

**DEVELOPING A FRAMEWORK TO IDENTIFY AND RESPOND TO HEALTH
LITERACY NEEDS USING COMMUNITY-BASED EMERGENCY FIRST AID
RESPONDERS IN THE LAVENDER HILL**

by

Jennifer Bress

(Student number: BRSJEN003)

SUBMITTED TO THE UNIVERSITY OF CAPE TOWN

In fulfilment of the requirements for the degree

Master of Science Degree in Emergency Medicine

Faculty of Health Sciences

UNIVERSITY OF CAPE TOWN

Date of submission: August 15, 2014

Supervisors: Jared Sun, PhD

Honorary Lecturer, Division of Emergency Med

Michele Twomey, PhD

Senior Public Health Consultant

Western Cape Department of Health

Richard Osborne, PhD

Head, Public Health Innovation

Deakin University, Melbourne Australia

The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

DECLARATION

I, **Jennifer Bress**, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

I empower the university to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signature:

Signed by candidate

Date:

August 12, 2014

Signature removed

ACKNOWLEDGEMENTS

The author would like to express her sincere thanks to Lee Wallis, Jared Sun, Gerry Gordon, Michele Twomey, and Richard Osborne for their patience, guidance, and sense of humour over the past year. The author also would like to thank all of the facilitators at Mothers Unite for their dedication. A sincere thanks also goes to the Ophelia research team for their flexibility and faith in my project, with a special thanks to Alison Beauchamp for her patience and support with statistics. This project would not have been possible without all of your help!

ABSTRACT

Data regarding health literacy in South Africa is limited, yet health literacy is critical to consider when addressing the needs of a population that is underserved by the medical community. An increase in health literacy can have a dramatic impact upon community members' quality of life, life expectancy, and patient outcomes, as well as the successful advancement of the country.

Townships and informal settlements surrounding Cape Town have limited access to timely health services, including life-saving emergency care. In recent years a community-based emergency first aid responder (EFAR) program has been created to address this need. EFARs have expressed interest in participating in other health related projects, and have the potential to help address health literacy needs in the Cape Town area.

The aim of this study was to validate the use of the HLQ (Health Literacy Questionnaire) in South Africa and use it to develop a framework for EFARs to measure and respond to health literacy needs.

After some revision, a validated combined Afrikaans/English HLQ was created for use in South Africa. Data was collected from groups of community members, EFARs, and patients at a local clinic. There were minimal differences in responses between the three groups. Data was presented in a feedback workshop and early plans for interventions successfully developed. A model is proposed for how the EFAR program can continue to operate health literacy research in any of their branches.

There are numerous health literacy needs in the greater Lavender Hill area. A new tool to identify those needs has now been validated. Information from the HLQ can help guide local leaders and providers toward unique interventions designed to address identified needs. The EFAR program network has the potential to serve a critical role within this framework to identify and respond to health literacy needs in South Africa. Further investigation is required regarding the feasibility and success of health literacy pilot interventions.

TABLE OF CONTENTS	PAGE NO
DEFINITION OF KEY TERMS	I
ACRONYMS AND ABBREVIATIONS	II
LIST OF FIGURES	IV
LIST OF TABLES	V
LIST OF APPENDICES	VI
 CHAPTER 1: INTRODUCTION	 1
1.1 Background	1
1.2 Motivation	4
1.3 Aims	4
1.4 Objectives	4
 CHAPTER 2: LITERATURE REVIEW	 6
2.1 Health literacy	6
2.1.1 Definitions	6
2.1.2 Associations	8
2.1.3 Health literacy and health inequities	9
2.1.4 Health literacy and emergency medicine	10
2.1.5 Health literacy internationally	12
2.1.6 Interventions	13
2.1.7 Current measurement tools	16

2.2	The Health Literacy Questionnaire and Ophelia process	17
2.2.1	The Health Literacy Questionnaire (HLQ)	17
2.2.2	The Ophelia process	19
2.2.3	Relevance to other populations	20
2.3	South African background	20
2.3.1	The City of Cape Town	21
2.3.2	Healthcare system	22
2.3.3	Emergency Medicine	23
2.3.4	Pre-hospital emergency medical care	24
2.4	The Emergency First Aid Responder (EFAR) program	26
2.4.1	Creation and evolution of the EFAR program	26
2.4.2	Structure of each branch	28
2.4.3	The Mothers Unite EFAR branch	30
2.4.4	The EFAR program and health literacy	31
CHAPTER 3: METHODOLOGY		32
3.1	Overview	32
3.2	Provisional translation of Health Literacy Questionnaire into Afrikaans	32
3.2.1	Background	32
3.2.2	Roles in translation procedure	33
3.2.3	Steps in translation	34
3.3	Validation, cultural adaptation, and final translation	36

3.3.1	Background	36
3.3.2	Cognitive interviews	37
3.3.3	Feedback from HLQ administrators	38
3.3.4	Final validation and Afrikaans translation	39
3.4	Administration of the HLQ	40
3.4.1	Setting	40
3.4.2	Population	40
3.4.3	Predictions	40
3.4.4	HLQ administration	42
3.4.5	Sampling strategy	43
3.4.6	Data collection	44
3.5	HLQ data analysis and vignette development	46
3.5.1	HLQ scoring	46
3.5.2	Comparing groups	47
3.5.3	Cluster analysis	47
3.5.4	Vignette formation	48
3.6	Feedback workshop	49
3.6.1	Background	49
3.6.2	Design	50
3.6.3	Setting	51
3.6.4	Population	51
3.6.5	Sampling strategy	51
3.6.6	Data collection	52

3.6.7	Data analysis	52
3.7	Ethical considerations	52
3.7.1	Autonomy	52
3.7.2	Anonymity	52
3.7.3	Beneficence	53
CHAPTER 4:	FINDINGS	54
4.1	Translation of the HLQ	54
4.1.1	Provisional forward translation	54
4.1.2	Testing provisional forward translation	60
4.1.3	Changes to translation	61
4.1.4	Creation of combined HLQ	64
4.2	Validation of the HLQ	65
4.2.1	Validation of the HLQ in English	65
4.2.2	Validation of the HLQ in Afrikaans	74
4.2.3	Validation of the combined HLQ	84
4.3	HLQ data	85
4.3.1	Demographics	85
4.3.2	Comparisons of three study groups	87
4.3.3	Cluster analysis	99
4.3.4	Vignettes	100
4.4	Feedback workshop	100
4.4.1	Overview	100

4.4.2	Discussion of vignettes in Patient group	103
4.4.3	Discussion of vignettes in Community/EFAR group	108
4.4.4	Discussion of dimensions	113
4.4.5	Summary of workshop recommendations	114
CHAPTER 5:	DISCUSSION	116
5.1	Importance of addressing health literacy in South Africa	116
5.2	Language and the Health Literacy Questionnaire	117
5.3	Validity of the combined-language HLQ	120
5.4	Comparison of health literacy across participant groups	123
5.5	Formation and use of vignettes	134
5.6	Reflections on the feedback workshop	135
5.7	Identified health literacy needs and early interventions	136
5.8	Relationship to Ophelia process and Public Health Innovation (PHI)	139
5.9	Using the EFAR program to address health literacy	140
5.10	A model for identifying and responding to health literacy needs using the EFAR program	142
CHAPTER 6:	CONCLUSION AND RECOMMENDATIONS	145
6.1	Conclusions	145
6.1.1	Utility of studying health literacy in South Africa	145
6.1.2	Validity of the English, Afrikaans, and combined language HLQ for use in South Africa	145

6.1.3	Health literacy data from Lavender Hill	145
6.1.4	Workshop	146
6.1.5	Collaborations with the Ophelia research team and the EFAR program	146
6.2	Limitations	146
6.3	Recommendations	147
6.3.1	Further work	147
6.3.2	Implementation of the EFAR health literacy model	148
	REFERENCES	149

DEFINITION OF KEY TERMS

Cluster analysis: A statistical technique that separates responses into groups that are more similar to each other than they are to other groups.

Emergency First Aid Responder (EFAR): a lay volunteer who has been trained by the EFAR program to provide basic, life-saving first aid care.

Emergency Medical Services (EMS): A nationwide network of pre-hospital care providers that provide medical assistance, stabilisation, and transport from primary response to definitive care.

Health literacy: Definitions vary, but most definitions of health literacy used in current literature are multifactorial and refer to a person's ability to find, comprehend, and use health information.

Health Literacy Questionnaire (HLQ): Multidimensional health literacy measurement tool that assesses an individual's health literacy across nine domains.

Health promotion: The process of enabling people to increase control over and to improve their health so as to reach a state of complete physical, mental, and social well being¹.

Ophelia process: A systematic, grounded process designed to improve health outcomes and decrease health inequities by addressing health literacy concerns at local, community health, and government levels.

Scale: A graduated range of values that serve as a standard system for measuring or grading something. There are two types of scales within the HLQ. There are nine scales that are each designed to measure a specific domain of health literacy (for example, Navigating the healthcare system). There are also two measurement scales (Agree/Disagree and Easy/Difficult), which are used to grade the strength of a response to questions on the other nine scales.

Vignette: A brief impressionistic description of an individual.

ACRONYMS AND ABBREVIATIONS

AE: (“Active engagement”)- abbreviation for the scale “Ability to actively engage with healthcare providers”

ALS: Advanced Life Support

AMH: (“Actively managing health”)- abbreviation for the scale “Actively managing my health”

BLS: Basic Life Support

CA: (“Critical appraisal”)- abbreviation for the scale “Appraisal of health information”

CBO: Community based organisation

CHC: Community Health Clinic

EC: Emergency centre

EFAR: Emergency First Aid Responder

EMS: Emergency Medical Services

FHI: (“Find health information”)- abbreviation for the scale “Ability to find good health information”

HLQ: Health Literacy Questionnaire

HP: Healthcare provider

HPS: (“Healthcare provider support”)- abbreviation for the scale “Feeling understood and supported by healthcare providers”

HSI: (“Having sufficient information”)- abbreviation for the scale “Having sufficient information to manage my health”

ILS: Intermediate Life Support

NHS: (“Navigating healthcare system”)- abbreviation for the scale “Navigating the healthcare system”

PHI: Public health innovation

SS: (“Social support”)- abbreviation for the scale “Social support for health”

UHI: (“Understanding health information”)- abbreviation for the scale
“Understanding health information well enough to know what to do”

LIST OF FIGURES

Figure 1: Adaptable EFAR system model	28
Figure 2: 95% Confidence intervals for nine health literacy scales	89
Figure 3: Frequency plots- HPS	90
Figure 4: Frequency plots- HSI	90
Figure 5: Frequency plots- AMH	90
Figure 6: Frequency plots- SS	91
Figure 7: Frequency plots- CA	91
Figure 8: Frequency plots- AE	91
Figure 9: Frequency plots- NHS	92
Figure 10: Frequency plots- FHI	92
Figure 11: Frequency plots- UHI	92

LIST OF TABLES

Table 1: Nine health literacy scales and their respective possible score ranges	46
Table 2: Main concerns discussed at the first translation teleconference regarding the initial Afrikaans translation	54
Table 3: Main concerns discussed at the second translation teleconference regarding the provisional Afrikaans translation	61
Table 4: Summary of validation processes for the English HLQ	65
Table 5: Summary of validation processes for the Afrikaans HLQ	75
Table 6: Demographic data from HLQ participants	86
Table 7: Health conditions reported amongst HLQ participants	86
Table 8: Summary of health literacy scores	87
Table 9: Test of homogeneity of variance	93
Table 10: Robust ANOVA of NHS scale using Brown-Forsythe method	94
Table 11: Post hoc testing of NHS scale using Games-Howell method	94
Table 12: One-way ANOVA for all scales besides NHS	95
Table 13: Post hoc testing of all scales besides NHS using Gabriel method	97
Table 14: Identification of clusters into high, moderate, mixed, and low categories	100
Table 15: Summary of discussion of patient vignettes in workshop	103
Table 16: Summary of discussion of community member and EFAR vignettes in workshop	108

LIST OF APPENDICES

Appendix 1: Participant information and consent form

Appendix 2: Demographic form

Appendix 3: HLQ scales and items

Appendix 4: HLQ item intent and translation management

Appendix 5: Early Afrikaans HLQ

Appendix 6: Combined HLQ

Appendix 7: Community cluster summary sheet

Appendix 8: EFAR cluster summary sheet

Appendix 9: Patient cluster summary sheet

Appendix 10: Community vignettes

Appendix 11: EFAR vignettes

Appendix 12: Patient vignettes

Appendix 13: Workshop report

CHAPTER 1: INTRODUCTION

1.1 Background

Low levels of education and general literacy have been shown to significantly contribute to the disease burden of developing countries, with significant implications for social and economic development^{2–4}. However, South Africa has one of the highest general literacy rates in all of Africa, but is also known to be one of the most severely affected by a burden of diseases and traumatic injuries². It is believed that it is health literacy—a distinct form of literacy—that is a more primary determinant of a region's general health, and that its paucity can explain why a region can have poor health even with high general literacy rates^{2,5,6}.

In recent decades, literature in the field of health literacy has been exploding. While specific details vary, most definitions of health literacy used in current literature are multifactorial and refer to a person's ability to find, comprehend, and use health information. An individual with a high level of health literacy is empowered by their ability to obtain and apply knowledge to improve their health, given that health is a key component in the capacity to function at a high level in society^{2,5}. Because individuals exist within complex socioeconomic environments and healthcare systems vary profoundly by region, health literacy is best conceptualised by considering both individual capacities and the capacity of a healthcare system or organisation to allow their members to access, understand, engage with, and use their services^{6–9}.

Low health literacy has been associated with a number of poor health outcomes, including increased mortality^{10–13}, increased hospitalisation and use of inpatient services^{14–18}, lower use of preventive services^{15,19–25}, and less disease knowledge and self-management skills^{26–28}. Importantly, it is believed that poor health literacy contributes to health inequalities along racial/ethnic lines and at differing levels of education, as well as across immigrant status, language, and income divisions^{4,21,24,29}.

As the “safety net” of healthcare, Emergency Medicine practitioners frequently encounter patients with low health literacy, who have been shown to have increased emergency and urgent care visits^{14–18,30–32}. This has prompted some researchers to suggest that health literacy interventions might be highly effective if administered through an emergency centre^{15,33,34}. As another possibility, many health promotion or education campaigns have had great success by incorporating community members, lay volunteers, or family members that are already closely connected to patients and well-versed in the culture of an area^{35–37}.

The majority of research and interventions in health literacy have been performed in developed countries. However, developing countries often experience high health inequities, poor health outcomes, and a disproportionate burden of trauma due to rapid industrialisation and urbanisation^{38–44}. South Africa is one example of a developing country with vast health disparities that are worsened by the burden of widespread unemployment, poverty, crime, substance abuse, HIV/AIDS, and tuberculosis. In a country like South Africa, increasing health literacy may have a dramatic impact upon quality of life, life expectancy, and health disparities, as well as the successful advancement of the country on a larger scale^{2,5}.

One place to consider implementing a health literacy intervention is through pre-hospital Emergency Medical Services. These providers are on the front line of the healthcare system and therefore, like other emergency providers, frequently encounter patients with low health literacy. An even more powerful option may be focusing on a recently developed intervention to provide basic life-saving care in resource-poor areas: the Emergency First Aid Responder (EFAR) program.

The EFAR system is a program that trains local volunteers in townships surrounding Cape Town that have high rates of violence and accidents to be first responders for emergency incidents³⁹. It differs from some other first-responder systems because it integrates and coordinates the volunteers with

the existing emergency response system in the area, as opposed to being a stand-alone parallel entity. This basic care can have a dramatic impact in a resource-poor area, considering that up to 90% of trauma-related deaths occur in developing countries, with the majority in a pre-hospital setting⁴⁵.

The success of the program has been attributed partly to a trusting relationship formed between local community leaders and those creating the EFAR system. The EFAR model relies upon a community-based organisation to run the program for their particular community³⁹. Local leaders and community members are able to provide essential information for the researchers to adapt the EFAR system to each particular area's local culture and context^{39,46}. EFARs in the townships surrounding Cape Town have expressed their motivation to help solve the problem of increased emergency incidents and that their desire to help and learn extends to health issues outside of emergencies (Jared Sun, personal communication, Oct-Dec 2012). The EFAR program, therefore, could serve as a critical bridge between the community, physicians, and officials attempting to improve health literacy amongst the community members in the developing townships.

