geriatric syndrome characterized by weakness, weight loss, and low activity, and is defined as a state of increased vulnerability for developing higher dependency and mortality when exposed to stressors. <sup>39,51,102,138–140</sup> Namely, persons living with frailty experience increased rates of adverse health outcomes including hospitalization, morbidity, and mortality resulting from an accumulation of deficits across multiple systems in the body. <sup>51,138,140–144</sup> Thus, it is critical to assess frailty to help inform patient care, as this can enable clinicians to identify the most appropriate interventions. <sup>138,145</sup> The relationship between HIV and frailty has also been long acknowledged since the beginning of the HIV/AIDS epidemic. <sup>39</sup> For example, one study reported a strong association between HIV infection and the frailty-related phenotype

created using the Multicenter AIDS Cohort Study data.<sup>39,46</sup> Notably, these findings were most pronounced among men with longer durations of infection, high viral loads, low CD4 counts, AIDS diagnoses, and older age.<sup>39,46</sup>

Similar findings on the association between HIV and frailty have been identified in other studies. In the Women's Interagency HIV Study, frailty was found to be more common across HIV-infected women with low CD4 counts and AIDS diagnoses compared to women with higher CD4 counts, no AIDS diagnoses, and women without an HIV infection. <sup>39,146</sup> Further, in the African setting, one of the first reports of frailty was identified in a cohort of persons in South Africa. <sup>39,147</sup> In a study of 504 South Africans, frailty was found to be the highest among HIV-positive participants not on ARTs, followed by those on ARTs, and HIV-negative participants respectively. <sup>39,147</sup> Overall, these HIV-related factors which have continued to be found to be associated with frailty can help clinicians to identify more appropriate interventions for older persons living with HIV.

As a result of the abovementioned association, frailty was identified as a critical outcome to assess for differences across HIV-positive and negative older adults in central Uganda. For this thesis, frailty among study participants was determined using the Clinical Frailty Scale Version 2.0 (CFS2). The CFS2 scale is a revised version of the Clinical Frailty Scale (CFS), a clinical judgement-based frailty tool that evaluates various domains including function, cognition, and comorbidity.  $^{138,148}$  Notably, the CFS2 has been validated in a crosswalk to the Resident Assessment Instrument – Home Care (RAI-HC) assessment and adapted for the Check-Up to characterize frailty. On the CFS2, a score of 1 indicates very fit, 2 – 3 indicates fit to managing well, 4 – 5 indicates very mild frailty to mild frailty, and 6 – 7 indicates moderate to severe frailty.  $^{102}$  For this thesis, to produce CFS2 scores for study participants using Check-Up data, support was received from the author who first described scoring the classification tree variant of the CFS assessment items from the RAI-HC assessment.  $^{149}$ 

#### 3.4.5.5 Additional Outcome Variables

Following the input of assessment responses into RAIsoft, a suite of outcome scores and CAPs were automatically calculated for each patient through standardized algorithms.

### A. Check-Up Output Scales

The following scales which are embedded in the interRAI Check-Up can be used to assess the clinical status of an individual.<sup>73</sup> Each scale has been comprehensively evaluated to ensure they are comparable to more conventional clinical practice measures.<sup>73</sup>

- Activities of Daily Living Hierarchy (ADLH)
- Activities of Daily Living Short Form (ADLSF)
- Assessment Urgency Algorithm (AUA)
- Changes in Health, End-Stage Disease, Signs, and Symptoms (CHESS)
- Cognitive Performance Scale (CPS)
- Cognitive Performance Scale Version 2 (CPS2)
- Communication Scale (COMM)
- Detections of Indicators and Vulnerabilities for Emergency Room Trips (DIVERT)
- Falls Scale (FALLS)
- Instrumental Activities of Daily Living Capacity Hierarchy (IADLCH)
- Major Comorbidity Count (MCC)
- Pain Scale (PAIN)
- Self-Rated Mood (SR Mood)
- The Self-Reliance Index (SRI)
- Vulnerable Persons Risk (VPR)

#### B. Check-Up Output – Clinical Assessment Protocols

The following CAPs which are embedded in the interRAI Check-Up can be used to provide common protocols across healthcare settings to support care planning continuity. <sup>74</sup> Each CAP is based on large interRAI data holdings and systematic reviews of international literature and is designed to engage patients and care providers in dialogue to promote collaborative care planning. <sup>74</sup>

- Activities of Daily Living (ADL)
- Cardiorespiratory Conditions (CARDIO)
- Cognitive Loss (COGNIT)
- Communication (COMMUN)
- Dehydration (DEHYD)

- Falls (FALLS)
- Instrumental Activities of Daily Living (IADL)
- Mood (MOOD)
- Pain (PAIN)
- Physical Activities Promotion (PACTIV)
- Social Relationships (SOCFUNC)
- Tobacco and Alcohol Use (ADD)
- Urinary Incontinence (URIN)

### 3.4.6 Statistical Analysis

All statistical analyses were performed in SAS Studio Enterprise 3.8. <sup>150,151</sup> Study analysis was undertaken to determine risk factors for ADL impairment, cognitive impairment, health instability, and frailty among older persons in Uganda. The identified risk factors for these outcomes included HIV status (HIV; 0=Negative, 1=Positive), gender (gender; 1=Male, 2=Female), and age (age; in years). However, for this study, gender was not included in any statistical modelling as the sample size for males (n=16) was extremely low compared to females (n=114).

For analysis, each outcome of interest was categorized into two groups (described in results) for ease of interpretation, and as this study was interested in looking at higher levels of impairment across older persons. Following exploratory data analysis (EDA) procedures, logistic regression analyses were performed to identify any statistically significant differences in the outcomes of interest for older adults with a positive versus negative HIV status. A type 1 error of  $\alpha=0.05$  was used to determine the significance of these models. Mean and standard deviation (SD) were used to describe the continuous age variable, and descriptive statistics including percent and frequency distributions as well as p-values were used to describe sample patient characteristics. Chi-square tests were used to calculate p-values for categorical variables with sufficient cell counts, and Fisher's exact test was used to calculate p-values for categorical variables with insufficient cell counts. Characteristics and outputs of interest were then summarized and presented according to HIV status. Using logistic regression, the following hypotheses which were outlined in section 3.2.1 were tested:

 $H_0$ : older adults with a positive HIV status *do not* differ from older adults with a negative HIV status in their ADLs, cognitive function, health stability, and frailty in the Kampala district.

 $H_1$ : older adults with a positive HIV status do differ from older adults with a negative HIV status in their ADLs, cognitive function, health stability, and frailty in the Kampala district.

## 3.4.7 Missing Data

All Check-Up assessment data was manually entered from Qualtrics into RAIsoft to calculate the necessary outcome scores. During this first round of review, all missing data points and data which needed to be confirmed, such as duplicate participant codes, were recorded in a tracking sheet. Once all data had been transferred, the tracking sheet was sent to project team leads in Uganda to attend to each query. Next, while awaiting queries to return, a data input quality assessment was completed by a research volunteer. Namely, each assessment that was entered into RAIsoft was reviewed and compared to the original Qualtrics survey. This was done to ensure that the assessments entered into RAIsoft matched the original survey responses to reduce possible human error made during the transfer.

Following the quality assessment, missing data queries from the first review were returned for final entry into RAIsoft. Once all missing data from this round was entered, a second review was completed, and any remaining missing data points were recorded to be confirmed on a separate tracking sheet. This step also involved the removal of any duplicate assessments. This sheet was then sent back to the project team leads in Uganda to attend to each query. Once all missing data were returned, a final review was completed to ensure all participant codes, gender, and birth dates were accurately represented in RAIsoft before locking each assessment. Each assessment in RAIsoft was then finalized and locked one by one, prior to exporting the data for analysis.

### 3.5 Phase Two: Interviews

# 3.5.1 Research Approach

Interviews with service providers were intended to inform care planning at the individual and system level. The qualitative portion of the project commenced following the completion of

quantitative data collection and analysis activities. This phase consisted of key informant interviews with twelve health service providers at Reach Out to characterize the acceptability of using the Check-Up in the central Ugandan setting. Specifically, study participants were interviewed over a two-week period from Friday, June 3<sup>rd</sup> – Friday, June 17<sup>th</sup>, 2022.

To assess the acceptability of the tool, an interview guide was developed which was informed by the Theoretical Framework of Acceptability (TFA).<sup>8</sup> The TFA is a conceptual framework that was designed to assess the acceptability of healthcare interventions.<sup>152</sup> Specifically, the TFA can guide assessments of acceptability from the perspectives of both intervention receivers and deliverers, and across three temporal perspectives, namely, before, during, and after participation.<sup>152</sup> The framework is composed of seven component constructs that assist in the identification of intervention characteristics that may be improved.<sup>152</sup> These include affective attitude, burden, ethicality, intervention coherence, opportunity costs, perceived effectiveness, and self-efficacy.<sup>8</sup>

In 2022, a theory-informed questionnaire based on the TFA was developed. <sup>152</sup> This generic questionnaire is an adaptable tool that was designed to support clinicians and researchers to measure the acceptability of interventions across healthcare settings. <sup>152</sup> For this project, acceptability was defined as a reflection of the extent to which service providers delivering the Check-Up intervention considered it to be appropriate, based on their experienced or projected responses to its implementation. <sup>8</sup> Through a considerable review of the generic TFA questionnaire, the interview guide for this project was developed to best align with the Check-Up instrument being assessed. <sup>152</sup>

### 3.5.2 Sampling and Recruitment

Key stakeholders from parishes in the Nakawa division of Kampala district were identified prior to interview commencement. These individuals included project team leads at Reach Out, community health workers, and all other persons involved in assessment facilitation in Phase One. Each participant was recruited following the assessment of whether they fulfilled the study selection criteria. Namely, it was required that participants be health service workers affiliated with Reach Out, be aged  $\geq 18$  years, and possess the ability to provide free and informed consent. These eligibility requirements were made following an in-depth review of other similar study designs involving interviews with healthcare service providers. First,

team leads for the project at Reach Out were approached and recruited for participation in a oneon-one interview. These individuals also assisted in the planning, recruitment, and scheduling of the remaining interviews with community health workers and other team members involved in Phase One data collection procedures.

Interviews were first scheduled with two administrative team leads on June 3<sup>rd</sup> and June 10<sup>th</sup>, 2022. The remaining interviews were scheduled for June 15<sup>th</sup>, 2022, whereby the clinical lead for the project at Reach Out mobilized all research personnel, and interviews were held consecutively one by one throughout the day. Each participant was provided with a recruitment letter, followed by an informed consent letter for their review and signature. Once consent forms were obtained by research personnel, one-on-one interviews were held. The form was provided virtually, and participants were given the option to complete it online with an e-signature, print and fill out the form and scan back to researchers, or complete it using the survey pre-loaded into the Qualtrics software on mobile tablets. Once completed, each of the signed consent forms was obtained and saved before moving into the interview.

#### 3.5.3 Data Sources and Procedures

Interviews were conducted using the semi-structured interview guide informed by the TFA. To accommodate several barriers to conducting research internationally and reduce incurred study costs, interviews were completed over the Zoom platform. Each Zoom interview was automatically recorded, as participants agreed to a recording for transcription purposes in the consent form. Interviews first consisted of the confirmation of the completion of the consent form, followed by a brief description of the purpose of the study. Next, the interviewer moved into asking a series of close-ended questions, followed by a series of open-ended qualitative questions. Close-ended questions ascertained participant contextual factors, including demographics, education level, and participant experience in the health field. Open-ended questions aimed to capture information on participant perspectives of the Check-Up instrument to assess the acceptability of the tool and are described in greater detail below.

Participants were asked fifteen key open-ended interview questions, with responses audio-recorded and transcribed for subsequent analysis. Notably, the interview guide was adjusted following the completion of the first interview, which contained twelve open-ended questions. This was done to better ascertain perspectives on the acceptability of the instrument.

Specifically, certain questions were added and adjusted through close consultation of the TFA generic questionnaire to obtain more specific feedback on each component construct of the TFA. Participants were asked each question in order, and prompted, as necessary, to obtain adequate responses using the interview guide to characterize the acceptability of the Check-Up instrument.

The completion of this phase was designed to allow researchers to assess the acceptability of the Check-Up, including any potential barriers to the implementation of the tool by service providers or any gaps in service provision support. This also allowed researchers to identify any areas of the instrument requiring modifications (i.e., questions, examples, outputs produced) for this context. Overall, this aimed to (i) improve the applicability of the Check-Up instrument to the older adult population in central Uganda, and (ii) better inform clinical care practices at both an individual and system level.

## 3.5.4 Data Analysis

Following interviews with key stakeholders, a deductive thematic analysis was employed which was informed by the TFA and followed the six phases outlined by Braun and Clarke. 8,155 Through qualitative data analysis, the following research question which was outlined in section 3.2.2 was investigated: *Is the use of a standardized CGA tool acceptable to inform clinical care practices at an individual and system level in the Kampala district of central Uganda?* 

First, researchers familiarized themselves with the data. Each interview was completed over the Zoom platform and was audio recorded and saved to the cloud. The transcript function in Zoom was also enabled, so that following each interview, a rough transcript of the meeting would be automatically produced alongside the recording to be used as a template. This allowed for a more seamless transcription process. Specifically, each transcript was reviewed three times during the transcription procedure. First, the rough transcript that was produced by Zoom was studied and sorted generally into researcher and participant text. Next, each interview was reviewed and edited while consulting the audio recording. Then, one final review of the transcripts was completed while consulting the audio recording to ensure that the transcripts were completely accurate before moving into coding procedures.

Each interview transcript was then uploaded into the NVivo Qualitative Data Analysis Software and reviewed again while recording initial ideas and impressions of the data. 155,156

Next, initial codes in each interview transcript were generated and systematically grouped across the entire dataset. <sup>155,156</sup> The codes identified in the previous step were then collated into the component constructs of the TFA. <sup>155</sup> The TFA is comprised of seven component constructs (i.e., affective attitude, burden, perceived effectiveness, ethicality, intervention coherence, opportunity costs, and self-efficacy) which were pre-determined as the relevant themes for thematic analysis for assessing the acceptability of the Check-Up intervention. <sup>8</sup> All of the data which was coded into the TFA constructs along with other identified themes were then reviewed to ensure that they represented the dataset accurately, and each of the themes was further defined within the dataset to help illustrate the story which was being presented. <sup>155,156</sup> Finally, the defined themes were used to produce a final report of the data, which outlined relevant findings and their implications in this setting. <sup>155</sup>

### **CHAPTER 4: RESULTS**

## 4.1 Phase 1: Check-Up Instrument

### **4.1.1 Patient Characteristics**

In Phase One, 130 older persons were assessed with the Check-Up in the community to investigate potential differences across HIV status. Of the 130 participants, 70 were HIV positive, and 60 were HIV negative. Only 16 participants in this sample were male compared to 114 females, and the average age of participants was 68.71 (SD=7.46). Most participants were either widowed or separated (n=112) and the remaining few were married (n=18). 104 persons lived in a private residence or assisted/semi-independent living, and 26 were homeless, living either with or without shelter. Within their homes, only 10 participants lived alone, 16 lived with only their partner or their partner and others, 77 lived with their children (n=56) or siblings (n=21), and 27 lived with either other relatives or non-relatives. Finally, most participants had not had an overnight hospital stay (n=116), emergency room visit (n=122), or visit with a doctor or nurse practitioner (n=93) in the last 90 days.

Table 1: Participant Charac	Table 1: Participant Characteristics					
Variables	Total	<b>HIV Negative</b>	<b>HIV Positive</b>	P		
Frequency (Percent)	(n=130)	(n=60)	(n=70)			
Gender				0.74		
Female	114 (87.69)	52 (40.00)	62 (47.69)			
Male	16 (12.31)	8 (6.15)	8 (6.15)			
Age (mean, SD)	68.71 (7.46)	71.25 (8.40)	66.53 (5.76)	0.0002		
Marital Status				0.02		
Married	18 (13.85)	13 (10.00)	5 (3.85)			
Widowed / Separated	112 (86.15)	47 (36.15)	65 (50.00)			
Living Arrangement				0.08		
Private Home/ Apartment/Rented Room	104 (80.00)	44 (33.85)	60 (46.15)			
or Assisted Living/						
Semi-Independent Living						
Homeless (With or	26 (20.00)	16 (12.31)	10 (7.69)			
Without Shelter)				0.19		
Residence Inhabitants						
Alone	10 (7.69)	5 (3.85)	5 (3.85)			

With Spouse/Partner or Spouse/Partner & Other(s)	16 (12.31)	11 (8.46)	5 (3.85)	
With Child	56 (43.08)	20 (15.38)	36 (27.69)	
With Sibling(s)	21 (16.15)	10 (7.69)	11 (8.46)	
With Other Relative(s) or	27 (20.77)	14 (10.77)	13 (10.00)	
Non-Relative(s)				
Healthcare Service Use				0.44
Overnight Hospital				0.41
0	116 (89.23)	55 (42.31)	61 (46.92)	
1+	14 (10.77)	5 (3.85)	9 (6.92)	
Emergency Room Visit				0.29
0	122 (93.85)	58 (44.62)	64 (49.23)	
1+	8 (6.15)	2 (1.54)	6 (4.62)	
Visits with Doctor/ Nurse				0.45
Practitioner				
0	93 (71.54)	41 (31.54)	52 (40.00)	
1+	37 (28.46)	19 (14.62)	18 (13.85)	

## **4.1.2** Assessment Data

# 4.1.2.1 Activities of Daily Living

In this sample, 47.69% of participants had no ADL impairment, whereas 28.46% were minimally impaired. 5.38% of persons were mildly impaired, 10% were moderately impaired, and the remaining 8.46% were highly impaired. On average, HIV-negative participants had minimal impairment (Mean=3.28; SD=4.73), and HIV-positive participants also had minimal impairment (Mean=3.76; SD=5.27).

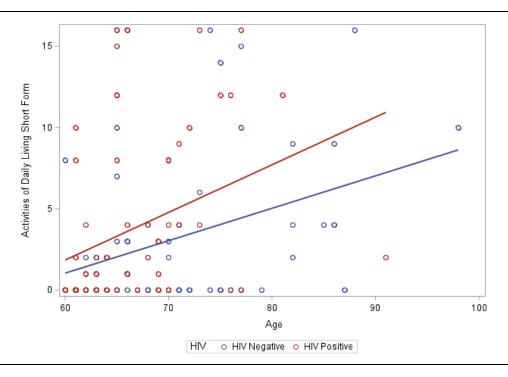
Table 2: ADLSF Frequencies						
Scale	Total	HIV Negative	HIV Positive			
Frequency (Percent)	(n=130)	(n=60)	(n=70)			
No Impairment						
0	62 (47.69)	29 (22.31)	33 (25.38)			
Minimal						
Impairment						
1	8 (6.15)	3 (2.31)	5 (3.85)			
2	10 (7.69)	4 (3.08)	6 (4.62)			
3	6 (4.62)	4 (3.08)	2 (1.54)			
4	13 (10.00)	7 (5.38)	6 (4.62)			

Mild Impairment			
5	0 (0.00)	0 (0.00)	0 (0.00)
6	1 (0.77)	1 (0.77)	0 (0.00)
7	1 (0.77)	1 (0.77)	0 (0.00)
8	5 (3.85)	1 (0.77)	4 (3.08)
Moderate			
Impairment			
9	3 (2.31)	2 (1.54)	1 (0.77)
10	5 (3.85)	3 (2.31)	2 (1.54)
11	0 (0.00)	0 (0.00)	0 (0.00)
12	5 (3.85)	0 (0.00)	5 (3.85)
High Impairment			
13	0 (0.00)	0 (0.00)	0 (0.00)
14	1 (0.77)	1 (0.77)	0 (0.00)
15	2 (1.54)	1 (0.77)	1 (0.77)
16	8 (6.15)	3 (2.31)	5 (3.85)
Mean, SD	3.54 (5.02)	3.28 (4.73)	3.76 (5.27)

### **Statistical Analysis**

For ADLS, ADLSF scores were categorized into two groups for analysis. ADLSF scores of 0 – 8 were categorized as No – Mild Impairment and ADLSF scores of 9 – 16 were categorized as Moderate – High Impairment (ADLSF; 0=No – Mild Impairment, 1=Moderate – High Impairment). First, EDA was conducted using numerical and visual techniques, with tables and figures located in the appendices. When accounting for sample size, the frequencies for ADLSF (Table 2, Figure 5) suggest that there are very minimal differences between HIV-positive and negative participants. Further, when ADLSF and age are plotted by HIV status (Figure 1), it is suggested that age is associated with ADLSF, as there appears to be a positive linear relationship between ADLSF scores and age for both HIV-positive and negative persons.

Figure 1: Scatter Plot for ADLSF vs Age



With  $\alpha=0.20$ , bivariate EDA (Table 10) suggested that HIV is not independently associated with ADLSF (P=0.62), and that age is independently associated with ADLSF (P=0.0009). Next, with  $\alpha=0.05$ , the likelihood ratio suggested that at least one of the predictor variables HIV and age is significantly associated with ADLSF (P=0.0008). Thus, interaction effects for HIV and age were tested. After running the model with the interaction effect between HIV and age (Table 11), it was found that the interaction term should not be included in the model (P=0.93). By removing this variable, we were left with the main effects model, and binary logistic regression analyses were conducted.

Table 3: Odds Ratio Estimates for ADLSF Regressed on HIV and Age						
Predictor Variable	Point Estimate	95% Wald Cor	nfidence Limits	P		
HIV Positive vs HIV Negative (Ref)	2.62	0.88	7.77	0.08		
Age	1.13	1.05	1.20	0.0005		

The logistic regression produced an odds ratio of 2.62 for HIV (Table 3) which suggests that the odds of Moderate – High ADL impairment is 2.62 times higher for HIV-positive

persons. However, this association is not statistically significant (CI=0.88, 7.77; P=0.08). Next, the logistic regression produced an odds ratio of 1.13 for age which suggests that for each additional year of age, the odds of Moderate – High ADL impairment is 1.13 times higher. Namely, for each additional year, the odds of Moderate – High ADL impairment is increased by 13%. This association is statistically significant (CI=1.05, 1.20; P=0.0005).

## **4.1.2.2** Cognitive Performance

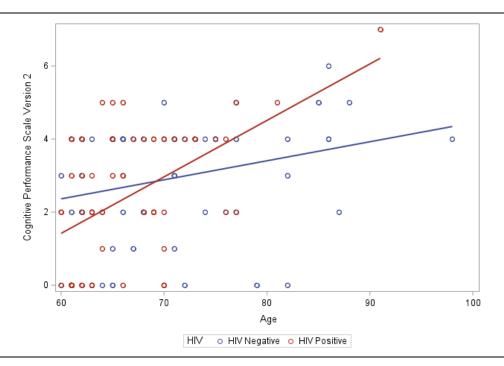
In this sample, 23.85% of participants had fully intact cognition, whereas 30.77% of individuals were borderline impaired. The largest group of participants (43.84%) were moderately impaired, and the remaining 1.54% were severely impaired. On average, HIV-negative participants were borderline impaired (Mean=2.95; SD=1.58), and HIV-positive participants were also borderline impaired (Mean=2.43; SD=1.79).

Table 4: CPS2 Frequence	cies		
Scale	Total	<b>HIV Negative</b>	<b>HIV Positive</b>
Frequency (Percent)	(n=130)	(n=60)	(n=70)
<b>Intact Performance</b>			
0	26 (20.00)	8 (6.15)	18 (13.85)
1	5 (3.85)	3 (2.31)	2 (1.54)
Borderline			
Impairment			
2	28 (21.54)	11 (8.46)	17 (13.08)
3	12 (9.23)	6 (4.62)	6 (4.62)
Moderate			
Impairment			
4	48 (36.92)	27 (20.77)	21 (16.15)
5	9 (6.92)	4 (3.08)	5 (3.85)
Severe Impairment			
6	1 (0.77)	1 (0.77)	0 (0.00)
7	1 (0.77)	0(0.00)	1 (0.77)
8	0 (0.00)	0 (0.00)	0 (0.00)
Mean, SD	2.67 (1.71)	2.95 (1.58)	2.43 (1.79)

#### **Statistical Analysis**

For cognition, CPS2 scores were categorized into two groups for analysis. CPS2 scores of 0 – 3 were categorized as Intact – Borderline Intact and CPS2 scores of 4 – 8 were categorized as Moderate – Severe Impairment (CPS2; 0=Intact – Borderline Intact, 1=Moderate – Severe Impairment). First, EDA was conducted using numerical and visual techniques, with tables and figures located in the appendices. When accounting for sample size, the frequencies for CPS2 (Table 4, Figure 6) suggest that there are very minimal differences between HIV-positive and negative participants. When CPS2 and age are plotted by HIV status (Figure 2), it is suggested that age is associated with CPS2, as there appears to be a positive linear relationship between CPS2 scores and age for both HIV-positive and negative persons.





With  $\alpha=0.20$ , the bivariate EDA (Table 12) suggested that HIV is independently associated with CPS2 (P=0.09), and that age is independently associated with CPS2 (P=0.0001). Next, with  $\alpha=0.05$ , the likelihood ratio suggested that at least one of the predictor variables HIV and age is significantly associated with CPS2 (P=0.0006). Therefore, interaction effects for HIV and age were tested. After running the model with the interaction effect between HIV and age (Table 13), it was found that the interaction term should not be included in the model

(P=0.09). By removing this variable, we were left with the main effects model, and binary logistic regression analyses were conducted.

Table 5: Odds Ratio l	Table 5: Odds Ratio Estimates for CPS2 Regressed on HIV and Age						
Predictor Variable	Point Estimate	95% Wald Co	nfidence Limits	P			
HIV Positive vs HIV Negative (Ref)	0.81	0.38	1.73	0.59			
Age	1.10	1.04	1.17	0.002			

The logistic regression produced an odds ratio of 0.81 for HIV (Table 5), which suggests that the odds of Moderate – Severe cognitive impairment is 0.19 times lower for HIV-positive persons. However, this association is not statistically significant (CI=0.38, 1.73; P=0.59). Next, the logistic regression produced an odds ratio of 1.10 for age, which suggests that for each additional year of age, the odds of Moderate – Severe cognitive impairment is 1.10 times higher. Namely, for each additional year, the odds of Moderate – Severe cognitive impairment is increased by 10%. This association is statistically significant (CI=1.04, 1.17; P=0.002).

# 4.1.2.3 Health Stability

In this sample, 21.54% of patients had no health instability, and 10% of persons had minimal health instability. The largest group of older persons (46.15%) had low health instability, whereas 13.08% were moderately unstable, and 9.23% were highly unstable. On average, HIV-negative participants had low health instability (Mean=1.82; SD=1.28) and HIV-positive participants also had low health instability (Mean=1.76; SD=1.12).

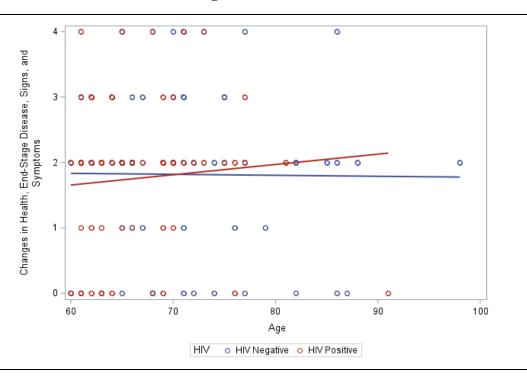
Table 6: CHESS Frequencies						
Scale	Total	HIV Negative	<b>HIV Positive</b>			
Frequency (Percent)	(n=130)	(n=60)	(n=70)			
No Instability						
0	28 (21.54)	14 (10.77)	14 (10.77)			
Minimal / Low						
Instability						
1	13 (10.00)	6 (4.62)	7 (5.38)			
2	60 (46.15)	24 (18.46)	36 (27.69)			

Moderate / Very High Instability			
3	17 (13.08)	9 (6.92)	8 (6.15)
4	12 (9.23)	7 (5.38)	5 (3.85)
5	0 (0.00)	0 (0.00)	0 (0.00)
Mean, SD	1.79 (1.19)	1.82 (1.28)	1.76 (1.12)

#### **Statistical Analysis**

For health stability, CHESS scores were categorized into two groups for analysis. CHESS scores of 0-2 were categorized as No – Low Instability and CHESS scores of 3-5 were categorized as Moderate – High Instability (CHESS; 0=No – Low Instability, 1=Moderate – High Instability). First, EDA was conducted using numerical and visual techniques, with tables and figures located in the appendices. When accounting for sample size, the frequencies for CHESS (Table 6, Figure 7) suggest that there are very minimal differences between HIV-positive and negative participants. Further, when CHESS and age are plotted by HIV status (Figure 3), it is suggested that age is not associated with CHESS, as there does not appear to be a linear relationship between CHESS scores and age for both HIV-positive and negative persons.

Figure 3: Scatter Plot for CHESS vs Age



With  $\alpha=0.20$ , bivariate EDA (Table 14) suggested that HIV is not independently associated with CHESS (P=0.27) and that age is also not independently associated with CHESS (P=0.94). Next, with  $\alpha=0.05$ , the likelihood ratio suggested that neither of the predictor variables HIV and age is significantly associated with CHESS (P=0.52). Thus, from the exploratory analyses conducted, it was identified that neither HIV nor age was significantly associated with Moderate – High Instability on the CHESS scale. Therefore, further statistical analyses were not conducted.

### **4.1.2.4 Frailty**

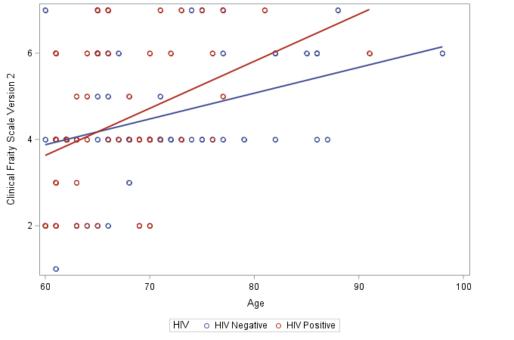
In this sample, less than 1% of participants were very fit, and only 13.08% and 3.08% were fit and managing well respectively. The largest group of older persons were living with very mild frailty (48.46%), and 5.38% were living with mild frailty. 17.69% of participants were living with moderate frailty, and the remaining 11.54% of individuals were living with severe frailty. On average, HIV-negative participants had mild frailty (Mean=4.55; SD=1.38) and HIV-positive participants had very mild frailty (Mean=4.34; SD=1.60).

Table 7: CFS2 Frequencies						
Scale	Total	HIV Negative	HIV Positive			
Frequency (Percent)	(n=130)	(n=60)	(n=70)			
Very Fit						
1	1 (0.77)	1 (0.77)	0 (0.00)			
Fit / Managing Well						
2	17 (13.08)	4 (3.08)	13 (10.00)			
3	4 (3.08)	1 (0.77)	3 (2.31)			
Very Mild / Mild						
4	63 (48.46)	33 (25.38)	30 (23.08)			
5	7 (5.38)	3 (2.31)	4 (3.08)			
Moderate / Severe						
6	23 (17.69)	12 (9.23)	11 (8.46)			
7	15 (11.54)	6 (4.62)	9 (6.92)			
Mean, SD	4.44 (1.50)	4.55 (1.38)	4.34 (1.60)			

### **Statistical Analysis**

For clinical frailty, CFS2 scores were categorized into two groups for analysis. CFS2 scores of 1 – 4 were categorized as Very Fit – Very Mild Frailty, and CFS2 scores of 5 – 7 were categorized as Mild Frailty – Severe Frailty (CFS2; 0=Very Fit – Very Mild Frailty, 1=Mild Frailty – Severe Frailty). First, EDA was conducted using numerical and visual techniques, with tables and figures located in the appendices. When accounting for sample size, the frequencies for CFS2 (Table 7, Figure 8) suggest that there are very minimal differences between HIV-positive and negative participants. When CFS2 and age are plotted by HIV status (Figure 4), it is suggested that age is associated with CFS2, as there appears to be a positive linear relationship between CFS2 scores and age for both HIV-positive and negative persons.

Figure 4: Scatter Plot for CFS2 vs Age



With  $\alpha=0.20$ , bivariate EDA (Table 15) suggested that HIV is not independently associated with CFS2 (P=0.93), and that age is independently associated with CFS2 (P=0.0005). Next, with  $\alpha=0.05$ , the likelihood ratio suggested that at least one of the predictor variables HIV and age is significantly associated with CFS2 (P=0.001). Therefore, interaction effects for HIV and age were tested. After running the model with the interaction effect between HIV and age (Table 16), it was found that the interaction term should not be included in the model

(P=0.22). By removing this variable, we were left with the main effects model, and binary logistic regression analyses were conducted.

Table 8: Odds Ratio Estimates for CFS2 Regressed on HIV and Age						
<b>Predictor Variable</b>	<b>Point Estimate</b>	95% Wald Con	fidence Limits	P		
HIV Positive vs HIV Negative (Ref)	1.60	0.70	3.66	0.26		
Age	1.11	1.04	1.17	0.0007		

The logistic regression produced an odds ratio of 1.60 for HIV (Table 8), which suggests that the odds of Mild Frailty – Severe Frailty is 1.60 times higher for HIV-positive persons. However, this association is not statistically significant (CI=0.70, 3.66; P=0.26). Next, the logistic regression produced an odds ratio of 1.11 for age, which suggests that for each additional year of age, the odds of Mild Frailty – Severe Frailty is 1.11 times higher. Namely, for each additional year, the odds of Mild Frailty – Severe Frailty is increased by 11%. This association is statistically significant (CI=1.04, 1.17; P=0.0007).

### **4.2 Phase 2: Interviews**

#### **4.2.1 Service Provider Characteristics**

In Phase Two, twelve service providers at Reach Out were interviewed to assess their perspectives on the acceptability of the Check-Up instrument. Of the twelve participants, eight were female, four were male, and all were of Ugandan nationality residing primarily in the Kampala district. The average age of participants was 38.58 (SD=9.48), the majority were married (n=8), and the remaining few were either single or widowed. All individuals also identified at least one other language spoken in addition to English, including Luganda, Luo, Swahili, and Ateso. For half of the providers, the highest level of education completed was Senior 1 – Senior 4 (lower secondary education), <sup>157</sup> three had bachelor's degrees, and two had master's degrees. Most providers also shared that they worked as community health workers or as social workers, and the remaining three worked in administrative roles. Seven participants were in their respective fields and at Reach Out for 1 – 10 years, and the remaining five for 11 or more years. Finally, most providers were based out of the Kinawataka site, with the remaining five located at either Mbuya or Banda parishes.