One problem with implementing health literacy research in an entirely new setting is that it may be difficult to determine what the health literacy levels or needs are of the target population. Measuring "health literacy" has historically been a challenge. Some of the more common measures focus only on narrow definitions of health literacy, have mainly been used in English-speaking developed countries, and have been shown to have significant psychometric weaknesses^{7,47,48}. To address these shortcomings, researchers in Australia have recently developed the Health Literacy Questionnaire (HLQ), a multidimensional health literacy measurement tool that has the potential to measure several diverse aspects of health literacy as well as to inform administrators where to focus health literacy interventions⁷. The same researchers have begun developing a framework that uses the HLQ to identify and respond to health literacy needs in order to improve health inequities.

These tools may prove extremely helpful in health literacy research within South Africa.

1.2 Motivation

Overall, literature regarding health literacy in South Africa is limited. There is a lack of information on the health literacy of individuals in the Lavender Hill area of Cape Town. The literature points to a need for developing a framework for improving health outcomes and decreasing health inequalities.

A multidimensional health literacy measurement tool has been developed that measures nine indicators of health literacy. There also exists a proposed scheme called the Ophelia process that uses this tool to identify and respond to health literacy needs.

These tools suggest a way for the EFAR program to be able to measure nine dimensions of health literacy among populations in the Lavender Hill area and respond to the data by developing interventions at the community and healthcare provider level. If successful, a framework can be created for other EFAR branches to implement similar targeted health literacy interventions in their communities, with the ultimate goal of helping improve health and health equity in that community.

1.3 Aims

The first aim is to study the use of the HLQ in South African populations.

The second is to study and develop a framework to allow community leaders, EFAR leaders, and healthcare providers to understand the health literacy of their community members, and to respond to them by creating tailored interventions.

1.4 Objectives

The first objective is to translate the HLQ and study its validity and cultural relevance in South African populations.

The second is to collect HLQ data from three groups within the Lavender Hill area and analyse the data using cluster analysis as well as narrative writing.

The third objective is to present HLQ data to a workshop group of community, EFAR, and healthcare service participants that are interested in addressing health literacy, and to develop proposed health literacy interventions.

The last is to create a formal model for EFAR programs in the future to be able to implement an assessment of health literacy needs in their community in order to respond to them with focused interventions.

CHAPTER 2: LITERATURE REVIEW

2.1 Health literacy

Education and general literacy are well-known fundamental determinants of health^{2,49}. High levels of illiteracy have been shown to significantly contribute to the disease burden of developing countries, with significant implications for social and economic development²⁻⁴. However, there are several examples of countries where there are high disease burdens despite high general literacy rates. South Africa has some of the highest general literacy rates in all of Africa (over 80%), but is also known to be one of the most severely plagued by the epidemic of HIV/AIDS². Because of this, it is believed that it is health literacy—a distinct form of literacy—that is a more primary determinant of a region's general health, and that its paucity can explain why a region can have poor health even with high general literacy rates^{2,5,6}.

2.1.1 Definitions

Definitions of health literacy vary. Three of the most often cited definitions in current literature come from the World Health Organisation⁵⁰, the USA Institute of Medicine⁹, and the American Medical Association's Ad Hoc Committee for Health Literacy for the Council on Scientific Affairs^{6,51}. The World Health Organisation defines health literacy as:

The cognitive and social skills that influence people's motivation and ability to gain access to, understand, and use information in ways which promote and maintain good health⁵⁰.

A similar definition is presented by the National Library of Medicine and used by the USA Institute of Medicine's report "Health Literacy: A Prescription to End Confusion":

The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions⁹.

The Ad Hoc Committee for Health Literacy for the Council on Scientific Affairs of the American Medical Association has defined health literacy as:

A constellation of skills, including the ability to perform basic reading and numerical skills required to function in the health care environment⁵¹.

The term “health literacy” was created in the 1970s, and since that time, definitions have evolved significantly before reaching those above. Initially, most only considered basic abilities to read and understand words and numbers in health-related information. At present, definitions often refer to a more complex interaction between an individual’s abilities and their healthcare system and providers⁶. A more recent definition presented by Freedman et al (2009) has even expanded this concept to include the idea of “public health literacy”:

The degree to which individuals and groups can obtain, process, understand, evaluate, and act upon information needed to make public health decisions that benefit the community⁵².

A 2012 review of health literacy literature combined health literacy definitions across 17 studies from 1998-2009 into the comprehensive definition:

Health literacy is linked to literacy and entails people’s knowledge, motivation, and competences to access, understand, appraise, and apply health information in order to make judgements and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course⁶.

Thus, though specific details vary, most definitions of health literacy used in current literature refer to a person’s ability to find, comprehend, and use health information. An individual with a high level of health literacy is empowered by their ability to cognise and apply knowledge to improve their health, given that health is a key component in the capacity to function at a high level in society^{2,5}. In addition, individuals with high levels of health literacy often impact the health of their families or community.

Importantly, health literacy is now understood to be extremely multifactorial. An individual's health literacy certainly varies with their personal literacy and numeracy skills, motivation to find information and services, and ability to access these services. However, individuals exist within complex social and economic environments, and healthcare systems vary profoundly by region. Health literacy is best conceptualised by considering both individual capacities and the capacity of a healthcare system or organisation to allow their members to access, understand, engage with, and use their services⁶⁻⁹

2.1.2 Associations

Numerous studies have been performed examining the impact of low or inadequate health literacy upon health outcomes and the use of services⁵³. Low health literacy is linked with increased mortality¹⁰⁻¹³. It has been associated with increased hospitalisation and use of inpatient services among various patient populations, including the elderly^{14,15}, asthmatics^{16,17}, and patients with congestive heart failure¹⁸. It has also been linked with lower use of preventive services, including colon cancer screening^{15,19}, Pap smears for cervical dysplasia^{15,19,20}, mammography^{15,19,21,22}, sexually transmitted infection testing²³, and immunisations^{19,21,24,25}.

Low health literacy has been linked to lower adherence with medication and treatment regimens⁵⁴⁻⁵⁸. However, more recent data on this association has given mixed results⁵⁶⁻⁶³. Some studies have reported that this association is mediated by factors like treatment knowledge and medication self-efficacy⁵⁷, stigma tied to medications⁶⁰, and social support⁶⁴.

Individuals with lower health literacy are more likely to have symptoms of depression^{14,25,65-70}. In addition, they may be at higher risk for chronic illnesses like diabetes and heart failure^{4,71,72}. Elderly patients with low health literacy are associated with a lower self-reported health status^{15,21,24,25,73,74}, and patients with chronic conditions and suboptimal health literacy have less disease knowledge and self-management skills²⁶⁻²⁸. It has also been suggested that

patients with low health literacy have trouble engaging and communicating with healthcare providers⁷⁵.

Health literacy may affect healthcare costs. A report from 1999 by the USA National Academy on an Aging Society claims that low health literacy skills increase national health care expenditures by \$73 billion⁷⁶. Studies on Medicare and Medicaid patients in the US have mixed results- Medicare patients with low health literacy have increased emergency centre costs but no significant differences overall¹⁴, whereas Medicaid patients with low health literacy have been associated with higher overall costs⁷⁷. More work is needed regarding the impact of health literacy on healthcare costs.

Few studies have examined the mechanisms of low health literacy leading to poor health outcomes. However, considering the various definitions of health literacy, it is not difficult to imagine why a person with low health literacy may be more prone to poor health. These individuals often lack sufficient knowledge about health and the mechanisms of disease, and may not understand that unhealthy lifestyles or medication mismanagement can lead to poor health. Additionally, they have trouble understanding or complying with chronic disease treatments, whether due to their own lack of skills, difficulties following complex labels or treatment plans due to poorly organised health services, or both. Finally, many individuals with poor health literacy take less responsibility for their health. They see healthcare as something that is imposed upon them rather than a partnership with a provider to better their own condition. A lack of motivation and responsibility prevents individuals from investing the time and effort required to maintain their health knowledge, obtain and perform preventive health measures, and manage diseases. Importantly, if entire groups of people are predisposed to poor health outcomes due to low health literacy, this may contribute significantly to health disparities.

2.1.3 Health literacy and health inequities

In response to the proliferation of literature regarding the association of poor health outcomes with low health literacy, many researchers began to question

whether differences in health literacy contribute to health disparities. Given that poor health literacy is often associated with lower socioeconomic status, higher medical comorbidities, lower use of preventive services, and lower medication adherence, it makes sense that patients with lower health literacy may be more prone to poor overall health status^{25,56,57}.

Preliminary work in this area strongly suggests that poor health literacy greatly contributes to health inequalities. Several studies have shown that health literacy may help explain health disparities along racial/ethnic lines and at differing levels of education^{4,21,24}. Some studies have also noted that health literacy accounts for some of the effect of disparities related to immigrant status, language, and income²⁹.

In particular, it has been suggested that health literacy is a more significant and realistic factor contributing to a person's health than statistical measures like "educational attainment," which provide a numerical value for years of formal schooling but do not necessarily reflect an individual's ability to comprehend or use information⁴. Accordingly, literature points to a need to improve health education and communication techniques to help minimise health disparities^{29,51,56,57}. Thus, it is imperative that in places with known health disparities or poor health outcomes, health literacy is considered by any individual, provider, group, or organisation seeking to improve these inequities. It is particularly important that providers of emergency medical services consider the health literacy levels of their patients.

2.1.4 Health literacy and emergency medicine

While the structure and accessibility of emergency medical services vary by country, in most places, patients receive an evaluation when they present for emergency medical care regardless of insurance status or ability to pay. Emergency centres are often referred to as the "safety net" of healthcare, serving as a last resort and default medical provider for those with inadequate access to routine healthcare services. Patients with poor access to health

services and low use of preventive care are therefore perhaps encountered most often in emergency centres.

Several studies have shown an association between low or inadequate health literacy and increased emergency and urgent care visits^{14–18,30–32}, as well as higher emergency centre costs¹⁴. Additionally, numerous studies have demonstrated that poor health literacy in parents and caregivers is a major risk factor for overuse of emergency services for paediatric patients^{29,78,79}. This is not surprising, given that patients with low health literacy are less likely to have access to routine/preventive care, more prone to have chronic medical problems, and less able to understand or manage their medical problems.

Emergency providers are in a unique position: they routinely encounter patients with low health literacy and may be the only providers ever seeing or treating these patients. Interventions designed to improve health literacy therefore might reach the greatest number of patients with low health literacy through emergency healthcare services. However, emergency providers are faced with numerous obstacles to providing care and adequate counselling for their patients, including overcrowding, constant distractions, time constraints, language barriers, and a lack of any prior history about many patients.

Unfortunately, it has been shown that low health literate patients departing emergency centres often very poorly comprehend or adhere to their treatment plans or medications. This has been shown to be true even when discharge paperwork is very comprehensive, and is seen both when patients are discharged home or admitted to inpatient medical services^{80–83}. In some ways, this is an ethical concern, as patients who don't actually adequately understand their medical problems are nonetheless required to give consent for treatment or agree to a plan of care based on their very limited information, often in times of crisis⁸⁴.

In response, a handful of studies have suggested that it may be feasible to begin screening patients in emergency centres in order to better understand their health literacy level and give appropriate counselling^{15,33,34}. It may also be

possible to incorporate health literacy assessments into electronic health records, where available⁸⁵. One study even suggests that targeted interventions for parents with low health literacy can successfully decrease subsequent emergency centre utilisation for their children⁷⁸.

2.1.5 Health literacy internationally

Since its recognition as a separate entity in the 1970s, the majority of research performed on health literacy has been in the United States and Canada. However, in recent years, more work has been done internationally. Australia and the European Union recognise health literacy in health policies, and research has been accumulating in these areas^{6,53,86–88}. In addition, work has been done in Asia, with groundwork being laid to extend the field to work with character-based languages^{88,89}. Researchers, non-profit organisations, and collaborative work groups have been reporting global expansion, including into developing countries⁸⁸.

There is a lack of research on health literacy in South Africa, with only a few isolated studies mentioning the term in specific fields like Speech-Language Pathology and epilepsy^{90,91}. However, there are several government programs aimed at health promotion in general or the improvement of communication with patients. Both government-funded and independent programs targeting HIV/AIDS in recent years have contributed to a shift in focus in healthcare to a more patient-centred, biopsychosocial approach. Research in this area might contribute valuable experience using health promotion techniques⁸⁸.

Additionally, it is likely that a majority of healthcare services recognise the importance of health literacy, but don't use the specific term "health literacy". With growing awareness of health literacy and its applications, a more precise and agreed-upon concept may be reached in the near future, making it more feasible for organisations to benefit from a common body of literature and best practices⁸⁸. Best practices would include successful interventions that have been used to improve health literacy, particularly if this was shown to improve health outcomes or health inequities.

2.1.6 Interventions

How does one improve health literacy? Addressing this complex concept with a single intervention could certainly be difficult. It is essential to remember that several distinct entities have roles in a given individual's health literacy. Individual factors play a prominent role: a person's intellect, values, and motivation will heavily influence their health literacy. However, the same individual's development is also heavily influenced by their upbringing, environment, and culture. A young teenager might have very different impressions of the right time to start her family if she was raised by a successful teen mother versus a poor couple in their forties.

Similarly, healthcare systems and providers also play prominent roles in the health literacy of their patients and community members. A system that is non-judgmental, open every day for 24 hours, and has the luxury of offering 60-minute appointments with a responsive, caring physician is strikingly different from a crowded, understaffed, low-resource government hospital that necessitates patients waiting a full day for 15 minutes of evaluation by an overworked, stressed provider. Patients attending these healthcare centres and living in their catchment areas will understandably have different opinions about health and capabilities to access and interact with healthcare providers.

Health literacy interventions can therefore take many forms, and may tackle one or more different aspects of health literacy. Luckily, this allows individuals interested in health literacy to take advantage of the large body of literature that exists regarding health promotion in general. "Health promotion" is defined as:

The process of enabling people to increase control over and to improve their health so as to reach a state of complete physical, mental, and social well being¹.

Health promotion interventions often take the form of health education campaigns tailored to a particular group of people. However, such campaigns

face several obstacles in the developing world, including shortage of trained staff, low baseline education, and cultural barriers⁹².

However, education programs can be effective in several ways, including communicating information to patients, improving adherence to antibiotics and other medications, improving malaria prophylaxis and treatment, and encouraging self-management of chronic conditions such as COPD and diabetes. In particular, successful past programs are noted to have performed extensive initial research on the problem, with attention to socio-cultural influences and an initial needs assessment. They also often trained staff in communication skills and cultural sensitivity³⁵.

Cultural barriers between a physician or healthcare provider and a patient can certainly prove deleterious to a successful treatment course. AIDS activist campaigns often encounter challenges when trying to educate groups in resource-poor regions⁹². For instance, local teachers may question the scientific knowledge of the visiting activists and their biologic perspective, particularly if other authorities within the community attribute the disease to supernatural or religious issues. Outsiders also often encounter resistance based upon gender, age, and sexual customs, as well as a lack of proper language to discuss issues in a culturally-sensitive manner⁹².

Sometimes, well-meaning physicians provide inadequate guidance simply because they are unaware of other hurdles a patient faces when trying to comply with their recommendations. For instance, in a study examining interactions between healthcare providers and HIV-positive women in resource-poor settings, a group of women reported dissatisfaction at receiving advice to exclusively bottle-feed to prevent mother-to-child transmission because they did not have adequate access to bottles or formula. The study also reported that the healthcare providers who counselled women about infant feeding options were often completely unaware of the stigma these women faced from their neighbours if they decided to bottle-feed, resulting in less compliance⁹³.

Conversely, numerous studies on HIV, tuberculosis, and cardiovascular disease therapy have demonstrated that patient medication compliance and outcomes improved when time was consistently spent with a healthcare provider who gave adherence counselling^{36,37,94,95}. An important international HIV study on patient health literacy and treatment adherence concluded that more time spent counselling by healthcare providers also led to an increase in understanding about HIV resistance⁹⁴. An increase in patient health literacy and compliance with medication regimens is critical, as many believe that persistent adherence to treatment is more important than the potency of any antiretroviral treatment⁹⁵. Thus, physicians and other healthcare providers can be most effective if they can navigate the socio-cultural context of their patients and their diseases, as well as have a program for administering care that allows them to educate patients on relevant health issues.