Table 9: Service Provider Characteristics				
Variables	Total (n=12)	Female (n=8)	Male (n=4)	
Age (Mean, SD)	38.58 (9.48)	41.88 (9.69)	32.00 (4.90)	
Nationality				
Ugandan	12	8	4	
Other	0	0	0	
District				
Kampala	11	7	4	
Mukono	1	1	0	
<b>Marital Status</b>				
Single / Widowed	4	2	2	
Married	8	6	2	
Languages Spoken				
English	12	8	4	
Luganda	8	5	3	
Luo	7	6	1	
Swahili	6	4	2	
Ateso	3	2	1	
Other	3	1	2	
Education				
Lower Secondary	7	5	2	
(S1-S4) / Other				
Bachelor's Degree	3	2	1	
Master's Degree	2	1	1	
Occupation				
Patient-centred	9	7	2	
Community Health				
Worker / Social				
Worker				
Administrative	3	1	2	
Internet Tech /				
Research				
Reach Out Site			_	
Mbuya	4	1	3	
Kinawataka	7	6	1	
Banda	1	1	0	

To analyze interviews with service providers, the TFA was used. The seven component constructs of the TFA, namely, affective attitude, burden, ethicality, intervention coherence, opportunity costs, perceived effectiveness, and self-efficacy were used to assess the acceptability of the Check-Up in the central Ugandan setting. These constructs and additional relevant findings are discussed below, with square brackets used within quotations to improve reader understanding.

#### 4.2.2 Affective Attitude

The first component construct of the TFA that was used to assess qualitative interview data was affective attitude. For assessing the acceptability of the Check-Up, affective attitude aims to identify how an individual feels about the instrument. Affective attitude was found to be positive for the Check-Up assessment, contributing well to the determination of the instrument's acceptability in the Ugandan setting. During interviews, service providers felt strongly that the Check-Up was a good tool, was both comprehensive and holistic in nature, and provided useful information to help inform clinical decision-making. While the tool was found to be difficult at the beginning for some due to the learning curve associated with using a new form of technology, individuals shared that the assessment was very easy to use and helped reduce workload by streamlining care practices. Providers also discussed the applicability of the tool to the older adult population, and their thoughts on how patients would get something positive out of it.

Of the twelve service providers interviewed, ten of them indicated that the Check-Up was a good tool. When asked what their overall impression of the tool was, one of the community health workers stated, "Wow, that tool. I can tell you it was so fantastic." In line with community health worker attitudes, one administrative provider said that:

"To me, it was a good tool. Actually, I would say it was a very good tool because it looked into things [about older adults] that sometimes we don't give so much attention [to]."

Irrespective of their roles in the organization, these providers were able to come to similar conclusions about the value of the Check-Up at Reach Out and in the Ugandan setting at large. Several participants also shared that when they began using the Check-Up instrument, it was a bit challenging. However, once they had practiced using the tool in the community, it became much easier to implement. For example, one community health worker shared that "In the beginning, it was a bit hard" and another said "for the first few people I accessed one, two, three, it was a bit difficult, it took some minutes. But after it was a good tool; it was not difficult to use actually." Several of the remaining participants, including community health workers and administrative personnel, did not share that it was difficult in the beginning, and instead simply highlighted that the Check-Up "was very easy to use" and "was easy to be administered." The ease of use discussed by different members of the care team supports the notion that the Check-Up is acceptable in this setting, as implementing the tool is not seen as a major barrier. Further, the difficulty noted by a few participants when first using the assessment highlights a potential area requiring upscaled training and opportunities for practice prior to full-scale integration of the tool.

Of the twelve interview participants, ten individuals discussed how the Check-Up was comprehensive and holistic in nature. One of the administrative providers stated that the instrument "has a number of areas that are very critical in terms of us serving the elderly" and another shared that the assessment "covered things, me personally, I would not think to give so much attention." This was considered one of the major strengths of the tool by service providers, as it allowed them to "dive deep" into the status of the elderly population they serve and determine "how they relate in the community" as well as "how they are doing psychologically, socially, emotionally, [and] physically." While providers did find that the tool gave a holistic "picture of a person's health", there were two participants who mentioned that there were "some little gaps" when asked if they thought the tool was comprehensive. Relevant gaps identified in the instrument are discussed at the end of this section.

Most participants described how the tool was useful and informative by assisting in the identification of certain health challenges older persons were facing. For one community health worker, they liked how the Check-Up "was actually addressing or trying to find out what happens with these old people" and one of the administrative providers liked how "these kinds of aspects [of the instrument are] very informative to understand how a person is." The usefulness of the tool was also captured by one of the administrative personnel when they said the following:

"I believe, with the outcome of the tool within a very small time, or within a snapshot, we shall be able to diagnose better, we shall be able to make informed decisions... and we shall be able to minimize time."

This quotation provides a clear representation of how the Check-Up can benefit Reach Out and the elderly populations they serve moving forward. Providers learned how "these questions are quite informative, and... can build up in a format to inform how their health conditions [really] are", further demonstrating the usefulness and numerous benefits of the Check-Up for healthcare providers and their patients. Next, many participants found that the Check-Up was highly applicable to the older adult population served at Reach Out. One community health worker expressed how the tool "was directed to them, particularly because that is what they are actually going through in their day-to-day life" and another shared that they liked how "all the questions which were usually in the tool, were exactly... in the day-to-day activities of the grandmothers in the community."

By making these comparisons, providers helped to demonstrate how the tool would positively function for older persons in this setting. A few additional participants also commented on the perspectives of the older persons, and how they expressed that the tool would benefit them. Specifically, one community health worker shared how the assessment "is motivating for them... so, as you talk to them, they feel there is something they are going to get from what you're assessing from them." Another shared how the older adults "really...appreciate it" and how they were excited to have someone engaging with them that was interested in supporting their health. With excitement presented from older adults regarding persons being involved in their care, these comments illuminate the current gaps in the geriatric healthcare

service model in Uganda. Namely, if the elderly population was being adequately supported, older adults would not be taken aback by health workers taking interest in their care.

A few participants commented on the straightforward nature of the assessment, which aided in the understanding of questions by older persons. Community health workers expressed how the tool "was straight to the point" and that "it was easy to get information" from participants due to how the instrument was designed. Similarly, one of the administrative providers shared how "everything is quite direct" and another community health worker highlighted how "it was really open, and the questions aren't very difficult for [the older adults] to understand." As a result, the tool was also found to help reduce the workload of health providers while simultaneously improving the care received by older persons in the community.

## **Missing Assessment Components**

In addition to the findings outlined above, several trends were also identified regarding components that providers felt were missing from the Check-Up. Namely, participants felt that there were gaps in the instrument's coverage of economic stability, living arrangement, physical environments, nutrition, languages offered, as well as behavioural, emotional, psychological, and spiritual components.

The majority of participants specified that the Check-Up did not adequately include questions on the economic stability of participants, which can have a negative impact on an individual's health. One of the social workers shared that "mainly [the Check-Up] didn't cover the parts of [the older adults] financial [circumstance], where they get their money" and another community health worker stated that "their source of income, I didn't see the tool capturing that." A couple of providers touched on the last two questions of the assessment on finances and stressors and discussed how for the Ugandan setting, these questions "do not give you in detail" the information needed to truly understand the condition of these individuals. In relation to these discussions, a few providers mentioned limitations in assessment coverage of living arrangements and household size, which can also affect financial security and support received. Many participants also mentioned how "there are missing gaps" concerning how older persons are "being supported in the community." Specifically, they were interested in knowing where these individuals obtain their income. For example, one community health worker stated:

"These grandmothers, you see... they are over 60, they have no job, they do these petty, petty business[es]. But the tool has not asked how these people get their money for their survival, or if they have any support from any good wisher[s], well-wisher[s]."

The discussion surrounding the financial stability of participants is important to note, as concerns suggest that older persons often struggle in this area. Further, potential sources may have differential impacts on their health which are important for providers to understand. In addition to this, several participants also mentioned the need to include additional questions about the physical environment where older persons reside, as this relates heavily to their accessibility to necessary goods, services, and overall health. One social worker shared that:

"The tool did not consider the different settings, in terms of the environments where they live. We have rural areas, we have towns, we have villages, we have war-inflicted areas. So, if you bring this tool to... maybe four grandmothers who are coming each from these kinds of settings, you would get... totally different feedback."

By discussing the different types of physical settings older persons may live in, this provider helps to improve understanding of how one's community may impact their health outcomes. Many participants expanded further on the reasons for these differences across settings, including access to food or health services. One community health worker shared that:

"Some of them have to move longer distances to go to government hospitals since they don't have the money to go to the private [hospitals], and it becomes a bit hard, [and] when you look at the urban areas, it's really a longer distance, compared to the areas of Kampala."

Unfortunately, it has been expressed that this is why most older persons do not access these services, and instead "they remain [in the community] and die with their diseases." This is an important finding, as it highlights not only issues with accessibility but economic stability as well as a constant need for older persons to make sacrifices about quality care and personal health. Similarly, many participants felt that the questions in the Check-Up that covered nutrition

were not comprehensive enough to truly gauge the older adult experience in the Ugandan setting. It was shared that responses may have less to do with individual-level health and hunger, and more to do with accessibility. For example, one administrative provider expressed that "the assessment didn't cover much about the food security [of older adults]" and another shared that:

"A few grand people of those 60 years... live in survival mode. Like their daily income is what determines what they are going to eat that particular day, they are not so sure about tomorrow... So, the assessment did not cover that part of nutrition."

This quotation paints a clear picture of the everyday struggles faced by Ugandan older adults, and how these experiences may impact their overall health and well-being. Further, participants expressed how an individual's food security is highly associated with their physical environment and economic stability. For example, a social worker shared that if individuals live in a rural or village setting, "food may not be a problem" as they may "have gardens" where they can access healthy foods at a low cost. However, if an individual resides in a more urban setting, they may face increased barriers to accessing nutritious foods due to cost and distance to markets.

Several participants also identified the need to offer the Check-Up in further languages in Uganda to reach more older persons in the community. Community health workers stated that "the tool has only two languages, which [are] English and Luganda", however, "in the community where we are there are those people who cannot understand English, there are those ones who cannot understand Luganda." One social worker shared that "we have people coming from different... ethnicities, and the languages are quite different", and so the two languages offered would not suffice for all older persons in the Ugandan setting. In addition to English and Luganda, service providers suggested that the Check-Up be offered in "Luo", "Swahili", and "Acholi", to help improve their reach as well as the validity of responses recorded for participants.

Lastly, a few interview participants also identified small gaps in the level of coverage in the assessment pertaining to behavioural, emotional, psychological, and spiritual well-being. When discussing the questions on the Check-Up, one of the administrative providers shared that

the assessment is "lacking quite a number of behaviour aspects that affect the health part of an individual" and another discussed how:

"It was covering about health. Yes. But health is a combination of the mental, physical, spiritual, [and] psychological... Some of those, the assessment did not cover much about them."

With these comments brought forth, it appears that the Check-Up may be missing some key components that would aid service providers in better supporting Ugandan older adults. This was particularly apparent with the lack of coverage on spiritual well-being. One community health worker shared more about how they did not see anything about spirituality, "whether they go to church [and] how they relate with God." They specified that this should be included in the assessment because "it's important also."

#### **4.2.3 Burden**

The second component construct used to assess qualitative data was participant burden. Within the TFA, burden is defined as the level of effort required from individuals to participate in an intervention. For this thesis, the burden of intervention deliverers was investigated primarily, rather than intervention recipients. The level of burden associated with the Check-Up was found to be mild by interview participants, contributing well to the determination of the instrument's acceptability in the Ugandan setting. By assessing burden, service providers identified potential barriers with the use of technology, implementation costs, and length of time to complete the assessment. Overall, the burden identified was primarily about accessing the necessary resources needed to utilize the tool, rather than the actual burden associated with applying the instrument, which was found to be low.

Several interview participants identified technological barriers associated with using the Check-Up at Reach Out. First, the number of tablets available for use by community health workers was seen as a potential barrier to reaching older adults in the community. One social worker requested that "next time you add more [tablets] because we have more community health workers who can ... do this work also, but because the [tablets] are few, also few members can use [them] in the community." Other administrative coordinators mentioned how the use of

the required technology "means that we need to train more participants in using this tool." Through using the Qualtrics survey software, most service providers also identified barriers with data collection as they were unable to go back to review or correct responses once they had been entered. One community health worker shared that for them:

"In the beginning, it was a bit hard. That what I have done, I cannot review it. It was something challenging. But after realizing that it is the way to go, I had to do it better."

There were other participants, however, who highlighted the strengths of the technology used. One administrative provider shared that:

"The good thing [is that] the tool can work without [the] internet. You download the assessment, you go to the field, gather the information, and come back."

Another community health worker mentioned how the technology "was good" as "nowadays... technology is worldwide", and individuals appreciated the opportunity to learn how to use it. These quotations showcase provider understanding of the usefulness of transitioning to more technologically based healthcare solutions, as well as their adaptability to these changes.

Next, some service providers discussed the financial burden that would be involved with implementing the Check-Up. One of the administrative leads mentioned that using the instrument "will also call for budget lines... to cover this activity" and another social worker stated that "the funds. Yes, they are needed." This, however, was not seen as a major barrier, as service providers were confident that Reach Out would be able to lobby for funds and allocate them accordingly to support the use of the Check-Up instrument. It is also important to note that several different members of the care team recognized the need for financial resources to support Check-Up integration ahead of time. This is an important understanding, as it will enable providers to adequately prepare for Check-Up use before implementation procedures are initiated.

A few participants identified the length of time required to complete the Check-Up as a barrier for both service providers and intervention recipients. For example, one of the administrative providers stated that the only issue with the Check-Up is that "it's quite long, and

if you are in a community setting, you would require a lot of time to administer it to a particular individual." However, they also shared that "if a person is in a closed setting and is comfortable and is ready to give you enough time" they believed that "it will be appropriate." These comments display how the length of time required to complete the assessment was shown to not be a huge issue for providers. In fact, one social worker shared that they "appreciate that [as] much as it's long, it is giving us a wider perspective of the client. So, that is okay." Importantly, this means providers will be more likely to take their time on the Check-Up when assessing clients, which will help to improve the accuracy of assessment results and subsequent care planning strategies.

### **4.2.4** Ethicality

The third component construct used to assess qualitative data was ethicality. To assess acceptability, ethicality aims to identify the extent to which an intervention has a good fit with the value system of an individual or organization.<sup>8</sup> Ethicality of the Check-Up was found to be particularly high among service providers, further contributing to the identification of the instrument's acceptability in the Ugandan setting.

Across each interview, all twelve participants shared that the Check-Up instrument had a good fit with the value system of Reach Out. In response to the question on whether the instrument aligned well with Reach Out's values for serving the older adult population, many providers, including social workers and community health workers, simply responded with phrases such as "Yeah, it does", "Exactly, it is really good", or "Yes, I think that the Check-Up is aligned with the Reach Out values." Some participants mentioned specific values of Reach Out that the Check-Up aligns with such as "client focus", "teamwork", improving quality of life, and the direct engagement of "clients in activities that concern them." Others discussed how the Check-Up aligned with the aims and implementation process of the Grandmothers' Project at Reach Out. Specifically, individuals mentioned this program and how the instrument would be beneficial for its objectives, mainly due to their current lack of a standardized assessment designed specifically for the older adult population.

A few participants also touched on the tools that are currently used at Reach Out to assess other populations they serve, such as orphans and vulnerable children. These providers discussed how the Check-Up aligns well with these other instruments. Markedly, it was highlighted that the

organization values these kinds of assessment tools, but that they currently do not have one designed for older persons, and instead rely on other tools which mostly lack relevant information for the elderly population. When discussing the questions in the Check-Up assessment, one community health worker stated that "some of them are like the ones we use in our Reach Out assessments. They are somehow related." While some participants mentioned the need for a few areas to be adjusted to fit better into the Ugandan setting, overall, the tool and what it aims to do was found to be very well aligned with the values of the organization. For example, it was shared by one of the administrative leads that "the tool is really a good fit. Except [for] maybe a few areas that don't fit into the Ugandan setting."

#### 4.2.5 Intervention Coherence

The fourth component construct used to assess qualitative data was intervention coherence. To assess instrument acceptability, intervention coherence works to identify the extent to which an individual understands the intervention and how it works. Intervention coherence of the Check-Up was found to be positive across all service providers, further contributing to the tool's acceptability in the Ugandan setting. Through the assessment of intervention coherence, it was determined that all service providers had a very good understanding of the Check-Up instrument's purpose, what it is meant to achieve, and how it works.

Each participant discussed how the instrument was designed "to assess the health of the old people" and how this enables service providers to "understand our beneficiaries in detail." Service providers also explained how from their understanding, the Check-Up involved identifying how individuals "live in the community when they reach their old age" and how this information can be used to "inform care" to improve their health outcomes. Furthermore, one of the administrative participants shared that according to their understanding, the instrument:

"Simplifies work and in so doing, it enables any healthcare provider[s], researchers, or practitioners, to effectively make decisions, informed decisions... to effectively diagnose or effectively support the decisions that need be taken towards the elderly populations we serve."

### **4.2.6 Opportunity Costs**

The fifth component construct used to assess service provider interviews was opportunity costs. Within the TFA, opportunity costs are defined as the extent to which values, benefits, or profits must be given up to engage in an intervention. Opportunity costs associated with Check-Up implementation were found to not be present by service providers, further supporting the acceptability of the assessment in the Ugandan setting. Across all interviews, participants were very confident that the Check-Up intervention would not interfere with other priorities or necessary activities at Reach Out. As well, several providers also shared that using the Check-Up with their older adult population is a priority and will help them to improve the care that they provide. One community health worker stated that:

"It doesn't actually interfere at all, because implementing it makes us get some information that we didn't have, or we didn't know of. So ... it enables us to actually serve the elderly people much better since we also work with some of them at the facility."

Notably, since the view of the Check-Up is that it will not get in the way of other priorities, it will be implemented and likely upscaled in this setting. In response to the question on whether the Check-Up would interfere, many other providers, including administrative personnel, a social worker, and community health workers, simply responded with phrases such as "No, I don't think so", "No. Actually, it will just help us to improve" and "No, I don't think it will interfere. It will just make us do more than what we have been doing, but it won't interfere." This is an important distinction, as it highlights how there is a similar perspective of providers, regardless of their roles within the organization.

#### **4.2.7 Perceived Effectiveness**

The sixth component construct used to assess qualitative data was perceived effectiveness. To assess acceptability, perceived effectiveness aims to identify the extent to which an instrument is perceived to achieve or to have achieved its intended purpose. Perceived effectiveness of the Check-Up was found to be positive for all service providers, contributing highly to the determination of the instrument's acceptability in the Ugandan setting. Across all interviews, participants believed that the Check-Up would achieve its intended purpose. When

asked the question of whether the tool would accomplish what it aims to do, several providers just simply responded with phrases such as "Yes, it will" or "Yes, of course". One participant also shared that they "think the Check-Up will achieve" and that it "will achieve the objectives for [Reach Out] as well." A few providers, including a social worker, did highlight that "certain areas need to be polished a bit" but they were confident that the instrument would still accomplish what it aims to do. For example, participants specified that the Check-Up "can help us to understand better... who is more at risk, and who deserves maybe more support than the other" and "it also helps us to ... prioritize."

### 4.2.8 Self-Efficacy

The seventh and final component construct used to assess qualitative data was self-efficacy. Within the TFA, this construct aims to assess the level of confidence of individuals that they will be able to perform the behaviour(s) needed to participate in an intervention. Self-efficacy of the Check-Up was found to be particularly high, further contributing to the identification of the instrument's acceptability in Uganda. Through the assessment of self-efficacy, it was determined that service providers were confident that they would be able to perform the behaviours needed to participate in the Check-Up moving forward. Namely, three trends were identified. Specifically, (i) providers were confident the Check-Up would be used at Reach Out, (ii) they were confident that Reach Out would be able to perform the tasks needed to implement the Check-Up, and (iii) they would implement the Check-Up in the community setting, at healthcare facilities, and within the Grandmothers' program.

Across all interviews, every service provider indicated that they were confident Reach Out would implement the tool moving forward. For example, one of the lead administrative participants said:

"Yes, I believe we will use the tool, which will really give us good insights [in] to our people, the people we serve, because we need to come up with programs that benefit them, but we just can't develop programs that don't target specific people, specific needs, and I believe this tool is good enough to do that."

Other participants, including a social worker and community health workers, indicated that "we can use this tool at Reach Out" and that it "would help us really a lot, to assess those elderly people." Next, all participants discussed how they were confident Reach Out would be able to perform the necessary tasks required to implement the Check-Up. When asked the question about whether they thought Reach Out would be able to effectively implement the tool, several providers just simply responded with phrases such as "Yes, very confident", "Yes they can", and "100% they can." Other participants gave much more detailed responses about the needed steps to be taken. For example, one of the social workers stated:

"Yes, I think we can implement the tool moving forward. But like, you know, of course... you don't just wake up one day and implement that tool, you need to have a plan, you need to have maybe some budget lines, and that is why I say that it is... a good basis for us to set up, maybe a project, [or] a proposal to get funds to support."

This is a very realistic understanding of the implementation process requirements for the Check-Up moving forward. Having this understanding at this stage demonstrates Reach Out's capacity to prepare and take the necessary preliminary steps for tool integration. For example, some activities were highlighted, primarily "the financial part" associated with implementation, but providers were confident that Reach Out would be able to address these activities to use the tool moving forward. One of the administrative persons stated that "based on the results, it will trigger Reach Out to... lobby for funds, in order to help", which would support the use of the tool at Reach Out and the older adult population at large.

In terms of how the tool would be implemented, nine of the providers interviewed stated that they would use the Check-up at Reach Out health facilities, but that it would be used primarily in the community by their HBC team. One administrative participant stated that "this is a tool that can cut across" and another said that "either way, it's literally important in the clinic, but at the same time it will do more good in the community." The three remaining participants indicated that the tool would be used in the community setting but did not specify whether it would also be implemented at Reach Out facilities. This is important to note for instrument acceptability, as the Check-Up was designed for use with community-dwelling older adults. Further, by using the tool primarily in the community, service providers will be able to expand

the range of older persons they serve. This will allow them to ascertain critical health information about more vulnerable members of the population that are not normally assessed, as they are unable to come into the healthcare facility. Lastly, three providers also mentioned that the Check-Up would be most useful within the Grandmothers' Project in the community setting. One community health worker stated:

"Yeah, we can use this at Reach Out, because since we are also having that program for grandmothers, it will help us to ... put in more ... details, according to the tool we have. So, we shall combine them and see how best we can help our grandmothers in the community."

Another social worker indicated that:

"We can use this tool at Reach Out. Like I mentioned earlier to you that we have a Grandmothers' Project in Luweero... and these grandmothers are quite a number that if this tool was administered to them, it would help us to get... overall interventions."

The quotations above help to demonstrate not only the confidence in the ability of Reach Out to use the Check-Up but also the similarities in thought process among different members of their healthcare team. This is supportive of tool acceptability in this setting, as relative opinions of self-efficacy are highly consistent across different service providers.

#### 4.2.9 Additional Findings

#### 4.2.9.1 Gender Differences

The presence of gender differences was also a major finding through the completion of interviews. Potential gender differences across older persons in this setting were explored in addition to the TFA constructs to further understand the acceptability of the Check-Up in Uganda, as well as potential implementation strategies. From this, several differences across male and female older adults were identified and shared by providers, which can offer insights for service provider training moving forward, as well as additional context for trends observed in quantitative data.

Across interviews, three participants mentioned that in the communities that Reach Out serves, there are more women than men, and most of their older clients are female. For example, one community health worker shared that "even in Reach Out as a whole, we have more female[s] than male[s]" and another social worker shared that "in our community, we have more female[s] than male[s] there." In addition to there being more women in the community, four participants also discussed how women are more accessible in the community than men. Specifically, one community health worker mentioned how:

"It's that women, they are reachable. Any time when you go to the community you can find them, but for men, it's hard, because, for them, they like going to the bars, they like doing other things... but for women, they are reachable and it's easy."

This is an important distinction, as it may help to explain the low sample size of males for Phase One, but also showcases potential barriers for males in accessing quality healthcare. Next, eight participants shared that the women were more engaged and more willing to take the time needed to complete the Check-Up with assessors. It was found that "Most of the people who literally gave it a lot of time were women, and men, of course, the timing was quite limited." Also, "the affirmative response and the concentration came a lot from the women." As a result of this, women were also found to be easier to work with. For example, one community health worker shared that for women, "the way they communicate is… better than the men… so, I think women, working with them is easy. Better than men."

Many participants also found that women are stronger than men, resulting in higher activity levels in older age. Specifically, two community health workers shared "You see the grandmothers... they're stronger than the grandfathers, maybe all the older men" and "women are always stronger than the men. They do more activities. They can help themselves, much better than the men." Several participants also shared that women "are overloaded with the responsibilities" referring to ADLs, whereas men obtain more assistance with these tasks due to cultural gender norms. For example, it was shared by an administrative lead that "Culturally to this setting, much of the responsibilities are given to the women" whereas for men:

"They are basically dependent on caretakers... they have caretakers to do the washing, to do the cooking for them."

Interestingly, two male participants also indicated that the questions on the assessment were primarily only applicable to women. One community health worker stated that "most questions favoured... more favoured female[s] than male[s]" and another social worker mentioned that "[the] majority part of it was only for female[s]." These quotations help to showcase the depth of these gender norms in the Ugandan culture, seeing that even some of the healthcare providers viewed ADLs as only applying to women. The last trend that was mentioned by some of the service providers was that it is easier for older persons to share information about their health and well-being with individuals who are of the same gender as them. One administrative participant shared that for:

"Those healthy and private kinds of issues, it's easy for a man to explain to a man, it's easy for a woman to explain to a woman. So, it's not about the tool, it's about who is doing the interview and who is being interviewed."

It was also highlighted that this may impact the accuracy of reporting on the Check-Up, as one participant explained how:

"If I'm a man and a woman is asking me, I may not give you genuine answers... But if it's man-to-man, yeah, I will be genuine, which means I'm giving honest answers."

The above two quotations help paint a picture of the barriers faced by Ugandan older adults, particularly males, in accessing quality healthcare. This may also have had implications for Phase One of this study using the Check-Up. Currently, at Reach Out, most community health workers who support older persons in the community are female, which was also reflected in this study for those who completed Phase One data collection. Based on the comments made, this suggests that males may have a lower comfortability with service providers, which may have also had implications for Check-Up responses, and help to explain the low male sample size in this study.

## **4.2.9.2 Benefits to Providers**

Several benefits to Reach Out service providers were also identified in qualitative interviews. Specifically, providers discussed how they were positively impacted through the implementation of the Check-Up with older persons in the community. For example, some participants mentioned the benefits they received from learning how to use a new form of technology. As well, numerous comments were also made on how the tool allowed them to go into the community and see the population they serve, which enabled providers to not only learn about the issues they face but also about the older adult experience in general. Rather than just learning about the individual experiences of the elderly, participants described how using the Check-Up opened their minds and provided them with an opportunity to learn things about older people that they did not know before. For example, one community health worker stated:

"What I liked from the tool [was] I got to know what I didn't know before, what elderly people go through. Like some were saying they were constipated... which I didn't know before. That's what was so interesting because the elderly people were open to us."

Various health conditions were also identified as areas that providers were not previously aware of as being a part of the older adult experience. One community health worker shared:

"[I] didn't know that old age [could] bring all that dizziness and vomiting at the same time, and loss of appetite. But in this assessment tool, really all of this has come out."

They also discussed terminology, and how the Check-Up equipped them with a higher vocabulary on the experience and conditions of older persons. For example, the lead social worker for the project discussed how:

"We got to learn new things, actually, they are not new, but maybe they are a little new to the team about Alzheimer's disease and... the different situations of the elderly... So now we know... when someone talks about Alzheimer's, we know what they mean, we know what dementia means."

The above two quotations are highly important, as they highlight the limitations in the training received in geriatric care by community health workers and other providers. With comments made by the clinical lead for the project about how even they learned new things through the assessment, this points to a gap in training for all personnel, including team members responsible for heading up the care and support of older persons. This is an important distinction, especially with aims to provide self-sustained capacity training moving forward. These findings also further characterize the gaps in care received by older adults in Uganda, as their primary providers lack a comprehensive understanding of their conditions, their experience, and the issues they face more generally.

# 4.2.9.3 Health Status of Older Persons

Through qualitative interviews, the low health status among the older adult population in Uganda was characterized. Nearly all providers shared something about the poor living conditions, vulnerability, and ill health of the older persons they interacted with in the community. One of the social workers stated that "in our country as a whole... generally the condition of our grandmothers is not good" and an administrative lead mentioned how "most of them are left undiagnosed, untreated, [and] unknown." Another community health worker discussed how:

"Though we have positive grandmothers whom we are following at Reach Out Mbuya, there are a majority of negative grandmothers outside that are crying for help, but they can't get it."

The above quotations are particularly concerning. Markedly, these comments help to demonstrate the numerous challenges experienced by both HIV-positive and negative older persons in this cultural context, as well as the substantial need for more integrated, personcentred geriatric care practices. Further, these findings point to significant system-level barriers in the provision of senior-friendly care for older adults in Uganda, and the active role that the interRAI Check-Up can play in addressing these gaps moving forward.

### **CHAPTER 5: DISCUSSION**

**5.1 Phase One: Check-Up Instrument** 

#### **5.1.1 Health Status of Older Persons**

The findings from Phase One showcase the high degree of sickness and overall health challenges faced by the older Ugandan population. Through completion of the Check-Up assessment, it was found that participants in this sample had high levels of ADL impairment, cognitive impairment, health instability, and frailty. For example, over 50% of participants had some form of ADL impairment, only 24% had fully intact cognition, nearly 80% had some form of health instability, and 85% were living with frailty. Notably, these findings were also consistent with results from Phase Two, where service providers shared that the condition of older persons is not good, that they are "left undiagnosed, untreated, [and] unknown', and how they are "crying for help, but they can't get it." Together, presented scores and discussions held with Reach Out service providers help to demonstrate the need for a more integrated and targeted program for older persons living in the Ugandan setting.

# **5.1.2 HIV Status Similarities**

For the main outcome variables examined in this study, namely, ADLs, cognitive function, health stability, and frailty, it was found that there were no statistically significant differences between HIV-negative and positive participants. Through consultation of key literature as well as Reach Out service providers, several factors were identified which may have influenced these characteristics. First, the impact of age is considered. While the Ugandan population is aging, the relative age of their older adult population remains relatively young. Of 1,430,577 older persons aged 60 or higher reported in 2014, the vast majority fell between the ages of 60 - 64 (n=440,053) and 65 - 69 (n=301,150), and only 130,396 persons were aged 85 or more. This was also represented in our study findings.

Of the 130 participants in our sample, only 25 persons were over the age of 75, and only 8 persons were over the age of 85. This may have had considerable impacts on HIV-associated health declines, as this has also been shown to have an age-related component. For example, in the final report for the UPHIA for 2016 - 2017, a positive correlation was found between the age of participants and the overall burden of HIV infection reported. Further, in a study that

reported a strong association between HIV and the frailty-related phenotype, findings were most pronounced among participants with high viral loads and older age. <sup>39,46</sup> Thus, it is possible that because of the low life expectancy, average population age, and age of participants in this sample, HIV-associated health declines are not yet fully present or observed in this cohort. It is also possible that due to the low sample size, there was not enough power in the study to observe these differences in HIV-positive and negative participants.

Next, with strong adherence to ARTs at Reach Out as individuals age with HIV, the majority will achieve optimal viral suppression. <sup>159</sup> Viral suppression is characterized by "having less than 200 copies of HIV per milliliter of blood." <sup>160</sup> Markedly, a study conducted at Reach Out found that age and adherence were significantly associated with viral suppression. <sup>159</sup> Further, the World Health Organization and Centers for Disease Control and Prevention have reported that high ART retention and subsequent viral load suppression can prevent morbidity and mortality, and help persons living with HIV to stay healthy and maintain functioning. <sup>160,161</sup> As these trends were observed for the elderly population Reach Out serves, HIV-positive participants in this study have likely achieved high viral suppression, thus possessing similar health characteristics to their negative counterparts. Overall, this study has revealed that older persons in this setting are very sick, regardless of HIV status. Notably, the poor overall health status of older persons may have also contributed to the lack of differences observed across HIV-positive and negative participants. Namely, the high level of impairment in older adults and low sample size may have masked any effects of HIV, or differences across the two groups.

In Phase One, healthcare service use was also found to be similar across HIV-positive and negative participants. In the Check-Up, healthcare service encounters are characterized by question **H1** which asks, "*In the last 90 days, how many times did you use the following healthcare services?*" However, participants can only refer to encounters with the hospital, emergency department, physicians, and nurse practitioners in their response. It is widely recognized that these are not the traditional ways in which older persons in Uganda access healthcare services. Notably, older Ugandans often rely on community outreach and visits from community health workers to access care.<sup>2</sup> As a result, the assessment failed to identify the degree to which interactions occurred with health services for older adults through community health workers and Reach Out's HBC team.

These encounters have critical implications for older persons. For example, it has been shown that more frequent encounters with primary healthcare are associated with improved health outcomes. Therefore, due to the targeted nature of Reach Out's HBC team, it is possible that HIV-positive older persons have more frequent encounters with health providers, and thus, reduced levels of HIV-associated health declines. This may help to explain the similarities across the two groups, as HIV-positive persons at Reach Out are more frequently assessed compared to HIV-negative older persons, and as a result, receive more effective care planning strategies. It is therefore recommended that interactions with community health workers also be added to question **H1** in **Section H: Procedures / Treatments** on the Check-Up:

# H1. In the last 90 days, how many times did you use the following health care services? Enter "0" for no visits.

a.	Inpatient	hospital	with	overnight	stay		

- b. Emergency room visit (not counting an overnight stay)  $\Box\Box$
- c. Visits with a doctor or nurse-practitioner  $\Box\Box$
- d. Visits with a community health worker  $\Box\Box$

This will enable service providers to better assess these encounters moving forward, and further prioritize care for older patients.

# **5.1.3** Age-Related Associations

Through statistical analyses, an age-related association was identified for participant ADLs, cognitive performance, and clinical frailty. Notably, it was found that the odds of having higher levels of impairment for each of these outcomes increases with age. These findings are consistent with relevant literature, where ADLs, cognitive performance, and frailty have all been shown to naturally get worse throughout the life course. Markedly, this helps to demonstrate the construct validity of the Check-Up instrument in this setting, as expected results have been observed in our study sample.

Construct validity evaluates whether an instrument truly represents what it aims to measure, and can be further defined as the extent to which participant results represent true

findings among similar persons outside of the study. <sup>166,167</sup> This is further broken down into internal and external validity. <sup>167</sup> Internal validity refers to how well the observed results represent the truth in the population being studied and are therefore not a result of methodological error. <sup>167</sup> In this study, the internal validity of findings was supported through close examination of and comparison to the Grandmothers' Project Assessment Report for 2020. In this report, the vulnerability status of beneficiaries was described. Notably, this revealed an age-related association, in which members of the program were found to be more susceptible to critical vulnerability the older they became. <sup>2</sup>

The health and well-being of beneficiaries in the program were also assessed, which too appeared to have an age-related component.<sup>2</sup> For example, the majority of elderly persons were found to be experiencing illnesses impacting their health status and physical well-being.<sup>2</sup> Further, it should be noted that the Grandmothers' Project supports predominantly older females in the community, which was also reflected in our study sample. While this report is limited in its direct reporting of specific outcomes assessed for this project due to minimal research conducted in this population, parallels can be drawn between participant health and age-related findings to the ones within this study.