On the other end of the patient-physician relationship, there are strategies more directly related to patients that have been noted to improve outcomes in developing countries. A compelling, simple way to improve health literacy may be to include a patient's family members or other community members in the process of patient education. Many successful health education programs have included family members in the teaching, utilised lay volunteers from the area, or connected patients to self-help groups containing other patients they could more easily relate to³⁵.

Further, a study on maintaining blood pressure control in developing areas showed that the most successful patient outcomes were when both community healthcare providers and family members were educated about blood pressure management. In this study, community health workers delivered family-based home education, resulting in a two-fold increase in the number of patients with controlled blood pressure compared to when only either the families or healthcare providers were targeted³⁶. In another study on adherence with tuberculosis medications, patients had improved outcomes when their family members were supportive of their care and lay health workers from the area

were used to administer supervised therapy. The study also recognised that a community-based approach led to improved outcomes because the lay health workers were locating the patients that missed therapy and bringing them back to treatment³⁷. Community members, therefore, can be potent resources when trying to establish healthcare and develop health literacy in a resource-limited area, possibly not only because of their proximity to both patients and professional healthcare providers but also because they are already well-versed in the social-cultural context of their particular area.

Thus, there are several ways that health promotion efforts may successfully improve health literacy. However, prior to implementing such interventions, it would be beneficial to be able to measure and identify what a group or individual's health literacy level actually is, or what areas they could use the most improvement in.

2.1.7 Current measurement tools

Historically, measuring “health literacy” has been a challenge, particularly considering the evolving, more comprehensive definitions of health literacy that are used today. Some of the more common measures include the Rapid Estimate of Adult Literacy in Medicine⁹⁶, the Test of Functional Health Literacy in Adults⁹⁷, and the Newest Vital Sign⁹⁸. However, these measures focus only on narrow definitions of health literacy, such as numeracy skills and reading comprehension for medical texts. They also have predominantly been used in English-speaking, developed countries. Despite their widespread use, these measures have been shown to have significant psychometric weaknesses^{7,47,48}. In addition, these assessments provide little insight into interventions that should be taken based upon the results^{47,48}. To address these shortcomings, researchers at Deakin University and the Monash University (Australia) have recently developed the Health Literacy Questionnaire (HLQ), a multidimensional health literacy measurement tool, using systematic grounded methods and a validity-driven approach⁷. This questionnaire has the potential to measure several diverse aspects of health literacy as well as to inform administrators

where to focus health literacy interventions. The following section provides more information about the HLQ and its potential applications.

2.2 The Health Literacy Questionnaire and Ophelia process

As described above, health literacy is a multidimensional, important concept for public health. Historically, measuring health literacy has been difficult given its complexity and evolving definition. However, a research group in Australia has recently developed a new, comprehensive health literacy measurement tool designed to assess health literacy across nine domains. The same group has also published and begun executing a protocol for a framework to identify and respond to health literacy needs in order to improve health inequities.

This section aims to provide a broad overview of this important new frontier in health literacy research. The work discussed has been performed by a research group called Public Health Innovation (PHI) based at the School of Health and Social Development at Deakin University in Melbourne, Australia. The team is led by Richard Osborne, PhD, an epidemiologist and health services researcher⁹⁹.

2.2.1 The Health Literacy Questionnaire (HLQ)

In response to the lack of adequate measurement tools for health literacy, PHI sought to create a more comprehensive model. The first attempt at doing so was the Health Literacy Management Scale (HeLMS), which utilised concept mapping and patient interviewing¹⁰⁰. However, it was believed the HeLMS was only sensitive enough to measure severe health literacy deficits. The group then held consultations with patients and experts at an international rheumatology outcomes conference⁸. The data from both of these activities was combined and used to create a new model, the Health Literacy Questionnaire (HLQ)⁷.

The HLQ was developed using a validity-driven process. Both modern and classical approaches to instrument development were used, and constructs were carefully developed, tested, and retested in target populations⁷. The

questionnaire addresses nine separate indicators of health literacy relevant to individuals, healthcare providers, and policy makers, including:

- Feeling understood and supported by healthcare providers
- Having sufficient information to manage my health
- Actively managing my health
- Social support for health
- Appraisal of health information
- Ability to actively engage with healthcare providers
- Navigating the healthcare system
- Ability to find good health information
- Understanding health information well enough to know what to do

These nine concepts are conceptually strong and each are measured by a series of items that overall have excellent psychometric properties⁷. In the words of the researchers:

The nine scales capture a wide range of the lived experiences of people attempting to engage in understanding, accessing, and using health information and health services. Importantly, the scales also provide a reflection of the quality of health and social service provision⁷.

The HLQ is therefore a new tool designed to assess health literacy in a more comprehensive sense than any prior measurement tools. The HLQ provides information about both the individuals taking the questionnaires and the organisations that are serving those individuals, and therefore has the potential to influence decisions about interventions designed to address health literacy at a variety of levels. A proposed program called the “Ophelia process” has been

developed to systematically use the HLQ to create targeted health literacy interventions.

2.2.2 The Ophelia process

After creating the HLQ, the same researchers then developed an initiative of “Optimising health literacy to improve health and equity” (Ophelia), which seeks to identify and test interventions to address health literacy problems that have been identified through HLQ data. The process uses a systematic, grounded approach designed to improve health outcomes and decrease health inequities by addressing health literacy concerns at local, community health, and government levels. Ultimately, the goal is to create a framework that offers organisations intervention options to use when their members present with certain health literacy deficits¹⁰¹.

There are three main phases to the Ophelia process:

1. A needs assessment of health literacy concerns using the HLQ
2. Staff from organisations co-creating interventions in response to needs
3. Trial of interventions within each organisation

The current project is a large collaboration between the Victoria Department of Health, Deakin and Monash Universities, and eight test sites (including two local government organisations, one outreach nursing service, two hospital-based sub-acute programs, and three community healthcare organisations)¹⁰¹.

Each of the eight sites will provide a minimum of 100 completed HLQs from a diverse sample of their patients. This data will then be presented back to the organisations, who will co-create interventions that will be tested and refined by performing several Plan-Do-Study-Act cycles. Organisations will also be required to provide information regarding their structure, service environment, their organisational strategy and plans, and sociodemographic information about their patients¹⁰¹.

Importantly, the Ophelia process greatly respects, values, and attempts to harness the tacit knowledge and wisdom of the providers and managers at each of these organisations. It is also hoped that the organisations will collaborate with one another and eventually form communities of practice ¹⁰¹. Until recently, the HLQ and Ophelia process have been localised to organisations and communities within Australia.

2.2.3 *Relevance to other populations*

As part of the development process of the HLQ, the questionnaire was tested across a variety of individuals with variable levels of insurance, chronic medical conditions, and education. Similarly, the eight sites chosen for the Ophelia protocol represent rural and urban environments and serve a diverse array of patients. It is hoped that the robust instrument development processes used for the HLQ and the extensive, systematic approach of the Ophelia process will allow these tools to be used in a wide variety of contexts.

However, a new tool or framework always requires further testing in entirely novel settings before it may be deemed widely valid. Further empiric testing of both the HLQ and the Ophelia process will be required to assess their validity in other settings. This includes testing in other countries, in other languages, and amongst different types of organisations.

South Africa is one place where the HLQ and some techniques in the Ophelia process have been tested. The following section seeks to provide a very brief background of the Cape Town area and healthcare services in South Africa to provide a context for the current project.

2.3 South African Background

South Africa is a unique country, full of contrast and rich in diversity. Much of its culture is secondary to its dramatic history of conflict and change. South Africa has been recovering from Apartheid for the past 20 years, and there are still vast, deeply-entrenched inequalities affecting citizens in numerous aspects of their daily lives. Unemployment, poverty, crime, substance abuse, HIV/AIDS, and tuberculosis are major concerns. In a country like South Africa, increasing

health literacy may have a dramatic impact upon quality of life, life expectancy, and health disparities, as well as the successful advancement of the country on a larger scale^{2,5}.

2.3.1 The City of Cape Town

The city of Cape Town and its surrounding metropolis form the southern part of the Western Cape Province. The Cape Flats, part of the Cape Town metropolis, lie southeast of the city centre in an expansive, flat area. Race-based legislation during the Apartheid era forced non-White groups out of more urban neighbourhoods and into the Cape Flats, where they moved into townships and informal settlements. Lavender Hill, the primary site for this project, is part of the Cape Flats.

The majority of people in the Western Cape are Coloured (48.8%), with the next largest group Black Africans (32.8%), followed by Whites (15.7%) and Indians or Asians (1.0%). This is a different makeup than South Africa as a whole, which is 79.2% Black, 8.9% Coloured, 8.9% White, and 2.5% Indian or Asian¹⁰². Similarly, in the Western Cape the most prevalent first language spoken is Afrikaans, followed by isiXhosa and then English, whereas overall in South Africa most speak isiZulu, followed by isiXhosa, Afrikaans, and then English¹⁰². In the Western Cape, 57.5% of adults have had less than matric-level education, 28.1% have completed matric, and 14.4% have attained higher education, which is close to the rates seen countrywide¹⁰². However, education attainment varies greatly within provinces. For example, adults completing matric comprise only 1.6-16% of the population in informal settlements in the Cape Town metropolis¹⁰³. During Apartheid, education in Afrikaans was compulsory for most groups. However, English now predominates as a language of instruction, and other languages are getting more recognition and use in education.

In Cape Town, an estimated 18.2% of residents live in informal dwellings¹⁰². 47% of households in 2011 had a monthly income below the poverty level of 3200 Rand¹⁰⁴. 56.3% of residents in the Western Cape (compared to 64.8% in

South Africa) are without access to Internet at home, on a cell phone, at work, or elsewhere¹⁰².

Crime levels in Cape Town are twice the national average, and crime remains one of city's greatest challenges. Drug-related crimes, murder, and violent crimes have higher incidences in Cape Town than in any other South African metropolis¹⁰⁴. However, on-going rises in HIV/AIDS, tuberculosis, and chronic cardiovascular disease also contribute to the poor health status of many residents. Premature deaths are attributable mostly to HIV/AIDS, homicides, tuberculosis, road traffic, heart disease, stroke, and diabetes¹⁰⁵.

There are striking inequalities across gender, race, educational, and socioeconomic levels. In fact, South Africa has the highest level of inequality in the world, with the richest fifth of the population accounting for 72% of income and consumption¹⁰⁶. Currently, the healthcare system also reflects this level of inequality.

2.3.2 Healthcare system

The South African healthcare system is steeped in inequality. The Constitution protects the rights to equality, life, and access to healthcare. However, years of colonialism have left deep-seated inequalities that will take decades to address¹⁰⁶. South African spends 8.5% of Gross Domestic Product on healthcare, but this amount is unevenly distributed. The system is ineffective overall, with numerous barriers to accessing overcrowded free primary care services. Performance of the country on morbidity and mortality indicators is poor for a middle income country¹⁰⁷.

Currently, the healthcare system has two realms: private and public. However, 16% of the population with private insurance use 50% of the healthcare funds, leaving the other 84% of the population to depend upon a poorly-funded public system. Additionally, 59% of doctors, 93% of dentists, and 89% of pharmacists work in private practice, giving the private sector a significantly better healthcare provider to patient ratio^{106,107}.

The public sector uses a district health system approach with a focus on primary care. Most generalist doctors in South Africa enter practice immediately after undergraduate training to begin working in hospital settings. In the public service they work in regional or district hospitals, with limited work in community health centres or clinics, where nurses are often the first line of care¹⁰⁸. The district hospitals are the focus of care, and are staffed by non-specialist medical officers, who may refer patients to regional or central hospitals for further workup if needed¹⁰⁹. Recent health service reform has increasingly attempted to restructure this primary care approach to balance the existing hospital-centred care with more focus on health promotion and preventive services in the community¹⁰⁷.

In addition to healthcare services provided by the government or private sector, many South Africans consult traditional healers. The Department of Health estimates that there are 100 traditional healers for every 15 doctors with formal medical training, and at least 70% of South Africans consult these healers¹⁰⁶.

Since 2012, a new scheme of National Health Insurance has been undergoing development in preparation for implementation by 2025. This new scheme is designed to change the healthcare system to a socialised model, with all income earners and taxpayers making contributions and the entire population entitled to benefits¹⁰⁶. Healthcare would be treated as a social right rather than a market product¹⁰⁷. However, the proposed changes may effectively make patients somewhat more like consumers, with increased autonomy over their health¹⁰⁶. It will be interesting to see what changes this new scheme will bring, and how it impacts access to healthcare.

2.3.3 Emergency Medicine

Emergency healthcare is also viewed by the Constitution as a human right. All public emergency services are administered by the directorate of Emergency Medical Services (EMS) at the National Department of Health¹⁰⁹. Emergency centres exist at several levels of care, ranging from rural day hospitals to tertiary-care urban hospitals. Secondary-level hospital emergency centres are

typically staffed by general medical officers or junior doctors, while tertiary-level care has separate surgical and medical units and specialist consultants¹¹⁰.

South Africa's continuous high rates of trauma, violence, and medical emergencies ultimately has led over time to the development of specialised training for practitioners providing emergency care. Additionally, the introduction of Advanced Cardiovascular Life Support (ACLS), Advanced Trauma Life Support (ATLS), Paediatric Advanced Life Support (PALS), and similar programs inspired interest in emergency medicine within practitioners not routinely exposed to acute resuscitation¹¹¹. The first formal emergency medicine group, the Emergency Medical Society of South Africa, formed in the late 1990s and became a full member of the International Federation for Emergency Medicine in 2004¹⁰⁹.

In 2003, the Colleges of Medicine in South Africa (the certifying body for postgraduate training) recognised Emergency Medicine as a new specialty. In 2004, the College of Emergency Medicine of South Africa became the licensing and accrediting body for Emergency Medicine. Now, in 2014, there are over 100 specialists registered in the field^{109,110}. These specialists work closely with providers of pre-hospital emergency care.

2.3.4 Pre-hospital emergency medical care

Given that all South Africans have a constitutional right to healthcare (including emergency care), it is essential that the country have a system of providers who can treat and transport patients to facilities for definitive care. Ambulance services have been present in South Africa since the 1970s, when they were mostly associated with local fire departments. Since then, ambulance services have improved significantly. Currently, the regulating body for all EMS providers is the Health Professions Council of South Africa¹¹¹.

Similar to the distribution seen in the hospital-based healthcare system, pre-hospital emergency care has both private and public sectors. Like public hospitals, provincial public EMS services are understaffed and lack sufficient

resources. Transportation is mostly by road, often through hazardous conditions. There has been slowly increasing use of helicopters for transport in select areas¹⁰⁹.

Qualifications for EMS providers vary, but generally practitioners fall into three categories: basic, intermediate, and advanced life support (BLS, ILS, and ALS, respectively). BLS providers (sometimes called BAA for Basic Ambulance Assistants) have taken a one month training course to be able to provide basic life support. ILS providers have had a four month training course that allows them to provide additional care, including defibrillation and establishing intravenous access. There are several different pathways to becoming an ALS provider, each with slightly varying scope of practice. These include:

CCA: Critical care attendant (9 months of training)

ECT: Emergency care technician (2 years of training)

N. Dip: National Diploma: Emergency Medical Care (3 years of training)

B. Tech: Bachelor of Technology: Emergency Medical Care (1-2 years of postgraduate training after the National Diploma).

BEMC: Bachelor in Emergency Medical Care (4 years of training)^{111,112}.

In Cape Town, EMS providers work in shifts and are stationed at a base from which they are dispatched for calls. Ambulances are generally staffed with one BLS and one ILS provider each. ALS providers often are dispatched in their own ambulance to provide support to other ambulance crews. When an ambulance arrives to the scene of an emergency, they become responsible for managing the scene. Treatment of the patient and the coordination of their definitive care goes by default to the highest qualified medical personnel present. High level education and years of experience have led to South African paramedics becoming famous worldwide for being the best in their field¹¹¹.

In recent years, an important new form of pre-hospital care has been established in the Western Cape Province: the Emergency First Aid Responder

(EFAR) program. The next section introduces this program and its expanding role in pre-hospital care.

2.4 The Emergency First Aid Responder (EFAR) program

As discussed previously, community members can be potent resources when trying to establish healthcare and develop health literacy in a resource-limited area, possibly not only because of their proximity to both patients and professional healthcare providers but also because they are already well-versed in the social-cultural context of their particular area.