External validity refers to the generalizability of research findings. <sup>167</sup> For this study, external validity is supported by the examination of findings concerned with ADLs, cognitive performance, and frailty from several research projects conducted in other cultural contexts. A considerable body of research has shown that increasing age is highly associated with ADL impairment. <sup>112,118,163,168,169</sup> For example, from 1996 to 2017, the prospective Manitoba Follow-Up Study examined functional impairment in a cohort of aging men and identified a strong linear relationship between participant age and ADL impairments. <sup>163</sup> Further, the Survey of Health, Ageing, and Retirement in Europe found that declines in ADLs and IADLs significantly increased with age across both male and female participants. <sup>164</sup> In addition, there is also reported socio-cultural acceptance in Uganda that illness and disability are a natural part of aging. <sup>31</sup>

Research across African nations and several other diverse global regions has also identified a significant association between age and cognitive impairment. <sup>135,170,171</sup> A study that examined the first follow-up of the Health and Aging in Africa: A Longitudinal Study of an INDEPTH Community in South Africa (HAALSI) dataset found that older age was associated with a higher incidence of cognitive impairment. <sup>135</sup> Notably, these findings indicated that in

South Africa, cognitive decline impacts a meaningful proportion of older persons as they age. <sup>135</sup> This was also identified in a study of elderly persons in Djidja Benin. <sup>170</sup> Finally, as a geriatric syndrome, frailty has also been continuously shown to have a strong age-related component. <sup>140,142</sup> The Medical University of South Carolina has reported that frailty occurs as a result of aging and that it is defined by linear age-related deficits. <sup>172</sup> For example, one study that assessed older persons in Ghana, South Africa, India, China, Mexico, and Russia found that frailty increased with age in all countries. <sup>165</sup> However, it should be noted that due to the low sample size of males for this thesis, external validity cannot be fully determined, and additional research is required to fill this gap.

The identification of similar and expected age-related findings in this study helps to further support the acceptability of the Check-Up in this cultural context. Namely, by having findings from the Grandmothers' Project Assessment Report, several African nations, as well as other global regions also be presented in our data, this helps to showcase the validity of the responses provided by participants, and of the Check-Up instrument in this setting. Overall, this helps to display the potential of this tool at Reach Out moving forward, highlighting the benefits it can provide to the older adult population they serve. Contradictory to other outcome variables, an age-related association was not identified for health stability. In particular, age and health stability were not found to be statistically significantly associated. This can be explained in part by participant sourcing and recruitment procedures for this project.

Apart from age, the physical environment and socioeconomic characteristics of individuals play a critical role in their health. <sup>173</sup> Specifically, participant CHESS scores may be a reflection of who is provided access to a specialized program or study. In consideration of what goes into health instability (i.e., shortness of breath, changes in cognitive function, weight loss, etc.), if individuals are admitted to the program because they are failing, we would not expect much of a difference in this measure. <sup>101</sup> For this sample, participants were recruited from urban slum communities in Mbuya, Kinawataka, and Banda, and in these environments, service providers have identified that there are very minimal differences in the socioeconomic statuses of older persons. Notably, low variation in health stability across the age of participants could be attributed to this.

### **5.2 Phase Two: Interviews**

# **5.2.1** General Acceptability

In Phase Two of this thesis, the acceptability of the Check-Up assessment in central Uganda was demonstrated. Across each interview with service providers, all participants indicated that they were confident that the Check-Up was acceptable to be used in the Ugandan context. With a few minor adjustments, service providers demonstrated how the tool would obtain a high level of acceptability in this setting and be better equipped to inform care planning practices for the older adult populations they serve.

# **5.2.2 Recommendations**

Throughout qualitative interviews, service providers critically reflected upon Check-Up components and identified key areas where there were missing gaps of information as well as potential barriers to implementation. First, providers were very adamant about increasing Check-Up coverage of economic stability and food security. These factors can have major impacts on the daily lives of older persons, and an even larger effect on their overall health. Across the African continent, poverty is a pervasive problem that disproportionately impacts older persons. Recognized as a multidimensional issue, poverty encompasses not only financial insecurity, but also poor education, inadequate nutrition, low familial support, poor access to healthcare interventions, environmental challenges, and high levels of stress. 174–178

In the Africa Aging Report for 2020, it was found that in certain African countries, 9 out of 10 older persons lack formal education, and approximately 50% live in households in the bottom two wealth quintiles. <sup>176</sup> Notably, the extensive levels of poverty experienced by aging African adults can lead to accelerated rates of age-related illnesses and diseases. <sup>178</sup> Similarly, in Uganda, due to widespread deprivation across the entire population, the vast majority of older adults are poor and live in impoverished households. <sup>31</sup> With consistent historical shocks, inadequate healthcare, as well as a heavy reliance on low incomes throughout the life course, poverty is often exacerbated in older adulthood for Ugandans. <sup>31</sup> Poverty in old age has also been shown to be highly gendered across the nation, with women fairing worse as a result of cultural restrictions on economic decision-making power, and an inability to accumulate resources. <sup>31,179,180</sup>

The economic circumstances of older persons are central to the opportunities and challenges facing Africa's aging population. <sup>176,181</sup> Across high-income nations, the prevalence of employment later in life is dependent upon statutory retirement and formal pensions. <sup>176</sup> For example, in North America, virtually all older persons above the statutory pensionable age, typically set at 60 – 65, are covered by this income security, which results in lower rates of labour force participation in older age. <sup>182</sup> Comparatively, across African nations South of the Sahara, less than one-quarter of older persons are covered by a pension who are above the statutory retirement age. <sup>176</sup> Unfortunately, the bulk of labour in African nations continues to be informal, and available retirement and pensions only cover a small proportion of older adults who had worked in the formal economy. <sup>176,183</sup> These challenges are also present for the elderly population in Uganda. For example, the Senior Citizen's Grant which was introduced in 2010 was only made available for 15 of 112 districts and was set at only 25,000 UGX. <sup>17,19</sup> Further, without any form of income security, many older persons in Uganda are forced to engage in labour-intensive work for low pay, stripping them of their right to age in dignity. <sup>31,184</sup>

As a result of these challenges, the final two questions on the Check-Up assessment, II and I2, which ask about financial trade-offs and major life stressors, were specifically discussed by providers during qualitative interviews. The consensus from these discussions was that service providers felt these questions did not provide any useful additional information for the Ugandan context. This was due in part to the belief that financial trade-offs and major life stressors are not uncommon for older adults in this setting, and thus, they would expect most individuals to answer yes to both questions. This is particularly important, as observing this finding across a larger subset of the population would help to highlight challenges faced by older Ugandans and enable more appropriate policy formulation and resource allocation to take place. Further, before offering recommendations for the most appropriate presentation or adjustment of these questions, additional research is also needed. Thus, to address barriers identified in older adults supporting themselves financially, it is recommended that an additional question be added to Section I: Finances and Stressors, to better gauge the economic stability of elderly persons in Ugandan communities. Namely, it is recommended that a question be added that aims to determine where older persons obtain their finances:

### I3. What is your primary source of income? $\Box$

- 1. Personal labour
- 2. Government aid
- 3. Familial support
- 4. External support/sponsorship
- 5. Other

Identifying primary sources of income among older persons is important for service providers to note, as each can differentially impact their health. For example, an older adult participating in manual labour for their primary income who is exposed to more dangerous work conditions will have a much different experience compared to an individual in a sponsorship program. Notably, having a question that ascertains this information was discussed by several providers, as they felt that this was important to know for allocating resources and streamlining care practices. Thus, through the addition of question **13**, providers will be better equipped to assess the financial security of older persons in Uganda, in conjunction with questions on participant living arrangements which are discussed next. This is an important consideration, due to higher rates of informal economic contributions which have been found among the geriatric population in Africa towards dependents.<sup>176</sup>

Living arrangements and household size were additional areas that some providers felt were not adequately covered for this setting. Household size refers to the number of persons living together in a private household. <sup>185</sup> In the Status of Older Persons Report for 2014, it was found that among households headed by older adults, 57.8% had at least four people residing there, most of whom were dependents. <sup>17</sup> In Uganda, dependents include individuals who often rely on older persons for aid and support, including grandchildren, orphans/vulnerable youth, other older adults, and persons living with disabilities. <sup>17,186</sup> As a result of the HIV/AIDS epidemic, many families in Africa have been left without a middle generation, leaving grandchildren to be cared for by grandparents. <sup>176</sup> For example, among older adult-headed households in Uganda in 2014, it was reported that 67.2% had at least one orphan as a dependent in the home, increasing economic strain and caregiver burden experienced. <sup>17</sup> Importantly, the odds of extreme poverty in older persons is much higher for those living in these skippedgeneration households. <sup>31</sup> Due to the complexities of the household structure of older adults in Uganda, Check-Up question **A9** which asks, "who do you live with now?" with the available

responses does not suffice to characterize their true living arrangement. Thus, it is recommended that this question be modified to include grandchildren as a potential response option:

# A9. Who do you live with now? $\Box$

- 1. Alone
- 2. With spouse/partner only
- 3. With spouse/partner and other(s)
- 4. With child (not spouse/partner)
- 5. With grandchild(ren) (not spouse / partner)
- 6. With parent(s) or guardian(s)
- 7. With sibling(s)
- 8. With other relative(s)
- 9. With nonrelative(s)

Next, it is also recommended that an additional question be added to this section of the Check-Up which asks older persons to report their household size:

# A10. What is your household size? (i.e., yourself included, how many people currently live in your home) $\Box$

- 1. One person
- 2. Two persons
- 3. Three persons
- 4. Four or more persons

The recommended adjustment to question **A9** and the addition of question **A10** will allow providers to better assess levels of dependency, as well as potential avenues of support for older persons within the household. Further, while conducting service provider training for Check-Up implementation, it was also identified by all providers in attendance that question **A8** which asks, "where do you live now?", did not have applicable response options (e.g., long-term care facility) for older adults in the Ugandan setting. This was reflected in the responses received in Phase One, as only three of the available options were utilized, one of which only had one response

which may have resulted from error. Notably, providers highlighted that question responses should be adjusted to the following to better characterize the type of housing:

# **A8.** Where do you live now? $\Box$

- 1. Temporary housing
- 2. Semi-permanent housing
- 3. Permanent housing

Through modification of question **A8**, providers identified that responses would be much more informative and that they would be better equipped to assess the overall risk and stability of older persons in the community. Next, the physical environment was also found to be an area that was not adequately covered for the Ugandan setting. The physical environment where older persons reside can have significant impacts on individual-level health and well-being. For example, relevant literature has shown that seniors face increased barriers to accessing quality care resulting from transportation requirements, distance, and service availability. <sup>112,187</sup> Notably, a study conducted in South Africa found that older persons experience increased barriers through lower means of transportation and higher levels of distance between healthcare facilities and places of residence. <sup>103</sup> Further, environmental issues such as poor sanitation, toileting, and hygiene practices may also affect their health. <sup>178</sup>

For the Ugandan population, service providers have identified four major physical environments where an older person may reside which can differentially impact their health. Environments identified included towns/urban areas, rural settings, villages, and war-inflicted areas. Across African regions, a substantial proportion of older persons are concentrated in rural settings, resulting from urban migration of the younger generation, and the return of older migrants who have aged. <sup>176,188</sup> In 2014, 82.2% of Uganda's older adult population aged 60 and over lived in rural areas of the nation. <sup>176</sup> However, while remaining primarily rural, African older adults are urbanizing, just at more gradual rates compared to the rest of the population. <sup>176</sup>

The everyday challenges experienced by the elderly population are partially dependent on their environmental location. For example, across several interviews, service providers identified how older persons in a village setting may face barriers with distance to health services, whereas persons living in an urban town may be close to health facilities but experience challenges with the cost of services and nutritious foods:

"Some of them have to move longer distances to go to government hospitals since they don't have the money to go to the private [hospitals], and it becomes a bit hard, [and] when you look at the urban areas, it's really a longer distance, compared to the areas of Kampala."

In the Status of Older Persons Report for 2014, differences were identified in the degree of distance to health facilities across urban and rural households headed by older persons. <sup>17</sup> In urban settings, 81.4% of households were less than 5km away from the nearest public health facility, and 80.5% were less than 5km away from the nearest private health facility. <sup>17</sup> In comparison, only 61.9% of rural households were less than 5km away from the nearest public health facility, and only 50.3% were less than 5km away from the nearest private health facility. <sup>17</sup>

The findings outlined above are important, as they point to additional barriers being faced by older adults in rural communities in accessing healthcare. However, it should be noted that these findings did not take into account whether older persons access these services, nor did they include residences of older adults who were not household heads.<sup>17</sup> Thus, the number of older persons using these services is likely much lower than the numbers reported, regardless of relative distance to facilities. In addition to issues identified with healthcare service accessibility, the 2014 Housing Census also revealed that in urban areas, there was a higher proportion of literate older adults (52.4%) compared to those in rural settings (35.3%).<sup>17</sup> For example, Kampala was found to have the highest proportion of literate older persons at 78.3%, whereas Karamoja, a rural sub-region in Uganda, had the lowest proportion at a mere 8.1%.<sup>17</sup> Notably, this highlights additional differences concerning the access to education among rural and urban settings in Uganda, which has important implications for poverty and overall health. Thus, it is recommended that prior to Check-Up implementation, an additional question be added to Section A: Identification Information which ascertains the physical environment the participant currently resides:

# A11. Which of the following environments best characterizes where you currently

#### live? □

- 1. Town/urban setting
- 2. Rural setting
- 3. Village setting
- 4. War-inflicted area

While there is some overlap in the available responses (e.g., rural setting versus village setting), these distinctions are important to characterize for healthcare providers when assessing the needs of elderly persons in the community setting. The addition of this question to the Check-Up will help service providers to better assess risk and align resources for older persons in the community by identifying their level of accessibility to relevant services.

In addition to the discussion around the physical environment, the available languages the Check-Up was offered in were also found to not be comprehensive enough for the Ugandan setting. It has been reported that in areas of social organization and language, countries across the African continent have much higher levels of diversity than European nations. <sup>189</sup> This is particularly true for Uganda, which has 112 districts with a high degree of socioeconomic, geographic, and cultural diversity. <sup>17,31</sup> For example, the 2014 Status Report for Older Persons identified 65 tribal groupings in Uganda, as reported in the 1995 Constitution. <sup>17</sup> As a result, while English is an official language of Uganda, there are numerous other languages spoken across the nation, which can present a challenge for older adults in receiving quality healthcare due to low language proficiency and higher rates of illiteracy. <sup>190</sup> According to the 2014 National Population and Housing Census, only 38.2% of older persons in Uganda are literate, with a greater proportion of literate males (56.8%) compared to females (24.2%). <sup>17</sup>

For this thesis, a front and back translation of the Check-Up into Luganda, the most widely spoken Indigenous language in the Kampala district, was completed. However, during qualitative interviews, service providers identified local languages of Luo, Swahili, and Acholi that would be beneficial to have the Check-Up available in for Ugandan older persons. Making the Check-Up available in more diverse cultural languages will help older persons to overcome barriers to accessing healthcare in Uganda. Regardless of fluency in the participant's selected language, due to the nature of the Check-Ups design, healthcare providers will be able to deliver

assessment questions, and easily interpret the results produced. Ultimately, this will allow older adults to receive more appropriate quality care, irrespective of existing language barriers between them and healthcare providers.

It is therefore recommended that the Check-Up undergo a front and back translation into the languages identified by service providers using the following procedure. First, as there is a Swahili version of the Check-Up through other projects being initiated by interRAI, this version would be easy to access and adjust for use in Uganda. Next, as was specified by service providers, to accommodate the largest proportion of additional older persons in the community, the Check-Up should undergo a front and back translation into the most applicable Luo dialect. This should then be followed by Acholi using the same process to further cater to community-dwelling older adults.

The final component-related findings discussed by providers involved gaps in the Check-Ups coverage of areas such as spirituality. As mentioned in the previous section, Uganda has a very diverse culture, encompassing tribes, traditions, beliefs, religion, and value systems. For older persons living in Uganda, religious groups and non-governmental organizations are particularly important, holding strong ties to additional support available for the elderly population. For example, Reach One Touch One Ministries (ROTOM) is a non-profit Christian organization that provides support to older persons living in Uganda. Notably, ROTOM aims to improve the health of older adults, reduce the burden of their dependents, improve their food and income security, as well as increase awareness of the current needs of this population. From this, it is evident that individuals with higher ties to such institutions may be at an advantage for their overall health and well-being through additional support received. Thus, pending the degree of the interRAI allotment of 5% variability, it may be of benefit to include an additional question on the Check-Up about spirituality and/or religious affiliation.

The distinction of affiliation may also be of importance, due to increased barriers faced by more marginalized religious groups in the nation, such as Islam.<sup>192</sup> For example, Muslims in Uganda constitute only 13.7% of the population and experience high levels of marginalization and a narrowing of opportunities across the country.<sup>190,192</sup> As such, aging Muslims in Uganda may experience additional barriers to accessing quality healthcare as well as poorer health outcomes in older age. However, prior to the addition of any questions concerning spirituality or

religious affiliation, this area should be further explored, as disclosure of this information may have unintended negative impacts on this population.

Moving away from component-related recommendations, the following sections highlight several suggestions which can help to better support the sustainability of the Check-Up in the Ugandan setting. First, during stakeholder interviews, healthcare providers identified technological barriers to Check-Up implementation. Specifically, providers outlined potential limitations with having access to enough tablets to adequately implement the Check-Up in the community. For this project, Reach Out was equipped with ten tablets for data collection purposes. Of the tablets used, two were approved to remain at the organization for use moving forward, and eight tablets were returned to researchers. As there is a large network of community health workers at Reach Out, and larger groups of these individuals travel to the community to support clients, it would be most beneficial for providers to have access to enough tablets to allow everyone to use them simultaneously. Further, it was also shared that even with the ten tablets that were made available for Phase One, additional tablets would have enabled health workers to recruit and assess more participants in the community. Thus, it is recommended that Reach Out be equipped with additional tablets that can be retained permanently to support the integration of the Check-Up assessment.

Next, participants also discussed the burden associated with the Qualtrics survey software that was used for data collection. While this software was selected for numerous research purposes, providers identified challenges with the inability to review and correct responses once they had been entered. Further, using Qualtrics also meant that service providers were unable to access person-level assessment results immediately following Check-Up completion, as this software is not set up with the proper metrics to calculate relevant scales and CAPs. It is therefore recommended that Reach Out be equipped with the appropriate access to the commercial-grade software offered by RAIsoft. This will allow them to input participant data, adjust responses as necessary, as well as gain immediate access to scales and CAPs once the assessment is completed. This will also enable providers the ability to monitor patients on an ongoing basis, complete necessary follow-up assessments as required, and pool assessment results at the organizational level to inform more broad healthcare system planning.

Lastly, while challenges were present with Qualtrics, providers did also highlight the strengths of using this software in its ability to work in the community without access to the internet. This is a key priority in the Ugandan setting and at Reach Out specifically, as the majority of support provided to older persons is done through community outreach rather than in healthcare facilities.<sup>2</sup> This was the main motivator for selecting Qualtrics for data collection procedures, as surveys can be accessed and implemented offline. Thus, it is recommended that the RAIsoft permissions granted to Reach Out contain an offline feature so that providers can use the instrument in the field without requiring internet access. Then, once assessors return to Reach Out facilities, assessments that were completed offline in the field will be automatically uploaded to the organization's secure health record system.

# **5.2.3 Service Provider Training**

Through the conduction of stakeholder interviews and the initial training session for this project, the lack of focus on and training delivered to health service providers on geriatric care in the Ugandan setting was highly evident. Notably, these findings point to significant healthcare system limitations for adequately serving this population, as a lack of prioritization of elderly care needs is displayed. Across African nations, there is a considerable lack of health human resources, further compounded by inadequate levels of training and expertise in geriatrics. 193,194 In 2019, a study conducted in Uganda found that there was low readiness to provide geriatricfriendly care in public health facilities. This was attributed to a lack of human health resources with skills in geriatrics, low levels of geriatric leadership and departments in hospitals, a lack of relevant health information systems to monitor elderly care needs, as well as minimal funding availability. An additional study in Uganda also identified gaps in geriatric healthcare competencies among nurses at all levels. 195 Notably, these barriers were found to be a result of several factors, including a lack of elderly care training in the nursing curriculum, an absence of clinical care guidelines and integrated geriatric care practices, low communication skills in the senior care setting, negative attitudes of nurses toward the elderly, as well as limited trainers available with skills in geriatrics. 195

Across African regions, countries like Uganda rely heavily on contributions made by lay health workers to support older adults in the community.<sup>2</sup> Particularly, for this project, the Check-Up was administered to older persons in the field by lay community health workers at Reach Out. While these individuals did undergo a full-day training prior to assessment implementation, it became clear during this session and subsequent provider interviews that there

were still significant gaps in basic-level knowledge needed to utilize the tool effectively moving forward. This was also evident for other members of the care team, including project coordinators responsible for overseeing research activities in the community. For example, a few providers demonstrated a lack of basic understanding of certain geriatric conditions and diseases, including dizziness, vomiting, dementia, and Alzheimer's disease. These findings are particularly concerning, as they come from team members who are primary care providers for older persons in the community.

First, it is important to consider the relevant background of service providers at Reach Out who will be supporting older adults using the Check-Up. Notably, this can affect not only the knowledge they hold about the relevant experience and care needs of the geriatric population but can also impact the way they interact with older persons in the community. Providers working with Uganda's elderly population should have a good standing in the community, have strong interpersonal communication skills, as well as have the capacity to build trust with the older persons they serve. It is also imperative that providers involved in assessment implementation have an adequate base level of knowledge and skills in geriatrics and Check-Up procedural guidelines to allow for appropriate use of the tool moving forward. Thus, all providers, inclusive of community health workers, clinicians, administrative personnel, and team coordinators, should be trained in the following key areas prior to integration: cultural competency; consent and patient confidentiality; Check-Up assessment components and facilitation protocols; and emergent medical scenarios.

Employing effective training procedures means that providers will be better equipped to serve the elderly population, both while using the assessment, and during separate healthcare interactions moving forward. In addition to these procedures, team coordinators should undergo additional training in cultural competency, geriatric care, and research protocols. This will allow them to better prepare for the supervision of team members to (i) ensure that data protocols are followed, and data quality is upheld, (ii) ensure assessments are being completed accurately and efficiently, and (iii) to better equip them to deliver required capacity training with team members moving forward. This ability for coordinators to deliver ongoing capacity training will be key for Check-Up integration to ensure that knowledge and understanding of how to properly use the tool is not lost.

Next, through interviews, it also became clear that there are prominent gender norms in the Ugandan setting that can impact how the assessment is used and understood. Gender differences have large implications for the provision of health services as well as the overall well-being of the older adult population. For example, women in Africa have been shown to have longer life expectancies than men, and this is also true in Uganda. <sup>17,176</sup> As a result, women are more likely than males to survive to widowhood and experience multimorbidity associated with aging. <sup>17</sup> Further, for Ugandan men, the impact of masculine identities has been shown to increase barriers to HIV testing, treatment, and drug adherence to avoid threatening societal gender norms which has crucial implications for their overall health. 196 From these examples, it becomes clear that gender differentially impacts the way that men and women interact with the health system in Uganda. Thus, cultural gender norms must be considered when developing service provider training so that this understanding can be reflected in the work done in the community. For example, one of the differences providers identified was that older persons feel more comfortable discussing their health and potential challenges with providers of the same gender. Markedly, this may help to explain the low sample size of males in Phase One, as there were significantly more female assessors in the field for this project compared to males.

It is critical that service providers be sensitized and adequately trained on the presence of gender norms in this community, as well as their relative implications for Check-Up integration and healthcare service use. Therefore, where possible, it is recommended that patients be matched with providers they feel most comfortable with. From the findings discussed above, this suggests pairing older persons with providers of the same background or similar experience (e.g., gender, age, culture, etc.) to encourage participation and accurate reporting. Further, it is also recommended that assessors work in teams of two, composed of one female and one male. This will allow for some flexibility to accommodate patient preferences, as well as lend additional security to providers in the community. Lastly, to implement this procedure, it may also be beneficial for Reach Out to recruit additional male community health workers to support not only Check-Up implementation but also the provision of care to older males in the community moving forward.

### **5.2.4 Framework Appropriateness**

The TFA was highly beneficial in its ability to determine the overall acceptability of the Check-Up intervention for the central Ugandan setting. With the comprehensive and holistic nature of the seven component constructs, this framework enabled acceptability to be assessed on multiple levels through conversations with service providers. Further, the availability of the general TFA questionnaire guide was also highly useful for this project. This made the process of designing relevant interview questions and analyzing qualitative results very straightforward. However, while the TFA was effective overall in guiding the assessment of the acceptability of the Check-Up, there were some areas identified where adjustments could be made to better assist researchers with the use of this framework for similar projects moving forward.

First, the findings discussed in the previous section suggest that the TFA is unable to identify gender differences for both providers and patients. For this project, the presence of gender differences was seen as a key component of instrument acceptability. However, this was not covered in the component constructs of this framework, nor the available guide for the development of interview questions. Thus, additional questions were included in the interview guide for this study to assess potential differences which fell outside of the lines of the framework. Second, the TFA was also limited in its ability to detect gaps in intervention deliverer knowledge required for implementing the tool effectively. For example, in this project, it was identified that Reach Out providers gained several benefits from implementing the Check-Up. However, this reflects the extent to which the Ugandan healthcare system fails to adequately train service providers in geriatric care, which may have negatively impacted how they implemented the tool in the field.

### **CHAPTER 6: CONCLUSION**

### **6.1 Summary of Main Findings**

This thesis employed a mixed methods approach to investigate the care planning needs of older persons in central Uganda and determine the acceptability of the interRAI Check-Up instrument in this setting. As such, quantitative and qualitative findings were presented in phases and discussed separately. In Phase One, 130 Check-Up assessments were administered to HIV-positive and negative older adults living in the Nakawa division of Kampala. Statistical analyses revealed that HIV status was not statistically significant for this study, with similarities observed attributed to participant age, study sample size, viral suppression, and healthcare service use. For ADLs, cognitive function, and frailty, an age-related association was identified, which is consistent with relevant literature. Notably, this helped to showcase the construct validity of this study. However, this association was not identified for health stability, which was attributed to participant sourcing and recruitment procedures for this project.

In Phase Two, twelve semi-structured interviews were executed with Reach Out service providers involved in Check-Up implementation in Phase One. Analysis procedures revealed that the Check-Up is acceptable for use in the central Ugandan setting, but that it would benefit from certain component modifications and implementation strategies to improve the degree of its acceptability. Several suggestions were made, including approaches to better assess participant economic stability and living arrangement, as well as reduce implementation barriers through increasing Check-Up language availability and provider access to relevant interRAI software.

The combined results from Phase One and Phase Two of this project are of great importance. With high levels of impairment, health instability, and frailty identified in this population coupled with the identification of tool acceptability, integration of the interRAI Check-Up has proven to be an extremely valuable resource for the Ugandan population. Further, with significant limitations identified in the current geriatric healthcare service model in Uganda, findings from this study suggest that the Check-Up can help to fill these gaps and form the basis of a more integrated and effective senior-friendly care system across the nation.

### **6.2 Strengths and Limitations**

# 6.2.1 Strengths

This thesis project had several strengths. First, through the completion of qualitative interviews with service providers, researchers were able to identify needed modifications and determine barriers to using the Check-Up in the Ugandan setting. As such, this project was a great opportunity to further identify the generalizability of the Check-Up tool while simultaneously improving care planning practices for older Ugandans and the international community at large. At several points during the training and interview process, participants indicated the extent to which older adults were excited about the assessment and were looking forward to hearing results to inform their care. This was also a common theme among service providers, who discussed how the assessment enabled them to gain an increased understanding of the challenges faced by older persons. This is an important finding, as it will enable service providers to better align resources and care planning strategies for their elderly patients. Finally, the data which was collected through the Check-Up will allow Reach Out to continue to support older adults in the community. This is due in part to the newfound potential to apply for funding, as the organization is now better equipped to describe the elderly population, which can help to further identify needs for improved support.

### **6.2.2 Limitations**

#### 6.2.2.1 Pre-Data Collection

Prior to implementation, researchers experienced significant administrative barriers in obtaining approval to complete data collection procedures. This greatly affected project timelines and resulted in a reduced time frame for data collection and analysis to take place. First, to complete data collection in Uganda, researchers were required to obtain ethical and/or administrative approval from several review boards. These included the University of Waterloo Research Ethics Committee, the Reach Out Mbuya Community Health Initiative (administrative data collection site clearance), the Clarke International University Research Ethics Committee (local ethics review board), and the Uganda National Council for Science and Technology. Each of these applications was required to be submitted separately and in sequence. Further, each board in Uganda had an associated fee that required approval from interRAI before review completion.

As there was both an exchange of goods (i.e., tablets) and money (i.e., ethics board approval fees, transportation costs, training, etc.) for this project, a contract was also required by the University of Waterloo before transfer occurrence, which further increased the time of this process. Finally, major challenges were also experienced with sending tablets to Uganda for data collection procedures. Tablets were retained at the Uganda Post office and additional funds were requested for them to be released, as claims were made that researchers failed to complete a customs form and inaccurately reported the value of tablets, which was incorrect. This resulted in a lengthy back and forth between Uganda Post officials and research personnel. However, this was eventually resolved, and the tablets were released following the involvement of the Canadian consulate in Uganda and a review of proof of payment and shipping details.

# **6.2.2.2** Phase One: Check-Up Instrument

The primary limitation of Phase One was the participant sample size. First, the sample size of 130 older adults did not have enough power to reasonably assess the relationship between HIV status and the outcomes of interest for this project. Further, the low number of males in this sample limited the ability of researchers to assess gender differences in statistical modeling and study generalizability. Next, as a result of low income and education levels, older persons in Uganda are limited in their ability to self-report certain health conditions. <sup>197</sup> Thus, false reporting may have been an issue in areas of the assessment such as disease diagnoses, functional ability, and healthcare utilization. However, diagnosis by self-report has been widely used in other studies for older persons in this context and therefore, was a necessary starting point to characterize this population. <sup>35,198,199</sup> As well, to mitigate these barriers, certain assessment components and missing data were confirmed through the completion of chart reviews and via consultation of service providers at Reach Out.

Next, human error by participants, service providers, and research personnel was also a potential limitation for Phase One. First, in the assessment, there was a glitch in the Qualtrics survey where the two final questions on financial trade-offs and major life stressors shifted to being after the thank you letter appeared. As a result, these two questions were not answered by any of the participants during quantitative data collection. To address this, these questions were included in the missing data spreadsheet, and Reach Out team leads were requested to identify responses for each participant, enabling researchers to input this missing data into RAIsoft.

Further, the potential for human error was also present during the transfer of assessment data from Qualtrics into RAIsoft. To help mitigate these barriers, a quality assessment was completed by a research volunteer following the initial transfer and input of data. Finally, service providers also identified language barriers for participants in Phase One, as not all individuals were fluent in English or Luganda. Therefore, it is possible that for some participants, information was incorrectly translated into their local language, resulting in some inaccurate question responses.

#### **6.2.2.3 Phase Two: Interviews**

Due to several challenges posed by the COVID-19 pandemic, researchers were unable to conduct in-person interviews with service providers. As such, interviews were held virtually through Zoom, and consent was obtained electronically. Further, all interviews were prescheduled at a time that was most convenient for study participants to avoid potential barriers due to time zone differences. Personant technological barriers. Due to a poor network connection at the Mbuya site, multiple participants were cutting in and out throughout the interview conduction. Namely, during the second half of the interviews which took place on June 15, 2022, Reach Out was required to move to the use of a generator due to a power outage. This affected three service providers whereby, each time a network error occurred, participants needed to sign out of the meeting and re-connect. This marginally increased the time to complete the interviews while simultaneously impacting the interview flow. To help reduce the impact of this barrier, Reach Out IT personnel were on standby and were contacted to provide support during network interruptions, and questions were re-prompted for participants as necessary.

Finally, language barriers also presented some challenges during one-on-one interviews. As interviews were delivered in English, some participants experienced barriers where English was not their first language. To reduce potential bias from miscommunication issues, before each interview, participants were instructed to inform the interviewer if they required additional clarification or needed questions to be repeated throughout the conversation. Another option provided to participants included the provision of interview questions in writing, through the Zoom chat function. As well, each interview was audio recorded and subsequently transcribed for data analysis, to account for any potential misunderstanding on the interviewer's part.

# **6.3 Implications**

Given the overwhelming lack of data on Uganda's current older adult population, the execution of this project was of great importance. First, this project has offered important information describing the needs of aging Ugandans and provided insight into how a standardized instrument can help support both individual care and system planning. Through a comprehensive review of the literature, it is clear that this project was novel in investigating a potential association between HIV diagnosis in Ugandan older adults and their ADLs, cognitive function, health stability, and clinical frailty. Notably, this thesis has provided critical information regarding the care needs of older persons living both with and without HIV in urban central Uganda. It has also further demonstrated the relationship between these outcomes and aging overall.

Next, the partnership that was formed between researchers at the University of Waterloo and Reach Out in Uganda was instrumental. This relationship has already greatly benefitted the elderly Ugandan population and will continue to drive community-informed projects to further support older persons in this setting at large. As was hinted in previous sections, interRAI comprehensive assessment systems have only been utilized in South Africa across African nations. This further points to the presence of an information gap in Uganda and the subsequent strengths of this project. Starting with activities through the Reach Out partnership, the increased understanding of the specific issues faced by this population will translate into a more appropriate formulation of evidence-based policies and care practices for Ugandan older adults. As a whole, this project was an important step in establishing an interRAI community of practice in East Africa that can facilitate the development of an integrated care system across the continent.

#### **6.4 Recommendations**

There is an ongoing need to adequately plan for the growing population of older persons in Uganda to ensure individuals can live fulfilled and dignified lives.<sup>17</sup> Remarkably, the findings from this project are a critical starting point for developing a more senior-friendly system of care across the nation. However, due to the low sample size of older adults recruited for Phase One, additional research is needed to better assess the association between HIV status and participant ADLs, cognitive function, health stability, and frailty in this population. As well, as the study

sample for this thesis was predominantly female, further research conducted should include a greater proportion of male participants to better reflect the population in this setting. Ultimately, this will help to support the generalizability of these findings.

Next, this project was conducted in the Nakawa division of Kampala in urban central Uganda. Thus, further studies are also needed with similar aims across more rural districts to characterize the needs of older persons in these settings. Finally, ongoing assessments of the acceptability of the Check-Up self-report instrument are highly recommended to further support the effective integration of the tool moving forward. Particularly, as interRAI geriatric assessment systems continue to be upscaled throughout Uganda and the greater African continent, further acceptability testing is needed to ensure these tools adequately support and reflect the populations they aim to serve.