To date, community members have already successfully served other critical roles within the healthcare system of developing countries. As an important example, lay volunteers have been trained to be first responders responsible for providing basic pre-hospital emergency care in developing townships with high rates of emergency incidents³⁹. This basic care can have a dramatic impact in a resource-poor area, considering that up to 90% of trauma-related deaths occur in developing countries, with the majority in a pre-hospital setting⁴⁵. The disproportionate burden of trauma associated with emerging cities is an inevitable consequence of rapid industrialisation and urbanisation without adequate resources to simultaneously create a rapid emergency response system^{38–44}. Given the current rate of rapid development worldwide, this leads to traumatic injury and violence accounting for the loss of about 15% of disability-adjusted life years, more than almost any individual medical problem¹¹³.

This section introduces a successful program to train lay volunteers in resource-poor areas to serve as first responders in South Africa.

2.4.1 Creation and evolution of the EFAR program

Need for the program

Manenberg is a developing township located in the Cape Flats part of Cape Town. This township has a long reputation of violence and gang warfare. Most

residents are unemployed and living in abject poverty. A researcher interested in pre-hospital care (Jared Sun) observed in 2009-2010 that despite high rates of traumatic injury, Cape Town EMS were able to respond to only 65% of life-threatening incidents within 15 minutes. In many cases, help would arrive only hours later, even when patients were in critical condition³⁹. Even today, ambulances often experience great delays reaching a scene in the townships and informal settlements, where roadways are typically unmarked and a large portion of shacks are accessible only by convoluted footpaths. This is not surprising; often Westernized EMS systems that rely upon rapid access to EMS lack enough resources to meet the demand of developing countries¹¹⁴.

Given the clear need for better access to pre-hospital care, Sun et al decided to create a tailored, local first responder program for Manenberg. Importantly, the program sought to provide a community-based approach that was cost effective and could work in conjunction with the emerging EMS services. This would allow volunteers to be integrated into a coordinated emergency response, with a goal of improving access to pre-hospital care to ultimately improve patient outcomes. A key contributor to the successful development of this program was that Sun et al modelled the first responder service delivery after community-based organisations that had already been serving Manenberg well³⁹.

Current state of the program

Today, the Emergency First Aid Responder (EFAR) system is an established program for training local volunteers in townships surrounding Cape Town that have high rates of violence and accidents³⁹. Branches of the EFAR program have extended throughout the Western Cape Province, with on-going demand from additional community leaders and organisations to implement a branch in their area. The EFAR program differs from some other first-responder systems because it integrates and coordinates the volunteers with the existing emergency response system in the area, as opposed to being a stand-alone parallel entity, and has been officially adopted by the provincial Western Cape EMS and recommended by the African Federation for Emergency Medicine for

the rest of Africa (personal communication, Prof. Lee Wallis and Jared Sun, 2012).

The success of the EFAR program has been attributed partly to a trusting relationship formed between local community leaders and those creating the EFAR system. The EFAR model relies upon a community-based organisation to run the EFAR program for their particular community³⁹. This partnership allows local leaders to take ownership and manage their own EFAR system, communicate in their own language with volunteer EFARs, engage the trainees, and produce higher training exam scores than foreigners or local physicians could⁴⁶. The community members are also able to provide essential information for the researchers to adapt the EFAR system to each particular area's local culture and context^{39,46}.

2.4.2 Structure of each branch

An adaptable EFAR system model is presented below, in Figure 1. This model represents how a branch of an EFAR is run through a community site.

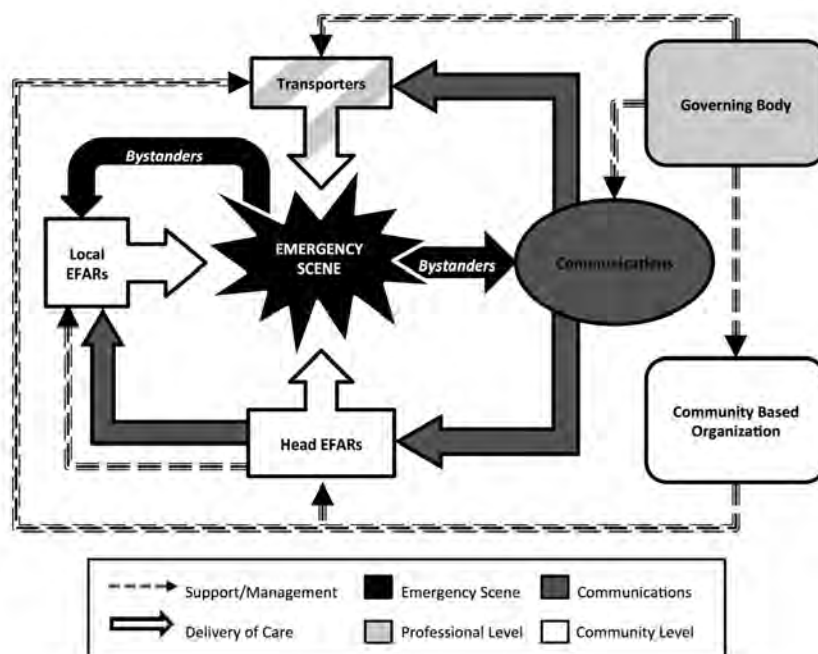


Figure 1: Adaptable EFAR system model. ¹¹⁵

At the scene of an emergency

When an emergency occurs, bystanders on the scene activate a local EFAR either by finding one that is nearby or personally contacting one. The Local EFAR provides care until a Transporter arrives to take the patient to a hospital. Depending on the area, ambulances, law enforcement vehicles, private vehicles, and public modes of transportation may all be used as Transporters. EFARs transport the patient by whichever method becomes available earliest¹¹⁵.

Communications circuit

In the above model, note that it is also possible for bystanders to activate a communications hub, which in turn activates both a Head EFAR and Transporter. Head EFARs are familiar with the geography of their area and aware of EFARs that reside nearby, and can either attend the scene to provide additional care or activate local EFARs by contacting their mobile phone and directing them to the scene. Transporters may be called by bystanders, EFARs, or a communications dispatch centre. This may be an area's existing EMS service, as is the case in the townships surrounding Cape Town.

A formal communication dispatch system for mobile phones is in its final stages of development in Cape Town. However, in the absence of this dispatch centre, the above roles still apply (just without one single dispatch service to simultaneously activate Head EFARs and Transporters)¹¹⁵.

Management

All local EFARs are overseen by a Head EFAR, who has had additional first aid training and experience and has proven commitment and availability for the program. In each geographic area, all Head EFARs in a branch are managed by a community-based organisation, which is in turn provided on-going support by a governing body that is common to the entire EFAR program.

Community-based organisations play the most critical role in any given branch of EFAR. They are responsible for overseeing training of all EFARs in their region and modifying the program to best serve their community. They also provide important feedback to the governing body. Community-based organisations may be non-profit organisations, schools, religious associations, or any group that is stably acquainted with and respected by their community.

The governing body is any professional body willing to manage and fund the entire system. It oversees issues relevant to all EFAR branches, such as the availability of communications, relationship with transporters, and on-going research and development for EFAR. Governing bodies may be the local EMS, universities, or healthcare providers like hospitals¹¹⁵.

2.4.3 The Mothers Unite EFAR branch

One branch of EFAR is run through the non-profit organisation Mothers Unite in Lavender Hill. Lavender Hill makes up part of the Cape Flats, an expansive area to the southeast of Cape Town where several coloured and black South Africans were forced during apartheid. Almost all of its inhabitants are poverty stricken, with high rates of unemployment, violence, and health problems. Mothers Unite, for some, is an oasis, embracing children and providing for them holistically. The organisation also works with families as a whole and extends several projects to adults in the community. Mothers Unite has been respected and valued immensely within the Lavender Hill area since its founding in 2008, and has grown significantly since that time thanks to donations and awards for their on-going efforts.

Mothers Unite was chosen as the main site for this project for its stability and respected position in its community, as well as because of the excellent relationships between the director, Western Cape EMS, and the EFAR Coordinator for the Western Cape Province. The director of Mothers Unite is enthusiastic about health literacy and has expressed interest in developing ways to improve health literacy in the community. In addition, Mothers Unite has the highest number of trained Head EFARs (six) that are present on site on a

regular basis. These Head EFARs are respected members of the Lavender Hill community and were also enthusiastic about playing critical roles within this research project.

2.4.4 The EFAR program and health literacy

EFARs in the townships surrounding Cape Town have expressed their motivation to help solve the problem of increased emergency incidents and that their desire to help and learn extends to health issues outside of emergencies (Jared Sun, personal communication, Oct-Dec 2012). The EFAR program, therefore, could serve as a critical bridge between the community, physicians, and officials attempting to improve health literacy amongst the community members in the developing townships. The implications of this are monumental: a developing region with models for setting up early first-responder emergency care systems (that are scheduled to happen anyway) combined with a method to increase health literacy has the potential to rapidly improve the overall health and wellbeing of the communities. This potential would extend beyond emergency incidents and could include any relevant health concerns for a particular area.

CHAPTER 3: METHODOLOGY

3.1 Overview

This chapter outlines the stepwise process of validating the HLQ for use in South Africa, collecting HLQ responses from the study population, and conducting a workshop to respond to the data.

Prior to use of the HLQ in South Africa, the tool was translated into Afrikaans. The translated version as well as the original English language version underwent preliminary field testing and cultural adaptation, with adjustments made if needed. After the translation process, the HLQ had to be further validated by conducting cognitive interviews with participants.

After validation, the HLQ was ready for use. It was administered to three groups of participants: community members, EFARs, and patients at a local health clinic. HLQ data was analysed using basic descriptive statistics as well as cluster analysis techniques. The data was also presented in the form of vignettes that tell stories to help describe the HLQ results.

The data (including the results of the cluster analysis and vignettes) was presented in a feedback workshop, where healthcare providers, Department of Health employees, community leaders, EFARs, and EFAR leaders were able to respond to the results. Interventions were suggested for how to respond to the identified health literacy needs.

3.2 Provisional translation of Health Literacy Questionnaire into Afrikaans

3.2.1 Background

Translating psychometric questionnaires demands careful attention to ensure that concepts and scales are represented properly. Original concepts must maintain cultural and linguistic equivalence in the target language. The Health Literacy Questionnaire scales each contain a set of questions that are designed to measure independent, specific elements of a person's health literacy.

However, these questions are designed to work carefully together within the scale. It is important that the translated version respects these concepts and the nuanced relationships between questions within each scale.

Special attention must be given to the questionnaire scales in order to achieve measurement equivalence in addition to cultural and linguistic equivalence. The scales in the original questionnaire were designed to reveal high and low extremes of the target question, as well as gradations between them.

Importantly, the gradations across the continuum of the measurement scales were designed to be equidistant from one another, with the difference between any two adjacent points on the scale comparable to a similar interval elsewhere on the scale. All items within a scale must be considered simultaneously to ensure item level differences are maintained.

The translation procedure detailed below was used to produce an attempted Afrikaans translation of the HLQ that was conceptually equivalent to the English language version, used natural and acceptable Afrikaans language and phrasing, and achieved a measurement performance equivalent to the original.

3.2.2 Roles in translation procedure

Coordinator: responsible for managing the translation process, commissioning appropriately qualified professional translators, and documenting the translation process. The coordinator has extensive experience with the English language and some experience with issues that may arise when translating technical documents from English to other languages. This role was jointly fulfilled by Jennifer Bress and Richard Osborne.

Forward translator (FT): translates the HLQ from English to Afrikaans. The FT is a native speaker of Afrikaans with verified technical qualifications, as well as an extensive knowledge of English.

Independent checker (IC): checks the forward translation. The IC is a native speaker of Afrikaans with verified technical qualifications, as well as an extensive knowledge of English.

Back translator (BT): translates the forward translation from Afrikaans back into English. The BT is a native English speaker with an extensive knowledge of Afrikaans.

Developer: an author of the original HLQ who has in-depth knowledge of the purpose, construction, and application of the questionnaire. Richard Osborne served as the Developer associated with this translation process.

Chairperson: oversees the translation process, ensures the procedure is followed, and leads the discussion of the translation. The Chairperson is responsible for ensuring the Afrikaans version is an excellent representation of the original English HLQ items and constructs, with measurement fidelity. Richard Osborne served as the Chairperson.

Bilingual health workers and lay people: at least two bilingual health workers or laypersons with in-depth knowledge of local language and culture that can participate in discussions about the most universal wording and phrases of items.

Principal Investigator: the main researcher associated with this project in Cape Town, Jennifer Bress.

3.2.3 Steps in translation

1. Intent of questions: a document was distributed containing each item on the questionnaire, carefully constructed to help translators understand the meanings of words, phrases, and ideas. This document helped the translators obtain a detailed understanding of what each item, across each scale, was intended to capture.
2. Briefing of translators: the Chairperson provided the FT and IC with written instructions on the translation procedure, the English language HLQ, and the intent of questions. He then briefed these translators and gave parties a chance to clarify the process and address any questions the translators had regarding the intent or meaning of items or scales.

3. Forward translation: the FT translated the original HLQ to Afrikaans. Then, the FT conferred with the IC and the item intent document for each item. The FT and IC worked together to achieve a final recommended forward translation that they agreed is as close to the conceptual meaning of the original English questionnaire as possible, could be understood by people with low literacy skills, and used natural language appropriate for Afrikaans speakers. Attempts were made to keep the number of words to a minimum to make it easier for participants taking the questionnaire in the future.
4. Provisional forward translation: the forward translation agreed upon by the FT and IC was passed to the BT. If there were any persistent discrepancies between the FT and IC about how a concept should be translated, both alternatives would be presented to the BT.
5. Back translation: the BT translated the provisional forward translation back into English, with a goal of revealing how close in meaning the Afrikaans provisional forward translation is to the original English. Importantly, the BT was kept blind to both the original English version and the item intent descriptions.

The Chairperson then prepared a commentary on the translation document. Special attention was given to discrepancies, possible linguistic issues, back translation issues, and errors discovered by the BT.
6. Forward and back translators alerted to discrepancies: the Coordinator prepared a document listing items from the back translation that caused concern, as well as the rationale for concern. Each translator reviewed this document independently and prepared a response for each of the items. Translators could identify errors, develop explanations, or choose to agree with the other translators.
7. Conference to finalise questionnaire in Afrikaans: a teleconference involving the FT, BT, Chairperson, Coordinator, Principal Investigator, and two local bilinguals (a health worker and a lay person) was held to

clarify and agree upon any concerns regarding the provisional forward translation. Final wording of all items was negotiated and agreed upon. The FT then made final changes, and this was considered the final provisional translation¹¹⁶.

This initial translation was subjected to field testing and cultural adaptation before being considered valid for use. The next section outlines this process.

3.3 Validation, cultural adaptation, and final translation

3.3.1 Background

The purpose of any validation and cultural adaptation process is to ensure that using a tool in a new population achieves an equivalent measure to that of the original tool, in its original target population. In addition, a validation process ensures that a tool is able to measure the same constructs that the questionnaire was designed to investigate. These processes are a critical part of validating a questionnaire for use with a new population, even if the language of the questionnaire is the same.

The initial goal of this study was to validate the use of the HLQ separately in both English and Afrikaans for use in South Africa. The HLQ in English was therefore tested in South Africa before considering this tool valid for use. Similarly, the translated HLQ was tested on the target populations before being accepted as the final Afrikaans version.

It was predicted that the English version would be understood in a comparable way to the intent of the original questionnaire. However, unforeseen barriers may always arise that prohibit the use of this questionnaire with a new English-speaking population. These possibilities include differing connotations of words or concepts, difficulty understanding the concept of a scale, or English vocabulary limitations.

The cultural adaptation process began in the final stage of the provisional translation, when bilingual health workers participated in a teleconference to

help arrive at a consensus Afrikaans translation that retained the intent of the English version. This process continued through testing the Afrikaans version in cognitive interviews with local Afrikaans speakers and feedback sessions with HLQ administrators.

3.3.2 Cognitive Interviews

Cognitive interviews were performed in order to test the intent of each question within the target group. Cognitive interviews were conducted in exclusively English as well as exclusively Afrikaans, using HLQs with exclusively one language. Additionally, bilingual participants underwent cognitive interviewing with a version of the HLQ that had both the English and Afrikaans text available. The interviewing technique involved asking participants about their answers on the questionnaires to ensure that they understood the questions according to their original intent.