# **Key Action Items**

There are several key takeaways from this thesis on how to improve the acceptability of the Check-Up in the Ugandan setting, and at Reach Out specifically. Major action items include:

- adjustment of question H1 in the Check-Up to include interactions with community health workers;
- addition of question I3 in the Check-Up which ascertains the primary source of income for older persons;
- adjustment of question **A9** in the Check-Up to include grandchild(ren);
- addition of question A10 to ascertain household size;
- adjustment of question **A8** in the Check-Up to include only temporary housing, semipermanent housing, and permanent housing as available responses;
- addition of question **A11** in the Check-Up to ascertain the physical environment of the participant's residence;
- complete necessary front and back translations of the Check-Up to offer the tool in Swahili, Luo, and Acholi in addition to English and Luganda;
- provide organizations with the necessary equipment and software to effectively use the Check-Up in the community setting; and

•	velop and implement ongoing culturally sensitive capacity training for service oviders involved in Check-Up implementation.					

#### REFERENCES

- 1. Ssensamba JT, Mukuru M, Nakafeero M, Ssenyonga R, Kiwanuka SN. Health systems readiness to provide geriatric friendly care services in Uganda: A cross-sectional study. BMC Geriatr. 2019;19:1–13.
- 2. Sendaula E, Buwembo M. Grandmothers' project assessment report. Kampala; 2020.
- 3. Maniragaba F, Nzabona A, Asiimwe JB, Bizimungu E, Mushomi J, Ntozi J, et al. Factors associated with older persons' physical health in rural Uganda. PLoS One. 2019;14(1):1–15.
- 4. Nawagi F, Söderberg M, Berggren V, Midlöv P, Ajambo A, Nakasujja N. Sociodemographic characteristics and health profile of the elderly seeking health care in Kampala, Uganda. Curr Gerontol Geriatr Res. 2018;2018:1–9.
- 5. Suzman R, Beard JR, Boerma T, Chatterji S. Health in an ageing world what do we know? Lancet. 2015;385(9967):484–6.
- Geffen L, Kelly G, Morris J, Howard E. Peer-to-peer support model to improve quality of life among highly vulnerable, low-income older adults in Cape Town, South Africa. BMC Geriatr [Internet]. 2019;19:1–12. Available from: https://doi.org/10.1186/s12877-019-1310-0
- 7. Heckman G, Gray LC, Hirdes J. Addressing health care needs for frail seniors in Canada: the role of interRAI instruments. Can Geriatr J. 2013;3(1):8–16.
- 8. Sekhon M, Cartwright M, Francis JJ. Acceptability of healthcare interventions: An overview of reviews and development of a theoretical framework. BMC Health Serv Res [Internet]. 2017;17:1–13. Available from: http://dx.doi.org/10.1186/s12913-017-2031-8
- 9. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. BMJ. 2008;337:1–6.
- Diepeveen S, Ling T, Suhrcke M, Roland M, Marteau T. Public acceptability of government intervention to change health-related behaviours: a systematic review and narrative synthesis. BMC Public Health [Internet]. 2013;13:1–11. Available from: http://www.biomedcentral.com/1471-2458/13/756
- 11. Stok F., de Ridder DT., de Vet E, Nureeva L, Luszczynska A, Wardle J, et al. Hungry for an intervention? Adolescents' ratings of acceptability of eating-related intervention

- strategies. BMC Public Health. 2016;16:1–8.
- 12. Fisher P, McCarney R, Hasford C, Vickers A. Evaluation of specific and non-specific effects in homeopathy: feasibility study for a randomised trial. Homeopathy. 2006;95(4):215–22.
- Hommel K, Hente E, Herzer M, Ingerski L, Denson L. Telehealth behavioral treatment for medication nonadherence: a pilot and feasibility study. Eur J Gastroenterol Hepatol. 2013;25(4):469–73.
- 14. Borrelli B, Sepinwall D, Ernst D, Bellg A, Czajkowski S, Breger R, et al. A new tool to assess treatment fidelity and evaluation of treatment fidelity across 10 years of health behavior research. J Consult Clin Psychol. 2005;73(5):852–60.
- 15. Proctor E, Landsverk J, Aarons G, Chambers D, Glisson C, Mittman B. Implementation research in mental health services: an emerging science with conceptual, methodological, and training challenges. Adm Policy Ment Heal Ment Heal Serv Res. 2009;36(1):24–34.
- 16. The World Bank. Life expectancy at birth, total (years) Uganda [Internet]. The World Bank. 2019 [cited 2020 Nov 5]. Available from: https://data.worldbank.org/indicator/SP.DYN.LE00.IN?locations=UG
- Uganda Bureau of Statistics. The national population and housing census 2014 status of older persons in Uganda, thematic report series [Internet]. Uganda Bureau of Statistics.
   Kampala; 2019. Available from: https://www.ubos.org/wp-content/uploads/publications/09\_2019OLDER\_PERSONS\_MONOGRAPH\_-\_FINAL.pdf
- 18. Nzabona A. Data assessment study of population ageing in Uganda [Internet]. Kampala; 2016. Available from: https://www.un.org/development/desa/ageing/wp-content/uploads/sites/24/2019/04/Assessment-Uganda.pdf
- 19. Kidd S. Uganda's senior citizens' grant: a success story from the heart of Africa. Kampala; 2017.
- 20. Iheme L, Hirdes JP, Geffen L, Heckman G, Hogeveen S. Psychometric Properties, Feasibility, and Acceptability of the Self-Reported interRAI Check-Up Assessment. J Am Med Dir Assoc [Internet]. 2022;23(1):117–21. Available from: https://doi.org/10.1016/j.jamda.2021.06.008
- 21. Wagner J, Bachmann L, Boult C, Harari D, von Renteln-Kruse W, Egger M, et al. Predicting the risk of hospital admission in older persons- validation of a brief self-

- administered questionnaire in three European countries. J Am Geriatr Soc. 2006;54(8):1271–6.
- 22. Aboderin I, Ferreira M. Linking ageing to development agendas in sub-Saharan Africa: challenges and approaches. J Popul Ageing. 2008;1(1):51–73.
- 23. Suzman R. Guest Editorial: The INDEPTH WHO-SAGE multicentre study on ageing, health and well-being among people aged 50 years and over in eight countries in Africa and Asia. Glob Health Action [Internet]. 2010 Sep 27;3(Suppl 2):5–7. Available from: http://www.ncbi.nlm.nih.gov/pubmed/20959876
- 24. Vithalani J, Herreros-Villanueva M. HIV epidemiology in Uganda: survey based on age, gender, number of sexual partners and frequency of testing. Afr Health Sci. 2018;18(3):523–30.
- 25. Mayo Clinic. HIV/AIDS [Internet]. Mayo Clinic. [cited 2022 Mar 26]. Available from: https://www.mayoclinic.org/diseases-conditions/hiv-aids/symptoms-causes/syc-20373524
- 26. Government of Canada. HIV and AIDS: For health professionals [Internet]. Government of Canada. 2022 [cited 2022 Mar 26]. Available from: https://www.canada.ca/en/public-health/services/diseases/hiv-aids/health-professionals.html
- 27. World Health Organization. HIV [Internet]. World Health Organization. 2021 [cited 2022 Mar 27]. Available from: http://www.who.int/en/news-room/fact-sheets/detail/hiv-aids
- 28. National Institute of Allergy and Infectious Diseases. Antiretroviral drug discovery and development [Internet]. National Institute of Allergy and Infectious Diseases. [cited 2021 Apr 29]. Available from: https://www.niaid.nih.gov/diseases-conditions/antiretroviral-drug-development#:~:text=In March 1987%2C AZT became,Drug Administration for treating AIDS.
- Centers for Disease Control and Prevention. HIV treatment [Internet]. Centers for Disease Control and Prevention. 2021 [cited 2022 Mar 27]. Available from: https://www.cdc.gov/hiv/basics/livingwithhiv/treatment.html
- 30. Volberding PA, Deeks SG. Antiretroviral therapy and management of HIV infection. Lancet [Internet]. 2010;376(9734):49–62. Available from: http://dx.doi.org/10.1016/S0140-6736(10)60676-9
- 31. Ministry of Gender Labour and Social Development. The state of older persons in Uganda situational analysis report [Internet]. Kampala; 2020. Available from:

- https://www.developmentpathways.co.uk/wp-content/uploads/2020/10/ESP-OP-Study-Final-12-Oct.pdf
- 32. Wandera SO, Kwagala B, Maniragaba F. Prevalence and determinants of recent HIV testing among older persons in rural Uganda: a cross-sectional study. BMC Public Health [Internet]. 2020;20:1–10. Available from: https://doi.org/10.1186/s12889-020-8193-z
- 33. Ministry of Health. Uganda population-based HIV impact assessment (UPHIA) 2016-2017: final report [Internet]. Kampala; 2019. Available from: https://phia.icap.columbia.edu/wp-content/uploads/2019/07/UPHIA\_Final\_Report\_Revise\_07.11.2019\_Final\_for-web.pdf
- 34. Kitara DL, Amone C, Okello C. Knowledge and misconceptions about HIV counseling and testing (HCT) among the post-conflict youths of Gulu, Northern Uganda. A prospective study design. Pan Afr Med J [Internet]. 2012;12(1). Available from: http://www.panafrican-med-journal.com/content/article/12/31/full/
- 35. Mugisha JO, Schatz EJ, Randell M, Kuteesa M, Kowal P, Negin J, et al. Chronic disease, risk factors and disability in adults aged 50 and above living with and without HIV: findings from the wellbeing of older people study in Uganda. Glob Health Action [Internet]. 2016;9. Available from: https://doi.org/10.3402/gha.v9.31098
- 36. Mahy M, Autenrieth CS, Stanecki K, Wynd S. Increasing trends in HIV prevalence among people aged 50 years and older: Evidence from estimates and survey data. AIDS. 2014;28(Suppl 4):S453–9.
- 37. Foebel AD, Hirdes JP, Lemick R, Tai JWY. Comparing the characteristics of people living with and without HIV in long-term care and home care in Ontario, Canada. AIDS Care [Internet]. 2015;27(10):1343–53. Available from: http://dx.doi.org/10.1080/09540121.2015.1058893
- 38. Work Group for HIV and Aging Consensus Project. Summary report from the human immunodeficiency virus and aging consensus project: treatment strategies for clinicians managing older individuals with the human immunodeficiency virus. J Am Geriatr Soc. 2012;60(5):974–9.
- 39. Erlandson KM, Schrack JA, Jankowski CM, Brown TT, Campbell TB. Functional impairment, disability, and frailty in adults aging with HIV-infection. Curr HIV/AIDS Rep. 2014;11(3):279–90.

- 40. Guaraldi G, Orlando G, Zona S, Menozzi M, Carli F, Garlassi E, et al. Premature agerelated comorbidities among HIV-infected persons compared with the general population. Clin Infect Dis. 2011;53(11):1120–6.
- 41. Antiretroviral Therapy Cohort Collaboration. Life expectancy of individuals on combination antiretroviral therapy in high-income countries: a collaborative analysis of 14 cohort studies. Lancet. 2008;372(9635):293–9.
- 42. Erlandson K, Allshouse A, Jankowski C, Duong S, Mawhinney S, Kohrt W, et al. A Comparison of functional status instruments in HIV-infected adults on effective antiretroviral therapy. HIV Clin Trials. 2012;13(6):324–34.
- 43. Oursler K, Sorkin J, Smith B, Katzel L. Reduced aerobic capacity and physical functioning in older HIV-infected men. AIDS Res Hum Retroviruses. 2006;22(11):1113–21.
- 44. Richert L, Dehail P, Mercié P, Dauchy F, Bruyand M, Greib C, et al. High frequency of poor locomotor performance in HIV-infected patients. AIDS. 2011;25(6):797–805.
- 45. Nweke M, Mshunqane N, Govender N, Akinpelu AO, Ukwuoma M. Impact of HIV-associated cognitive impairment on functional independence, frailty and quality of life in the modern era: a meta-analysis. Sci Rep [Internet]. 2022;12(1):1–10. Available from: https://doi.org/10.1038/s41598-022-10474-8
- 46. Desquilbet L, Jacobson L, Fried L, Phair J, Jamieson B, Holloway M, et al. HIV-1 infection is associated with an earlier occurrence of a phenotype related to frailty. Journals Gerontol Biol Sci Med Scienes. 2007;62(11):1279–86.
- 47. Erlandson K, Allshouse A, Jankowski C, Duong S, Mawhinney S, Kohrt W, et al. Risk factors for falls in HIV-infected persons. J Acquir Immune Defic Syndr. 2012;61(4):484–9.
- 48. Womack J, Goulet J, Gibert C, Brandt C, Chang C, Gulanski B, et al. Increased risk of fragility fractures among HIV infected compared to uninfected male veterans. PLoS One. 2011;6(2):1–6.
- 49. Young B, Dao C, Buchacz K, Baker R, Brooks J, HIV Outpatient Study (HOPS) Investigators. Increased rates of bone fracture among HIV-infected persons in the HIV outpatient study (HOPS) compared with the US general population, 2000-2006. Clin Infect Dis. 2011;52(8):1061–8.

- 50. Tisminetzky M, Bayliss E, Magaziner J, Allore HG, Anzuoni K, Boyd C, et al. Research priorities to advance the health and health care of older adults with multiple chronic conditions. J Am Geriatr Soc. 2017;65(7):1549–53.
- 51. Rolfson DB, Heckman GA, Bagshaw SM, Robertson D, Hirdes JP. Implementing frailty measures in the Canadian healthcare system. J frailty aging. 2018;7(4):208–16.
- 52. Muscedere J, Afilalo J, Araujo de Carvalho I, Cesari M, Clegg A, Eriksen HE, et al. Moving towards common data elements and core outcome measures in frailty research. J frailty aging. 2020;9:14–22.
- 53. Rosen SL, Reuben DB. Geriatric assessment tools. Mt Sinai J Med. 2011;78(4):489–97.
- 54. Reuben DB, Rosen S. Principles of geriatric assessment. In: Halter JB, Ouslander JG, Tinetti ME, Studenski S, High KP, Asthana S, editors. Hazzard's Geriatric Medicine and Gerontology. 6th ed. New York: McGraw-Hill; 2009. p. 1–21.
- 55. Hirdes JP, Ljunggren G, Morris JN, Frijters DH, Finne Soveri H, Gray L, et al. Reliability of the interRAI suite of assessment instruments: A 12-country study of an integrated health information system. BMC Health Serv Res. 2008;8.
- 56. Hirdes J, Fries BE, Morris JN, Steel K, Mor V, Frijters D, et al. Integrated health information systems based on the RAI/MDS series of instruments. Healthc Manag forum. 1999;12(4):30–40.
- 57. Carpenter GI. Accuracy, validity and reliability in assessment and in evaluation of services for older people: The role of the interRAI MDS assessment system. Age Ageing. 2006;35(4):327–9.
- 58. interRAI. About interRAI [Internet]. interRAI. [cited 2022 Mar 25]. Available from: https://interrai.org/about-interrai/
- 59. Bernabei R, Gray L, Hirdes J, Pei X, Henrard JC, Jonsson P V, et al. International gerontology. In: Halter JB, Ouslander JG, Tinetti ME, Studenski S, High KP, Asthana S, editors. Hazzard's Geriatric Medicine and Gerontology. 6th ed. New York: McGraw-Hill; 2009. p. 69–96.
- 60. Betini R, Hirdes J, Curtin-Telegdi N, Gammage L, Vansickle J, Poss J, et al. Development and validation of a screener based on interRAI assessments to measure informal caregiver wellbeing in the community. BMC Geriatr. 2018;18:1–14.
- 61. Hawes C, Morris J, Phillips C, Mor V, Fries B, Nonemaker S. Reliability estimates for the

- minimum data set for nursing home resident assessment and care screening (MDS). Gerontologist. 1995;35(2):172–8.
- 62. Hogeveen S, Chen J, Hirdes J. Evaluation of data quality of interRAI assessments in home and community care. BMC Med Inform Decis Mak. 2017;17:1–15.
- 63. Martin-Khan M, Edwards H, Wootton R, Counsell S, Varghese P, Lim W, et al. Reliability of an online geriatric assessment procedure using the interRAI acute care assessment system. J Am Geriatr Soc. 2017;65(9):2029–36.
- 64. Poss J, Jutan N, Hirdes J, Fries B, Morris J, Teare G, et al. A review of evidence on the reliability and validity of minimum data set data. Healthc Manag Forum. 2008;21(1):33–9.
- 65. Sgadari A, Morris J, Fries B, Ljunggren G, Jonsson P, DuPaquier J, et al. Efforts to establish the reliability of the resident assessment instrument. Age Ageing. 1997;26(Suppl 2):27–30.
- 66. Kim H, Jung Y, Sung M, Lee J, Yoon J, Yoon J. Reliability of the interRAI long term care facilities (LTCF) and interRAI home care (HC). Geriatr Gerontol Int. 2015;15(2):220–8.
- 67. Geffen LN, Kelly G, Morris JN, Hogeveen S, Hirdes J. "establishing the criterion validity of the interRAI check-up self-report instrument." BMC Geriatr. 2020;20:1–8.
- 68. Morris J, Berg K, Fries B, Steel K, Howard E. Scaling functional status within the interRAI suite of assessment instruments. BMC Geriatr [Internet]. 2013;13:1–12. Available from: http://www.biomedcentral.com/1471-2318/13/128
- 69. Gray LC, Berg K, Fries BE, Henrard JC, Hirdes JP, Steel K, et al. Sharing clinical information across care settings: The birth of an integrated assessment system. BMC Health Serv Res [Internet]. 2009;9. Available from: http://www.biomedcentral.com/1472-6963/9/71
- 70. interRAI. Getting started [Internet]. interRAI. [cited 2022 Aug 19]. Available from: https://interrai.org/about-interrai/getting-started/
- 71. interRAI. Applications [Internet]. interRAI. [cited 2022 Aug 19]. Available from: https://interrai.org/applications/
- 72. Daniels R, van Rossum E, de Witte L, Kempen GIJM, van den Heuvel W. Interventions to prevent disability in frail community-dwelling elderly: A systematic review. BMC Health Serv Res. 2008;8.
- 73. interRAI. Status and outcome scales [Internet]. interRAI. [cited 2022 Jun 23]. Available

- from: https://interrai.org/applications/status-and-outcome-scales/
- 74. interRAI. Clinical assessment protocols (CAPs) [Internet]. interRAI. [cited 2022 Jun 23]. Available from: https://interrai.org/applications/clinical-assessment-protocols-caps/
- 75. Kuo H-K, Scandrett K, Dave J, Mitchell S. The influence of outpatient comprehensive geriatric assessment on survival: a meta-analysis. Arch Gerontol Geriatr. 2004;39(3):245–54.
- 76. Stuck A, Iliffe S. Comprehensive geriatric assessment for older adults. BMJ [Internet]. 2011;343:d6799. Available from: https://doi.org/10.1136/bmj.d6799
- 77. Hirdes, JP, Mitchell L, Maxwell C, White N. Beyond the "iron lungs of gerontology": using evidence to shape the future of nursing homes in Canada. Can J Aging. 2011;30(3):371–90.
- 78. Hirdes J, Poss J, Curtin-Telegdi N. The method for assigning priority levels (MAPLe): a new decision-support system for allocating home care resources. BMC Med [Internet]. 2008;6. Available from: http://www.biomedcentral.com/1741-7015/6/9
- 79. Fries B, Schneider D, Foley W, Gavazzi M, Burke R, Cornelius E. Refining a case-mix measure for nursing homes: resource utilization groups (RUG-III). Med Care. 1994;32(7):668–85.
- 80. Fries B, Schroll M, Hawes C, Gilgen R, Jónsson P, Park P. Approaching cross-national comparisons of nursing home residents. Age Ageing. 1997;26(Suppl 2):13–8.
- 81. Morris J, Berg K, Topinkova E, Gray L, Schachter E. Developing quality indicators for inpatient post-acute care. BMC Geriatr [Internet]. 2018;18:2–13. Available from: https://doi.org/10.1186/s12877-018-0842-z
- 82. Morris J, Carpenter I, Berg K, Jones R. Outcome measures for use with home care clients. Can J Aging/La Rev Can du Vieil. 2000;19(S2):87–105.
- 83. Sinn C, Betini R, Wright J, Eckler L, Chang B, Hogeveen S, et al. Adverse events in home care: identifying and responding with interRAI scales and clinical assessment protocols. Can J Aging. 2018;37(1):60–9.
- 84. Costa A, Hirdes J, Bell C, Bronskill S, Heckman G, Mitchell L, et al. Derivation and validation of the detection of indicators and vulnerabilities for emergency room trips scale for classifying the risk of emergency department use in frail community-dwelling older adults. J Am Geriatr Soc. 2015;63(4):763–9.

- 85. Hirdes J, Poss J, Mitchell L, Korngut L, Heckman G. Use of the interRAI CHESS scale to predict mortality among persons with neurological conditions in three care settings. PLoS One [Internet]. 2014;9(6):e99066. Available from: https://doi.org/10.1371/journal.pone.0099066
- 86. Fries B, Morris J, Bernabei R, Finne-Soveri H, Hirdes J, interRAI consortium. Rethinking the resident assessment protocols. J Am Geriatr Soc. 2007;55(7):1139–40.
- 87. World Health Organization. World report on ageing and health. [Internet]. Geneva; 2015. Available from: https://apps.who.int/iris/handle/10665/186463
- 88. Canadian Coalition for Global Health Research. Uganda research ethics [Internet]. [cited 2021 Apr 27]. Available from: https://www.ccghr.ca/resources/harmonization/uganda/uganda-research-ethics/
- 89. Reach Out Mbuya Community Health Initiative. Vision and mission [Internet]. Reach Out Mbuya Community Health Initiative. [cited 2020 Nov 2]. Available from: https://www.reachoutmbuya.org/vision-mission/
- 90. Reach Out Mbuya Parish HIV/AIDS Initiative. 2019 annual report [Internet]. Kampala; 2020. Available from: https://www.reachoutmbuya.org/annual-reports/
- 91. Reach Out Mbuya Community Health Initiative. About us [Internet]. Reach Out Mbuya Community Health Initiative. [cited 2022 Mar 29]. Available from: https://www.reachoutmbuya.org/about-us/
- 92. Kamunvi E. Reach out Mbuya Parish HIV/AIDS initiative. Heal Policy Dev [Internet]. 2005;3(1):312–20. Available from: https://tspace.library.utoronto.ca/handle/1807/6074
- 93. Reach Out Mbuya Community Health Initiative. 2021 annual report [Internet]. Kampala; 2022. Available from: https://www.reachoutmbuya.org/annual-reports/
- 94. Reach Out Mbuya Community Health Initiative. Community support home-based care [Internet]. Reach Out Mbuya Community Health Initiative. [cited 2021 May 10]. Available from: https://www.reachoutmbuya.org/home-based-care/
- 95. Ministry of Health. Village health team strategy and operational guidelines [Internet]. Kampala; 2010. Available from: http://library.health.go.ug/sites/default/files/resources/VHT-strategy-and-operational-guidelines.pdf
- 96. Reach Out Mbuya Community Health Initiative. 2020 annual report [Internet]. Kampala;

- 2021. Available from: https://www.reachoutmbuya.org/annual-reports/
- 97. Reach Out Mbuya Community Health Initiative. Grandmothers' project [Internet]. Reach Out Mbuya Community Health Initiative. [cited 2022 Jun 14]. Available from: https://www.reachoutmbuya.org/grandmothers-project/
- 98. Kankaka M. ROM changes Kasaala grandmothers' story through skilling [Internet]. Reach Out Mbuya Community Health Initiative. 2022 [cited 2022 Jun 14]. Available from: https://www.reachoutmbuya.org/rom-changes-kasaala-grandmothers-story-through-skilling/
- 99. Okello V. Grannies our unsung heroes [Internet]. Reach Out Mbuya Community Health Initiative. 2021 [cited 2022 Jun 14]. Available from: https://www.reachoutmbuya.org/grannies-our-unsung-heroes/
- 100. Hogeveen S. Code for ADL short format scale on the check-up. Waterloo: interRAI; 2019.p. 1–6.
- 101. InterRAI. Scales: status and outcome measures [Internet]. [cited 2021 Apr 30]. Available from: https://www.interrai.org/scales.html
- 102. Rockwood K, Theou O. Using the clinical frailty scale in allocating scarce health care resources. Can Geriatr J. 2020;23(3):210–5.
- 103. Magazi B, Stadler J, Delany-Moretlwe S, Montgomery E, Mathebula F, Hartmann M, et al. Influences on visit retention in clinical trials: insights from qualitative research during the VOICE trial in Johannesburg, South Africa. BMC Womens Health. 2014;14:1–8.
- 104. Maniragaba F, Kwagala B, Bizimungu E, Wandera SO, Ntozi J. Predictors of quality of life of older persons in rural Uganda: A cross sectional study. AAS Open Res. 2018;1.
- 105. The UN Refugee Agency. Emergency handbook older persons [Internet]. Available from: https://emergency.unhcr.org
- 106. Statistics South Africa. Protecting South Africa's elderly [Internet]. Statistics South Africa. [cited 2021 May 10]. Available from: http://www.statssa.gov.za/?p=13445
- 107. Sabates-Wheeler R, Wylde E, Ulrichs M, Aboderin I, Bayisenge J, Irambeshya A. Population ageing in Rwanda: current needs, future projections, and implications for policy [Internet]. 2018. Available from: https://assets.publishing.service.gov.uk/media/5b6c063440f0b640a5370011/Implications\_of\_Demographic\_Change\_in\_Rwanda\_FULL\_REPORT.pdf

- 108. Ssentanda M, Nakayiza J. English rules in Uganda, but local languages shouldn't be sidelined. The Conversation [Internet]. 2015 Nov 4; Available from: https://theconversation.com/english-rules-in-uganda-but-local-languages-shouldnt-be-sidelined-49381
- 109. Colina S, Marrone N, Ingram M, Sánchez D. Translation quality assessment in health research: a functionalist alternative to back-translation. Eval Health Prof. 2016;40(3):267–93.
- 110. World Health Organization. Process of translation and adaptation of instruments [Internet]. [cited 2021 Apr 27]. Available from: https://www.who.int/substance\_abuse/research\_tools/translation/en/
- 111. RAIsoft. Assessment tools [Internet]. RAIsoft. [cited 2022 Aug 22]. Available from: https://www.raisoft.com/en/software/assesment-tools.html
- 112. Edemekong P, Bomgaars D, Sukumaran S, Levy S. Activities of daily living [Internet].

  Treasure Island: StatPearls Publishing; 2022. Available from:

  https://www.ncbi.nlm.nih.gov/books/NBK470404/?report=reader#\_NBK470404\_pubdet\_
- 113. Katz S. Assessing self-maintenance: activities of daily living, mobility, and instrumental activities of daily living. J Am Geriatr Soc. 1983;31(12):721–7.
- 114. Guidet B, de Lange D, Boumendil A, Leaver S, Watson X, Boulanger C, et al. The contribution of frailty, cognition, activity of daily life and comorbidities on outcome in acutely admitted patients over 80 years in European ICUs: the VIP2 study. Intensive Care Med. 2020;46(1):57–69.
- 115. Costenoble A, Knoop V, Vermeiren S, Vella R, Debain A, Rossi G, et al. Comprehensive overview of activities of daily living in existing frailty instruments: a systematic literature search. Gerontologist. 2021;61(3):e12–22.
- 116. Cahn-Weiner D, Boyle P, Malloy P. Tests of executive function predict instrumental activities of daily living in community-dwelling older individuals. Appl Neuropsychol. 2002;9(3):187–91.
- 117. Morgan EE, Iudicello JE, Weber E, Duarte NA, Riggs K, Delano-Wood L, et al. Synergistic effects of HIV infection and older age on daily functioning. J Acquir Immune Defic Syndr. 2012;61(3):341–8.
- 118. Geriatric Medicine Research Collaborative. Delirium is prevalent in older hospital

- inpatients and associated with adverse outcomes: results of a prospective multi-centre study on World Delirium Awareness Day. BMC Med. 2019;17(1):229.
- 119. interRAI. interRAI Check-Up Brief Scale Guide Version 1. 2020.
- 120. Centers for Disease Control and Prevention. Cognitive impairment: a call for action, now! [Internet]. 2011. Available from: https://www.cdc.gov/aging/pdf/cognitive\_impairment/cogimp\_poilicy\_final.pdf
- 121. Morris JN, Howard EP, Steel K, Perlman C, Fries BE, Garms-Homolová V, et al.

  Updating the cognitive performance scale. J Geriatr Psychiatry Neurol. 2016;29(1):47–55.
- 122. Brookmeyer R, Evans D, Hebert L, Langa K, Heeringa S, Plassman B, et al. National estimates of the prevalence of Alzheimer's disease in the United States. Alzheimer's Dement. 2011;7(1):61–73.
- 123. Royall D, Palmer R, Chiodo L, Polk M. Normal rates of cognitive change in successful aging: the freedom house study. J Int Neuropsychol Soc. 2005;11(7):899–909.
- 124. Wang M, Gamo N, Yang Y, Jin L, Wang X, Laubach M, et al. Neuronal basis of agerelated working memory decline. Nature. 2011;476(7359):210–3.
- 125. Alford K, Banerjee S, Nixon E, O'Brien C, Pounds O, Butler A, et al. Assessment and management of HIV-associated cognitive impairment: experience from a multidisciplinary memory service for people living with HIV. Brain Sci. 2019;9(2):1–13.
- 126. Greene K, Carpenter A, Catona D, Magsamen-Conrad K. The brief disclosure intervention (BDI): facilitating African Americans' disclosure of HIV. J Commun [Internet]. 2013;63(1):138–58. Available from: https://doi.org/10.1111/jcom.12010
- 127. Morgan EE, Woods SP, Grant I, HIV Neurobehavioral Research Program (HNRP) Group. Intra-individual neurocognitive variability confers risk of dependence in activities of daily living among HIV-seropositive individuals without HIV-associated neurocognitive disorders. Arch Clin Neuropsychol. 2012;27(3):293–303.
- 128. Woods SP, Weber E, Weisz B., Twamley E., Grant I, HIV Neurobehavioral Research Programs Group. Prospective memory deficits are associated with unemployment in persons living with HIV infection. Rehabil Psychol. 2011;56(1):77–84.
- 129. Gorman AA, Foley J., Ettenhofer ML, Hinkin CH, van Gorp WG. Functional consequences of HIV-associated neuropsychological impairment. Neuropsychol Rev. 2009;19(2):186–203.

- 130. Alford K, Vera JH. Cognitive impairment in people living with HIV in the ART era: a review. Br Med Bull. 2018;127(1):55–68.
- 131. Grant I, Atkinson JH, Hesselink JR, Kennedy CJ, Richman DD, Spector SA, et al. Evidence for early central nervous system involvement in the acquired immunodeficiency syndrome (AIDS) and other human immunodeficiency virus (HIV) infections. Studies with Neuropsychologic testing and magnetic resonance imaging. Ann Intern Med. 1987;107(6):828–36.
- 132. Maschke M, Kastrup O, Esser S, Ross B, Hengge U, Hufnagel A. Incidence and prevalence of neurological disorders associated with HIV since the introduction of highly active antiretroviral therapy (HAART). J Neurol Neurosurg Psychiatry. 2000;69(3):376–80.
- 133. Heaton RK, Clifford DB, Franklin Jr DR, Woods SP, Ake C, Vaida F, et al. HIV-associated neurocognitive disorders persist in the era of potent antiretroviral therapy: CHARTER Study. Neurology. 2010;75(23):2087–96.
- 134. Wang Y, Liu M, Lu Q, Farrell M, Lappin JM, Shi J, et al. Global prevalence and burden of HIV-associated neurocognitive disorder: A meta-analysis. Neurology. 2020;95(19):e2610–21.
- 135. Kobayashi LC, Farrell MT, Langa KM, Mahlalela N, Wagner RG, Berkman LF. Incidence of cognitive impairment during aging in rural South Africa: evidence from HAALSI, 2014 to 2019. Neuroepidemiology. 2021;55(2):100–8.
- 136. Hirdes JP, Frijters DH, Teare GF. The MDS-CHESS scale: a new measure to predict mortality in institutionalized older people. Am Geriatr Soc. 2003;51(1):96–100.
- 137. Ogarek JA, McCreedy EM, Thomas KS, Teno JM, Gozalo PL. Minimum data set changes in health, end-stage disease and symptoms and signs scale: a revised measure to predict mortality in nursing home residents. J Am Geriatr Soc. 2018;66(5):976–81.
- 138. Church S, Rogers E, Rockwood K, Theou O. A scoping review of the clinical frailty scale. BMC Geriatr [Internet]. 2020;20:1–18. Available from: https://doi.org/10.1186/s12877-020-01801-7
- 139. Theou O, Rockwood K. Should frailty status always be considered when treating the elderly patient? Aging health. 2012;8(3):261–71.
- 140. Fedarko N. The biology of aging and frailty. Clin Geriatr Med. 2011;27(1):27–37.