An effort was made to include participants from all study groups (community members, emergency first aid responders, and patients; see 3.4 below for further details). Interviewees elected to answer questions about either one half or a full set of questionnaire responses. Enough interviews were performed to ensure that each individual question and scale has been asked about between three and five times.

Interviews were performed face-to-face in a private, secure area. Prior to the interview, participants were asked to sign a consent form and also check “Yes” under question 2 on the Consent form: “I consent to being interviewed by a researcher about my HLQ survey answers” (see Appendix 1).

Structure of the interviews

The interviewer began by thanking the participant for taking the time to complete the questionnaire and assuring them that there are no right or wrong answers, but that answers should be selected based on one’s own experiences. Participants were reminded that the questionnaire was confidential and entirely voluntary. If the participant agreed, the interview proceeded.

The interviewer read through each of the questions with the participant and observed carefully how the participant answered. A note was made if the participant took a long time to answer, asked questions or for clarification, or appeared confused. The interviewer did not answer questions, explain, or paraphrase items. The participant filled out the entire questionnaire.

After the answers had been selected, the interviewer went back to the beginning of the questionnaire and went through some (or all) of the questions and scales in detail with the participant. Special attention was given to those questions the participant had difficulty answering. Participants were asked the following questions:

What were you thinking about when you were answering that question?

What does that question mean to you?

Why did you select that answer?

All responses and comments about the questions and scales were recorded. In addition to cognitive interviewing, information about the validity and cultural relevance of the HLQ was obtained by soliciting feedback from HLQ administrators.

3.3.3 Feedback from HLQ administrators

HLQs were administered by the Principal Investigator of the present study, a supervisor of the present study, or community-based level 1 or 3 EFARs. All individuals completed a brief training course regarding proper HLQ administration before being allowed to do so (further details in 3.4). As all study data was ultimately obtained by these individuals, the administrators were a critical “front line” for the study and had the most direct experience using the HLQ with participants.

Therefore, both formal and informal feedback from all HLQ administrators was obtained regarding the use of both the English and Afrikaans versions of the

HLQ within the target populations. All comments, questions, and identified difficulties were recorded.

3.3.4 *Final validation and Afrikaans translation*

Cognitive interviews proceeded until each question and scale had been asked about between three and five times, both exclusively in English and exclusively in Afrikaans. At least three participants from each study group were interviewed during this process (community members, EFARs, and patients). An effort was made to include participants who appeared to score high, moderate, and low overall on the HLQ, though the actual numerical scores for the HLQ responses were not available at the time of the interviews.

Informal feedback from HLQ administrators was on-going, throughout the course of the study. Formal feedback occurred with each administrator after they returned at least five completed HLQs. In addition, two scheduled feedback sessions with all administrators occurred during the first two months of use with the Afrikaans translation.

After cognitive interviews were complete, data from feedback sessions was combined with interview data to identify areas of concern regarding the translation language, scale applicability, and how participants understood the intent of the question items.

English version: a decision was made whether the English HLQ is valid for use with the target populations.

Afrikaans version: the Chairperson, Developer, FT, Principal Investigator, and two local bilinguals had a second teleconference to consider whether any changes to the Afrikaans translation were warranted. As above, a decision was made regarding whether the final Afrikaans HLQ was valid for use with the target populations.

Once the HLQ was validated, it was ready for use with the target population. The next section describes how HLQs were administered in Lavender Hill, as well as how the data was collected and analysed.

3.4 Administration of the HLQ

3.4.1 Setting

The area of interest for this study was the greater Lavender Hill area, defined as the formal settlements of Lavender Hill, Retreat, Seawinds, Hillview, St. Montague Village, and Capricorn/Vrygrond, the informal settlements of Military Heights, Village Heights, and Overcome Heights, and the suburbs of Steenberg, Grassy Park, and Cafda Village.

These particular areas were chosen for their centrality to Mothers Unite and the Retreat Community Health Clinic (CHC), as well as their relatively similar profile of social and healthcare issues. The Mothers Unite EFAR program has actively trained EFARs serving all of these areas.

3.4.2 Population

There were three distinct study groups. The initial goal was to obtain 80-100 HLQ responses from each group. All individuals reside in the greater Lavender Hill area as defined above.

Group 1: Community members. These individuals were encountered at Mothers Unite or in the community. They do not have any training with the EFAR program.

Group 2: EFARs. These individuals have an active Basic, Level 1, or Level 3 EFAR certification that was obtained through training at Mothers Unite.

Group 3: Patients. These individuals were patients presenting for care at the Retreat CHC.

3.4.3 Predictions

It was predicted that amongst the three groups, EFARs would have the highest overall health literacy scores. However, health literacy scores overall for all groups were predicted to be moderate (in the vicinity of a score of 3, where 1=very low health literacy and 4.48=very high).

Additionally, relevant to the Community group, it was predicted that EFARs would score significantly higher on four scales:

- Having sufficient information to manage my health

- Actively managing my health

- Ability to find good health information

- Understanding health information well enough to know what to do

These predictions were made based on the fact that EFARs have already demonstrated interest in learning health information that can be used within their community to save lives. In addition, EFARs have access to on-going support and educational resources through Mothers Unite for years following their training. The training itself also provides a decent amount of health information, and EFARs had to demonstrate mastery of this information in order to be certified as an EFAR.

Relevant to the Community group, it was predicted that patients would score significantly higher on four scales as well:

- Feeling understood and supported by healthcare providers

- Actively managing my health

- Ability to actively engage with healthcare providers

- Navigating the healthcare system

These predictions were made based on the hypothesis that individuals encountered in the clinic were already demonstrating they were taking initiative to manage their health, and had been able to successfully locate and attend the CHC to obtain an appointment for care. Additionally, it was thought that we

would be more likely to encounter patients with chronic medical conditions who had more experience interacting with healthcare providers, so they may have developed skills communicating with them over time.

3.4.4 HLQ administration

All HLQs were administered in person. There were eight individuals who were responsible for administration:

6 Full-time facilitators at Mothers Unite. All have extensive experience with the EFAR course and general programs at Mothers Unite. Five of these individuals have current Level 3 EFAR certification and are fluent in both English and Afrikaans. One has a Level 1 certification and can speak English fluently.

Jennifer Bress. Principal Investigator of the present study. English speaker. Has a current Basic EFAR certification.

Michele Twomey. Co-supervisor of the present study. Fluent in both English and Afrikaans. Extensive experience with the entire EFAR program.

Prior to administering any HLQs, the above individuals underwent a one-hour training session on proper administration technique. This training session served several purposes:

1. Introduced administrators to background information regarding health literacy and the research project.
2. Introduced the HLQ and the Ophelia process.
3. Instructed administrators in proper technique for identifying and approaching participants.
4. Educated administrators about the importance of informed consent and how to obtain proper consent before beginning data collection.
5. Instructed administrators on how to properly give the HLQ, whether the participant chose to complete the HLQ on their own or have it

administered orally. Administrators acknowledged that they may not prompt, explain, or answer questions.

3.4.5 Sampling strategy

Across all groups, participants were required to give consent before the questionnaire was started. Inclusion and exclusion criteria are defined below:

Inclusion criteria: all participants had to be 18 years of age or older and describe being fluent and comfortable with English, Afrikaans, or both languages. The age minimum was set to 18 because the original HLQ was validated only for this adult age group. Participants had to report their residence as part of the defined greater Lavender Hill area.

Exclusion criteria: HLQs were excluded if there were too many missing values for a score to be obtained in one of the nine scales of health literacy. For scales with 4-5 questions, no more than 2 missing values were allowed. For scales with 6 questions, no more than 3 missing values were allowed.

Only one HLQ was allowed per individual, even if a participant belonged to multiple of the study groups (for example, a patient is technically also a community member). When duplicates occurred, the first HLQ completed by the individual was retained and the rest were discarded, and the study group was assigned based on whether the person held active EFAR training or was encountered in the CHC as a patient.

Group 1 (Community members): non-probability, convenience sampling strategies were used. Safety of the administrators was a principal concern, making it necessary for most recruited participants to be already known to the administrators. Approximately 50% of responses were collected by HLQ administrators offering the questionnaires to their extended personal networks. 30% of responses were collected by administrators traveling on foot from Mothers Unite and offering HLQs to individuals on the street in Lavender Hill

and Seawinds. 20% of responses were obtained by offering HLQs to parents who regularly appeared at Mothers Unite to pick up their children.

Group 2 (EFARs): non-probability, purposive and convenience sampling strategies were used. HLQs were offered to EFAR-certified staff at Mothers Unite as well as active EFARs that were well known to the HLQ administrators. HLQs were also offered after all EFAR support sessions and training sessions at Mothers Unite between September 2013 and February 2014. Finally, an electronic database of contact information for all active EFARs trained at Mothers Unite was utilised to send SMS invitations to participate to all EFARs with a current phone number. EFARs who wanted to participate had to travel to Mothers Unite to take the HLQ in person. Approximately 70% of responses were obtained from EFARs attending support or training sessions at Mothers Unite, 20% were from Mothers Unite staff and well-known active EFARs, and 10% were volunteers who responded to the SMS invitations.

Group 3 (Patients): non-probability, convenience sampling strategies were used. HLQ administrators went to Retreat CHC (Community Health Clinic), a rural district hospital in the Cape Flats, on four separate days and approached patients at random in the main waiting areas of the clinic. Patients who claimed residence in the defined greater Lavender Hill area were offered the HLQ and were assured their decision and participation would have no impact on their medical care.

3.4.6 Data collection

All potential participants had the research introduced to them and had a Participant Information and Consent form (Appendix 1) read to them in the language of their preference (English or Afrikaans). Participants who wished to participate could then choose to either sign the consent form or give verbal consent and have a witness (typically the HLQ administrator) sign for them. Participants kept the Participant Information form, which had their study ID on it in case they decided to call later to have their results removed from the study.

Participants all had the option of providing contact details (a name and phone number) if they were willing to participate in further interviewing about their responses in the future. Participants who chose to do so were instructed that they may or may not actually be contacted for an interview, and they had no obligation to provide these details.

HLQs were administered in a private area, far enough away from other persons to ensure confidentiality and privacy. Participants could choose to read and complete the HLQ on their own, have it read to them by a friend or family member, or have it read to them by the HLQ administrator.

Following completion of the HLQ, participants were offered a Demographic form (Appendix 2). They were told that they were not required to complete this portion, but that the results would help the researchers better understand the health literacy needs of certain groups of people in their community.

Data was put into an Excel spreadsheet, coded for data analysis. Questions from the HLQ were assigned a point value to allow quantitative analysis to be performed. For Part 1 of the HLQ, questions were answered with a four-point measurement scale. These four options and the point values assigned were:

Strongly disagree	1
Disagree	2
Agree	3
Strongly agree	4

For Part 2 of the HLQ, questions were answered using a five-point measurement scale. These five options and the point values assigned were:

Cannot do	1
Very difficult	2
Quite difficult	3
Quite easy	4

After data was quantified, it was ready to be analysed further, using statistics as well as narrative writing. These steps are discussed in the following section.

3.5 HLQ data analysis and vignette development

3.5.1 HLQ scoring

SPSSv21 was used to calculate missing values using an Expectation Maximization (EM) algorithm. Scales with 4-5 items allowed for 2 missing values to be imputed. Scales with 6 items allow for 3 missing values to be imputed. Any HLQ that had more missing values than this were excluded from the study.

A scoring algorithm was then applied to produce unweighted scale scores for the 9 dimensions of the HLQ. The final score for each scale represented an average score across all items forming the scale. An overall score was also produced. Thus, each participant had 9 numerical scores representing their health literacy in each separate dimension, as well as an overall health literacy score that took into account answers from all dimensions.

The 9 scales and the score range for each are listed in Table 1. A complete list of each of the actual questions comprising each of these scales is attached (Appendix 3).

Health literacy scale / dimension	Score range
Feeling understood and supported by healthcare providers (HPS)	1-4
Having sufficient information to manage my health (HSI)	1-4
Actively managing my health (AMH)	1-4
Social support for health (SS)	1-4

Appraisal of health information (CA)	1-4
Ability to actively engage with healthcare providers (AE)	1-5
Navigating the healthcare system (NHS)	1-5
Ability to find good health information (FHI)	1-5
Understanding health information well enough to know what to do (UHI)	1-5

Table 1: Nine health literacy scales and their respective possible score ranges.

3.5.2 Comparing groups

Within each study group, Excel formulas were used to calculate mean scores for each of the 9 scales, as well as the overall health literacy score. This produced 10 mean scores for each of the three study groups.

Frequency plots for each of the 9 scales in the 3 different groups were prepared, and a test of homogeneity of variance was performed for all ten scores. For any scale that had a statistically significant Levene statistic (with significance <0.05), a robust ANOVA (analysis of variance) was performed using the Brown-Forsythe method, which can be used for data violating the assumptions of normal distribution and variances. Post hoc testing for these scales was done using the Games-Howell method of multiple mean comparisons.

For the other scales, an ANOVA was performed to examine whether there were significant differences between the groups, with a p value <0.05 . Post hoc testing for these scales was done using the Gabriel method of multiple mean comparisons because the group sizes were slightly different.

3.5.3 Cluster analysis

Hierarchical cluster analysis using Ward's linkage method was performed on the data for each of the three study groups following the HLQ scoring, using an algorithm designed and used by the Ophelia research team. For each group, cluster analysis was performed to obtain final results of 3 to 18 clusters. The common socio-demographic characteristics of each cluster were followed as the number of clusters increased, and a meaningful final number of clusters decided upon for each of the three groups. At this final number, it was believed that further breaking apart into additional clusters no longer reflected meaningful differences between participants in different clusters.

Each of the final clusters was then given a numerical identifier (for easier reference) and a short narrative description to reflect an overall sense of the health literacy of an individual in that cluster. These narrative descriptions were referred to as vignettes.

3.5.4 Vignette formation

During the course of HLQ administration and data analysis, semi-structured "Vignette interviews" were performed. The purpose of these interviews was to get a sense of participants' experience with their health and better understand strengths and challenges across the dimensions of health literacy. These interviews involved mostly unstructured conversations between the Principal Investigator and a participant after taking an HLQ. A person's experience with chronic disease, utilisation of the healthcare system, and social support for health were common discussions in these interviews. Some of these interviews occurred with facilitators and other contacts at Mothers Unite, while others took place with the same participants who underwent cognitive interviewing for the initial validation of the HLQ. A couple of interviews were brief phone interviews with participants who provided their phone numbers on their consent forms. Information from these interviews was kept entirely confidential by Jennifer Bress, and recorded with only a study ID and no other identifying information.

After cluster analysis was performed, clusters were each described with a vignette - a story much like what was discussed during the vignette interviews.

The goal of presenting data in this format was to transform a table of numbers into a meaningful description of a group of people with unique health literacy strengths and weaknesses. Vignette interview data was used as inspiration for creating most of the cluster vignettes. It was hoped that the vignettes would help feedback workshop participants recognise a common type of person with specific health literacy needs, somebody they already interact with on a regular basis in the community or clinic.

Data was now considered ready for discussion and interpretation. This occurred at a feedback workshop, where interventions were proposed in response to the identified health literacy needs. The next section describes this workshop.

3.6 Feedback workshop

3.6.1 Background

An individual's health literacy (and scores on the HLQ) are not simply a reflection of a person's inherent strengths and weaknesses. Health literacy varies across different contexts and cultures. An individual who is an expert navigator of the South African healthcare system might be utterly lost trying to get care in the United States. A young, healthy patient might do an excellent job actively managing their health until they sustain a sudden injury and require treatment and rehabilitation. Achieving a good score on a dimension like "Ability to actively engage with healthcare providers" depends as much on a patient's traits as those of their healthcare providers and the level of interaction that a healthcare system allows the two to have. Therefore, an individual's health literacy strengths and challenges will vary over time.

However, at any given time, there are groups within a healthcare system that are experiencing similar issues and barriers to achieving health. These barriers exist at multiple levels, including at the individual level, amongst practitioners, in organisations, or within healthcare policy. Individuals belonging to each of these groups or practices have encountered these barriers throughout their careers,

and often have evolved creative solutions or methods to overcome them and achieve better healthcare.

One of the unique aspects of the Ophelia process is profound respect and utilisation of this local knowledge and insight. Thus, a critical stage of the present research study involved a feedback workshop with community members, healthcare providers, and health department employees. The goal of the feedback workshop was to present data to these workshop participants, harness some of their local expertise and wisdom, and co-create interventions to address the unique health literacy needs of people in the greater Lavender Hill area¹⁰¹. Details about the workshop are below.

3.6.2 Design

The feedback workshop was led by the Principal Investigator of the present study, who began the session with a brief background review of health literacy, the HLQ, the Ophelia method, and where data collection had occurred. To further equip participants for understanding the HLQ data, demographic information and an overview of the nine dimensions of health literacy were provided.

Workshop participants then split into two separate groups. Participants were allowed to choose what group they took part in. One group, facilitated by Jennifer Bress (Principal Investigator), discussed the cluster and vignette data from the Patient group. The other group, facilitated by Michele Twomey (Co-supervisor), discussed the cluster and vignette data from both the Community member and EFAR groups. During these discussions, the facilitator chose a particular cluster with a unique profile, briefly reviewed its relative scoring on the HLQ and the average demographics, and read the associated vignette. Then, the workshop participants were asked to reflect and respond to this information. Some guiding questions for these discussions were:

Is this a type of person/patient that is familiar to you?

What does this health literacy profile mean for this client?

What strategies could you use for an individual like this to improve health literacy or health outcomes?

What could you do if you had many clients like this in your organisation?

After discussing several vignettes, all participants joined back into one group. A spokesperson from each small group shared their ideas for one of their vignettes with the other half of the workshop group.

For the last part of the workshop, Jennifer Bress and Michele Twomey facilitated a group discussion regarding what participants might do for clients who scored low in a particular health literacy dimension. Guiding questions were similar to those used in the smaller groups. Participants were encouraged to consider potential intervention strategies at the level of individuals, practitioners, organisations, or policy.

3.6.3 Setting

The workshop was held at Alphen Hall in Constantia, Cape Town on 20 February, 2014. This municipal facility was chosen for its availability, space, safety, and central proximity to many of the workshop participants.

3.6.4 Population

Any individual involved in healthcare or health policy affecting the greater Lavender Hill area was considered an appropriate participant for the workshop. This included individuals responsible for creating provincial or national policies that impact services at Retreat CHC and other clinics in the Lavender Hill area. In addition, local community members and leaders were desired to help address health literacy needs at a grassroots, community level. Finally, EFAR leaders were desired to identify future roles for EFARs and the EFAR program.

3.6.5 Sampling strategy

A non-probability, purposive, convenience sampling strategy was used to invite a limited number of local health workers, healthcare providers, community

members, EFARs, and EFAR leaders to the workshop. Although the potential population for sampling from is quite large, it was advantageous to limit the attendance at the workshop to 10-20 participants, as a larger or smaller group may have encountered difficulties generating reflective feedback or interventions together. Participants that were recruited included all healthcare providers, Retreat CHC employees, EFARs, and community leaders that had already been educated about the project in its earlier phases. Invitations were sent by email, and invitees were allowed to pass the message along to other parties they felt might be interested in attending the workshop. In addition, invitations were given verbally to EFARs and community members associated with Mothers Unite.

3.6.6 Data collection

Recorders were used during the entirety of the feedback workshop to capture reflections and ideas generated by the participants. When the workshop split into two smaller groups, each group had its own recorder. In addition, two volunteer participants took written notes during the workshop about some of the issues and ideas that were discussed.

3.6.7 Data analysis

After the workshop, all recordings and notes were reviewed at least twice. A report was generated listing which clusters/vignettes and scales were discussed, what the reactions to them were, and what interventions were suggested. Recommendations were made for how to start formalising interventions based on the health literacy needs most commonly emphasized by the feedback sessions.

3.7 Ethical considerations

Ethical approval for all research was granted by the University of Cape Town (HREC ref: 644/2013).

3.7.1 Autonomy

All prospective participants (both HLQ responders and workshop attendees) were adequately informed of the aims and objectives of the study. There were no risks or direct benefits from participating in the study.

Participants could choose whether or not to provide contact information or participate in interviews. HLQ participants were informed that they could withdraw from the study by directly contacting the Principal Investigator and providing their study ID, given to them with their copy of the Participant Information form.

3.7.2 Anonymity

All data was collected anonymously. No personal or identifying details were collected aside from participants who chose to provide contact information on their consent forms. Participants were given the option to give a verbal consent and have a witness sign the consent form for them. Consent forms with any contact details were kept separate from the HLQs so that HLQ responses could not be connected with names or phone numbers on consent forms.

HLQ responses were entered into an electronic spreadsheet with no identifying information and only study numbers. Access to consent forms and HLQs was restricted to Jennifer Bress. HLQs and consent forms were kept in secure, separate boxes in a locked room accessible only by Jennifer Bress.

3.7.3 Beneficence

The creation of a framework for identifying and responding to health literacy needs has the potential to greatly improve the ability of the greater Lavender Hill community members to manage their own health. Ultimately, addressing health inequities in the Cape Town area may improve lives of several marginalised groups with unique health needs. In addition, creating a framework that works in association with the existing EFAR program structure allows for the possibility of extending these benefits to other EFAR sites in the future.

CHAPTER 4: FINDINGS

This chapter presents the findings of the research steps that were outlined in Chapter 3. First, the results of the translation process for obtaining an Afrikaans HLQ are presented. Then, the validation process for English, Afrikaans, and combined-language HLQs is described. HLQ data is presented next, followed by reports from the feedback workshop.

4.1 Translation of the HLQ

4.1.1 Provisional forward translation

The translation agency used in Cape Town was Folio Online. Overall, the initial translation appeared mostly straightforward, with most back translations matching the original English statements identically or very similarly. The HLQ item intent and translation management document summarising the creation of the provisional forward translation is attached (Appendix 4).

Noteworthy issues regarding this translation are presented in Table 2, below. The concerning questions or scales are identified, a summary of the concern given, and the final decision regarding the translation provided.

Question/scale	Concern	Decision
First measurement scale: Verskil ten sterkste / Verskil / Stem saam / Stem ten sterkste saam (Strongly disagree / Disagree / Agree / Strongly agree)	<i>Length of translated phrases for the first measurement scale.</i> It was noted that there was a greater number of words in the Afrikaans translation. Of particular concern were “Verskil ten sterkste” for “Strongly disagree” and “Stem ten sterkste saam” for “Strongly agree”. One of the stated goals in translation is to keep the number of words to a minimum (while preserving the correct meaning) to minimise the burden on participants taking the questionnaire. However, it is also extremely important to preserve the same measurement intervals and levels of intensity as	The original translation of the scale was accepted, as it was expressed by the professional translators and bilinguals that this reflects a normal difference in how Afrikaans adverbs are expressed

	the original English version.	grammatically.
Throughout entire questionnaire	<i>Word used for “healthcare provider”.</i> Discrepancy over how the term “healthcare provider” is interpreted is a known concern, discovered by the creators of the HLQ. For this reason, a clause is included in the first page of the HLQ, stating: “In this questionnaire, please consider healthcare providers as doctors and any other allied health professional”. The intent of the term “healthcare providers” is to indicate “doctors, psychologists, nurses, social workers, physical therapists, i.e. doctors and any allied health professional providing advice, care, or support” ⁷.	Prior to the consensus teleconference, the term used for “healthcare providers” was “gesondheids-orgverskaffer”. In the teleconference it was agreed upon that a preferable, simpler term was “gesondheidswerker” meaning “health worker”.
Scale 3, question 16: “I make plans for what I need to do to be healthy”	<i>The active intent of a statement.</i> The proposed forward translation for this statement was “Ek beplan vir wat ek moet doen om gesond te wees”, which was back translated as “I plan for what I need to do to be healthy”. The Chairperson was concerned that the concept of “I plan” is not as active as “I make plans”.	All translators and bilinguals agreed that conceptually the statement in Afrikaans retains the same description of purposeful action, so the forward translation remained the same.
Scale 7, question 8: “Get to see the healthcare providers I need	<i>The active intent of a statement.</i> The proposed forward translation for this statement was “Om die gesondheidsorgverskaffers te sien wat ek moet”, which was back translated as “To see the	After discussion in the teleconference, the statement was changed slightly to

to"	health care providers that I should". Again, the Chairperson was concerned that the concept of "To see" does not reflect the same active intent as the original "Get to see". The original intent of the question is to ask how easy or difficult it is for somebody to work out how to identify a service and schedule an appointment. In addition, "I should" is not exactly equivalent with the original "I need to", which describes a higher level of necessity.	"Om die gesondheids-werkers te kan sien wat ek moet" (note: as described above, "gesondheids-werkers" used for "healthcare providers").
Scale 3, question 31: "There are things that I do regularly to make myself more healthy"	<i>Order of concepts.</i> Translation was first proposed to be "Ek doen gereeld dinge om myself gesonder te maak", which was back translated to "I regularly do things to make myself healthier". The concern was that the original intent of the statement was to imply that there are set entities of things that are done regularly to make a person healthier, whereas the back translation seemed to imply a person does small, occasional, random acts to generally be healthier (rather than well-defined entities).	It was agreed that the translation would be changed to "Daar is dinge wat ek gereeld doen om myself gesonder te maak" to better reflect the original intent.
Scale 9, question 5: "Confidently fill medical forms in the correct way"	<i>Order of concepts.</i> The proposed translation for this statement was "Om mediese vorms met vertroue op die regte manier te voltooi", which was back translated as "To fill in medical forms in the correct way with confidence".	It was believed the discrepancy reflected differences in Afrikaans sentence structure but that the intent was understood the same, so the proposed

		translation was accepted without any changes.
Scale 4, question 29: "I have strong support from family or friends"	<i>"Have" vs. "receive"</i> . The proposed translation was "Ek ontvang sterk ondersteuning deur familie of vriende", which was back translated as "I receive strong support from family or friends". There was a question whether "receive" retained the same intent as the original "have".	The forward translation was ultimately changed slightly to "Ek kry sterk ondersteuning van familie of vriende" for more clarity.
Scale 5, question 10: "When I see new information about health, I check up on whether it is true or not"	<i>Formality of Afrikaans for common people.</i> There are several dialects of Afrikaans in South Africa. How proper or colloquial the language is utilised often reflects the education and social group a person identifies with. For example, descendants of Dutch settlers often are taught and speak a "proper" version of Afrikaans that closely matches Dutch, whereas some Coloured groups are known for speaking a more colloquial Afrikaans with more intermixed English and Bantu language words. The two bilingual laypersons in the teleconference were concerned that certain words in the proposed translation would not be understood by those speaking this more colloquial version of Afrikaans, and that it may be embarrassing or upsetting to individuals taking the HLQ if they have difficulty comprehending words that are technically part of a language they speak regularly.	To make this statement more acceptable for a common South African Afrikaans speaker, it was changed to "Wanneer ek nuwe inligting oor gesondheid sien, maak ek seker of dit waar is of nie". Here, "maak ek seker" ("Make sure of") replaces "kontroleer" for "check up on".

	This was first translated as “Wanneer ek nuwe inligting oor gesondheid sien, kontroleer ek of dit waar is of nie”, which was back translated as “When I see new information on health, I check [up on] whether it is true or not”. The bilinguals were concerned about the use of the verb “kontroleer”.	
Scale 9, question 17: “Read and understand all the information on medication labels”	<i>Formality of Afrikaans for common people, as above.</i> This was first translated as “Om al die inligting op medikasie-etikette te lees en verstaan”, which was back translated as “To read and understand all the information on medicine labels”.	Again, for clarity and better understanding by common people, this was changed to “Om al die inligting op medikasie-verpakking te lees en verstaan”. This change substitutes the word for “label” with “packaging”, which is a more common term.
Scale 6, question 15: “Discuss things with healthcare providers until you understand all you need to”	<i>Formality of Afrikaans for common people, as above.</i> This was originally translated to “Om goed met gesondheidsorgverskaffers te bespreek totdat jy alles verstaan wat jy moet”.	Changed slightly to “Om dinge met gesondheids-werkers te bespreek totdat jy alles verstaan wat jy moet” (as described previously, using “gesondheids-

		workers”).
Second measurement scale: Kan dit nie doen nie / Baie moeilik / Taamlik moeilik / Taamlik maklik / Baie maklik (Cannot do / Very difficult / Quite difficult / Quite easy / Very easy)	<i>Strength of descriptive words for measurement.</i> For this measurement scale, it was important to make sure the Afrikaans translation had appropriate relative levels of ease or difficult. Adjectives had to be selected so that each point on the scale was the same distance apart.	“Baie” for “Very” and “Taamlik” for “Quite” were agreed upon as appropriate terms to ensure an equivalent measurement scale.
Scale 6, question 7: “Have good discussions about your health with doctors”	<i>Difference between “discussions” and “conversations”.</i> The proposed translation was “Om goeie gesprekke oor jou gesondheid met dokters te hê”, which was back translated as “To have good conversations with doctors about your health”. There was some concern that “conversations” is not equivalent in meaning to “discussions”, which are intended to refer to two-way conversations where issues are aired and fulfilling interchanges are achieved.	After some discussion, the intent of the proposed translation was believed to be the same, and no changes were made.
Scale 6, question 20: “Ask healthcare providers questions to get the health information you need”	<i>“All” making a statement stronger.</i> The proposed translation was “Om vir gesondheidsorgverskaffers vrae te vra om al die gesondheidsinligting te kry wat jy nodig het”, which was back translated as “To ask health care providers questions in order to get all the health information you need”. It was felt that the additional “al” (“all” in English) made the statement slightly stronger than the original	The “al” was removed. The final agreed translation was “Om vir gesondheidswerkers vrae te vra om die gesondheidsinligting te kry wat jy

	intent.	nodig het”.
Scale 8, question 6: “Find health information from several different places”	<i>Describing a number of places.</i> The proposed translation was “Om gesondheidsinligting by heelwat, verskillende plekke te vind”, which was back translated as “To find health information in a considerable number of different places”. There was some concern that “considerable number of places” did not retain the same intent as “several”, which implied more than two but fewer than “many” places.	This was changed slightly to “Om gesondheidsinligting by verskeie ander plekke te vind”.

Table 2: Main concerns discussed at the first translation teleconference regarding the initial Afrikaans translation.

4.1.2 Testing provisional forward translation

Feedback from the HLQ administrators was first used to get a sense of how the proposed Afrikaans HLQ was understood (see Appendix 5 for this initial Afrikaans HLQ). Immediately upon initial field testing with the provisional forward translation, it was clear that there were problems understanding the first measurement scale, and participants had difficulty completing the first half of the questionnaire. Over half of the participants who were bilingual asked to switch to the English version after starting the Afrikaans one.

When asked to point out specifically which questions or measurement scales were difficult to understand, many individuals had trouble providing an answer. Most said that overall the Afrikaans was too formal. Many pointed out difficulty understanding the first measurement scale.

To address these concerns, a consensus amongst all bilingual HLQ administrators was reached regarding the most important changes that should be made to improve the translation and make it more accessible for the

common Afrikaans speaker in the greater Lavender Hill area. See 4.1.3 below for specific details regarding these proposed changes.

4.1.3 Changes to translation

In response to the concerns from the HLQ administrators regarding the Afrikaans version, a second consensus teleconference was held to address changes to the translation.

Participants included the Developer/Chairperson, Principal Investigator, and the same translation agency representatives as the first teleconference. However, two new local bilinguals participated: a cosupervisor of the project and the director of Mothers Unite. The cosupervisor and director both had served as initial HLQ administrators. Proposed changes and final decisions are summarised in Table 3 below.

Phrase / word / scale of concern	Proposed change	Final decision	Rationale
First measurement scale English: Strongly disagree / Disagree / Agree / Strongly agree Initial Afrikaans: Verskil ten sterkste / Verskil / Stem saam / Stem ten sterkste saam	Stem glad nie saam nie / Stem nie saam nie / Stem saam / Stem baie sterk saam	Stem glad nie saam nie / Stem nie saam nie / Stem saam / Stem baie sterk saam	The proposed change was believed to reflect a more colloquial version of the measurement intervals. Importantly, it was believed to retain the same relative levels of intensity and overall range of measurement. Although it is preferable to use a smaller number of words, it is more important for the measurement scale to be understood clearly, as this scale affects half of the questions on the HLQ.