- 141. Clegg A, Young J, Iliffe S, Rikkert M, Rockwood K. Frailty in elderly people. Lancet [Internet]. 2013;381(9868)):752–62. Available from: https://doi.org/10.1016/S0140-6736(12)62167-9
- 142. Fried L, Ferrucci L, Darer J, Williamson J, Anderson G. Untangling the concepts of disability, frailty, and comorbidity: implications for improved targeting and care. Journals Gerontol Biol Sci Med Scienes. 2004;59(3):255–63.
- 143. Conroy S. Defining frailty—the holy grail of geriatric medicine. J Nutr Health Aging. 2009;13(4):389.
- 144. Lang P, Michel J, Zekry D. Frailty syndrome: a transitional state in a dynamic process. Gerontology. 2009;55(5):539–49.
- 145. Morley J, Vellas B, van Kan G, Anker S, Bauer J, Bernabei R, et al. Frailty consensus: a call to action. J Am Med Dir Assoc [Internet]. 2013;14(6):392–7. Available from: https://doi.org/10.1016/j.jamda.
- 146. Terzian A, Holman S, Nathwani N, Robison E, Weber K, Young M, et al. Factors associated with preclinical disability and frailty among HIV-infected and HIV-uninfected women in the era of cART. J Women's Heal. 2009;18(12):1965–74.
- 147. Pathai S, Gilbert C, Weiss H, Cook C, Wood R, Bekker L, et al. Frailty in HIV-infected adults in South Africa. J Acquir Immune Defic Syndr. 2013;62(1):43–51.
- 148. Sternberg S, Schwartz A, Karunananthan S, Bergman H, Clarfield A. The identification of frailty: a systematic literature review. J Am Geriatr Soc. 2011;59(11):29–38.
- 149. Turcotte LA, Zalucky AA, Stall NM, Downar J, Rockwood K, Theou O, et al. Baseline Frailty as a Predictor of Survival After Critical Care: A Retrospective Cohort Study of Older Adults Receiving Home Care in Ontario, Canada. Chest [Internet]. 2021;160(6):2101–11. Available from: https://doi.org/10.1016/j.chest.2021.06.009
- 150. SAS Institute Incorporated. SAS studio 3.8 and 3.81 single-user [Internet]. SAS Institute Incorporated. [cited 2022 Jul 28]. Available from: https://support.sas.com/downloads/package.htm?pid=1924
- 151. SAS Institute Incorporated. SAS studio: help center what are the differences between SAS studio and SAS enterprise guide? [Internet]. SAS Institute Incorporated. [cited 2022 Mar 30]. Available from: https://support.sas.com/software/products/sas-studio/faq/SASStudio\_vsEG.htm

- 152. Sekhon M, Cartwright M, Francis JJ. Development of a theory-informed questionnaire to assess the acceptability of healthcare interventions. BMC Health Serv Res [Internet]. 2022;22(1):1–12. Available from: https://doi.org/10.1186/s12913-022-07577-3
- 153. Chandler CIR, Kizito J, Taaka L, Nabirye C, Kayendeke M, DiLiberto D, et al. Aspirations for quality health care in Uganda: how do we get there? Hum Resour Health. 2013;11(1):1–12.
- 154. Twimukye A, King R, Schlech W, Zawedde FM, Kakaire T, Parkes-Ratanshi R. Exploring attitudes and perceptions of patients and staff towards an after-hours co-pay clinic supplementing free HIV services in Kampala, Uganda. BMC Health Serv Res. 2017;17(1):1–10.
- 155. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101.
- 156. McNiff K. Thematic analysis of interview data: 6 ways NVivo can help [Internet]. NVivo. 2016 [cited 2021 Jul 1]. Available from: https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/resources/blog/thematic-analysis-of-interview-data-nvivo
- 157. National Curriculum Development Centre. Secondary curriculum [Internet]. National Curriculum Development Centre. [cited 2022 Aug 13]. Available from: https://www.ncdc.go.ug/curriculum-type/secondary-curriculum
- 158. Aberg JA. Aging and HIV infection: focus on cardiovascular disease risk. Top Antivir Med. 2020;27(4):102–5.
- 159. Sendaula E, Buwembo M, Opio D. Clinical profile of HIV-infected adults receiving a holistic approach of care model in Nakawa, Kampala District. PLoS One [Internet]. 2022;17(7):1–8. Available from: http://dx.doi.org/10.1371/journal.pone.0272039
- 160. Centers for Disease Control and Prevention. HIV treatment as prevention [Internet]. Centers for Disease Control and Prevention. 2022 [cited 2022 Jul 29]. Available from: https://www.cdc.gov/hiv/risk/art/index.html
- 161. World Health Organization. Viral suppression for HIV treatment success and prevention of sexual transmission of HIV [Internet]. World Health Organization. 2018 [cited 2022 Jul 29]. Available from: https://www.who.int/news/item/20-07-2018-viral-suppression-for-hiv-treatment-success-and-prevention-of-sexual-transmission-of-hiv

- 162. Shi L. The impact of primary care: a focused review. Scientifica (Cairo). 2012;2012:1–22.
- 163. St John PD, Swift AU, Tate RB. Patterns of functional impairment over time amongst older men—the Manitoba follow-up study. Can Geriatr J. 2021;24(2):144–50.
- 164. Hajek A, König H-H. Longitudinal predictors of functional impairment in older adults in Europe evidence from the survey of health, ageing and retirement in Europe. PLoS One. 2016;11(1):1–12.
- 165. Biritwum RB, Minicuci N, Yawson AE, Theou O, Mensah GP, Naidoo N, et al.

  Prevalence of and factors associated with frailty and disability in older adults from China,
  Ghana, India, Mexico, Russia and South Africa. Maturitas. 2016;91:8–18.
- 166. Middleton F. The 4 types of validity in research | Definitions & examples [Internet]. Scribbr. 2022 [cited 2022 Aug 26]. Available from: https://www.scribbr.com/methodology/types-of-validity/
- 167. Patino CM, Ferreira JC. Internal and external validity: Can you apply research study results to your patients? J Bras Pneumol. 2018;44(3):183.
- 168. Courtney-long EA, Carroll DD, Zhang QC, Stevens AC, Griffin- Blake S, Armour BS, et al. Prevalence of disability and disability type among adults United States, 2013. Morb Mortal Wkly Rep. 2015;64(29):777–83.
- 169. Bursack CB. The importance of activities of daily living (ADLs) [Internet]. Aging Care. 2022 [cited 2022 Jul 27]. Available from: https://www.agingcare.com/articles/activities-of-daily-living-why-this-measure-matters-186853.htm
- 170. Guerchet M, Houinato D, Paraiso MN, von Ahsen N, Nubukpo P, Otto M, et al. Cognitive impairment and dementia in elderly people living in rural Benin, West Africa. Dement Geriatr Cogn Disord. 2009;27(1):34–41.
- 171. Olayinka OO, Mbuyi NN. Epidemiology of dementia among the elderly in sub-Saharan Africa. Int J Alzheimers Dis. 2014;2014:1–15.
- 172. Medical University of South Carolina. Frailty: a new predictor of outcome as we age [Internet]. Medical University of South Carolina Health. [cited 2022 Jul 28]. Available from: https://muschealth.org/medical-services/geriatrics-and-aging/healthy-aging/frailty
- 173. Wang J, Geng L. Effects of socioeconomic status on physical and psychological health: lifestyle as a mediator. Int J Environ Res Public Health. 2019;16(2):1–9.
- 174. Alkire S, Foster J, Seth S, Santos ME, Roche JM, Ballon P. Multidimensional poverty

- measurement and analysis. Oxford: Oxford University Press; 2015.
- 175. The World Bank. Poverty and shared prosperity 2018: piecing together the poverty puzzle. Washington, DC; 2018.
- 176. He W, Aboderin I, Adjaye-Gbewonyo D. Africa aging: 2020 [Internet]. Washington; 2020. Available from: https://www.census.gov/content/dam/Census/library/publications/2020/demo/p95\_20-1.pdf
- 177. Aboderin I. Global ageing: perspectives from sub-Saharan Africa. In: Phillipson C, Dannefer D, editors. Handbook of Social Gerontology. London: SAGE Publications Ltd; 2010. p. 405–19.
- 178. Ogwumike F, Aboderin I. Exploring the links between old age and poverty in anglophone West Africa: evidence from Nigeria and Ghana. Gener Rev. 2005;15(2):7–15.
- 179. Oloka-Onyango J. Equal opportunity, age-based discrimination and the rights of elderly persons in Uganda. Kampala; 2008. (Human Rights and Peace Centre). Report No.: 21.
- 180. Najjumba-Mulindwa I. Chronic poverty among the elderly in Uganda: perceptions, experiences and policy issues. Kampala: Institute of Statistics and Applied Economics, Makerere University; 2003. p. 1–38.
- 181. Aboderin I, Gelfand L. A demographic dividend for Africa: the value of investing in the older population, position paper. Nairobi; 2019.
- 182. International Labour Organization. Social protection for older persons: policy trends and statistics 2017–19. Geneva; 2018. (Social Protection Policy Papers). Report No.: 17.
- 183. International Labour Office. Women and men in the informal economy: a statistical picture. Third edition [Internet]. Geneva; 2018. Available from: https://www.ilo.org/wcmsp5/groups/public/---dgreports/---dcomm/documents/publication/wcms\_626831.pdf
- 184. Golaz V, Wandera S, Rutaremwa G. Understanding the vulnerability of older adults: extent of and breaches in support systems in Uganda. Ageing Soc. 2017;37(1):63–89.
- 185. Statistics Canada. Dictionary, census of population, 2016 household size [Internet]. Statistics Canada. 2017 [cited 2022 Aug 2]. Available from: https://www12.statcan.gc.ca/census-recensement/2016/ref/dict/households-menage010-eng.cfm

- 186. Dictionary.com. Dependent [Internet]. Dictionary.com. [cited 2022 Aug 2]. Available from: https://www.dictionary.com/browse/dependent
- 187. Gorges R, Sanghavi P, Konetzka R. A national examination of long-term care setting, outcomes, and disparities among elderly dual eligibles. Health Aff. 2019;38(7):1110–8.
- 188. Deotti L, Estruch E. Addressing rural youth migration at its root causes: a conceptual framework [Internet]. Rome; 2016. Available from: https://www.fao.org/3/i5718e/I5718E.pdf
- 189. Apt NA. Aging in Africa: past experiences and strategic directions. Ageing Int. 2012;37(1):23–103.
- 190. Uganda Bureau of Statistics. National population and housing census 2014—main report [Internet]. Kampala; 2016. Available from: https://www.ubos.org/wp-content/uploads/publications/03\_20182014\_National\_Census\_Main\_Report.pdf
- 191. Reach One Touch One Ministries Canada. Reach One Touch One Ministries Canada annual report 2021 [Internet]. Oakville; 2022. Available from: https://reachonetouchone.org/wp-content/uploads/RC-2021-Annual-Report-Final.pdf
- 192. Muslim Centre for Justice and Law. Marginalisation of Muslims and measures to promote minority rights in access to justice in Uganda position paper. Kampala: Muslim Centre for Justice and Law; 2017. p. 1–26.
- 193. Elkhalifa G. The current crisis in human resources for health in Africa. South Sudan Med J. 2014;7(1):7–8.
- 194. Frost L, Navarro A, Lynch M, Campbell M, Orcutt M, Trelfa A, et al. Care of the elderly: survey of teaching in an aging sub-Saharan Africa. Gerontol Geriatr Educ. 2015;36(1):14–29.
- 195. Nawagi F, Mukisa J, Najjuma JN, Nabirye RC. "We are never taught anything about the elderly." Establishing the gap in elderly health care competencies in nursing education in Uganda. BMC Nurs [Internet]. 2022;21:1–11. Available from: https://doi.org/10.1186/s12912-022-00936-9
- 196. Russell S. Men's refashioning of masculine identities in Uganda and their self-management of HIV treatment. Qual Health Res [Internet]. 2019;29(8):1199–212. Available from: https://doi.org/10.1177/1049732318823717
- 197. Wandera SO, Kwagala B, Ntozi J. Determinants of access to healthcare by older persons

- in Uganda: a cross-sectional study. Int J Equity Health. 2015;14(1).
- 198. Yaya S, Idriss-Wheeler D, Sanogo NA, Vezina M, Bishwajit G. Self-reported activities of daily living, health and quality of life among older adults in South Africa and Uganda: a cross sectional study. BMC Geriatr [Internet]. 2020;20:1–11. Available from: https://doi.org/10.1186/s12877-020-01809-z
- 199. Wandera SO, Golaz V, Kwagala B, Ntozi J. Factors associated with self-reported ill health among older Ugandans: a cross sectional study. Arch Gerontol Geriatr [Internet]. 2015;61(2):231–9. Available from: http://dx.doi.org/10.1016/j.archger.2015.05.006
- 200. WorldData.Info. Eastern Africa time (EAT) [Internet]. WorldData.Info. [cited 2021 Apr 26]. Available from: https://www.worlddata.info/timezones/eat-eastern-africa-time.php
- 201. Morris J, Howard E, Geffen L, Hirdes J, Hogeveen S, Berg K, et al. interRAI check-up (CU) assessment, supplement, and self-reported forms and user's manual. Version 10.1. Washington, DC; 2018.
- 202. Nova A. OH West raisoft data analysis. Waterloo; 2021.
- 203. Harling G, Payne CF, Davies JI, Gomez-Olive FX, Kahn K, Manderson L, et al. Impairment in activities of daily living, care receipt, and unmet needs in a middle-aged and older rural South African population: findings from the HAALSI study. J Aging Health. 2020;32(5–6):296–307.
- 204. Rujumba J, Mbasaalaki-Mwaka CL, Ndeezi G. Challenges faced by health workers in providing counselling services to HIV-positive children in Uganda: a descriptive study. J Int AIDS Soc [Internet]. 2010;13(1):9. Available from: https://doi.org/10.1186/1758-2652-13-9
- 205. Rujumba J, Tumwine JK, Tylleskär T, Neema S, Heggenhougen HK. Listening to health workers: lessons from Eastern Uganda for strengthening the programme for the prevention of mother-to-child transmission of HIV. BMC Health Serv Res. 2012;12:1–12.
- 206. Nuwagaba-Biribonwoha H, Mayon-White RT, Okong P, Carpenter LM. Challenges faced by health workers in implementing the prevention of mother-to-child HIV transmission (PMTCT) programme in Uganda. J Public Health (Bangkok). 2007;29(3):269–74.
- 207. Ayakaka I, Ackerman S, Ggita JM, Kajubi P, Dowdy D, Haberer JE, et al. Identifying barriers to and facilitators of tuberculosis contact investigation in Kampala, Uganda: a behavioral approach. Implement Sci. 2017;12:1–13.

- 208. Cattamanchi A, Miller CR, Tapley A, Haguma P, Ochom E, Ackerman S, et al. Health worker perspectives on barriers to delivery of routine tuberculosis diagnostic evaluation services in Uganda: a qualitative study to guide clinic-based interventions. BMC Health Serv Res. 2015;15:1–10.
- 209. Fusch P, Ness L. Are we there yet? Data saturation in qualitative research. Qual Rep. 2015;20(9):1408–16.
- 210. interRAI. Correct coding: guide for coding IADLs and ADLs. Information for home and community care assessors [Internet]. interRAI. 2016. Available from: https://www.interrai.co.nz/assets/Documents/ESS-Coding/c7ea4a01c1/Correct-Coding-Guide-for-coding-IADLs-and-ADLs.pdf
- 211. TIBCO. What is analysis of variance (ANOVA)? [Internet]. TIBCO. [cited 2022 Mar 30]. Available from: https://www.tibco.com/reference-center/what-is-analysis-of-variance-anova#:~:text=Analysis of Variance (ANOVA) is,the means of different groups.
- 212. National Cancer Institute. Antiretroviral therapy [Internet]. National Cancer Institute. [cited 2022 Mar 30]. Available from: https://www.cancer.gov/publications/dictionaries/cancer-terms/def/antiretroviral-therapy
- 213. Government of Ontario. Introduction to the comprehensive geriatric toolkit [Internet]. Government of Ontario. [cited 2022 Mar 30]. Available from: https://cgatoolkit.ca/
- 214. Caulfield J. How to do thematic analysis | A step-by-step guide & examples [Internet]. Scribbr. 2022 [cited 2022 Mar 30]. Available from: https://www.scribbr.com/methodology/thematic-analysis/#:~:text=Different approaches to thematic analysis,-Once you've&text=An inductive approach involves allowing,on theory or existing knowledge.
- 215. Magnuson A, Sattar S, Nightingale G, Saracino R, Skonecki E, Trevino KM. A practical guide to geriatric syndromes in older adults with cancer: a focus on falls, cognition, polypharmacy, and depression. Am Soc Clin Oncol Educ B. 2019;(39):e96–109.
- 216. Reach Out Mbuya Community Health Initiative. Home-based care [Internet]. Reach Out Mbuya Community Health Initiative. [cited 2022 Jun 23]. Available from: https://www.reachoutmbuya.org/home-based-care/
- 217. NVivo. Homepage [Internet]. NVivo. [cited 2022 Mar 30]. Available from: https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home

### **APPENDICES**

### **Appendix A: Phase One Recruitment and Consent Materials**

### **Recruitment Letter for Clients – English Version**

[Insert Date]

Dear Client:

Brittany Kroetsch is a master's student working under the supervision of Dr. George Heckman in the School of Public Health Sciences at the University of Waterloo. As part of her degree, she is conducting a research study on the acceptability of using a standardized clinical assessment instrument for older adults in the Kampala district of Uganda.

As a client of the Reach Out Mbuya Community Health Initiative, she would appreciate obtaining information on your current health condition through the completion of the interRAI Check-Up assessment. This is a standardized geriatric assessment which collects information on overall health status, such as medical conditions, health service use, and ability to complete certain tasks.

Your involvement in this assessment is entirely voluntary and there are very minimal anticipated risks to participation in this study, and service providers at Reach Out are well equipped to deal with these. If you agree to participate, the assessment should not take more than about 30 minutes to complete. The questions are quite general (for example, *how well do you hear? How well do you see in adequate light?*), however, you may decline answering any questions you feel you do not wish to answer. Your identity will be confidential and will be grouped with responses from other participants. Further, you will not be identified by name in any thesis, report, or publication resulting from this study. The data collected will be kept in a secure location at the University of Waterloo and retained for a minimum of *seven years*.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #43401).

For all other questions, or if you would	l like additional information	to assist you in reaching a
decision about participation, please fee	l free to contact Brittany at	or Dr.
Heckman at		

Thank you in advance for your interest in this project.

Yours sincerely,

**Brittany Kroetsch**University of Waterloo
Faculty of Health

### Recruitment Letter for Clients - Luganda Version

Ssebo/Nyabo:

Brittany Kroetsch muyizi owensoma eyawagulu akolera wansi wobulabilizi bwa Dr. George Heckman musomero lya sayansi mutendekero ekulu elya Waterloo. Ng'ekitundu ku diguli ye, akola okunonyereza ku kukiriza okukozesa akakungo akomulembe akomuddwaliro ku bantu abakadde mu Kampala distrikiti mu Uganda.

Nga omulwadde wa Reach Out Mbuya Community Health Initiative, yandyagadde okusima okufuna obubaka obukwata kumbeera yo eyo bulamu ngabweri kati okuyita mukujjuza akakungo ka interRAI. Kano kakungo akomulembe akakwata ku bakadde akafuna obubaka bwona kumbeerayo eyobulamu, okugeza embeera yobujanjabi, enkozesa yobujanjabi, nobusobozi okutukiriza byoyina okukola.

Okwetabakwo mukunonyereza kuno kwabwanakyewa era obutyabaga butono nyo obusubilwa okubawo ngawetabye mukunoyereza kuno, era abawereza mu Reach Out Mbuya batendeke nyo okubwanganga. Bwokiriza okukwetabamu, okunonyereza tekulina kutwala eddakika ezisuka 30. Ebibuuzo byawamu (okugeza, Owulira otya? Olaba otya mukitangala ekimala?) naye osobola obutadamu ebibuzo byowulira nti tewandyetaze kubidamu. Obumanye bwo bujja kukumibwa ngabwakyama era bujja kutekebwa mukibinja nobulala okuva mubalala abetabyemu. Okugatta ku ekyo, tojja kuzulibwa nelinnya mumbeera yona, alipota oba ekiwandiko ekiva kukunonyereza kuno. Obubaka obukunganyiziddwa bujja kukumibwa mukifo ekyekusifu mutendekero lya Waterloo era bujja kukumibwa ekitono enyo myaka musanvu.

Okunonyereza kuno kwekenenyezebwa era nekufuna okukakasibwa okuyita kakiko kebyokunonyereza aka tendekero lya Waterloo.

Ebibuzo ebilala byonna,	oba bwoba	oyagala ol	bubaka	obulala	okuyamba	okukola	<u>o</u> kusalawo
kubyokwetabamu, beera	waddembe	okutukirira	Britta	ny ku			oba Dr.
Heckman ku		■.		_			

Webale nyo wadde ngatonaba kwetabamu okulaga okwagala mumulimu guno.

Nze owuwo,

**Brittany Kroetsch**University of Waterloo
Faculty of Health

### **Client Screening Questionnaire – English Version**

### **Client Screening Questionnaire**

P = Potential Participant; A = Assessor; In-Person

<u>See below if potential participant would like to complete the screening questionnaire to determine study eligibility</u>

- A: If you would like to participate in the study, eligibility screening criteria must be met. May I ask you several questions regarding screening eligibility?
  - A: (1) As of today [insert today's date], are you 60 years of age or greater?
  - A: (2) As of today [*insert today's date*], are you a permanent resident of the Kampala district?
  - A: (3) Are you able to provide free and informed consent for participation in this research study, with or without the presence of a care partner?

Assessor to note yes or no to the listed questions above. The assessor also notes the date and time the conversation occurred.

### See below if unsure of participant capacity to consent

- A: (4) What did you understand to be the purpose of the study?
- A: (5) What will you (or your loved one) be asked to do in this research study?
- A: (6) Do you (or your loved one) need to participate in the research study if you do not want to?
- A: (7) Can you please describe the potential risks and benefits of the research study?

Assessor to note yes or no to the listed questions above to denote whether the participant had a satisfactory or unsatisfactory response to the question.

**Client Screening Questionnaire Log** 

Participant	Date	(1)	(2)	(3)	(4)	(5)	(6)	(7)	Notes
Name	and	(y/n)	110165						
Tvaine	Time	(3/11)	(3/11)	(3/11)	(3/11)	(3/11)	(3/11)	(3/11)	
_	Time								
		□Yes							
		□ No							
			_						
		□Yes							
		□ No							
		□Yes							
		□ No							
		□Yes							
			□ No	□ No	□ No	□ No		□ No	
		□Vas	□Vas	□Vas	ΠVag		□Vag		
		□Yes							
		□ No							
		□Yes							
		□ No							

### Client Screening Questionnaire - Luganda Version

### Akakungo akasunsula eyandyetabyemu

P = Ayinza okwetabamu; A = Omunonyereza; mubuntu

# Tunula wansi oba eyandyetabyemu yandyagadde okujuza akakungo okulaba oba asanidde mukunonyereza kuno.

- A: Bwoba nga wandyagadde okwetaba mukunonyereza kuno obukwakulizo bwokusunsula buyina okutukirizibwa. Nkubuzeyo kubibuuzo ebyenjawulo ebikwatagana nokusunsulwa?
  - A: (1) Nga olwaleero (ennaku zomwezi) oli wamyaka 60 egyobukulu oba okusingawo?
  - A: (2) Nga olwaleero (ennaku zomwezi) oli mutuze owenkalakalira owomu Kampala distulikiti?
  - A: (3) Osobola okutuwa okukiriza kwo okwobwerere ate era ngotegedde bulungi okwetaba mukunonyereza kuno, nga waliwo oba nga tewali omuntu akulabilira?

Omunonyereza awandike yee oba nedda kubibuuzo ebiwandikiddwa wagulu. Omunonyereza era awandika ennaku zomwezi n'essawa emboozi webereddewo.

### Tunula wansi bwoba obusabusa obusobozi bwagenda okwetabamu okukiriza.

- A: (4) Kiki kyewategedde okuba ekigendererwa kyoku nonyereza kuno?
- A: (5) Gwe (oba omwagalwawo) mwetaga okwenyigira mukunonyereza kuno wadde nga temwandyagadde?
- A: (6) Osobola okunyonyola obutyabaga obuyinza okubeerawo n'emigaso egyokunonyereza kuno?
- A: (7) Osobola okunyonyola obutyabaga obuyinza okubeerawo n'emigaso egyokunonyereza kuno?

Omunonyereza awandika yee oba nedda kubibuuzo ebiwandikiddwa wagulu okwawulawo oba eyetabyemu yabadde nokuddamu okumatiza oba okutamatiza eri ekibuuzo.

Akakungo akasunsula Ayinza okwetabamu

Elinnya lye ye tabyemu	Ennaku zomwezi n'essawa	(1) (y/n)	(2) (y/n)	(3) (y/n)	(4) (y/n)	(5) (y/n)	(6) (y/n)	(7) (y/n)	Notes
		□Yee □ Nedda							
		□Yee □ Nedda							
		□Yee □ Nedda							
		□Yee □ Nedda							
		□Yee □ Nedda							
		□Yee □ Nedda							

### Script for Obtaining Client Informed Consent – English Version

### **Script for Obtaining Informed Consent from Clients**

P = Potential Participant; A = Assessor; In-Person

### **Introduction:**

A: Hello, my name is [insert assessor name] and I am a healthcare service provider at the Reach Out Mbuya Community Health Initiative. Through a partnership with the University of Waterloo, Canada, we are assisting in the conduction of a study that is looking to improve care practices for older adults in Uganda. Your name was provided to me because you are eligible to participate in the study. Is this a convenient time to provide you with further information on this study?

See below if potential participant would not like more information on the study.

- P: No, I am no longer interested in hearing more about the study.
- A: No problem, thank you for your time.

See below if potential participant would like more information on the study another time.

- P: No, I am too busy right now. Can we have this conversation another day and time?
- A: Of course. When would be the best date and time for you when we are conducting community visits?
- P: [says date and time].
- A: OK. I will return for a visit on [suggested date and time]. Thank you for your time.

See below if potential participant would like more information on the study now.

P: Yes, could you provide me with more information on this study you are conducting?

### What is the study about?

A: You are invited to participate in a research study about assessing the acceptability of the interRAI Check-Up comprehensive geriatric assessment instrument in the Kampala district of Uganda. The Check-Up is a standardized tool used in various countries to assess the health of older persons and inform care practices. We would like to invite you to participate in completing the Check-Up assessment. This is part of an international study for a master's project led by Student Investigator Brittany Kroetsch at the University of Waterloo which is looking to improve care practices for older adults with HIV in

Uganda. You are eligible to participate in this study because you are 60 years of age or older and are a permanent resident of the Kampala district.

### **Study Procedures**

- A: We are asking you to provide consent for allowing the researchers to collect information about yourself that to use to assess the acceptability of the Check-Up. This would involve the completion of the interRAI Check-Up comprehensive geriatric assessment which takes approximately 30 minutes complete, and collects information on demographics (age, gender, etc.), medical conditions/diagnoses, past health care service utilization, activities of daily living, pain, mood, falls risk, and cognition. This would also allow researchers to collect information from your medical records at Reach Out Mbuya Community Health Initiative. Specific data that would be collected include demographics (age, gender, etc.), medical conditions/diagnoses, past health care service utilization, new illnesses, or hospitalizations. With your permission, information collected during this study will be entered into a secure database for future Research Ethics Board approved studies, and for health service providers at the Reach Out Mbuya Community Health Initiative to inform your future care.
- A: Do you have any questions?

Assessor to answer any questions the potential participant may have.

### **Risks**

- A: Due to the nature of the assessment questions which require participants to reflect on their health, it is possible that you may experience short-term psychological or emotional harm. However, you do not need to answer questions on the Check-Up assessment that you do not want to answer or that make you feel uncomfortable. Your identity will be kept confidential. You can withdraw from or stop taking part in this study at any point in time and any data you have provided or allowed researchers to collect would be destroyed. Your participation is completely voluntary.
- A: Do you have any questions?

Assessor to answer any questions the potential participant may have.

### **Benefits**

A: Participation in this research may not benefit you directly, however, the outputs of the Check-Up assessment are designed to inform clinical care practices. We also hope that what is learned will help us to understand the barriers and facilitators to use of the Check-Up assessment in the central Ugandan context. Your identity will be kept confidential and only the research team and health service providers from the Reach Out Mbuya Community Health Initiative would have access to the data collected. Researchers will use codes instead of your name. All hard copy information and any electronic files would

be coded, encrypted, and stored in locked offices and on secure computers protected by a password.

A: Do you have any questions?

Assessor to answer any questions the potential participant may have.

### **Voluntary Participation**

- A: Participation in this study is completely voluntary. You have the right to withdraw from the study at any point in time, just by informing a member of the research team. If you decide to stop participation, there would be no consequences and any data you have provided or allowed researchers to collect would be destroyed. You may also choose not to have specific information collected for any reason.

A: Do you have any questions?

Assessor to answer any questions the potential participant may have.

### Letter of Information, Consent, and Verbal Consent

A: Would you like a letter of information, which has further details regarding the study as well as contact names and numbers, or would you like to complete the consent process verbally?

See below if potential participant would not like the letter of information or verbal consent.

- P: No, thank you.
- A: No problem, thank you for your time.

See below if potential participant would like the information and consent letter.

P: Yes, please.

A: Here is the letter of information with two consent forms attached. Please review the letter of information and consent form. Please let me know if you have any questions or concerns. If you would like to participate in the study, you will need to sign both consent forms. One copy of the consent forms will be yours to keep, and the second copy will be for me to keep as a record for the study.

Provide letter of information and consent forms.

Potential participant to sign all forms if they wish to participate.

Assessor to sign all forms and provide participant with one copy of the consent form for their records.

### See below if potential participant would like to complete their consent verbally.

- A: If you would like to participate in the study, voluntary consent is needed. May I ask you several questions regarding consent?
  - ➤ A: (1) Do you agree to complete the Check-Up assessment with myself or another assessor?
  - A: (2) Do you agree to allow research personnel to use information from the Check-Up for the purposes of this research?
  - A: (3) Do you agree to allow health service providers from Reach Out Mbuya Community Health Initiative to use information from the Check-Up to inform your care?
  - A: (4) Do you agree to allow research personnel to access your medical record to collect information for the purposes of this research?
  - A: (5) Do you consent to participate in this study knowing that you can withdraw at any point with no consequences?
  - A: (6) Do you consent to the release of your personal health information to research personnel for this study?
  - A: (7) Do you agree to allow research personnel to store your de-identified data on a secure database for future research?
  - A: (8) Do you agree to allow health service providers from Reach Out Mbuya Community Health Initiative to store your data on a secure database to inform your future care?

Assessor to note yes or no to the listed questions above. The assessor also notes the date and time the conversation occurred.

**Verbal Consent Log** 

Participant Name	Gender (m/f/o)	Date and Time	(1) (y/n)	(2) (y/n)	(3) (y/n)	(4) (y/n)	(5) (y/n)	(6) (y/n)	(7) (y/n)	(8) (y/n)	Summary of Results (y/n)	Notes
	☐ Male ☐ Female ☐ Other		□Yes □ No									
	☐ Male ☐ Female ☐ Other		□Yes □ No									
	☐ Male ☐ Female ☐ Other		□Yes □ No									
	☐ Male ☐ Female ☐ Other		□Yes □ No									
	☐ Male ☐ Female ☐ Other		□Yes □ No									
	☐ Male ☐ Female ☐ Other		□Yes □ No									

### Script for Obtaining Client Informed Consent – Luganda Version

### Enambika yokufunamu okukiriza okuva eri abalwadde

P = Ayinza okwetabamu; A = Omunonyereza, Mu buntu

### Enyanjula:

A: Nkulamusiza, Erinya lyange nze (eyekenenya) era ndi muwereza owebyobulamu ku Reach Out Mbuya Community Health Initiative. Ngatukwataganilwamu netendekero lye Waterloo, Canada, tuyambako mukunonyereza okugenderera okutumbula omutindo mundabilira yabakadde mu Uganda. Erinya lyo lyampebeddwa olwokuba nti osanidde okwetaba mukunonyereza kuno. Kino ekiseera kirungi gyoli okwongera okuwa obubaka obusingako wano kukunonyereza kuno?

Tunula wansi oba eyandyetabyemu teyandyagadde bubaka busingakawo kukunonyererza kuno

- P: Nedda, sikyayagala kuwulira ebisingakawo kubikwata kukunonyereza kuno.
- A: Tewali buzibu, webale olwebiseera byo.

<u>Tunula wansi oba eyandyetabyemu yandyagadde obubaka obusingakawo kukunonyereza kuno</u> ekiseera ekilala?

- P: Nedda, ndi mukukola nyo ebissera bino. Tusobola okunyumyamu olunaku olulala nebiseera?
- A: Awatli kubusabusa. Ennaku zomwezi ki enungi n'ebiseera gyoli bwetunaaba tukyalira ebyalo?
- P: Ayogera ennaku zomwezi n'ebiseera.
- A: Kale njakukyalira nga (ennaku zomwezi n'ebissera). Webale okuwayo ebissera byo.

<u>Tunula wansi oba eyandyetabyemu yandyagadde obubaka obusingakawo kukunonyereza kuno kati?</u>

P: Yee, osobola okumpa obubaka obusingakawo kukunonyereza kwokola?

### Okunonyereza kukwata kuki?

A: Oyanilizibwa okwetaba mukunonyereza okukwata kukwekenenya okukiriza okukozesa akakungo ka interRAI Check-Up akakozesebwa mu kwekenenya embeera yabakadde mu Kampala distulikiti mu Uganda. Akakungo ka Check-Up kyekikola ekyomutindo ekikozesebwa munsi ezenjawulo okwekenenya obulamu bwabakadde nokutegeza abawa endabilira. Twandygadde okukwaniliza okwetaba mukujuza akakungo kano aka Check-

Up. kino kitundu kyokunonyereza okwensi yonna okwadiguli enkulu ekukulembeddwa omuyizi anonyereza Brittany Kroetsch ku tendekero ekulu elya Waterloo erigenderera okutumbula endabilira yabakadde abayina akawuka kamukenenya mu uganda. Osanidde okwetaba mukunonyereza kuno kubanga oyina emyaka 60 egyobukulu oba okusingakawo era oli mutuze owenkalakalira awo mu Kampala distulikiti.

### Emitendera gyokunonyereza kuno

A: Tukusba okukiriza abanonyereza okukunganya obubaka obukukwatako obunakozesebwa okwekenenya okukiriza kwakakungo ka Check-Up. Kino kijja kutwaliramu okujuza akakungo aka interRAI Check-Up akakozesebwa okwekenenya embeera yabakadde era kitwala eddakika 30 okamaliriza, era kakunganya obubaka ku buzaale, embeera y'obulamu/okukeberebwa, embeera eyayita eyenkozesa yempereza, byokola ebyabulilunakku, obulumi, enewulira, akatyabaga kokugwa, nokutegera. Okunonyereza kuno kujja kukiriza abanonyereza okukunganya obubaka okuva mubiwandiko byo mu Reach Out Mbuya Community Health Initiative. Obubaka obwenjawulo obujja okukunganyizibwa butwaliramu obutonde bwo (emyaka, nekikula), embeera yobulamu/nokukeberebwa, enkozesa yempereza yobulamu eyayita, endwadde empya, oba okuwebwa ekitanda. Nolukusa lwo, obubaka obukunganyizibwa mukunonyereza kuno bujja kuyingizibwa muterekero lyamayengo okukozesebwa mubiseera ebijja okukakasa okunonyereza kuno oba kulwa abawa empereza yobulamu mu Reach Out Mbuya Community Health Initiative okutegeza endabilira mu biseera ebijja.

### A: Oyina ebibuzo byonna?

Omunonyereza okudamu ebibuzo byonna eyetabyemu byayinza okuba nabyo.

### Obutyabaga

- A: Okusinzira kumbeera yebibuzo byakakungo ebyetagisa eyetabyemu okufumitiriza kubulamu bwabwe, kisoboka nti oyinza okulumizibwa mundowoza n'enewulira. Naye tewetagisa kudamu bibuzo byonna mukakungo ka Check-Up byotandyagadde kudamu oba ebyo ebikufula nga totebenkedde. Obumanye bwo bujja kukumibwa nga bwakyama. Oyinza okubivako oba okuyimiriza okwetaba mukunonyereza kuno essawa yonna era obubaka bwonoba otuwadde oba bwonoba okikiriza abanonyereza okufunako bujja kusanyizibwawo. Okwetabamukwo kwbwanakyewa ddala.
- A: Oyina ebibuuzo byonna?