The word “bronne” for “sources” in Scale 5, questions 2 and 20. English: sources Initial Afrikaans: bronne	plekke	bronne	The Afrikaans word “bronne” was originally used for the English “sources” in two questions. The intent of “sources” is to refer to various places an individual may obtain health information, including internet sites, conversations with various healthcare providers, and written material. “Bronne” was commonly identified as a difficult vocabulary word for the tested population. However, it is the word with the most identical meaning to the English version. “Plekke” is more commonly spoken, but is back translated as “place” and can be mistaken as referring to only physical places (like the day clinic or library). For this reason, no changes were made.
“Effektief” rather than “doeltreffend” for “effectively” in Scale 2, question 23. English: I am sure I have all the information I need to manage my health <i>effectively</i> Initial Afrikaans: Ek is seker ek het al die	Ek is seker ek het al die inligting wat ek benodig om my gesondheid <i>effektief</i> te bestuur	Ek is seker ek het al die inligting wat ek benodig om my gesondheid <i>effektief</i> te bestuur	“Effektief” is an Anglicism, a direct translation of the English word. As such, it is preferably not used in formal Afrikaans. However, a majority of Afrikaans speakers use this term and it carries the same intent as the original English word, so the change was accepted.

inligting wat ek nodig het om my gesondheid <i>doeltreffend</i> te bestuur			
“Benodig” rather than “nodig het” in Scale 2, question 23 (also seen above) and Scale 1, question 26. English: need Initial Afrikaans: nodig het	benodig	benodig	This change was proposed for two questions. The change was believed to improve readability and understanding for these statements without changing the intent, so the changes were accepted.
Changing “kan kom” to “toe kan gaan” in Scale 4, question 24. English: I have at least one person who can come to medical appointments with me Initial Afrikaans: Ek het ten minste een persoon wat saam met my na mediese afspraak <i>kan kom</i>	Ek het ten minste een persoon wat saam met my na mediese afsprake <i>toe kan gaan</i>	Ek het ten minste een persoon wat saam met my na mediese afsprake <i>toe kan gaan</i>	The change was believed to improve readability and understanding for the statement without changing the intent, so the change was accepted.
Changing “gehalte” to “kwaliteit” for “quality” in Scale 5, question 30. English: quality Initial Afrikaans: gehalte	kwaliteit	kwaliteit	“Kwaliteit” is another Anglicism, a direct translation of the English word. As such, it is preferably not used in formal Afrikaans. However, a majority of Afrikaans speakers use this term and it carries the same intent as the original English word, so the

			change was accepted.
“Meer gesond” rather than “gesonder” for “more healthy” in Scale 3, question 31. English: more healthy Initial Afrikaans: gesonder	meer gesond	meer gesond	The change was believed to improve readability and understanding for the statement without changing the intent, so the change was accepted. The new version is also a more direct back translation to the English “more healthy”.
Rewording of a statement for clarity in Scale 1, question 32. English: I can rely on at least one healthcare provider Initial Afrikaans: Ek kan op ten minste een gesondheidswerker staatmaak	Ek kan ten minste op een gesondheidswerker staatmaak	Ek kan op ten minste een gesondheidswerker staatmaak	The change was requested to make the statement more natural and readable. However, it was pointed out that the change would alter the meaning of the statement, changing it from “I can rely on at least one healthcare provider” to “As least I can rely on one healthcare provider”. No changes were made.

Table 3: Main concerns discussed at the second translation teleconference regarding the provisional Afrikaans translation.

4.1.4 Creation of combined HLQ

Because so many South Africans (particularly in the greater Lavender Hill area) speak both English and Afrikaans, the decision was made to create a version of the HLQ with both languages present. This version is seen in Appendix 6.

The goal of creating this version was to improve the likelihood that any South African could take the questionnaire and be able to use one or both of the languages to properly understand the question and answer options. This

version of the HLQ then had to be validated in the same way that the English and Afrikaans versions were tested and validated.

4.2 Validation of the HLQ

4.2.1 Validation of the HLQ in English

One community member, five patients, and two EFARs underwent cognitive interviewing for the HLQ to help validate the English version. Seven participants were asked about the first half of the questionnaire and six were asked about the second half. All eight English interviews discussed the two measurement scales. Each interviewee spoke fluent English and claimed high confidence in their knowledge of the English language. In addition to the formal cognitive interviews, feedback from all HLQ administrators was obtained regarding the applicability and validity of the English HLQ for the greater Lavender Hill community. Table 4 (below) contains the results of these processes for each of the measurement and health literacy dimension scales.

Scale	Results of cognitive interviews	Feedback from HLQ administrators
First measurement scale: Strongly disagree / Disagree / Agree / Strongly agree Used for scales 1-5	All eight interviewees accurately described concepts of “agree” and “disagree” and made answer choices accurately based upon whether they felt a statement matched their position or differed from their thinking. Seven of the eight interviewees accurately chose “strongly” with their answer choice when they felt their position was very clear and certain. One of the eight interviewees was able to differentiate easily between “agree” and “disagree”, but was unable to articulate a	Feedback from HLQ administrators confirmed that all participants were able to understand the scale and the terms “agree” and “disagree”. A small percentage of participants that had the questionnaire administered orally made answer choices by stating these terms

	difference between “strongly disagree” and “disagree” or “strongly agree” and “agree.” This interviewee had all of her answer choices as “disagree” or “agree”.	or by shaking or nodding their head, and had to be asked further to specify whether their response indicated “agree” vs “strongly agree” (or “disagree” vs “strongly disagree”).
Scale 1: Feeling understood and supported by healthcare providers	All seven interviewees understood the intent of each question in this scale. They understood the concept of a healthcare provider after being told the description on the cover of the questionnaire. Interviewees were able to describe why or why not they trusted their healthcare providers or felt they could rely upon them, and knew what it meant to have providers that helped them with their care.	Feedback from HLQ administrators confirmed that participants appeared to understand the intent of the items on this scale. Additionally, participants described a range of reasons why they made their answer choices. Some chose responses to reflect whether they personally felt they were able to trust or have valuable discussions with healthcare providers, whereas others chose responses based on how feasible their health service made it for them to access and form relationships with

		particular providers.
Scale 2: Having sufficient information to manage my health	All seven interviewees understood the intent of each question in this scale. They were able to describe a sense of both the quality and volume of the health information they had, and were able to relate this to their own health by stating whether it was adequate information for them to manage their conditions. Importantly, interviewees were aware of the subtle differences in strength between statements like “I am sure I have all the information I need to manage my healthy effectively” and “I have all the information I need to look after my health”. As described in the original item intent by the developers of the HLQ, participants felt it was easier to say they had information to “look after” their health, but had to possess more confidence to answer the same way about if they could “manage” their health. Statements with “all” were interpreted as stronger.	Feedback from HLQ administrators confirmed that participants appeared to understand the intent of the items on this scale and the relative strengths of the statements.
Scale 3: Actively managing my health	All seven interviewees understood the intent of each question in this scale. They described answering certain questions by referring to how committed and engaged they are with making plans and taking actions to maintain or improve their health. Interviewees who described being too busy to prioritise their own wellbeing accordingly scored low on this scale. Interviewees were able to distinguish between making plans versus actually executing plans. All interviewees who agreed that they make plans, set goals, or do things	Feedback from HLQ administrators confirmed that participants appeared to understand the intent of the items on this scale and the different actions involved in the statements.

	regularly for their health were able to give specific examples of these.	
Scale 4: Social support for health	All seven interviewees understood the intent of each question in this scale. They were able to identify which questions were asking about the presence of multiple sources of support and empathy and which were asking specific questions about only one or a small number. For the statement “When I feel ill, the people around me really understand what I am going through”, interviewees all described choosing their answer while keeping in mind that the question asked about what happens when the person is not well. They also understood that “people around me” in this statement could refer to healthcare providers and community members in addition to friends and family. Interviewees who answered “strongly disagree” for “I have at least one person who can come to medical appointments with me” described a few different reasons for choosing this response. One interviewee chose it because she did not want to have somebody attend appointments with her, so she never asked, even though she thought she could find somebody to go if she needed it. One interviewee chose this response because it was too early in the morning for any of her friends or family to go with her. All interviewees who answered “strongly agree” on this statement named more than one	Feedback from HLQ administrators confirmed that participants appeared to understand the intent of the items on this scale.

	person who could attend.	
Scale 5: Appraisal of health information	Questions from this scale were responsible for the majority of long pauses, confusion, or questions asked during the cognitive interviews. Regarding the statement “I compare health information from different sources”, all interviewees were able to identify multiple potential sources of information, including different doctors, hospitals, encyclopaedias, and the internet. Two interviewees who both answered “agree” described “compare” as simply taking in and listening to or evaluating information, but did not explicitly describe contrasting or comparing the information. The rest of the interviewees did describe performing comparisons. Four of the interviewees took a long time to answer the statement “When I see new information about health, I check up on whether it is true or not”. Two people chose “disagree” because they felt they were too lazy to find out if something they are told is true or not. One person stated that he was not sure how to find out if something was true, and he usually did not bother trying to figure it out because he knew in his mind already whether a statement was true. The other four interviewees said they would find out if information was true by asking a healthcare provider or other people. The stronger statement “I always compare	Feedback from the HLQ administrators confirmed that these questions caused some confusion from participants, though most were able to answer the majority of the questions. Participants appeared to be aware of different sources for information and most would ask doctors about information to find out more about it, but less stated specifically that they asked about the quality of information or recalled making a decision after comparing sources.

	health information from different sources and decide what is best for me” was easier for the interviewees to respond to. Three people who answered “agree” described instances in the past where they had to evaluate information from multiple sources and make a decision regarding care (for instance, when deciding whether to take a medication, a patient described comparing information from the advertisement with testimonials from other patients regarding its efficacy). Two people again answered “disagree” because they tended not to bother evaluating information and chose to just listen to whatever their healthcare provider at the CHC recommended. The other two interviewees chose “agree” and gave examples of different sources, but did not specify whether they used this for an actual decision affecting their health. The statement “I know how to find out if the health information I receive is right or not” was the easiest question in this scale for interviewees to answer. All interviewees responded “agree” or “strongly agree” and stated that they would ask doctors questions about information to find out it is true. Only one interviewee added additional methods for investigating health information (encyclopaedias or laws). Responses to “I ask healthcare providers about the quality of the health information I find” seemed to be answered by most	
--	--	--

	interviewees as if the question were only “I ask healthcare providers about health information”; answers reflected whether the person spent time asking doctors questions about health. When asked what “quality” meant, four interviewees responded by saying this meant the correctness/accuracy of information; the other three interviewees added that the amount of details and completeness affected quality as well.	
Second measurement scale: Cannot do / Very difficult / Quite difficult / Quite easy / Very easy Used for scales 6-9	Seven of the interviewees very clearly described the difference between the five intervals on the scale. They accurately explain the relative difference between “quite” and “very” (difficult or easy) as it was intended with the original HLQ. They chose “cannot do” only for a task that was unable to be completed, either for individual reasons or because their health system or financial status were believed to be insurmountable barriers. One interviewee was able to easily and accurately explain the difference between “easy” and “difficult” and was able to say that “very” meant it was <i>more</i> easy or difficult. However, in the process of answering this half of the questionnaire, the interviewee seemed to answer as if the scale was still “agree or disagree”. The rationale for answers was given mostly based on whether a task was something the person did or not, rather than referencing specifically how easy	Feedback from HLQ administrators was that most participants did not appear to have any problems with the scale. However, some participants initially started to answer as if the scale was still “Agree / Disagree” and realised after a few questions that the scale was asking a different type of question.

	or difficult it was to do a task.	
Scale 6: Ability to actively engage with healthcare providers	All six interviewees understood the intent of each question in this scale. They answered questions based on how proactive and comfortable they felt in addressing questions and concerns with a healthcare provider. For the statement “Feel able to discuss your health concerns with a healthcare provider”, interviewees explained their answer choice in terms of how capable they personally felt regarding their ability to talk about their health issues. The other questions also took into consideration whether the healthcare providers were able to spend time listening to and talking with patients. One patient who answered “disagree” or “strongly disagree” to most items on this scale said he did not feel that healthcare providers actively listened to his concerns or ever helped him do anything in response to them.	Feedback from HLQ administrators confirmed that participants appeared to understand the intent of the items on this scale, and that responses tended to take into account both a person’s individual ability to voice concerns and a provider’s reciprocal ability to listen and engage in discussions.
Scale 7: Navigating the healthcare system	Overall, the six interviewees appeared to understand the intent for the majority of questions on this scale. Questions were answered based on how easy or difficult it was to find support or services to have needs met, though the concepts of the “right care”, “right place”, and “best care” varied for each individual. For instance, five of the six interviewees responded “quite difficult”, “very difficult”, or “cannot do” for “Get to see the healthcare providers I need to” and “Decide which healthcare provider you need to see” because the CHC would not allow them the	Feedback from HLQ administrators confirmed that participants appeared to understand the intent of most items on this scale, and that many people understood the idea of being entitled to services as being allowed to go to the

	option of choosing which provider to see. However, three of these interviewees responded “quite easy” or “very easy” on “Work out what is the best care for you” because they felt the only way to get to see any providers was through the CHC, (so they should always just start seeking care there), while the other two responded less positively to this statement because they felt they did not have enough of an influence on their care. There was some confusion regarding the statement “Find out what healthcare services you are entitled to”. Three interviewees felt that it was easy enough to find services they were allowed to use. Two interviewees stated that they were not aware whether or not they were entitled to any services, so they always just visited the CHC with any health concerns and followed the instructions they received there. One interviewee said he did not believe he was entitled to services because he did not have a pension, so he chose “Very difficult”.	CHC.
Scale 8: Ability to find good health information	Overall, the six interviewees appeared to understand the intent for the majority of questions on this scale. They answered questions based on how easy or difficult it is for them to find and comprehend health information from various sources. For the statement “Find health information from several different places”, “places” was	Feedback from HLQ administrators confirmed that most participants appeared to understand the intent of most items on this scale. Some were confused by the statement “Get

	mostly understood to be physical places like an office or hospital, rather than a source (like the Internet vs a book). For the statement “Get information about health so you are up to date with the best information”, four interviewees appeared to understand “up to date” as being current information, and “best information” as being correct. Two interviewees were confused by this statement and ultimately responded that it was “quite difficult” to do this task.	information about health so you are up to date with the best information”, and appeared to answer the question based just on how easy it was in general to get good health information.
Scale 9: Understanding health information well enough to know what to do	All six interviewees understood the intent of each question in this scale. All answered questions based on how easy or difficult it is for them to read and understand written information regarding their health. Most interviewees were confident in their abilities to read health information and follow instructions, and answered “quite easy” or “very easy” for all questions in this scale.	Feedback from HLQ administrators confirmed that most participants appeared to understand the intent of items on this scale.

Table 4: Summary of validation processes for the English HLQ.

4.2.2 Validation of the HLQ in Afrikaans

One community member, two patients, and two EFARs underwent cognitive interviewing in Afrikaans to help validate the translated version after the second round of changes were made. Four participants were asked about the first half of the questionnaire, and four were asked about the second half. All five Afrikaans interviews discussed the two measurement scales. Each interviewee spoke fluent Afrikaans and claimed high confidence in their knowledge of the language. In addition to the formal cognitive interviews, feedback from all HLQ

administrators was obtained regarding the applicability and validity of the Afrikaans HLQ (on its own, without the accompanying English version) for the greater Lavender Hill community. Below are the results of these processes for each of the measurement and health literacy dimension scales (Table 5).

Scale	Results of cognitive interviews	Feedback from HLQ administrators
First measurement scale: Stem glad nie saam / Stem nie saam nie / Stem saam / Stem baie sterk saam (Strongly disagree / Disagree / Agree / Strongly agree) Used for scales 1-5	All five interviewees accurately described concepts of “stem nie saam nie” and “stem saam” and made answer choices accurately based upon whether they felt a statement matched their position or differed from their thinking. Four of the five interviewees accurately chose either “stem glad nie saam” or “stem baie sterk saam” when they felt their position was very clear and certain. Similar to what was seen in the English version, one of the four interviewees was able to differentiate easily between “stem nie saam nie” and “stem saam” but was unable to articulate a difference between “stem glad nie saam” and “stem nie saam nie” or “stem baie sterk saam” and “stem saam”. This interviewee made had all of her answer choices as “stem nie saam nie” or “stem saam”.	Feedback from HLQ administrators confirmed that participants were able to understand the scale and the terms “stem saam” and “stem nie saam nie”. A small percentage of participants that had the questionnaire administered orally made answer choices by stating these terms or by shaking or nodding their head, and had to be asked further to specify whether their response indicated “stem saam” vs “stem baie sterk saam” (or “stem nie saam nie” vs “stem glad nie saam”).