Omunonyereza okudamu ebibuzo byonna eyetabyemu byayinza okuba nabyo.

### **Emiganyulo**

A: Okwetaba kwo mukunonyereza kuno kuyinza obutakuganyula buterevu, naye ebinava mukunonyereza kwa Check-Up bisengekebwa okutegeza endabilira yomuddwaliro. Era Tusubira nti ekiyigiddwa kijja tuyamba okutegera emiziziko nabawagira enkozesa

yakakungo ka Check-Up mumbeera yamakati ga Uganda. Obumanye bwo bujja kukumibwa nga bwakyama era abanonyereza nabawa empereza yobulamu mu Reach Out Mbuya Community Health Initiative bebajja okusobola okutuka kububaka obukungaziddwa. Abanonyereza bajja kukozesa enamba mukifo kyelinnya lyo. Obubaka obukubwa kumpapula nobunakumibwa mumayengo bujja kuweebwa enamba era bijja kuterekebwa mu yafesi ensibe era nemukompyuta ekumiddwa ekisumuluzo kye namba.

A: Oyina ebibuuzo byonna?

Omunonyereza okudamu ebibuzo byonna eyetabyemu byayinza okuba nabyo.

### Okwetabamu okwobwanakyewa

- A: Okwetaba muku nonyereza kuno kwabwanekyewa ddala. Oyina obuyinza okuva mukunonyereza esaawa yonna,otegeza omu kubanonyereza. Bwosalawo okuyimiriza okwetabamu, tewajja kuba kibonerezo era obubaka bwoba otuwadde oba bowba okirirza abanonyereza okukunganya bujja kusanyizibwawo. Oyinza okusalawo obutakiriza kukunganya obubaka obumu kulwensonga zo.
- A: Njagala kukakasa nti okunonyereza kuno kumaze okwekenenyezebwa nokukakasibwa okuyita mu kakiko akebyokunonyereza tendekero lya Waterloo, Uganda National Council for Science and Technology, the Clarke International University-Research Ethics Committee ne the Reach Out Mbuya Community Health Initiative. Bwoba oyina ebibuuzo byonna ebikwata ku dembe lyo nga eyetabyemu kunonyereza tukirira etendekero lya Waterloo Office of Research Ethics, ku , ext. , oba Uganda National Council for Science and Technology ku , oba Clarke International University-Research oba Ethics Committee ku oba , oba Reach Out Mbuya Community Health Initiative ku +256 414 222630 oba oba

A: Oyina ebibuuzo byonna?

Omunonyereza okudamu ebibuzo byonna eyetabyemu byayinza okuba nabyo.

### Ebaluwa y'obubaka, okukiriza n'kukiriza kwomubigambo

A: Wandyagadde ebaluwa y'bubaka,eyina ebisingako awo kukunonyereza nabantu nenamba zabwe, oba wandyagadde okumaliriza okukiriza mubigambo?

Tunula wansi oba eyandyetabyemu teyandyagadde baluwa y'obubaka oba okukiriza mubigambo.

- P: Nedda, webale
- A: Tewali buzibu, webale kulwebiseera byo.

Tunula wansi oba eyandyetabyemu yandyagadde ebaluwa y'obubaka nebaluwa y'okukiriza.

- P: Yee.
- A: Yeno ebaluwa yobubaka n'empapula bbiri ezokukiriza ezitekedwako. Wekenenye ebaluwa y'obubaka n'olupapula lwokiriza. Ntegezako bwoba oyina ebibuuzo byonna oba ensonga. Bowba wandyagadde okwetaba mukunonyereza, ojja kwetagisa okusa omukono kumpapula bbiri ezokukiriza. Olupapula olumu lujja kuba lulwo, ate olwokubiri lujja kuba lwange okulukuma kulwokunonyereza kuno.

Muwe ebaluwa y'obubaka n'empapula zokukiriza.

Eyandyetabyemu ateeka omukono ku mpapula zonna bwebaba bagala okwetabamu.

Omunonyereza ateeka omukono ku mpapula zonna nawako neyetabyemu olupapula olwokukiriza lumu.

Tunula wansi oba eyandyetabyemu yandyagadde okukiriza mu bigambo.

- A: Bwoba wandyagadde okwetaba mukunonyereza kuno, okukiriza okwobwanakyewa kwetagisibwa. Nsobola okubuzayo ebibuuzo ebiwerako ebikwata kukukiriza kwo?
  - A: (1) Okiriza okujuza akakungo ka Check-Up nange oba omunonyereza omulala?
  - A: (2) Okiriza abanonyereza okukozesa obubaka obuva mu kakungo ka Check-Up kulwekigendererwa kyokunonyereza kuno?
  - A: (3) Okiriza abawereza babyo bulamu okuva mu Reach Out Mbuya Community Health Initiative okukozesa obubaka obuva mu Check-Up okutegeza endabilirayo?
  - A: (4) Okiriza abanonyereza okufuna obubaka bwo bulamu bwo okukunganya obubaka kulwo kunonyereza kuno?
  - A: (5) Okiriza okwetaba mukunoyereza ngokimanyi nti osobola okubivamu essawa yonna nga tewali kibonerezo kyonna?
  - A: (6) Okiriza okutuwa obubaka bwo obwobulamu kulwo kunonyereza kuno?
  - A: (7) Okiriza abanonyereza okukuma obubaka bwo obuzuliddwa muterekero elykusifu olwokubukozesa mu kunonyereza mu masso?
  - A: (8) Okiriza abawereza babyobulamu okuva mu Reach Out Mbuya Community Health Initiative okukuma obubaka bwo mu terekero elyekusifu okutegeza endabilirayo mu masso?

Omunonyereza awandika wansi yee oba nedda kubibuuzo wagulu. Omunonyereza awandika ennaku z'omwezi n'essawa okwogera wekubereddewo.

Enambika yo'kukiriza mubigambo

Erinnya	Ekikula	Ennaku	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	Obufunze
lye'yetab yemu		z'omwezi n'essawa	(y/n)	bwebivudem u (y/n)							
	□ musajja □ mukazi □ Ekirala		□Yee □Nedda								
	□ musajja □ mukazi □ Ekirala		□Yee □Nedda								
	□ musajja □ mukazi □ Ekirala		□Yee □Nedda								
	□ musajja □ mukazi □ Ekirala		□Yee □Nedda								
	□ musajja □ mukazi □ Ekirala		□Yee □Nedda								
	□ musajja □ mukazi □ Ekirala		□Yee □Nedda								

### Information and Informed Consent for Clients - English Version

### **Informed Consent Form for Study Participants**

**Title of study:** Utility of the interRAI Check-Up Comprehensive Geriatric Assessment (CGA) Tool: Evaluating Check-Up Acceptability in Assessing Frailty and Care Needs of Older Adults with Human Immunodeficiency Virus (HIV) in Kampala District of Uganda

# Faculty Supervisor Dr. George Heckman, MD, MSc, FRCPC Associate Professor Public Health Sciences Schlegel Research Chair, Geriatric Medicine University of Waterloo Waterloo, Ontario, Canada Phone: Email: Student Investigator Brittany Kroetsch, BSc

# Public Health Sciences University of Waterloo Waterloo, Ontario, Canada Phone:

Phone: Email:

### **Co-Investigator**

Emmanuel Sendaula, MSc Monitoring, Research, and Evaluation Manager Reach Out Mbuya Community Health Initiative Kampala, Uganda Phone:

Email:

To help you make an informed decision regarding your participation, this letter will explain what the study is about, the possible risks and benefits, and your rights as a research participant. If you do not understand something in the letter, please ask one of the investigators prior to consenting to the study. You will be provided with a copy of the information and consent form if you choose to participate in the study.

### What is the study about?

You are invited to participate in a research study about assessing the acceptability of the interRAI Check-Up comprehensive geriatric assessment instrument in the Kampala district of Uganda. The Check-Up is a standardized tool used in various countries to assess the health of older persons and inform care. We would like to invite you to participate in completing the

Check-Up assessment. This is part of an international study for a master's project led by Student Investigator Brittany Kroetsch at the University of Waterloo which is looking to improve care practices for older adults with HIV in Uganda.

### I. Your responsibilities as a participant

### Who may participate in the study?

We are asking you to provide consent for allowing the researchers to collect information about yourself to use to assess the acceptability of the Check-Up. You are eligible to participate in this study because you are 60 years of age or older and are a permanent resident of the Kampala district.

### What does participation involve?

If you choose to participate, you would be asked to:

- Complete the interRAI Check-Up self-report comprehensive geriatric assessment which ascertains information on demographics (age, gender, etc.), medical conditions/diagnoses, past health care service utilization, activities of daily living, pain, mood, falls risk, and cognition.
- Allow researchers to collect information from your medical records at Reach Out Mbuya Community Health Initiative. Specific data that would be collected include demographics (ethnicity, district, etc.), medical conditions/diagnoses, past health care service utilization, new illnesses, or hospitalizations.
- Allow researchers to enter the information collected during this study into a secure database for future Research Ethics Board approved studies.
- Allow health service providers from the Reach Out Mbuya Community Health Initiative access to the information collected during this study and enter data into a secure database to help inform your future care.

### II. Your rights as a participant

### Are there any risks related to participating in this study?

Due to the nature of the assessment questions which require participants to reflect on their health, it is possible that participants may experience short-term psychological or emotional harm. You do not need to answer questions on the Check-Up assessment that you do not want to answer or that make you feel uncomfortable. Your identity will be kept confidential. Steps to protect your privacy are provided below. You can withdraw from or stop taking part in this study at any point in time and any data you have provided will be destroyed. Your participation is completely voluntary.

### What are the potential benefits related to participating in this study?

The research may not benefit you directly, however, the outputs of the Check-Up assessment are designed to inform clinical care practices. We also hope that what is learned will help us to understand the barriers and facilitators to the use of the Check-Up assessment in the central Ugandan context.

### Will I receive any remuneration for participating in this study?

You will not be paid for your participation in the research study.

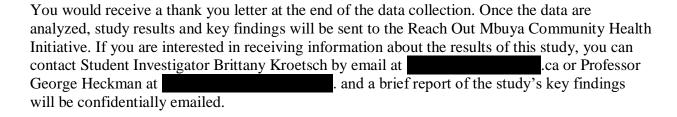
### How will my information be kept private?

Any personal identification associated with the data would be kept confidential and all data collected in this study would be securely stored. Only the research team and health service providers at the Reach Out Mbuya Community Health Initiative would have access to the data collected. Researchers will not use your name or any information that would allow you to be identified; we will use a participant code instead of your name. Your decision to participate or to withdraw from the study would also not impact the care that you receive at Reach Out Mbuya. All data will be coded, encrypted, and stored on secure computers protected by a password at the University of Waterloo and at the Reach Out Mbuya Community Health Initiative. All electronic data will be retained for a minimum of 7 years in a secure location that is password encrypted within Professor George Heckman's locked offices at the University of Waterloo and in locked offices at the Reach Out Mbuya Community Health Initiative, after which they would be destroyed. Any publications will present group data and any results reported will be in a summary format with very careful attention to exclude any information that could identify you.

### What if I change my mind about participating in this study?

Your participation in this study is completely voluntary. It is your choice to be part of the study or not. If you decide to withdraw, there would be no consequences. In cases of withdrawal, any information you provided up to that point would not be used and would be destroyed. You may decline to answer any question(s) you prefer not to answer.

### How will I learn about the results of this study?



# III. Questions, comments, or concerns

Who is funding this study	Who	is	fui	nding	this	stud	ľv	?
---------------------------	-----	----	-----	-------	------	------	----	---

This study is funded by interRAI Canada.

Has this study received clearance from a research ethics board?
This study has been reviewed and received ethics clearance through the University of Waterloo Research Ethics Board (REB#43401). If you have questions for the Board, contact the Office of Research Ethics, at ext. or
This study has also been reviewed and received ethics clearance through the Uganda National Council for Science and Technology (REB #HS2229ES). If you have questions regarding your rights as a research participant, contact the Executive Secretary UNCST at by email at
This study has also been reviewed and received ethics clearance through the Clarke International University-Research Ethics Committee in Uganda (REB #2022-338). If you have questions regarding your rights as a research participant, contact the Chairperson CIUREC at or by email at
This study has also been reviewed and received ethics clearance through the Reach Out Mbuya Community Health Initiative. If you have questions regarding your rights as a research participant, contact:  or by email:
The Research Ethics Board is a group of people who oversee the ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.
Who should I contact if I have questions regarding my participation in this study?
If you have any questions regarding this study or need more information to assist you in reaching a decision about participation, please contact Student Investigator Brittany Kroetsch by email at or Professor George Heckman at
Emmanuel Sendaula at .

### Statement of Consent

**Title of study:** Utility of the interRAI Check-Up Comprehensive Geriatric Assessment (CGA) Tool: Evaluating Check-Up Acceptability in Assessing Frailty and Care Needs of Older Adults with Human Immunodeficiency Virus (HIV) in Kampala District of Uganda

I have read and understood the information letter and consent form.

I have had sufficient time to consider the information provided and to ask questions.

I understand that my identity will be kept confidential, and that the information obtained from my assessment and medical record will be used for the research objectives.

I understand that de-identified data may be entered into a secure database for future use.

I understand that my participation in this study is voluntary and that I am completely free to refuse to participate or withdraw from this study at any time without any penalty.

I understand that I am not waiving any of my legal rights by signing this consent form and that there is no guarantee that this study will provide any benefits to me.

If I have any questions about this project, I can contact Student Investigator Brittany Kroetsch

I have been told that I will receive a dated and signed copy of this form.

[ ] or Pro	ofessor George Heckman [	] or co-	_
investigator Emmanuel Sendau	la [	] at any time.	
This study has been reviewed a	nd received ethics clearance thro	ough the University of Wate	rloo
Research Ethics Board, the Uga	anda National Council for Science	ce and Technology, the Clar	ke
International University-Resear	ch Ethics Committee, and the Re	each Out Mbuya Communit	y
Health Initiative. However, the	final decision to participate in th	ne study is completely yours	. If
you have any comments or con-	cerns resulting from your partici	pation in this study, please	
contact the University of Water	loo Office of Research Ethics, a	t , ext.	or
by email at	, the Uganda National Counc	il for Science and Technolog	gy
Executive Secretary at	or by email at	, the Clarke	
International University-Resear	rch Ethics Committee Chairperson	on at or b	Эy
email at , or the F	Reach Out Mbuya Community H	lealth Initiative at	•
or	by email at	. The Research Et	thics
	oversee the ethical conduct of rything you discuss will be kept		le are
	_		

service utilization, etc.) will be shared the Reach Out Mbuya Community Her information letter. I understand that th than my name. I agree to allow research person	Check-Up (demographics, diagnoses, past health care with research personnel and health service providers from alth Initiative from the various sources outlined in the is information will be linked to a participant code rather nnel and health service providers to use information from of this research to inform my care.
hospitalizations, etc.) will be shared w the information letter. I understand that participant code and will not be linked	nnel to use information from my medical
asked to provide information about my I agree to allow research person	each Out Mbuya Community Health Initiative will be a care and my health from my medical record.  nnel to access aspects of my health and care from my t Mbuya health service providers.
database for future research and to help I agree to allow research person	ected during this study may be entered into a secure p inform my future care.  nnel to use my de-identified data for future research and ervice providers to use my data to inform my future care.
I have read this form and I freely conse	ent to participate in this study.
Patient Name (please print):	Name of Researcher/Witness (please print):
Signature:	Signature:
Date:	Date

### Information and Informed Consent for Clients - Luganda Version

### Olukuusa nga ottegedde ebikwatta kukunonyeleza

**Omutwe gwokunonyereza**: Enkozesa yakakungo akayitibwa interRAI Check-Up akakozesebwa ku mbeera yabakadde: Okwekenenya okukiriza Check-Up mukwenenya embeera nebyetago byendabilira byabantu abakadde abayina akawuka kamukenenya mu distulikiti ye Kampala mu Uganda.

### Kalabalaba Wetendekero

Dr. George Heckman, MD, MSc, FRCPC
Associate Professor
Public Health Sciences
Schlegel Research Chair, Geriatric Medicine
University of Waterloo
Waterloo, Ontario, Canada
Phone:
Email:

### Omuyizi omunonyereza

Brittany Kroetsch, BSc Public Health Sciences University of Waterloo Waterloo, Ontario, Canada Phone:

Phone: Email:

### **Omunonyereza**

Emmanuel Sendaula, MSc Monitoring, Research, and Evaluation Manager Reach Out Mbuya Community Health Initiative Kampala, Uganda

Phone:
Email:

Okuyamba okukola okusalawo okulungi kubikwata mukwetabamu kwo, ebaluwa eno ejja kukunyonyola kubikwata kukunoyereza kuno, kubutyabaga obusulbirwa ne'migaso, neddembe lyo nga omuntu eyenyigidde mukunyereza. Bwoba toyina kyotegedde mu baluwa eno, tukusaba obuze kubamu kubanonyereza ngatonaba kukiriza kwetaba mukunonyereza kuno. Ojjakuwebwa obubaka n'ebaluwa eyokukiriza bwosalawo okwetaba mukunonyereza kuno.

### Okunonyereza kuno kukwata kuki?

Oyanilizibwa okwetaba mukunonyereza okukwata kukwekenenya kukukiriza ekikozesebwa ekiyitibwa interRAI Check-Up mukwekenenya embeera yabakadde mu distrikiti y'e Kampala. Check-Up kyekikozesebwa ekyomutindo ekikozesebwa mu nsi nyingi okwekenenya embeera

y'obulamu y'abantu abakadde awo nekituyamba mundabirira. Twandyagadde okukwaniriza okwetaba mukujuza enekenenya ya Check-Up. Kino kitundu kyokunonyereza okwensiyona okwomusomo omukulu okukulemberwa omuyizi omunonyereza Brittany Kroetsch ewetendekero ekulu elye Waterloo eritunulidde okutumbula endabilira y'abakadde abayina akawuka kamukenenya mu Uganda.

### I. Obuvunanyizibwa bwo nga e'yetabyemu

### Ani ayinza okwetaba mukunonyereza kuno?

Osanidde okwetaba mukunonyereza kuno kubanga oweza emyaka nkaga oba okusukawo ate era oli mutuze owenkalakalila mu distrikiti y'e Kampala.

### Okwetabamu kitwalilamuki?

Bwolondawo okwetabamu, ojja kubuzibwa oku:

- Okujuza akakungo ka interRAI akakwata kubulamu bwo akatwaliramu ebintu nga (emyaka gyo, ekikulakyo n'ebilala) embeera yobulamu/endwadde ezizuliddwa, enkozesa y'empereza y'ebyobulamu eyayita, n'ebikolwa ebyabulijo, obulumi, enewulira, obutyabaga bwokugwa, n'enkola yobwongo.
- Kiriza abanonyereza okufuna obubaka obukukwatako obwobulamu bwo okuva mu Reach Out Mbuya Community Health Initiative. Ebikukwatako ebija okufunibwa bitwaliramu obuzaliranwabwo (eggwanga, distrikiti), embeera yobulamu bwo, endwadde ezizuliddwa,enkozesa y'empereza y'ebyobulamu eyise, endwdde empya, oba okuwebwa ekitanda.
- Kiriza abanonyereza okuyingiza obubaka obukugiddwako muterekero lyobubaka elyesigika kituymbe akakiko akakulira ebyokunonyereza okukakasa okunonyereza kuno.
- Kiriza abasawo ba Reach Out Mbuya Community Health Initiative okufuna obubaka obukunganyiziddwa mukunonyereza kuno nokubuyingiza muterekero lyobubaka okuyamba okukyusa mumpereza yo mu biseera ebija.

### II. Eddembe lyo nga omuntu eyetabyemu

### Waliwo obutyabaga bwona obusubirwa nga wetabye mukunonyereza kuno?

Okusinzira kumbeera y'ebibuzo ebyetagisa eyetabyemu okufumintiriza kubulamu bwabwe, kisoboka nti eyetabyemu ayinza okuyita mukukosebwa okwekigero mundowoza, nenewulira. Toyina kudamu bibuzo mukakungo byotayagala kudamu oba ebyo ebikuletera ouwulira ngatotebenkedde. Obumanye bwo bujja kukumibwa nga bwakyama. Emitendera gyokukuma ebyekyama byo bitotondwa wansi. Osobola okuva oba okulekerawo okwetaba mu kunonyereza kuno essawa yona era obubaka bwonoba otuwadde tujja kubusanyawo. Okwetabamukwo ddala kwabwanekyewa.

### Miganyulo ki egiyinza okusubirwa egyekwanya mukwetaba mukunonyereza kuno?

Okunonyereza kuyinza obutakuganyula buterevu naye ebivamu mukakungo biyamba okukyusamu mundabilira yaffe eyomu ddwaliro. Tusubira nti ebiyigiddwa bijja tuyamba okutegera emiziziko nebiyinza okutuyamba munkozesa yakakungo ka Check-Up mumasekati nga Uganda.

### Nawebwa sente olwekwetaba mukunonyereza kuno?

Tojja kusasulwa olwokwetaba mukunonyereza kuno.

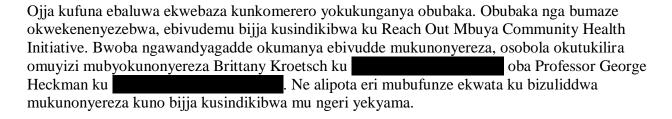
### Obubaka bwange bunakumibwa butya nga bwakyama?

Ebikwata kumuntu sekinomu ebimwawula ngabyekwanya kububaka bijja kukumibwa ngabyakyama era obubaka bwona obunakunganyizibwa mukunonyereza kuno buja kukumibwa bulungi. Abanonyereza bokka nabo abawa empereza y'ebyobulamu mu Reach Out Mbuya Community Health Initiative bebasobola okutuka kububaka obukunganyiziddwa. Abanonyereza tebaja kukozesa linnya lyo oba obubaka obusobola okuyamba okuzula; tuja kukozesa enamba mukifo kyelinnya lyo. Okusalawo kwo okwetaba or okubivamu mukunonyereza tekija kukosa mpereza gyofuna mu Reach Out Mbuya. Obubaka bwona kutekebwako kiggula lugi, era bikumibwe mubyuma kaimagezi ngabikumibwa kiggula lugi mutendekero ekulu elye Waterloo ne ku Reach Out Mbuya Community Health Initiative. Obubaka bwona obuli mumayengo buja kusigalayo ekitono enyo okumala emyaka musanvu mukifo ekyesigika ngakiriko kigula lugi mukakalabizo erigaddwa e lya kakensa George Heckman's erya Waterloo n'emu kakalabizo erigaddwa lya Reach Out Mbuya Community Health Initiative, oluvanyuma bija kusanyizibwawo. Obubaka bwona obukubiddwa buja kulaga obubaka obwawamu era alipota eyebivudemu ejja kubeera mubufunze nobwegenderza bungi okujamu obubaka obuyinza okuzula.

### Singa nkyusa ebirowoozo kubyokwetaba mukunonyereza kuno?

Okwetaba kwo mukunonyereza kuno kwabwanakyewa. Kusalawo kwo okwetaba mukunonyereza oba nedda. Bwosalawo okubivamu tewaja kubo kibonerezo. Singa obivamu, obubaka bwoliba owaddeyo okutukawo tebujja kukozesebwa era bujja kusanyizibwawo. Osobola obutadamu kibuzo kyonna kyowulira nga tewandyagadde.

### Namanya ntya ebivude mukunonyereza kuno?



# III. Ebibuzo, ebidibwamu, oba n'ebikwata ku bantu

	n		1	
Anı	Otii	ONIMIA	AZIIMANTIARAZA	ZIIIIO
$\mathbf{A}$	alu	yn na	okunonyereza	KUHUA
		<b>5</b>	011011011	

Okunonyererza kuno kufugirirwa ekibbina kya interRAI Canada.

Okunonyererza kuno kurugirirwa ekibolna kya interkat Canada.
Okunonyereza kuno kwafunye okukakasibwa okuva mukibina ekikulira okunonyereza?
Okunonyereza kuno kwekenenyezeddwa era nekukakasibwa okuyita kibiina kyokunonyereza ekye tendekero lya Waterloo (REB 43401). Bwoba oyina ebibuzo eri ekibbina tukirira ekakalabizo elyokunonyereza ku
Okunonyereza kuno kwekenenyezeddwa era nekukakasibwa okuyita mu National Council and Technology (REB #HS2229ES). Bwoba oyina ebibuzo ebkwata kudembe lyo nga eyetabyemu tufune omuwandisi UNCST ku + oba sindika obubaka ku
Okunonyereza kuno kwekenenyezebwa era nekukakasibwa akakiko kebyokunonyereza mu Uganda aketendekero lya Clarke International university (REB #2022-338). Bwoba oyina ebibuzo ebikwata kuddembe lyo nga eyetabyemu tufune sentebbe CIUREC ku oba sindika obubaka ku
Okunonyereza kuno kwekenenyezeddwa era nekufuna okukirizibwa okuyita mu Reach Out Mbuya Community Health Initiaitive. Bwoba oyina ebibuuzo ebikwata ku ddembe lyo nga eyetabye mukukunonyereza kuno tukukirira oba oba sindika obubaka ku
Akakiiko kemitendera mubyokunonyereza kyekibiina kyabantu abalabilira eneyisa eyemitendera mubyokunonyereza. Abantu abo si kitundu kukibinja ekikola kubyokunonyereza. Buli kyonna ekinakubaganyizibwako kijja kukumibwa ngabyakyama.
Ani gwenina okutukirira bwemba nina ebibuuzo ebikwata kukwetaba kwange mukunonyereza kuno?
Bwoba oyina ebibuuzo byonna ebikwata kukunonyereza kuno oba obubaka obusingawo okuyamba okutuka kukusalawo mukwetabamu, tukilira omuyizi mubyokunonyereza Brittany Kroetsch sindika obubaka ku oba Professor George Heckman ku oba Emmanuel Sendaula ku .

#### Ekiwadiko ekikwata ku lukuusa kukunonyeleza

Omutwe gwokunonyereza: Enkozesa Yakakungo ka InterRAI: Okwekenenya enzikiriza yokuzesa akakungo mu kwenenenya obunafu nebytago mu ndabilira yabakadde abayina akawuka kamukenenya mu Kampala District mu Uganda.

Nsoma era ntegedde obubaka mu baluwa nolupapula lowkukiriza.

Nfunye ebiseera ebimala okukiriza kububaka obumpebeddwa nokubuza ebibuuzo.

Ntegedde nti obumanye bwange bujja kukumibwa nga bwakyama nganobubaka obunzigiddwako mukakungo nebinkwatako ebyobulamu bijja kukozesebwa mubigendererwa byokunonyereza.

Ntegedde nti obubaka obunzigidwako bujja kuyingizibwa muterekero elyesigika nga buyinza okukozesebwa mudda.

Ntegedde nti okwetaba kwange mukunonyereza kuno kwabwanakyewa era nga ndi wadembe okugana okwetabamu oba okubivamu essawa yona awatali kubonerezebwa.

Ntegedde nti sityobodde dembe lyange ngateka omukono kulu papula lwokukiriza luno ate era tekikakasibwa nti okunonyerezakuno kujia kuvamu emigaso gyendi.

Ntegezeddwa nti njakufunna ekiwandiko ngakitekedwako ennaku zomwezi ngakitekedwako nomukono.

Bwemba nina ebibuzo byonna ekikwata kumulimu guno,nsobola okutukirira omuyizi

'a
a
ĺ
na
era

Buli kyonna ekinakubaganyizibwako kijja kukumibwa ngabyakyama.

Nkimamnyi nti obubaka mukakungo (obuzaale, ebizuliddwa, enkozesa yendabirila eyayita nebilala) bijja kugabanyizibwako nomuntu akola kubyokunonyereza mu Reach Out Mbuya

obubaka buno kutekebwako enamba so si lir Nzikiriza era mpa olukusa abantu aba	ia ezenjawulo ezinokoddwa mu baluwa. Ntegedde nti nya lyange. akola kubyokunonyrereza nabatuwa empereza ukakungo kulwekigendererwa kyokunoyereza
okuwebwa ekitanda mu ddwaliro nebilala) b ezinokodwa mukiwandiko kino. Ntegedde n ngabakozesa enamba era tebujja kukwasaga	a okukozesa obubaka bwange obukwata kubujanjabi
Nkimanyi nti abawa empereza mu Reach Oukusabibwa okuwayo obubaka bwange obukumuterekero lyange elyebyobulamu.  Nzikirza okuwa olukusa abanoyereza muterekero lyange kubawa empereza   Tyee  Nedda	wata kundabilira nobulamu bwange okuva a okufuna ebikwata ku bulamu nobujanjabi okuva
elyekusifu olwokunonyrereza okulikolebwa ebijja. Nzikirza okuwa olukusa abanoyereza	kunonyereza kuno bujja kuyingizibwa muterekero mu masso oba okukyusa mundabilira mubiseera a okukozesa obubaka bwange kulwokunonyereza apereza mu Reach Out Mbuya okubukozesa
Nsomye olupapula luno and nzikiriza muder	mbe okwetaba mukunonyerezakuno.
Elinya lyomulwadde	Elinya lyomunonyereza
Omukono gwe	Omukono gwe
Ennaku zomwezi	Ennaku zomwezi

# Information and Informed Consent for Substitute Decision Makers - English Version

# **Informed Consent Form for Study Participants**

**Title of study:** Utility of the interRAI Check-Up Comprehensive Geriatric Assessment (CGA) Tool: Evaluating Check-Up Acceptability in Assessing Frailty and Care Needs of Older Adults with Human Immunodeficiency Virus (HIV) in Kampala District of Uganda

# **Faculty Supervisor**

Dr. George Heckman, MD, MSc, FRCPC
Associate Professor
Public Health Sciences
Schlegel Research Chair, Geriatric Medicine
University of Waterloo
Waterloo, Ontario, Canada
Phone:

Phone: ext. Email:

#### **Student Investigator**

Brittany Kroetsch, BSc Public Health Sciences University of Waterloo Waterloo, Ontario, Canada Phone:

Email:

#### **Co-Investigator**

Emmanuel Sendaula, MSc Monitoring, Research, and Evaluation Manager Reach Out Mbuya Community Health Initiative Kampala, Uganda

Phone:
Email:

To help you make an informed decision regarding you and your loved one's participation, this letter will explain what the study is about, the possible risks and benefits, and you and your loved one's rights as research participants. If you do not understand something in the letter, please ask one of the investigators prior to consenting to the study. You will be provided with a copy of the information and consent form if you choose to participate in the study.

# What is the study about?

You and your loved one are invited to participate in a research study about assessing the acceptability of the interRAI Check-Up comprehensive geriatric assessment instrument in the Kampala district of Uganda. The Check-Up is a standardized tool used in various countries to assess the health of older persons and inform care. We would like to invite you to participate in

assisting your loved one to complete the Check-Up. This is part of an international study for a master's project led by Student Investigator Brittany Kroetsch at the University of Waterloo which is looking to improve care practices for older adults with HIV in Uganda.

# I. Your responsibilities as a participant

# Who may participate in the study?

We are asking you to provide consent for allowing the researchers to collect information about your loved one to use to assess the acceptability of the Check-Up. Your loved one is eligible to participate in this study because they are 60 years of age or older and are a permanent resident of the Kampala district.

# What does participation involve?

If you and your loved one choose to participate, you would be asked to:

- Assist your loved one in the completion of the interRAI Check-Up self-report comprehensive
  geriatric assessment which ascertains information on demographics (age, gender, etc.),
  medical conditions/diagnoses, past health care service utilization, activities of daily living,
  pain, mood, falls risk, and cognition.
- Allow researchers to collect information from your loved one's medical records at Reach Out
  Mbuya Community Health Initiative. Specific data that would be collected include
  demographics (ethnicity, district, etc.), medical conditions/diagnoses, past health care service
  utilization, new illnesses, or hospitalizations.
- Allow researchers to enter the information collected during this study into a secure database for future Research Ethics Board approved studies.
- Allow health service providers from the Reach Out Mbuya Community Health Initiative access to the information collected during this study and to enter data into a secure database to help inform your loved one's future care.

# II. Your rights as a participant

# Are there any risks related to participating in this study?

Due to the nature of the assessment questions which require participants to reflect on their health, it is possible that participants may experience short-term psychological or emotional harm. You and your loved one do not need to answer questions on the Check-Up assessment that you do not want to answer or that make you feel uncomfortable. You and your loved one's identity will be kept confidential. Steps to protect your privacy are provided below. You and your loved one can withdraw from or stop taking part in this study at any point in time and any data you have provided will be destroyed. Participation is completely voluntary.

# What are the potential benefits related to participating in this study?

The research may not benefit your loved one directly, however, the outputs of the Check-Up assessment are designed to inform clinical care practices. We also hope that what is learned will help us to understand the barriers and facilitators to the use of the Check-Up assessment in the central Ugandan context.

## Will I receive any remuneration for participating in this study?

You will not be paid for your participation in the research study.

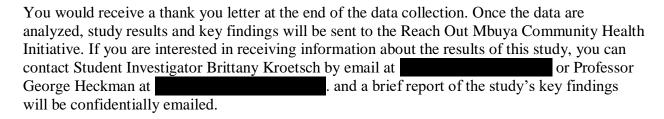
### How will my information be kept private?

Any personal identification associated with the data would be kept confidential and all data collected in this study would be securely stored. Only the research team and health service providers at the Reach Out Mbuya Community Health Initiative would have access to the data collected. Researchers will not use you or your loved one's name or any information that would allow you or your loved one to be identified; we will use a participant code instead of your name. You and your loved one's decision to participate or to withdraw from the study would also not impact the care that your loved one receives at Reach Out Mbuya. All data will be coded, encrypted, and stored on secure computers protected by a password at the University of Waterloo and at the Reach Out Mbuya Community Health Initiative. All electronic data will be retained for a minimum of 7 years in a secure location that is password encrypted within Professor George Heckman's locked offices at the University of Waterloo and in locked offices at the Reach Out Mbuya Community Health Initiative, after which they would be destroyed. Any publications will present group data and any results reported will be in a summary format with very careful attention to exclude any information that could identify you or your loved one.

# What if I change my mind about participating in this study?

Your participation in this study is completely voluntary. It is your choice to be part of the study or not. If you decide to withdraw, there would be no consequences. In cases of withdrawal, any information you provided up to that point would not be used and would be destroyed. You may decline to answer any question(s) you prefer not to answer.

#### How will I learn about the results of this study?



# III. Questions, comments, or concerns

Who is funding this study	Who	is	fund	ing	this	study	v?
---------------------------	-----	----	------	-----	------	-------	----

This study is funded by interRAI Canada.

Has this study received clearance from a research ethics board?
This study has been reviewed and received ethics clearance through the University of Waterloo Research Ethics Board (REB#43401). If you have questions for the Board, contact the Office of Research Ethics, at ext. or
This study has also been reviewed and received ethics clearance through the Uganda National Council for Science and Technology (REB # HS2229ES). If you have questions regarding your rights as a research participant, contact the Executive Secretary UNCST at by email at
This study has also been reviewed and received ethics clearance through the Clarke International University-Research Ethics Committee in Uganda (REB #2022-338). If you have questions regarding your rights as a research participant, contact the Chairperson CIUREC or by email at
This study has also been reviewed and received ethics clearance through the Reach Out Mbuya Community Health Initiative. If you have questions regarding your rights as a research participant, contact:  or by email:
The Research Ethics Board is a group of people who oversee the ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.
Who should I contact if I have questions regarding my participation in this study?
If you have any questions regarding this study or need more information to assist you in reaching a decision about participation, please contact Student Investigator Brittany Kroetsch by email at or Professor George Heckman at
Emmanuel Sendaula at .

# Statement of Consent

**Title of study:** Utility of the interRAI Check-Up Comprehensive Geriatric Assessment (CGA) Tool: Evaluating Check-Up Acceptability in Assessing Frailty and Care Needs of Older Adults with Human Immunodeficiency Virus (HIV) in Kampala District of Uganda

I have read and understood the information letter and consent form.

I have had sufficient time to consider the information provided and to ask questions.

I understand that my identity and my loved one's identity will be kept confidential, and that the information obtained from their assessment and medical record will be used for the research objectives.

I understand that de-identified data may be entered into a secure database for future use.

I understand that my participation in this study is voluntary and that I am completely free to refuse to participate or withdraw from this study at any time without any penalty.

I understand that I am not waiving any of my legal rights by signing this consent form and that there is no guarantee that this study will provide any benefits to me.

If I have any questions about this project, I can contact Student Investigator Brittany Kroetsch

I have been told that I will receive a dated and signed copy of this form.

	] or Professor George Heckman [	] or
Emmanuel Sendaula [		
at any time.		
This study has been revi	ewed and received ethics clearance through the Uni	versity of Waterloo
Research Ethics Board, t	the Uganda National Council for Science and Techn	ology, the Clarke
International University-	Research Ethics Committee, and the Reach Out Mb	ouya Community
Health Initiative. Howev	ver, the final decision to participate in the study is co	ompletely yours. If
you have any comments	or concerns resulting from your participation in this	s study, please
contact the University of	f Waterloo Office of Research Ethics, at	, ext. , or
by email at	, the Uganda National Council for Science	e and Technology
Executive Secretary at	or by email at , t	he Clarke
International University-	-Research Ethics Committee Chairperson at	or by
email at ,	or the Reach Out Mbuya Community Health Initiati	ve at
or	or by email at . 7	The Research Ethics
Board is a group of peop	ble who oversee the ethical conduct of research stud	ies. These people are
not part of the study tear	m. Everything you discuss will be kept confidential.	

I am aware that information from the Check-Up (demographics, diagnoses, health service utilization, etc.) will be shared with research personnel and health service providers from the Reach Out Mbuya Community Health Initiative from the various sources outlined in the

than mine or my loved one's name.  I agree to allow research personnel	formation will be linked to a participant code rather and health service providers to use information from his research and to inform my loved one's care.
diagnoses, etc.) will be shared with research information letter. I understand that this into code and will not be linked to my identity of	to use information from my loved one's
about my loved one's care and health from I agree to allow research personnel	Out Mbuya will be asked to provide information a their medical record. to access aspects of my loved one's health and care ach Out Mbuya health service providers.
database for future research and to help inf I agree to allow research personnel	d during this study may be entered into a secure form my loved one's future care. to use my loved one's de-identified data for future health service providers to use my data to inform my
I have read this form and I freely consent to	o participate in this study.
Patient Name (please print):	Name of Researcher/Witness (please print):
Signature:	Signature:
Date:	Date:

# Information and Informed Consent for Substitute Decision Makers – Luganda Version

# Olukuusa nga ottegedde ebikwatta kukunonyeleza

**Omutwe gwokunonyereza**: Enkozesa yakakungo akayitibwa interRAI Check-Up akakozesebwa ku mbeera yabakadde nebyetaago ebyendabilira yabakadde abayina akawuka kamukenenya mu Kampala distulikiti mu Uganda.

#### Kalabalaba Wetendekero

Dr. George Heckman, MD, MSc, FRCPC
Associate Professor
Public Health Sciences
Schlegel Research Chair, Geriatric Medicine
University of Waterloo
Waterloo, Ontario, Canada
Phone:
Email:

### Omuvizi omunonyereza

Brittany Kroetsch, BSc Public Health Sciences University of Waterloo Waterloo, Ontario, Canada Phone:

Email:

# Omunonyereza

Emmanuel Sendaula, MSc Monitoring, Research, and Evaluation Manager Reach Out Mbuya Community Health Initiative Kampala, Uganda

Phone: Email:

Okuyamba okukola okusalawo okulungi kubikwata kugwe nokwetabamu kwabagalwa bo, ebaluwa ejja kunyonyola okunonyereza kukwata kuki, obutyabaga obuyinza okubawo, emiganyulo, nawe nedembe ly'abagalwabo ngabetanye mukunonyereza kuno. Bwoba toyina kyotegedde mu baluwa eno, buza omu kuba nonyereza ngatonaba kukiriza kukunonyerezakuno. Ojja kuwebwa olupapula oluliko obubaka nolwokukiriza bwosalawo okwetaba mukunonyerezakuno.

### Okunonyereza kukwata kuki?

Gwe n'omwagalawo mwanilizibwa okwetaba mukunonyereza okukwata kukwekenenya enzikiriza yakakugo ka interRAI Check-Up akakozesebwa mukwekenenya embeera yabakadde mu Kampala distiulikiti mu Uganda. Check-Up kyekikola ekyomutindo ekikozesebwa munsi

ezenjawulo mukwekenenya embeera yobulamu yabakade nokutegeza endabilira. Twandyagadde okwaniliza okwetaba mu kuyamba abagalwabo okujja akakungo ka Check-Up. Kino kitundu ekyokusoma okwensi yonna mu diguli enkulu ekulemberwa omuyizi omunonyereza Brittany Kroetsch ku tendekero lya Waterloo erigenderera okutumbula endabilira yabakadde abayina akawuka kamukenenya mu Uganda.

# I. Obuvunanyizibwabwo nga eyetabyemu

### Ani ayinza okwetaba mukunonyereza kuno?

Tukusaba okukiriza abanonyereza okufuna obubaka obukwata kubagalwabo obukukozesa okwekenenya enzikiriza ya Check-Up. Omwagalwawo asobola okwetabamu kubanga ayina emyaka 60 oba okusingawo ate era mutuze owenkalakalira owe Kampala distulikiti.

#### Okwetabamu kitwaliramuki?

Gwe nomwagalwawo bwemusalawo okwetabamu musubire okubuzibwa oku:

- Okuyamba omwagalwawo okumaliriza akakungo ka interRAI Check-Up aka alipota eyomugundu ekwata kukunoyereza kumbera yabakadde etwaliramu obubaka ku kukikula (emyaka, nekikula) embeera yobulamu/nokukebera, enkozesa y'empereza yobulamu eyayita. ebikolwa ebyabulijjo, obulumi, enewulira, akatyabaga kokugwa, nentegera.
- Kiriza abanonyereza okukunganya obubaka okuva mubiwandiko byeddwaliro ku Reach
  Out Mbuya Community Health Initiative. Obubaka obwenjawulo obunakunganyizibwa
  butwaliramu ekikula (obuwangwa, distulikiti nebilala), embeera
  yobulamu/okukeberebwa, enkozesa y'endabilira y'obulamu eyayita, endwadde empya,
  oba okuwebwa ekitanda.
- Kiriza abanonyereza okuyingiza obubaka obukunganyiziddwa mukunonyereza kuno muterekero okusobola okukakasibwa akakiko akadukanya ebyokunonyereza mu biseera ebijja.
- Kiriza abawereza bebyobulamu okuva mu Reach Out Mbuya Community Health Initiative okufuna obubaka obukunganyiziddwa mukunonyereza kuno babuyingize muterekero elyekusifu okusobola okutegeza endabilira yomwagalwawo mu biseera ebijja.

# II. Eddembe lyo nga eyetabyemu

# Waliyo obutyabaga obukwatagana nokwetaba mukunonyereza kuno?

Okusinzira kukikula kyebibuuzo ebyetagisa okulowoza kubulamu bwabwe, kisoboka nti abetabyemu basobola okufuna okulumizibwa kundowoza nenewulira. Gwe nomwagalwawo temuyina kudamu bibuuzo byonna mukakungo ka Check-Up kyemuwulira temwagala kukidamu oba ekibafula abatali batebenkenvu. Obumanye bwo nobwomwagalwawo bujja kukumibwa nga

bwakyama. Emitendera gyokukuma obumanye butekeddwa wansi. Gwe nomwagalwawo musobola okubivamu oba okuyimiriza okwetaba mukunonyereza kuno essawa yonna era obubaka bwonoba otuwadde bujja kusanyizibwawo. Okwetabamu kwabwanakyewa ddala.

# Miganyulo ki egiyinza okusubilwa egikwatagana nokwetaba mukunonyereza kuno?

Okunonyereza kuno kuyinza obutakuganyula mwagalwawo buterevu, naye ebinava mukunonyereza kwa Check-Up bisengekebwa okutegeza endabilira yomuddwaliro. Era Tusubira nti ekiyigiddwa kijja tuyamba okutegera emiziziko nabawagira enkozesa yakakungo ka Check-Up mu semakati ga Uganda.

# Nafuna okusasulwa kwonna olwokwetaba mukunonyereza kuno?

Tojja kusasulwa olwokwetaba kwo mukunonyereza kuno.

# Obubaka bwange bunakumibwa butya nga bwakyama?

Obumanye bwomuntu yenna obukwatagana nobubaka bujja kukumibwa nga bwakyama era obubaka bwonna obukuknganyiziddwa mukunonyereza bujja kumibwa bulungi. Abanonyereza bokka nabawa empereza y'obulamu mu Reach Out Mbuya Community Health Initiative bebasobola okufuna obubaka obukunganyiziddwa. Abanonyereza tebajja kukozesa linnya lyo oba elyomwagalwawo oba obubaka bwonna obuyinza okuletera gwe oba omwagalwawo okutegerwa. Gwe nomwagalwawo okusalawo okwetaba oba okuva mukunonyereza kuno tekujja kukosa ndabilira omwagalwawo gyafuna ku Reach Out Mbuya. Obubaka bwonna bujja kukwekebwa era bukumibwe ku kompyuta ezesigika ezekumibwa nekisumuluzo kyenamba kutendekero lye Waterloo neku Reach Out Mbuya Community Health Initiative. Obubaka obuli mumayengo bujja kukumibwa ekitono ennyo okumala emyaka musanvu mukifo ekyesigika ekiyina ekisumuluzo kyenamba mu yafesi egaddwa e ya profesa George Heckman kutendekero lya Waterloo nemu yafesi egaddwa ku Reach Out Mbuya Community Health Initiative, oluvanyuma bujja kusanyizibwawo. Ekiwandiko kyonna kijja kufulumya obubaka obwawamu era nalipota ejja kuba mubufunze nobwegendereza okujamu obubaka bwonna obuyinza okulaga gwe oba omwagalwawo.

### Singa nkyusa ekirowoozo kubikwata kubyokwetaba mukunonyereza?

Okwetabamu kwo mukunonyereza kuno kwabwanakyewa. Kusalawo kwo okubeera mukunonyereza kuno oba nedda. Bwosalawo okubivamu, tewajja kuba kibonerezo. Singa obivamu, obubaka bwonoba otuwadde okutukawo tebujja kukozesebwa era bujja kusanyizibwawo. Osobola okugana okuddamu ekibuuzo kyonna kyewatandyagadde kudamu.

### Namanya ntya ebinava mukunonyereza?

Ojja kufuna ebaluwa ekwebaza ngatumazze okukunganya obubaka. Obubaka nga bumaze okwekenenyezebwa, ebinaba bivuddemu nebizuliddwa bijja kusindikibwa ku Reach Out Mbuya Community Health Initiative. Bwoba nga wandyetaze okufuna obubaka kubivuddemu kunonyereza kuno, osobola okutukirira omuyizi omunonyereza Brittany Kroetsch ku

oba Pulofesa George Heckman ku oba Emmanuel Sendaula ku alipota eri mubufunze ejja kusindikibwa mungeri yekyama.
III. Ebibuzo, ebidibwamu, oba n'ebikwata ku bantu
Ani afugirira okunonyereza kuno?
Okunonyererza kuno kufugirirwa ekibbina kya Inter RAI Canada.
Okunonyereza kuno kwafunye okukakasibwa okuva mukibina ekikulira okunonyereza?
Okunonyereza kuno kwekenenyezeddwa era nekukakasibwa okuyita kibiina kyokunonyereza ekye tendekero lya waterloo (REB 43401). Bwoba oyina ebibuzo eri ekibbina tukirira ekakalabizo elyokunonyereza ku 1 ext oba .
Okunonyereza kuno kwekenenyezeddwa era nekukakasibwa okuyita mu National Council and Technology (REB #HS2229ES). Bwoba oyina ebibuzo ebkwata kudembe lyo nga eyetabyemu tufune omuwandisi UNCST ku oba sindika obubaka ku
Okunonyereza kuno kwekenenyezebwa era nekukakasibwa akakiko kebyokunonyereza mu Uganda aketendekero lya Clarke International university (REB #2022-338). Bwoba oyina ebibuzo ebikwata kuddembe lyo nga eyetabyemu tufune sentebbe CIUREC ku oba sindika obubaka ku
Okunonyereza kuno kwekenenyezeddwa era nekufuna okukirizibwa okuyita mu Reach Out Mbuya Community Health Initiaitive. Bwoba oyina ebibuuzo ebikwata ku ddembe lyo nga eyetabye mukukunonyereza kuno tukukirira oba oba sindika obubaka ku
Akakiiko kemitendera mubyokunonyereza kyekibiina kyabantu abalabilira eneyisa eyemitendera mubyokunonyereza. Abantu abo si kitundu kukibinja ekikola kubyokunonyereza. Buli kyonna ekinakubaganyizibwako kijja kukumibwa ngabyakyama.
Ani gwenina okutukirira bwemba nina ebibuuzo ebikwata kukwetaba kwange mukunonyereza kuno?
Bwoba oyina ebibuuzo byonna ebikwata kukunonyereza kuno oba obubaka obusingawo okuyamba okutuka kukusalawo mukwetabamu, tukilira omuyizi mubyokunonyereza Brittany Kroetsch [

#### Ekiwadiko ekikwata ku lukuusa kukunonyeleza

Omutwe gwokunonyereza: Enkozesa yakakungo akayitibwa interRAI Check-Up akakozesebwa ku mbeera yabakadde nebyetaago ebyendabilira yabakadde abayina akawuka kamukenenya mu Kampala distulikiti mu Uganda.

Nsomye era ntegedde obubaka obuli mubaluwa nolupapula lwokukiriza.

Mbadde nobudde obumala okulowooza kububaka obumpededdwa nokubuuza ebibuuzo.

Ntegedde nti obumanye bwange nobwomwagalwa wange bujja kukumibwa nga bwakyama nganobubaka obunzigiddwako mukakungo nebinkwatako ebyobulamu bijja kukozesebwa mubigendererwa byokunonyereza.

Ntegedde nti obubaka obunzigidwako bujja kuyingizibwa muterekero elyesigika nga buyinza okukozesebwa mudda.

Ntegedde nti okwetaba kwange mukunonyereza kuno kwabwanakyewa era nga ndi wadembe okugana okwetabamu oba okubivamu essawa yona awatali kubonerezebwa.

Ntegedde nti sityobodde dembe lyange ngateka omukono kulu papula lwokukiriza luno ate era tekikakasibwa nti okunonyerezakuno kujia kuvamu emigaso gyendi.

Ntegezeddwa nti njakufunna ekiwandiko ngakitekedwako ennaku zomwezi ngakitekedwako nomukono.

Bwemba nina ekibuzo kyona ek	ikwata kumulimu guno	<u>, ns</u> obola okutukirira o	muyızı
omunonyereza Brittany Kroetsc	h [	] oba Professor Geo	orge Heckman
[ ess	awa yona.	<del></del>	
Okunonyereza kuno kumaze ok	wekenenyezebwa nokul	kirizibwa okuyita muka	akiko
akebyokunonyereza aketendeke	ro lya Waterloo ne Read	ch Out Mbuya Commu	ınity Health
Initiative. Naye okusalawo okw	enkomeredde okwetaba	mukunonyereza kuno	kuko. Bwoba
oyina ensoga yona oba okwemu	lugunya okuva mukwet	taba mukunonyereza ki	uno tukirira
etendekero lya Waterloo Office	of Research Ethics, at	, ext.	oba sindika
obubaka ku	, Uganda National C	Council for Science and	l Technology
omuwandisi UNCST ku	oba sindika	obubaka ku	, Clarke
International University-Research	ch Ethics Committee se	ntebbe CIUREC ku	
oba sindika obubaka ku	, oba Reach Out	Mbuya Community H	ealth Initiative ku
oba	oba sindika ob	ubaka ku	
Akakiko kebyokunonyereza kye	kibina kyabantu abalab	oirila eneyisa mubyoku	nonyereza. Abantu
bano si kitundu kubantu abanon	yereza. Kyona kyokuba	iganyako ebirowozo bi	jja kukumibwa nga
byakyama.	· · ·		

Nkimamnyi nti obubaka mukakungo (obuzaale, ebizuliddwa, enkozesa yendabirila eyayita nebilala) bijja kugabanyizibwako nomuntu akola kubyokunonyereza mu Reach Out Mbuya

obubaka buno kutekebwako enamba so si lin Nzikiriza era mpa olukusa abantu aba	akola kubyokunonyrereza nabatuwa empereza akakungo kulwekigendererwa kyokunoyereza
kukumibwa nga bwakayama ngabakozesa en bwange.	mu ddwaliro nebilala) bijja gabanyizibwako mukiwandiko kino. Ntegedde nti obubaka buno bijja amba era tebujja kukwasaganyizibwa nobumanye okukozesa obubaka bwomwagala wange obukwata
•	vata kundabilira nobulamu bwange okuva okufuna ebikwata ku bulamu bwomwagalwa o lyange okuva kubawa empereza mu Reach Out
	unonyereza kuno bujja kuyingizibwa muterekero mu masso oba okukyusa mundabilira mubiseera
Nzikirza okuwa olukusa abanoyereza	okukozesa obubaka bwange kulwokunonyereza pereza mu Reach Out Mbuya okubukozesa
Nsomye olupapula luno and nzikiriza muden	nbe okwetaba mukunonyerezakuno.
Elinya lyomulwadde.	Elinya lyomunonyereza
Omukono gwe	Omukono gwe
Ennaku zomwezi	Ennaku zomwezi

# Client Thank You Letter - English Version

University of Waterloo	[insert date
------------------------	--------------

Dear Client,

I would like to thank you for your participation in this study entitled "Utility of the interRAI Check-Up Comprehensive Geriatric Assessment (CGA) Tool: Evaluating Check-Up Acceptability in Assessing Frailty and Care Needs of Older Adults with Human Immunodeficiency Virus (HIV) in Kampala District of Uganda".

As a reminder, the purpose of this study is to determine the acceptability of using a standardized clinical assessment instrument for older adults in the Kampala district of Uganda.

The data collected using the interRAI Check-Up assessment will contribute to a better understanding of the needs of older adults in the Kampala district to help inform care planning practices.

This study has been reviewed and received ethics of	elearance through the University of Waterloo
Research Ethics Board (REB #43401), the Clarke I	International University Research Ethics
Committee, and the Uganda National Council for S	Science and Technology. If you have questions
for the Board, contact the Office of Research Ethic	s, at ext. or by email a
, the Clarke International Univer	sity Research Ethics Committee Chairperson
or by email at	, or the Uganda National Council for Science
and Technology Executive Secretary at	or by email at
For all other questions contact me at	or Dr. Heckman at
or Emmanuel Sendaula	at .

Your identity will be confidential. Once all the data are collected and analyzed for this project, I plan on sharing this information with the Reach Out Mbuya Community Health Initiative through seminars, conferences, presentations, and journal articles. Once this information is shared, you can also learn about the study results by contacting a member of the research department at the Reach Out Mbuya Community Health Initiative. In the meantime, if you have any questions about the study, please do not hesitate to contact me by email as noted below.

**Brittany Kroetsch** University of Waterloo

**Dr. George Heckman** University of Waterloo

# **Emmanuel Sendaula**

Reach Out Mbuya Community Health Initiative

# Chairperson

Clarke International University Research Ethics Committee

# **Executive Secretary**

Uganda National Council for Science and Technology

# Client Thank You Letter - Luganda Version

Entendekero lya Waterloo

### Ssebo/Nyabo:

Nkwebaza okwetaba mukunonyereza kuno okuyina omutwe "Enkozesa yakakungo akayitibwa interRAI Check -Up akakozesebwa ku mbeera yabakadde: Okwekenenya okukiriza ekozesa yakakungo ka Check-Up mukunonyereza ku bunafu nebyetago byendabilira yabakadde abayina akawuka kamukenenya mu Kampala distrikiti mu Uganda".

Nga ekyokwejuakanya, ekigendelerwa kyokunonyereza kuno kwekusalawo kukukiriza okukozesa yakakungo akomulembe akanonyereza kumbeera yobuamu bwabakadde mu Kampala district mu Uganda.

Ekyokwejuakanya, ekigendelerwa kyokunonyereza kuno kwekusalawo kukukiriza okukozesa yakakungo akomulembe akanonyereza kumbeera yobuamu bwabakadde mu Kampala district mu Uganda.

Obubaka obukungaziddwa ngatukozesa akakungo ka int ebyetaago byabantu abakadde mu Kampala distulikiti av Okunonyereza kuno kwekenenyezeddwa era nekukakas:	wo kiyambe mu bikolwa ibwa okuyita kibiina kyo	byendabilira kunonyereza
ekye tendekero lya Waterloo (REB 43401), Clarke Inter	rnational University Rese	earch Ethics
Committee, Uganda National Council for Science and T	Cechnology. Bwoba oyin	a ebibuzo eri
ekibbina tukirira ekakalabizo elyokunonyereza ku	ext ob	oa
, Clarke International University Rese	earch Ethics Committee s	sentebbe
CIUREC ku oba sindika obubaka ku	, Uganda	National
Council for Science and Technology omuwandisi UNCS	ST ku	oba sindika
obubaka ku		
Ebilara byonna ntukilira nze ku	oba Dr. Heckman ku	
oba Emmanuel Sendaula ku		

Obumanye bujja kukumibwa ngabwakyama. Obubaka bwonna nga bumaze okukunganyizibwa era nokwekekenenyezebwa obwomulimu guno, ntekateka okugabanya obubaka buno ne Reach Out Mbuya Community Health Initiative okuyita mumisomo, enkungana ezamanyi nebiwandiko. Obubaka buno nga bumaze ogabanyizibwa, nawe osobola okuyiga kubivudde kukunonyereza kuno ngotukilira ku memba wa dipatimenti yokunonyereza ku Reach Out Mbuya Community Health Initiative. Esaawa zino, bowba oyina ebibuuzo byonna kubikwata kukunonyereza tolemwa kuntukilira ngoyita ku.

Brittany Kroetsch University of Waterloo

# **Dr. George Heckman** University of Waterloo

# **Emmanuel Sendaula**

Reach Out Mbuya Community Health Initiative

# Chairperson

Clarke International University Research Ethics Committee

# **Executive Secretary**

Uganda National Council for Science and Technology

# Appendix B: interRAI Self-Report Check-Up Summary Report

# interRAI Check-Up Brief Scale Guide

# **ADLH (ADL Hierarchy Scale)**

Focus: Measures level of dependence in 4 basic activities of daily living (ADLs) from early to late loss (hygiene, moving around in home, toilet use, eating)

Scores: From 0 (all ADLs intact) to 6 (total dependence in all ADLs); ADLH 3+ indicates physical disability.

Consider: Adaptive equipment and/or support services; physical activity; caregiver support

#### **ADLSF (ADL Short Form)**

Focus: Sum of severity for 4 basic ADLs (Hygiene, moving around in home, toilet use, eating)
Scores: From 0 (no impairment) to 16 (high impairment)
Consider: Adaptive equipment and/or support services; physical activity; caregiver support

#### **AUA (Assessment Urgency Algorithm)**

**Focus:** Urgency for comprehensive geriatric assessment **Scores:** From 1 (lowest risk) to 6 (highest risk) **Consider:** AUA 3 is self-reliant but unwell. AUA 4 is not self-reliant. AUA 5-6 may need for specialized geriatrics.

# CHESS (Changes in Health, End-Stage Disease and Symptoms)

**Focus**: Frailty-related health instability **Scores**: From 0 (most stable) to 5 (most unstable);
CHESS 3+ indicates high risk of experiencing a serious adverse event within 3 months.

Consider: Urgent specialized geriatrics referral; stabilize unstable chronic conditions (based on history); identify problem areas (vomiting, edema, weight loss, dyspnea)

# **COMM (Communication Scale)**

Focus: Making self understood; understanding others Scores: From 0 (intact) to 2 (very severe impairment) Consider: Communication approach; adaptive

resources; caregiver support

#### **CPS (Cognitive Performance Scale)**

Focus: Cognition
Scores: From 0 (intact) to 6
(very severe impairment)
Consider: How impairment may
affect care plan (e.g., ADLs,
IADLs, communication,
decision-making), caregiver

status

CPS	MMSE	MoCA
0	25	25
1	22	23
2	19	20
3	15	17
4	7	-
5	5	-
6	0	-

#### **CPS2 (Revised CPS)**

**Focus:** Measure of cognition more sensitive to mild impairment **Scores:** From 0 (intact) to 8 (very severe impairment)

**Consider:** Short-term memory, daily decision-making, ADLs, medication & finance management, communication, walking

CPS2	MMSE
0	27
1	26
2	23
3	20
4	17
5	14
6	11
7	10
8	5

# DIVERT (Detection of Indicators and Vulnerabilities for Emergency Room Trips)

Focus: Risk of future unplanned ED visits based on cardiorespiratory risk, falls, recent ED visit, etc.

Scores: From 0 (lowest risk) to 6 (highest risk)

Consider: Consider medication review, symptom review, fall prevention, cardiorespiratory care program.

#### **FALLS (Falls Scale)**

Focus: Falls frequency Consider: Reason for fall, best practice for fall/fracture prevention (e.g., review bone health)

Score	Interpretation
0	No fall in last 90 days
1	No fall in last 30 days
	but fall 31-90 days ago
2	One fall in last 30 days
3	2+ falls in last 30 days

#### **Pain Scale**

Focus: Pain
Consider: Further
assessment re: source of
pain; best practice
approach to pain
management

Score	Interpretation	
0	No pain	
1	Mild	
2	Daily, moderate	
3	Daily, severe	
4	Daily, at times	
	excruciating	

#### **SRMood (Self-Rated Mood)**

**Focus:** Presence of self-reported mood symptoms **Scores:** From 0 (no self-reported symptoms) to 9 (more severe symptom burden); SRMood 3+ indicates possible mood disturbance

**Consider:** Cause of mood problem; availability of social supports; need for referral to mental health services

#### **VPR (Vulnerable Persons Risk)**

**Focus:** Identifies those most in need of support during public emergencies/disasters due to living arrangement, ADLs, cognition, vision, medical needs, etc.

Scores: From 0 (low vulnerability) to 2 (high vulnerability)

Consider: Creating a clear emergency/contingency plan



Cognition / Mental Health

# interRAI Check-Up Brief CAP Guide

### **Activities of Daily Living CAP**

**Indicates:** Acute change in mental status, fluctuating ADL ability, fall(s) OR had an acute episode / flare-up **Scores:** 0 = not triggered; 1 = prevent decline; 2 = facilitate improvement

**Focus:** Improving performance/decline in clients with some ADL deficits and minimal cognitive ability

#### **IADLs CAP**

**Indicates:** Some dependency in meal prep, housework, shopping and/or transportation; recent decline in ADLs.

Scores: 0 = not triggered; 1 = triggered

Focus: Improve IADLs in clients who are not dependent

in ADLs and have minimal cognitive ability

#### **Physical Activities Promotion CAP**

Indicates: Client cannot go up and down stairs or move indoors independently, and engaged in <2h of physical activity in last 3 days

Scores: 0 = not triggered; 1 = triggered

Focus: Physical activity in capable sedentary adults.

#### **Cognitive Loss CAP**

**Indicates:** Client has 2+ risk factors for cognitive decline (dementia, difficulty understanding others/making self understood, worsening decision making)

**Scores:** 0 = not triggered; 2 = prevent decline

Focus: Help persons remain as independent as possible

for as long as possible

#### **Communication CAP**

**Indicates:** Some ability in decision making and difficulty understanding others/making self understood

**Scores:** 0 = not triggered; 1 = potential for improvement; 2 = prevent decline

**Focus:** Facilitate improved communication and prevent decline in clients with some cognitive reserve (e.g., refer to speech-language pathologist, hearing aids, earwax)

#### **Mood CAP**

**Indicates:** Little interest in doing things they normally enjoy; feeling anxious, restless, or uneasy; sad, depressed or hopeless

Scores: 0 = not triggered; 1 = medium risk; 2 = high risk Focus: Identify depression (in those with pre-existing

diagnosis) or depressed mood

#### **Social Relationships CAP**

Indicates: Client feeling lonely OR distressed by

declining social activities

**Scores:** 0 = not triggered; 1 = triggered

**Focus:** Support social engagement (e.g., via referral to programs) in clients with reasonable cognitive assets

and some ability to understand others

#### **Cardiorespiratory Conditions CAP**

Indicates: Chest pain, shortness of breath, dizziness

Scores: 0 = not triggered; 1 = triggered

Focus: Cardiorespiratory problems (e.g., COPD, heart

disease)

#### **Dehydration CAP**

**Indicates:** Dehydration/insufficient water intake AND diarrhea, vomiting, dizziness, constipation, or unintended weight loss

**Scores:** 0 = not triggered; 1 = low risk; 2 = high risk **Focus:** Causes for or complications of dehydration

#### **Falls CAP**

Indicates: Client experienced previous falls

**Scores:** 0 = not triggered; 1 = medium risk; 2 = high risk **Focus:** Preventing future falls (e.g., assess bone health, orthostatic vitals, medications, physical activity)

#### **Pain CAP**

Indicates: Client has daily pain and pain intensity
Scores: 0 = not triggered; 1 = medium risk; 2 = high risk
Focus: Identify need for follow-up related to severity of
pain to improve general status

#### **Tobacco and Alcohol Use CAP**

Indicates: Client smokes daily and/or reports 5+ drinks

in a single sitting in last 3 days

**Scores:** 0 = not triggered; 1 = triggered **Focus:** Smoking cessation, reducing alcohol

consumption, harm-reduction

#### **Urinary Incontinence CAP**

**Indicates:** Bladder incontinence AND diarrhea or recent decline in ADLs

**Scores:** 0,1 = not triggered; 2 = prevent decline; 3 = facilitate improvement

**Focus:** Improve or prevent worsening urinary function for clients with recurring incontinence, and ability to respond to a treatment program; post-void residual

Last updated March 4, 2022



# **Appendix C: Phase One Sample Size Considerations**

For quantitative data collection using the Check-Up instrument, the sample size aim of n=138 older persons was determined using the one-way analysis of variance power calculation in R version 4.1.0. This was computed using data from an Ontario Health West sample of n=4948 older persons and through consultation of key literature on older persons living with HIV in South Africa. <sup>201–203</sup>

```
> #R code (within.var of 17.26369177 = 4.1549599^2 [4.1549599 = the SD from above])
> groupmeans<-c(4, 2)
>
> p <- power.anova.test(groups = length(groupmeans),
+ between.var = var(groupmeans), within.var = 17.26369177,
+ power=0.80,sig.level=0.05,n=NULL)
>
> p

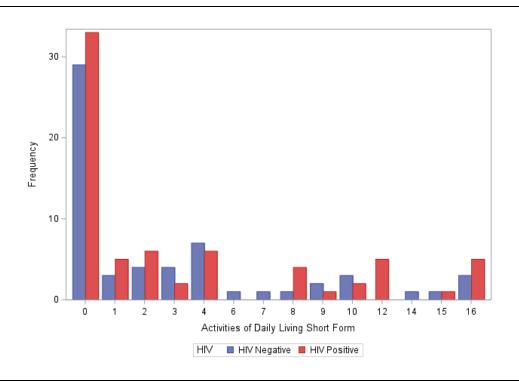
Balanced one-way analysis of variance power calculation

    groups = 2
        n = 68.72383
    between.var = 2
    within.var = 17.26369
    sig.level = 0.05
        power = 0.8

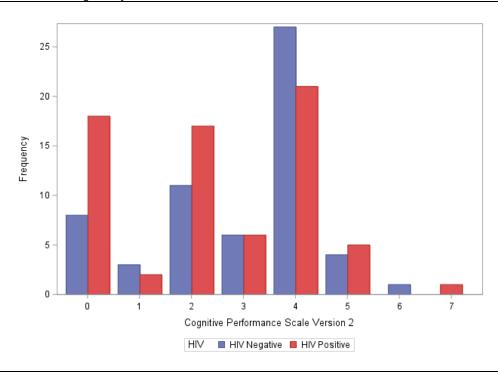
NOTE: n is number in each group
```

# **Appendix D: Figures and Tables for Exploratory Data Analyses**

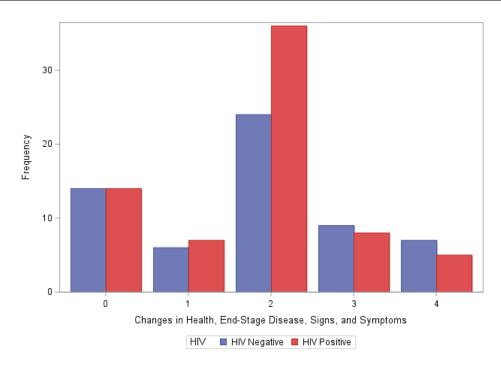
**Figure 5: ADLSF Frequency Distribution** 



**Figure 6: CPS2 Frequency Distribution** 



**Figure 7: CHESS Frequency Distribution** 



**Figure 8: CFS2 Frequency Distribution** 

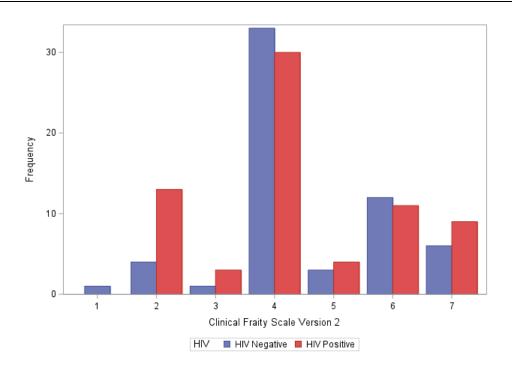


Table 10: Exploratory Data Analyses of ADLSF – Likelihood Ratio				
<b>Predictor Variable</b>	Chi-Square	DF	P	
HIV	0.24	1	0.62	
Age	11.11	1	0.0009	
HIV & Age	14.36	2	0.0008	

Table 11: Joint Tests for ADLSF Regressed on HIV, Age, and HIV*Age			
<b>Predictor Variable</b>	Wald Chi-Square	DF	P
HIV	0.08	1	0.77
Age	7.45	1	0.006
HIV*Age	0.009	1	0.93

Table 12: Exploratory Data Analyses of CPS2 – Likelihood Ratio			
Predictor Variable	Chi-Square	DF	P
HIV	2.85	1	0.09
Age	14.57	1	0.0001
HIV & Age	14.86	2	0.0006

<b>Table 13: Joint Tests</b>	for CPS2 Regressed on Hl	IV, Age, and HIV*	Age
<b>Predictor Variable</b>	Wald Chi-Square	DF	P
HIV	3.10	1	0.08
Age	2.86	1	0.09
HIV*Age	2.94	1	0.09

Table 14: Exploratory Data Analyses of CHESS – Likelihood Ratio				
<b>Predictor Variable</b>	Chi-Square	DF	P	
HIV	1.22	1	0.27	
Age	0.005	1	0.94	
HIV & Age	1.30	2	0.52	

Table 15: Exploratory Data Analyses of CFS2 – Likelihood Ratio			
<b>Predictor Variable</b>	Chi-Square	DF	P
HIV	0.01	1	0.93
Age	11.99	1	0.0005
HIV & Age	13.28	2	0.001

Table 16: Joint Tests for CFS2 Regressed on HIV, Age, and HIV*Age			
<b>Predictor Variable</b>	Wald Chi-Square	DF	P
HIV	1.23	1	0.27
Age	4.53	1	0.03
HIV*Age	1.47	1	0.22

# **Appendix E: Statistical Analysis Models**

# Main Effects General Hypothesized Model: ADLSF Regressed on HIV & Age

$$\eta_i = \beta_0 + \beta_1 X_{1i} + \beta_2 X_{2i}; \quad i = 1, ..., n$$

Where,

 $\eta_i$  is the log-odds of observed binary outcome value ADLSF (0=No – Mild Impairment,

1=Moderate – High Impairment; 0=Ref) for the *i-th* case;

 $X_{1i}$  is the observed binary predictor value for HIV (0=Negative, 1=Positive) for the *i-th* case;

 $X_{2i}$  is the observed predictor value for Age for the *i-th* case;

 $\beta_0$  is the unknown fixed intercept;

 $\beta_1$  is the unknown fixed regression coefficient for *HIV*;

 $\beta_2$  is the unknown fixed regression coefficient for Age;

# Main Effects General Hypothesized Model: CPS2 Regressed on HIV & Age

$$\eta_i = \beta_0 + \beta_1 X_{1i} + \beta_2 X_{2i}; \quad i = 1, ..., n$$

Where,

 $\eta_i$  is the log-odds of observed binary outcome value CPS2 (0=Intact – Borderline Intact,

1=Moderate – Severe Impairment; 0=Ref) for the *i-th* case;

 $X_{1i}$  is the observed binary predictor value for HIV (0=Negative, 1=Positive) for the i-th case;

 $X_{2i}$  is the observed predictor value for Age for the *i-th* case;

 $\beta_0$  is the unknown fixed intercept;

 $\beta_1$  is the unknown fixed regression coefficient for *HIV*;

 $\beta_2$  is the unknown fixed regression coefficient for Age;

# Main Effects General Hypothesized Model: CFS2 Regressed on HIV & Age

$$\eta_i = \beta_0 + \beta_1 X_{1i} + \beta_2 X_{2i}; \quad i = 1, ..., n$$

Where,

 $\eta_i$  is the log-odds of observed binary outcome value *CFS2* (0=Very Fit – Very Mild Frailty, 1=Mild Frailty – Severe Frailty; 0=Ref) for the *i-th* case;

 $X_{1i}$  is the observed binary predictor value for HIV (0=Negative, 1=Positive) for the i-th case;

 $X_{2i}$  is the observed predictor value for Age for the *i-th* case;

 $\beta_0$  is the unknown fixed intercept;

 $\beta_1$  is the unknown fixed regression coefficient for *HIV*;

 $\beta_2$  is the unknown fixed regression coefficient for *Age*;

# **Appendix F: Phase Two Recruitment and Consent Materials**

#### **Email Recruitment Letter for Service Providers**

<u>Subject Line: ROM Service Provider Interviews – Acceptability of Check-Up</u>

Hello,

My name is Brittany Kroetsch, and I am a master's student working under the supervision of Dr. George Heckman in the School of Public Health Sciences at the University of Waterloo. As part of my master's degree, I am conducting a research study on the acceptability of the interRAI Check-Up comprehensive geriatric assessment instrument in the Kampala district of Uganda. Given your role as a healthcare service provider at the Reach Out Mbuya Community Health Initiative who has worked with this instrument, I feel that you are well suited to provide insight into this topic and I would like to invite you to participate in this study.

If you decide to volunteer for this study, your participation will consist of a virtual one-on-one semi-structured interview that will take approximately 40 minutes of your time. During the interview, you will be asked questions that will capture what your role at Reach Out Mbuya entails, your experience with the Check-Up, as well as your thoughts of and perceptions of the instrument. With your permission, I would like to audio-record the interview to ensure accurate transcription and analysis.

This study has been reviewed and received ethics clearance through the University of Waterloo Research Ethics Board (REB #43401).

Please read the attached Information Letter for more details regarding what participation will involve. If you would like to participate, or you require additional information to assist you in reaching a decision about participation, please do not hesitate to contact me at . You may also contact my supervisor at .

Sincerely,

**Brittany Kroetsch**University of Waterloo
Faculty of Health

# **Telephone Recruitment Letter for Service Providers**

P = Potential Participant; I = Interviewer

- I May I please speak to [name of potential participant]?
- P Hello, [name of potential participant] speaking. How may I help you?
- I My name is Brittany Kroetsch, and I am a master's student in the School of Public Health Sciences at the University of Waterloo, Canada. I am currently conducting research under the supervision of Dr. George Heckman on the acceptability of the interRAI Check-Up comprehensive geriatric assessment instrument in the Kampala district of Uganda. As part of my thesis research, I am conducting interviews with healthcare service providers at the Reach Out Mbuya Community Health Initiative to discover their perspectives on the Check-Up instrument in this setting.

As you played a key role in the implementation of the Check-Up instrument at Reach Out Mbuya, I would like to speak with you about your perspectives on the Check-Up. Is this a convenient time to give you further information about the interviews?

P - No, could you call back later [agree on a more convenient time to call person back].

OR

P - Yes, could you provide me with some more information regarding the interviews you will be conducting?

#### I - Background Information:

- I will be undertaking interviews starting in *February of 2022*.
- The interview would last about forty minutes and would be arranged for a time convenient to your schedule.
- Involvement in this interview is entirely voluntary and there are no known or anticipated risks to participation in this study.
- The questions are quite general (for example, what did you think about the tool?).
- You may decline to answer any of the interview questions you do not wish to answer and
  may terminate the interview at any time. With your permission, the interview will be
  audio-recorded to facilitate the collection of information, and later transcribed for
  analysis.
- Your identity will be confidential.
- The data collected will be kept in a secure location and retained for a minimum of *seven* years.

<ul> <li>If you have any questions regarding this study or would like additional information to assist you in reaching a decision about participation, please feel free to contact either myself at</li></ul>
With your permission, I would like to email you an information letter that has all these details along with contact names and numbers on it to help assist you in making an informed decision about your participation in this study.
P - No thank you.
OR
P - Sure [get contact information from potential participant i.e., email address].
I - Thank you very much for your time. May I follow up with you in 2 or 3 days to see if you are interested in being interviewed? Once again, if you have any questions or concerns, please do not hesitate to contact me at or via email at or via email at .
P - Goodbye.

I - Goodbye.

# **Service Provider Screening Questionnaire**

P = Potential Participant; A = Assessor

See below if potential participant would like to complete the screening questionnaire to determine study eligibility

- A: If you would like to participate in the study, eligibility screening criteria must be met. May I ask you several questions regarding screening eligibility?
  - A: (1) As of today [insert today's date], are you 18 years of age or greater?
  - A: (2) As of today [*insert today's date*], are you a health service worker affiliated with the Reach Out Mbuya Community Health Initiative?
  - A: (3) Are you able to provide free and informed consent for participation in this research study?

Assessor to note yes or no to the listed questions above. The assessor also notes the date and time the conversation occurred.

# See below if unsure of participant capacity to consent

- A: (4) What did you understand to be the purpose of the study?
- A: (5) What will you be asked to do in this research study?
- A: (6) Do you need to participate in the research study if you do not want to?
- A: (7) Can you please describe the potential risks and benefits of the research study?

Assessor to note yes or no to the listed questions above to denote whether the participant had a satisfactory or unsatisfactory response to the question.

**ROM Service Provider Screening Questionnaire Log** 

Participant Name	Date and Time	(1) (y/n)	(2) (y/n)	(3) (y/n)	(4) (y/n)	(5) (y/n)	(6) (y/n)	(7) (y/n)	Notes
		□Yes □ No							
		□Yes □ No							
		□Yes □ No							
		□Yes □ No							
		□Yes □ No							
		□Yes □ No							

#### **Information and Informed Consent for Service Providers**

# **Informed Consent Form for Study Participants**

**Title of study:** Utility of the interRAI Check-Up Comprehensive Geriatric Assessment (CGA) Tool: Evaluating Check-Up Acceptability in Assessing Frailty and Care Needs of Older Adults with Human Immunodeficiency Virus (HIV) in Kampala District of Uganda

# **Faculty Supervisor**

Dr. George Heckman, MD, MSc, FRCPC **Associate Professor** Public Health Sciences Schlegel Research Chair, Geriatric Medicine University of Waterloo Waterloo, Ontario, Canada

Phone: Email:

# **Student Investigator**

Brittany Kroetsch, BSc Public Health Sciences University of Waterloo Waterloo, Ontario, Canada

Phone: Email:

### **Co-Investigator**

Emmanuel Sendaula, MSc Monitoring, Research, and Evaluation Manager Reach Out Mbuya Community Health Initiative Kampala, Uganda

Phone: Email:

To help you make an informed decision regarding your participation, this letter will explain what the study is about, the possible risks and benefits, and your rights as a research participant. If you do not understand something in the letter, please ask one of the investigators prior to consenting to the study. You will be provided with a copy of the information and consent form if you choose to participate in the study.

#### What is the study about?

You are invited to participate in a research study about assessing the acceptability of the interRAI Check-Up comprehensive geriatric assessment instrument in the Kampala district of Uganda. We would like to invite you to participate in an interview about the tool. This is part of an international study for a master's project led by Student Investigator Brittany Kroetsch at the University of Waterloo which is looking to improve care practices for older adults with HIV in Uganda. We would like to assess your perspectives on the standardized tool to determine its acceptability in the Ugandan setting.

## I. Your responsibilities as a participant

## Who may participate in the study?

We are asking you to provide consent for allowing the researchers to collect information about your experiences with the Check-Up to use to assess the acceptability of the tool. You are eligible to participate in this study because you are 18 years of age or older and are a service provider affiliated with the Reach Out Mbuya Community Health Initiative.

# What does participation involve?

Participation in the study will consist of a single one-on-one interview prior to the completion of the research study. The session is expected to last 40 minutes. The interview would be held virtually through a secure platform and a member of the research team would work with you to set up a date and time that is most convenient for you. We recognize that you are very busy, but we are flexible to accommodate any of your requests and preferences. First, you would be asked to complete a short demographic survey (age, gender, education, service provision role, etc.) and then the interviewer would guide the discussion around the Check-Up instrument and its acceptability in the Central Ugandan context. You do not need to answer any questions that you do not want to answer or that make you feel uncomfortable. The session would be audio recorded to ensure accurate transcription of the interview. With your permission, anonymous quotations may be used in publications and/or presentations, and information collected during your interview will be entered into a secure database for future Research Ethics Board approved studies.

#### II. Your rights as a participant

# Are there any risks related to participating in this study?

It is unlikely that there will be any harm or risks from participation in this study. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. Your identity will be kept confidential; management and other staff will not know any of your responses or be informed of your participation. Steps to protect your privacy are provided below. You can withdraw from or stop taking part in this study at any point in time and any data you have provided will be destroyed. Your participation is completely voluntary. The interview will be conducted over an online platform, MS Teams. MS Teams has implemented technical, administrative, and physical safeguards to protect the information provided via the Services from loss, misuse, and unauthorized access, disclosure, alteration, or destruction. However, no internet transmission is ever fully secure or error-free.

# What are the potential benefits related to participating in this study?

The research may not benefit you directly. We hope that what is learned will help us to understand the barriers and facilitators to the use of the interRAI Check-Up comprehensive geriatric assessment tool in the Central Ugandan context.

### Will I receive any remuneration for participating in this study?

You will not be paid for your participation in the research study.

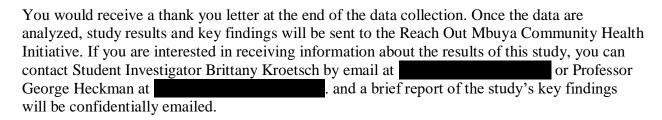
# How will my information be kept private?

Any personal identification associated with the data would be kept confidential and all data collected in this study would be securely stored. Only the research team would have access to the data collected. We will not use your name or any information that would allow you to be identified; we will use a participant code instead of your name. Identifying information will be removed from the transcripts and any quotations used in publications and presentations. Management and other staff members would not be informed if you agree to participate or not, or if you decide to withdraw from the study. Management would not know what information you provided in the interview unless you chose to tell them or disclose your responses. All data will be coded, encrypted, and stored on secure computers protected by a password at the University of Waterloo. Audio recordings, transcripts, and other electronic data will be retained for a minimum of 7 years in a secure location that is password encrypted within Professor George Heckman's locked offices at the University of Waterloo, after which they would be destroyed. Any publications will present group data and any results reported will be in a summary format with very careful attention to exclude any information that could identify you.

### What if I change my mind about participating in this study?

Your participation in this study is completely voluntary. It is your choice to be part of the study or not and in no way would your participation affect your employment. You may decide to leave the study at any time by informing the interviewer or any member of the research team. If you decide to withdraw, there would be no consequences. In cases of withdrawal, any information you provided up to that point would not be used and would be destroyed. You may decline to answer any question(s) you prefer not to answer.

#### How will I learn about the results of this study?



# III. Questions, comments, or concerns

Who is funding this study	Who	o is fu	nding	this	study	v?
---------------------------	-----	---------	-------	------	-------	----

This study is funded by interRAI Canada.

Has this study received clearance from a research ethics board?
This study has been reviewed and received ethics clearance through the University of Waterloo Research Ethics Board (REB#43401). If you have questions for the Board, contact the Office of Research Ethics, at ext. or
This study has also been reviewed and received ethics clearance through the Uganda National Council for Science and Technology (REB#HS2229ES). If you have questions regarding your rights as a research participant, contact the Executive Secretary UNCST at by email at
This study has also been reviewed and received ethics clearance through the Clarke International University-Research Ethics Committee in Uganda (REB#2022-338). If you have questions regarding your rights as a research participant, contact the Chairperson CIUREC or by email:
This study has also been reviewed and received ethics clearance through the Reach Out Mbuya Community Health Initiative. If you have questions regarding your rights as a research participant, contact:  or by email:
The Research Ethics Board is a group of people who oversee the ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.
Who should I contact if I have questions regarding my participation in this study?
If you have any questions regarding this study or need more information to assist you in reaching a decision about participation, please contact Student Investigator Brittany Kroetsch by email at contact Student Investigator Brittany Kroetsch by email at Emmanuel Sendaula at

#### Statement of Consent

**Title of study:** Utility of the interRAI Check-Up Comprehensive Geriatric Assessment (CGA) Tool: Evaluating Check-Up Acceptability in Assessing Frailty and Care Needs of Older Adults with Human Immunodeficiency Virus (HIV) in Kampala District of Uganda

I have read and understood the information letter and consent form.

I have had sufficient time to consider the information provided and to ask for advice if necessary.

I have had the opportunity to ask questions and have had satisfactory responses to my questions.

I understand that my identity will be kept confidential, and that the information obtained from my interview will be used for the research objectives.

I understand that de-identified data may be entered into a secure database for future use.

I understand that my participation in this study is voluntary and that I am completely free to refuse to participate or withdraw from this study at any time without any penalty.

I understand that I am not waiving any of my legal rights as a result of signing this consent form.

If I have any questions about this project, I can contact Student Investigator Brittany Kroetsch

I understand that there is no guarantee that this study will provide any benefits to me.

I have been told that I will receive a dated and signed copy of this form.

	or Professor George Heckman [	] or
Emmanuel Sendaula [	] at any time.	
		TT 1
This study has been review	red and received ethics clearance through the	e University of Waterloo
Research Ethics Board, the	Uganda National Council for Science and T	Γechnology, the Clarke
International University-Re	esearch Ethics Committee, and the Reach Or	ut Mbuya Community
	, the final decision to participate in the study	- · · ·
you have any comments or	concerns resulting from your participation i	n this study, please
contact the University of W	Vaterloo Office of Research Ethics, at	, ext. or
by email at	, or contact the Uganda National Cou	uncil for Science and
Technology Executive Sec	retary at or by email at	, the
Clarke International Univer	rsity-Research Ethics Committee Chairperso	on at or
by email at	or contact the Reach Out Mbuya Communit	ty Health Initiative at
or	or by email at	. The
Research Ethics Board is a	group of people who oversee the ethical con	nduct of research studies.
These people are not part o	of the study team. Everything you discuss wi	ll be kept confidential.

I am aware that the interview will be audio recorded to ensure accurate transcription and analysis.

□ Yes □	No		
that come	I give permission for the use of anonymous quotations in publications and presentation that come from this research.  ☐ Yes ☐ No  I am aware that de-identified data collected during this study may be entered into a sec database for future research.  ☐ Yes ☐ No		
database			
I have read this fo	orm and I freely conse	ent to participate in this study.	
Service Provider (please print):	Name	Name of Researcher/Witness (please print):	
Signature:		Signature:	
Date:		Date:	

#### Service Provider Thank You Letter

University of Waterloo	[insert date]
------------------------	---------------

#### Dear [Insert Service Provider Name]

I would like to thank you for your participation in this study entitled "Utility of the interRAI Check-Up Comprehensive Geriatric Assessment (CGA) Tool: Evaluating Check-Up Acceptability in Assessing Frailty and Care Needs of Older Adults with Human Immunodeficiency Virus (HIV) in Kampala District of Uganda".

As a reminder, the purpose of this study is to determine the acceptability of using a standardized clinical assessment instrument for older adults in the Kampala district of Uganda. The data collected during interviews will contribute to a better understanding of the acceptability of the interRAI Check-Up, as well as potential barriers and facilitators to its use in this setting.

This study has been reviewed and received ethics cl	earance through the University of Waterloo
Research Ethics Board (REB #43401) the Clarke In	ternational University Research Ethics
Committee, and the Uganda National Council for So	cience and Technology. If you have questions
for the Board, contact the Office of Research Ethics	ext. or by email a
, the Clarke International Univers	sity Research Ethics Committee Chairperson
at or by email at ,	or the Uganda National Council for Science
and Technology Executive Secretary at	or by email at .
For all other questions contact me at	or Dr. Heckman at
or Emmanuel Sendaula a	at

Your identity will be confidential. Once all the data are collected and analyzed for this project, I plan on sharing this information with the Reach Out Mbuya Community Health Initiative through seminars, conferences, presentations, and journal articles. If you are interested in receiving more information regarding the results of this study or would like a summary of the results, please provide your email address, and when the study is completed, anticipated by *August 2022*, I will send you the information. In the meantime, if you have any questions about the study, please do not hesitate to contact me by email as noted below.

# Brittany Kroetsch University of Waterloo

**Dr. George Heckman** University of Waterloo

#### **Emmanuel Sendaula**

Reach Out Mbuya Community Health Initiative

Chairperson
Clarke International University Research Ethics Committee

Executive Secretary
Uganda National Council for Science and Technology

## Appendix G: Interview Guide

	INTERVIEW GUIDE: Reach Out Healthcare Service Providers		
Na	Name: Date:		
A.	<b>Demographics and Contextual Factors</b>		
Community:		Age:	
District:		Gender: M / F / O	
	micity:	Occupation:	
Laı	nguage(s):	ROM Parish:	
Edi	ucation level completed:	Years at ROM:	
	rital status: Sing / Mar / Div / Wid / Oth	Years in practice:	
В.	Check-Up		
	Questions	Prompts	
1.	Can you tell me a little bit about what your	What does a typical day at Reach Out	
	role is at ROM?	look like for you? Administrative, clinic-	
		based, community-based, mobile health	
		team	
2.	Intervention Coherence	What do you think the tool is meant to	
		do/achieve? Assess health outcomes (e.g.,	
	What is your understanding of the purpose of	cognition, frailty, pain, health stability,	
	the tool?	etc.), inform system planning, inform	
		individual care planning, prioritize	
	1.00	patient care	
3.	Affective Attitude	What was your impression of the tool?	
		Comprehensive, useful, convenient,	
	What did you think about the tool?	accessible, easy to use	
1	Afficiation Assistant	What were the atversating of the to all	
4.	Affective Attitude	What were the strengths of the tool?	
	What did you like about the tool?	Outputs, clinical assessment protocol, self-report function	
	What did you like about the tool?	seij-report junction	
5.	Ethicality	Does it align well with Reach Out's	
٥.	Einicuity	values for serving the older adult	
	Do you think the Check-Up has a good fit	population? Person-centred, holistic,	
	with Reach Out's values?	comprehensive	
	with Reach Out's values?	Comprehensive	
6.	Affective Attitude	Did you find the tool comprehensive?	
0.	1111001110 11111111111	Complete, extensive, covered all relevant	
	What did you think about the range of topics	aspects	
	the tool covered?	aspecis	
	the tool covered.		
7.	Perceived Effectiveness	Do you think it will accomplish what it	
′ ·	2 of correct Differentials	aims to do? Inform care, assess risk,	
	Do you think the check-up will achieve its	prioritization	
	intended purpose?	promision	
	intended purpose.		

8.	Affective Attitude  Was there anything missing from the tool?	Is there anything that should be added to the assessment? Questions, outputs, sociodemographic information
9.	Burden  What was your experience in administering the instrument?	Did you find the tool easy to administer? Easy to follow, clear examples, unclear, interference with other priorities
10.	Gender Differences  Can you tell me about an experience of administering the tool to an older man versus an older woman?	Did you notice any differences in tool administration for men versus women? Openness, reliability of responses, willingness to share, overall understanding
11.	Self-efficacy  How do you think you might use the tool?	Can you think of anyone else who may be interested in the tool and its outputs? Clinic-based versus community-based, assessor versus self-report, individual level care planning, healthcare system planning, improve communication between sites, inform decision making
12.	Self-efficacy  Are you confident that Reach Out will be able to perform the tasks required to implement the check-up?	Do you think you will be able to effectively implement the tool? Identify at-risk older adults and decision-makers, administer Check-Up, analyze/deliver results
13.	Burden  Do you foresee any challenges in implementing the tool?	Do you anticipate any major barriers with using the tool? Personnel required, time to complete, appointment length, WIFI, technological barriers
14.	Opportunity Costs  Do you think that implementing the check-up at Reach Out will interfere with other priorities?	Will incorporating the check-up into normal care provision for older persons get in the way of other tasks? Projects, geriatric care
15.	General Acceptability  Overall, do you think the check-up is acceptable for use in the Ugandan setting?	Is the tool acceptable to be used with the older adult population Reach Out serves? Comprehensive, effective, feasible, useful

**Appendix H: Theoretical Framework of Acceptability Constructs**<sup>8</sup>

Theoretical Framework of acceptability ( TFA)	Definition	
Ethicality	The extent to which the intervention has good fit with an individual's value system	
Affective Attitude	Anticipated Affective Attitude: How an individual feels about the intervention, prior to taking part	
	Experienced Affective Attitude: How an individual feels about the intervention, after taking part	
Burden	Anticipated burden: The perceived amount of effort that is required to participate in the intervention	
	Experienced burden: the amount of effort that was required to participate in the intervention	
Opportunity Costs	Anticipated opportunity cost: The extent to which benefits, profits, or values must be given up to engage in the intervention	
	Experienced opportunity cost: the benefits, profits or values that were given up to engage in the intervention	
Perceived	Anticipated effectiveness: the extent to which the intervention is perceived to be likely to achieve its	
effectiveness	purpose	
	Experienced effectiveness: the extent to which the intervention is perceived to have achieved its intended purpose	
Self-efficacy	The participant's confidence that they can perform the behaviour(s) required to participate in the intervention	
Intervention Coherence	The extent to which the participant understands the intervention and how it works	

### Appendix I: Phase Two Sample Size Considerations

Initial sample size considerations involved consultation of key literature with a similar target population and methodology, which had an average of n=4 interviews per clinical data collection site. <sup>204–208</sup> Following the determination of data saturation, the final sample size of n=12 participants was reached which included all service providers involved in Check-Up implementation in Phase One. <sup>209</sup>

#### **Appendix J: Ethical Clearance Letters**

#### UNIVERSITY OF WATERLOO

#### Notification of Ethics Clearance to Conduct Research with Human Participants

Principal Investigator: George Heckman (School of Public Health Sciences)

Student investigator: Brittany Kroetsch (Faculty of Health)

File #: 43401

Title: Utility of the interRAI Check-Up Comprehensive Geriatric Assessment (CGA) Tool: Evaluating Check-Up Acceptability in Assessing Frailty and Care Needs of Older Adults with Human Immunodeficiency Virus (HIV) in Kampala District of Uganda

The Human Research Ethics Board is pleased to inform you this study has been reviewed and given ethics clearance.

#### Initial Approval Date: 10/22/21 (m/d/y)

University of Waterloo Research Ethics Boards are composed in accordance with, and carry out their functions and operate in a manner consistent with, the institution's guidelines for research with human participants, the Tri-Council Policy Statement for the Ethical Conduct for Research Involving Humans (TCPS, 2nd edition), International Conference on Harmonization: Good Clinical Practice (ICH-GCP), the Ontario Personal Health Information Protection Act (PHIPA), the applicable laws and regulations of the province of Ontario. Both Boards are registered with the U.S. Department of Health and Human Services under the Federal Wide Assurance, FWA00021410, and IRB registration number IRB00002419 (HREB) and IRB00007409 (CREB).

This study is to be conducted in accordance with the submitted application and the most recently approved versions of all supporting materials.

#### Expiry Date: 10/23/22 (m/d/y)

Multi-year research must be renewed at least once every 12 months unless a more frequent review has otherwise been specified. Studies will only be renewed if the renewal report is received and approved before the expiry date. Failure to submit renewal reports will result in the investigators being notified ethics clearance has been suspended and Research Finance being notified the ethics clearance is no longer valid.

Level of review: Delegated Review

Signed on behalf of the Human Research Ethics Board



20th 01 2022

Uganda National Council for Science and Technology Executive Secretary

Dear Sir.

# RE: ADMINISTRATIVE CLEARANCE FOR INVESTIGATORS; GEORGE HECKMAN AND BRITTANY KROETSCH

ROM is pleased to offer research clearance to the above-named investigators for a research study titled "Utility of the interRAI Check-Up Comprehensive Geriatric Assessment (CGA) Tool: Evaluating Check-Up Acceptability in Assessing Frailty and Care Needs of Older Adults with Human Immunodeficiency Virus (HIV) in Kampala District of Uganda" at our worksites in Reach Out Mbuya (ROM). ROM is a Faith-based Non-Governmental Organization that was started in 2001. Our Mission is to curb the further spread of HIV infections among the less privileged members of society and enable those already living with HIV/AIDS to live a responsible and dignified life. ROM does this by providing holistic care to those infected and affected by HIV/AIDS in urban Uganda. Over the past 20 years. ROM has served over 18,000 clients with comprehensive medical, psychosocial, economic and spiritual support services.

We are grateful to be part of this project, in terms of providing a research environment and participating in the implementation and finalization of this study.

ROM strongly supports this research study, which has a high potential to lead to improvements in geriatric healthcare.

Sincerely,





11/04/2022

To: Emmanuel Sendaula

Reach Out Mbuya HIV/AIDS Initiative

Type: Initial Review

Re: CLARKE-2022-338: Utility of the interRAI Check-Up Comprehensive Geriatric Assessment (CGA) Tool: Evaluating Check-Up Acceptability in Assessing Frailty and Care Needs of Older Adults with Human Immunodeficiency Virus (HIV) in Kampala District of Uganda, 1.0, 2022-02-22

I am pleased to inform you that the Clarke International University REC, through expedited review held on 07/04/2022 approved the above referenced study.

Approval of the research is for the period of 11/04/2022 to 11/04/2023.

As Principal Investigator of the research, you are responsible for fulfilling the following requirements of approval:

- 1. All co-investigators must be kept informed of the status of the research.
- Changes, amendments, and addenda to the protocol or the consent form must be submitted to the REC for rereview and approval prior to the activation of the changes.
- 3. Reports of unanticipated problems involving risks to participants or any new information which could change the risk benefit: ratio must be submitted to the REC.
- 4. Only approved consent forms are to be used in the enrollment of participants. All consent forms signed by participants and/or witnesses should be retained on file. The REC may conduct audits of all study records, and consent documentation may be part of such audits.
- 5. Continuing review application must be submitted to the REC **eight weeks** prior to the expiration date of **11/04/2023** in order to continue the study beyond the approved period. Failure to submit a continuing review application in a timely fashion may result in suspension or termination of the study.
- The REC application number assigned to the research should be cited in any correspondence with the REC of record.
- 7. You are required to register the research protocol with the Uganda National Council for Science and Technology (UNCST) for final clearance to undertake the study in Uganda.



### Uganda National Council for Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

Our Ref: HS2229ES 3 May 2022

Emmanuel Sendaula Reach Out Mbuya Parish HIV/AIDS Initiative (ROM) Kampala

Re: Research Approval: <u>Utility of the interRAI Check-Up Comprehensive Geriatric Assessment (CGA) Tool:</u>

Evaluating Check-Up Acceptability in Assessing Frailty and Care Needs of Older Adults

with Human Immunodeficiency Virus (HIV) in Kampala District of Uganda

I am pleased to inform you that on 03/05/2022, the Uganda National Council for Science and Technology (UNCST) approved the above referenced research project. The Approval of the research project is for the period of 03/05/2022 to 03/05/2023.

Your research registration number with the UNCST is **HS2229ES**. Please, cite this number in all your future correspondences with UNCST in respect of the above research project. As the Principal Investigator of the research project, you are responsible for fulfilling the following requirements of approval:

- 1. Keeping all co-investigators informed of the status of the research.
- Submitting all changes, amendments, and addenda to the research protocol or the consent form (where applicable) to
  the designated Research Ethics Committee (REC) or Lead Agency for re-review and approval prior to the activation
  of the changes. UNCST must be notified of the approved changes within five working days.
- For clinical trials, all serious adverse events must be reported promptly to the designated local REC for review with copies to the National Drug Authority and a notification to the UNCST.
- 4. Unanticipated problems involving risks to research participants or other must be reported promptly to the UNCST. New information that becomes available which could change the risk/benefit ratio must be submitted promptly for UNCST notification after review by the REC.
- Only approved study procedures are to be implemented. The UNCST may conduct impromptu audits of all study records.
- An annual progress report and approval letter of continuation from the REC must be submitted electronically to UNCST. Failure to do so may result in termination of the research project.

#### **GLOSSARY**

Acceptability: a reflection of the extent to which service providers delivering an intervention consider it to be appropriate, based on their experienced or projected responses to its implementation<sup>8</sup>

Acquired immunodeficiency syndrome: the final stage of human immunodeficiency virus characterized by profound immunosuppression, and defined by the development of cancerous tumors, opportunistic infections, wasting, and degeneration of the central nervous system<sup>24,27</sup>

Activities of daily living: the fundamental skills needed to take care of oneself independently including eating, bathing, walking, dressing, and toileting 112,113,210

Analysis of variance: a statistical analysis test used to compare variances across the means of different groups<sup>211</sup>

Antiretroviral therapies: treatment using drugs that inhibit the ability of retroviruses, including human immunodeficiency virus, to multiply in the body<sup>212</sup>

Basic activities of daily living: the skills needed to manage one's basic physical needs, such as eating, dressing, transferring, toileting, and personal hygiene<sup>112</sup>

Check-up self-report: a standardized interRAI comprehensive geriatric assessment instrument that was designed to address the care requirements of community-dwelling older adults by identifying the need for further support, care, intervention, or assessment<sup>7,67,69</sup>

Cognitive function: an individual's level of executive function, decision-making ability, and memory with impairments defined by difficulty with remembering, focusing, learning, or decision-making 101,120

Comprehensive geriatric assessment: a systemic evaluation across several health domains to identify health challenges and develop a coordinated care plan to maximize health with aging<sup>213</sup>

Deductive thematic analysis: an approach to analysis that involves coming to the qualitative data with some preconceived ideas of what you expect to find, based on existing knowledge or theory<sup>214</sup>

Frailty: a multidimensional geriatric syndrome characterized by weakness, weight loss, and low activity, and is defined as a state of increased vulnerability for developing higher dependency and mortality when exposed to stressors <sup>39,51,102,138–140</sup>

Geriatric syndromes: multifactorial clinical conditions prevalent in older persons such as falls, incontinence, functional decline, and delirium<sup>215</sup>

Health stability: a measure of how stable an individual's health is that takes into account factors such as health conditions, disease diagnoses, weight loss, changes in activities of daily living, and changes in decision-making capacity<sup>101</sup>

Home-Based Care: community program at Reach Out which links HIV-positive clients to community health workers to monitor treatment adherence and care retention<sup>216</sup>

Human immunodeficiency virus: a sexually transmitted and blood-borne infection that interferes with the body's normal immune response<sup>25,26</sup>

Instrumental activities of daily living: comprehensive thinking and organizational skills required to live independently, such as preparing meals, managing medications, shopping, and managing finances<sup>112,116</sup>

interRAI: a non-profit collaborative network of international researchers and clinicians that is committed to improving care practices for persons living with disability and those who are medically complex<sup>20,58,59</sup>

NVivo: a data analysis software that allows researchers to store, organize, transcribe, and analyze qualitative data<sup>217</sup>

RAIsoft: an industry partner of interRAI that provides commercial-grade software for use of interRAI geriatric assessment instruments<sup>111</sup>

SAS Studio Enterprise 3.8: a statistical analysis software that allows you to write and run codes through your web browser<sup>151</sup>

Theoretical framework of acceptability: a theoretical framework that can be used to guide the assessment of acceptability from the perspective of those implementing and receiving an intervention, where acceptability is represented by seven component constructs; ethicality, affective attitude, burden, opportunity costs, perceived effectiveness, self-efficacy, and intervention coherence<sup>8,152</sup>