Scale 1: Feeling understood and supported by healthcare providers	All four interviewees understood the intent of each question in this scale. They understood the concept of a healthcare provider (“gesonheidswerker” for health worker) after being told the description on the cover of the questionnaire; most described having either a social worker or a doctor in mind. Interviewees were able to describe why or why not they trusted their healthcare providers or felt they could rely upon them, and knew what it meant to have providers that helped them with their care.	Feedback from HLQ administrators confirmed that participants appeared to understand the intent of the items on this scale. Additionally, participants described a range of reasons why they made their answer choices. Some chose responses to reflect whether they personally felt they were able to trust or have valuable discussions with healthcare providers, whereas others chose responses based on how feasible their health service made it for them to access and form relationships with particular providers.
Scale 2: Having sufficient information to manage my health	All four interviewees understood the intent of each question in this scale. One interviewee misunderstood “goeie” in “Ek voel ek het goeie inligting oor gesondheid” (“I feel I have good information about health”) as “enough” rather than “good”. Otherwise, interviewees were able to describe a sense of both the quality and volume of the health information	Feedback from HLQ administrators confirmed that participants appeared to understand the intent of the items on this scale and the relative strengths of the

	they had, and were able to relate this to their own health by stating whether it was adequate information for them to manage their conditions. As in the English version, interviewees were aware of the subtle differences in strength between statements like “Ek is seker ek het al die inligting wat ek benodig om my gesondheid effektief te bestuur” (“I am sure I have all the information I need to manage my healthy effectively”) and “Ek het al die inligting wat ek nodig het om na my gesondheid om te sien” (“I have all the information I need to look after my health”). As described in the original item intent by the developers of the HLQ, participants felt it was easier to say they had information to “look after” their health, but had to possess more confidence to answer the same way about if they could “manage” their health. One interviewee felt it was OK to rely on his social worker to have information so that he could “look after” his health, but did not feel as confident answering as positively about “managing” his health because he did not possess the information himself. Statements with “all” were interpreted as stronger.	statements.
Scale 3: Actively managing my health	All four interviewees understood the majority of the intent of questions in this scale. They described answering certain questions by referring to how committed and engaged they are with making plans and taking actions to maintain or improve their health. Interviewees	Feedback from HLQ administrators confirmed that participants appeared to understand the intent of the items on

	who described being too busy to prioritise their own wellbeing accordingly scored low on this scale. Interviewees were able to distinguish between making plans versus actually executing plans. All interviewees who agreed that they make plans, set goals, or do things regularly for their health were able to give specific examples. There were slight differences in how this group of participants understood the concept of <i>managing</i> health, though all describing managing as taking specific, deliberate actions to maintain or improve their health. For instance, one interviewee thought he was managing his health by trying as best as possible to adhere to a physician's treatment instructions and medications, whereas another described managing their health by trying to stay fit and see a doctor regularly. One interviewee had difficulty understanding the words "doelwitte" and "fiksheid" in "Ek stel my eie doelwitte oor gesondheid en fiksheid" ("I set my own goals about health and fitness"), but had no difficulty answering the question later after the definitions were explained.	this scale and the different actions involved in the statements.
Scale 4: Social support for health	All four interviewees understood the intent of each question in this scale. They were able to identify which questions were asking about the presence of multiple sources of support and empathy and which were asking specific questions about only one or a small number.	Feedback from HLQ administrators confirmed that participants appeared to understand the intent of the items on

	For the statement “Wanneer ek siek voel, verstaan die mense rondom my werklik waardeur ek gaan” (“When I feel ill, the people around me really understand what I am going through”), interviewees all described choosing their answer while keeping in mind that the question asked about what happens when the person is not well. They also understood that “people around me” in this statement could refer to healthcare providers and community members in addition to friends and family. One interviewee answered this question by remembering when he was sick and his neighbours came in to check on him. One interviewee was initially confused by the word “staatmaak” in “Indien ek hulp benodig, het ek baie mense waarop ek kan staatmaak” (“If I need help, I have plenty of people I can rely on”), but was able to answer the question later when given a definition.	this scale.
Scale 5: Appraisal of health information	Again, questions from this scale were responsible for the majority of long pauses, confusion, or questions asked during the cognitive interviews. Regarding the statement “Ek vergelyk gesondheidsinligting van verskillende bronne” (“I compare health information from different sources”), all interviewees were able to identify multiple potential sources of information, including different doctors, books, and the internet. One interviewee	Feedback from the HLQ administrators confirmed that these questions caused some confusion from participants, though most were able to answer the majority of the questions. Participants appeared to be aware of different sources for information

	appeared to have difficulty understanding the word “vergelyk “ (“compare”) and described simply taking in and listening to or evaluating information, but did not explicitly describe contrasting or comparing the information. The rest of the interviewees did describe performing comparisons. Two of the interviewees took a long time to answer the statement “Wanneer ek nuwe inligting oor gesondheid sien, maak ek seker of dit waar is of nie” (“When I see new information about health, I check up on whether it is true or not”). Two people disagreed because they felt they were too lazy to find out if something they are told is true or not. All four interviewees said they could find out if information was true by asking a healthcare provider. The stronger statement “Ek vergelyk altyd gesondheidsinligting van verskillende bronne en besluit wat die beste vir my is” (“I always compare health information from different sources and decide what is best for me”) was easier for the interviewees to respond to. One person who agreed described an instance in the past where they had to evaluate information from multiple sources and make a decision regarding care. Two people again disagreed because they tended not to bother evaluating information and chose to just listen to whatever their healthcare provider at the CHC recommended. The other interviewee again had trouble understanding the term	and most would ask doctors about information to find out more about it, but less stated specifically that they asked about the quality of information or recalled making a decision after comparing sources.
--	--	---

	“vergelyk” but answered the question as though it was “I use health information from different sources and decide what is best for me”. For the statement “Ek weet hoe om uit te vind of die gesondheidsinligting wat ek ontvang, reg is of nie” (“I know how to find out if the health information I receive is right or not”), all interviewees agreed and stated that they would ask doctors about information to find out if it is true. Responses to “Ek vra gesondheidswerkers oor die kwaliteit van die gesondheidsinligting wat ek vind” (“I ask healthcare providers about the quality of the health information I find”) seemed to be answered by most interviewees as if the question were only “I ask healthcare providers about health information”; answers reflected whether the person spent time asking doctors questions about health. When asked what “kwaliteit” meant, three interviewees responded by saying this meant the correctness/accuracy of information; the other interviewee said that quality information would lead to an improvement in his condition.	
Second measurement scale: Kan dit nie doen nie / Baie moeilik / Taamlik moeilik	Three of the interviewees very clearly described the difference between the five intervals on the scale. They accurately explain the relative difference between “Taamlik” and “Baie” as it was intended with the original HLQ. They chose “Kan dit nie	Feedback from HLQ administrators confirmed that most participants understood the scale well, and only rarely chose “Kan dit

/ Taamlik maklik / Baie maklik (Cannot do / Very difficult / Quite difficult / Quite easy / Very easy) Used for scales 6-9	doen nie” only for a task that was unable to be completed, either for individual reasons or because their health system or financial status were believed to be insurmountable barriers. Two interviewees were able to explain the difference between “maklik” and “moeilik” and were able to say that “baie” meant it was <i>more</i> easy or difficult. However, in the process of answering this half of the questionnaire, the interviewees seemed to answer as if the scale was still “agree or disagree”. These interviewees tended to explain their answers by saying “yes, it is easy” or “no, it is difficult”, and had to be asked repeatedly to elaborate on their responses during the interviews.	nie doen nie” only when there was absolutely no chance something would be possible for them to achieve.
Scale 6: Ability to actively engage with healthcare providers	All four interviewees understood the intent of each question in this scale. They answered questions based on how proactive and comfortable they felt in addressing questions and concerns with a healthcare provider. For the statement “Om in staat te voel om jou gesondheidsorge met ’n gesondheidswerker te bespreek” (“Feel able to discuss your health concerns with a healthcare provider”), interviewees explained their answer choice in terms of how capable they personally felt regarding their ability to talk about their health issues. The other responses also took into consideration whether the healthcare providers were able to spend time listening to	Feedback from HLQ administrators confirmed that participants appeared to understand the intent of the items on this scale, and that responses tended to take into account both a person’s individual ability to voice concerns and a provider’s reciprocal ability to listen and engage in discussions.

	and talking with patients.	
Scale 7: Navigating the healthcare system	Overall, the four interviewees appeared to understand the intent for the majority of questions on this scale. Questions were answered based on how easy or difficult it was to find support or services to have needs met. As in the English version, there was some confusion regarding the statement “Om uit te vind op watter gesondheidsdienste jy geregtig is” (“Find out what healthcare services you are entitled to”). One interviewee felt that it was easy enough to find services they were allowed to use. Two interviewees stated that they were not aware what services they were entitled to, so they always just visited the CHC with any health concerns. One interviewee had difficulty understanding “gesondheidsdienste” but later described that his social worker helped him connect to services.	Feedback from HLQ administrators confirmed that participants appeared to understand the intent of most items on this scale, and that many people understood the idea of being entitled to services as being allowed to go to the CHC.
Scale 8: Ability to find good health information	Overall, the four interviewees appeared to understand the intent for the majority of questions on this scale. They answered questions based on how easy or difficult it is for them to find and comprehend health information from various sources. For the statement “Om gesondheidsinligting by verskeie ander plekke te vind” (“Find health information from several different places”), “places” was understood by two participants to be physical places like an	Feedback from HLQ administrators confirmed that most participants appeared to understand the intent of most items on this scale. Some were confused by the statement “Om inligting oor gesondheid te kry sodat jy op datum is

	office or hospital, rather than a source (like internet vs a book), though the other two interviewees understood it to refer to sources. For the statement “Om inligting oor gesondheid te kry sodat jy op datum is met die beste inligting” (“Get information about health so you are up to date with the best information”), two interviewee appeared to understand “up to date” as being current information and “best information” as being correct. One interviewee was confused by this statement and ultimately responded that it was difficult to do this task. One interviewee understood the statement to be asking how to obtain information regarding an appointment time and date.	met die beste inligting” (“Get information about health so you are up to date with the best information”), and appeared to answer the question based just on how easy it was in general to get good health information.
Scale 9: Understanding health information well enough to know what to do	All four interviewees understood the intent of each question in this scale. All answered questions based on how easy or difficult it is for them to read and understand written information regarding their health. Most interviewees were confident in their abilities to read health information and follow instructions, and answered that it was easy for all questions in this scale.	Feedback from HLQ administrators confirmed that most participants appeared to understand the intent of items on this scale.

Table 5: Summary of validation processes for the Afrikaans HLQ

4.2.3 Validation of the combined HLQ

One patient and two EFARs underwent cognitive interviewing in Afrikaans to help validate the combined Afrikaans/English version of the HLQ. Interviewees spoke fluent Afrikaans and English and claimed high confidence in their

knowledge of both languages. Additionally, extensive feedback from participants and HLQ administrators was sought as the new combined version was given.

Cognitive interviews revealed results similar to those in the separate English and Afrikaans validation process, with some improvement in the understanding of particular words that sometimes confused participants taking the Afrikaans version. The intent of all measurement and health literacy domain scales were clearly understood.

Specific words that Afrikaans speakers had asked questions about when administering the Afrikaans HLQ included “doelwitte”, “fiksheid,” “staatmaak,” “vergelyk,” “gesondheidsdienste,” “op datum,” and “bronne.” All three interviewees for the combined language HLQ expressed an understanding of the respective English translations for these words, and all three reported referring to the English at least once regarding statements with these words.

Feedback from HLQ administrators regarding their experience with the combined HLQ was overwhelmingly positive. All administrators expressed belief that the combined version was significantly better and easier to give than the exclusively Afrikaans version. All reported that participants using the combined version asked fewer questions and had minimal difficulty understanding the questions or measurement scales when provided with these items in both languages.

After testing the various forms of the HLQ, data was collected from each of the three participant groups. This HLQ data is presented in the next section.

4.3 HLQ data

4.3.1 Demographics

A summary of the demographic characteristics and health conditions within each group and overall is presented below, in Tables 6 and 7.

Demographic	Overall	Community	EFAR	Patient
Age (mean)	38.6 yrs	38.4 yrs [9]	35.1 yrs [12]	41.9 yrs [7]
Female (percent of total sample)	59%	57 (59%) [4]	49 (53%) [1]	64 (66%) [3]
Lives alone	8%	4 (4%) [10]	5 (6%) [7]	12 (12%) [2]
South African born	98%	90 (97%) [7]	85 (98%) [6]	96 (100%) [4]
Part high school or less	68%	64 (70%) [8]	54 (61%) [4]	70 (73%) [4]
Private insurance or medical aid	10%	8 (9%) [8]	11 (13%) [5]	6 (7%) [8]

Note: [#] denotes missing data. Data presented using numbers of cases as well as the percentage of the total sample.

Table 6: Demographic data from HLQ participants

	Overall	Community	EFAR	Patient
Arthritis	12%	15 (18%)	4 (5%)	13 (13%)
Back pain	21%	13 (16%)	17 (21%)	23 (24%)
Heart problems	5%	3 (4%)	2 (3%)	8 (8%)
Asthma	14%	8 (10%)	8 (10%)	20 (21%)
Cancer	1%	2 (2%)	0 (0%)	1 (1%)
Depression/anxiety	9%	4 (5%)	6 (8%)	12 (12%)
Seizures	4%	2 (2%)	2 (3%)	6 (6%)
Diabetes	13%	8 (10%)	9 (11%)	16 (16%)
Stroke	1%	0 (0%)	1 (1%)	1 (1%)

Other health condition	20%	8 (10%)	11 (14%)	33 (34%)
Reports no conditions	41%	40 (49%)	40 (50%)	25 (26%)
Did not answer about conditions	12%	18 (18%)	13 (14%)	3 (3%)

Note: [#] denotes missing data. Data presented using numbers of cases as well as the percentage of the total sample.

Table 7: Health conditions reported amongst HLQ participants

4.3.2 Comparisons of three study groups

A summary of the mean overall health literacy, nine health literacy domain scores, and descriptive statistics for each group is presented in Table 8. 95% confidence intervals for each of the nine domains are presented by group in Figure 2.

Scale	Group	N	Mean	Std. deviation	Std. error	95% confidence interval	
						Lower bound	Upper bound
Overall	Patients	100	3.39	0.42	0.04	3.31	3.48
	Community	100	3.41	0.48	0.05	3.32	3.51
	EFARs	93	3.44	0.52	0.05	3.34	3.55
	Total	293	3.42	0.43	0.03	3.36	3.47
HPS	Patients	100	2.84	0.66	0.07	2.71	2.97
	Community	100	2.82	0.64	0.06	2.70	2.95
	EFARs	93	2.88	0.74	0.08	2.73	3.03
	Total	293	2.85	0.68	0.04	2.77	2.92
HSI	Patients	100	2.84	0.59	0.06	2.73	2.96

	Community	100	2.99	0.57	0.06	2.88	3.11
	EFARs	93	2.90	0.62	0.06	2.77	3.03
	Total	293	2.91	0.59	0.03	2.84	2.98
AMH	Patients	100	3.18	0.52	0.05	3.08	3.28
	Community	100	3.11	0.55	0.06	3.00	3.22
	EFARs	93	3.07	0.66	0.07	2.93	3.20
	Total	293	3.12	0.58	0.03	3.05	3.19
SS	Patients	100	3.17	0.63	0.06	3.04	3.29
	Community	100	3.01	0.62	0.06	2.89	3.14
	EFARs	93	3.03	0.65	0.07	2.89	3.16
	Total	293	3.07	0.64	0.04	3.00	3.14
CA	Patients	100	2.96	0.50	0.05	2.86	3.06
	Community	100	2.98	0.49	0.05	2.89	3.08
	EFARs	93	2.99	0.58	0.06	2.87	3.11
	Total	293	2.98	0.52	0.03	2.92	3.04
AE	Patients	100	3.92	0.71	0.07	3.78	4.06
	Community	100	3.94	0.74	0.07	3.80	4.09
	EFARs	93	4.03	0.70	0.07	3.89	4.18
	Total	293	3.96	0.72	0.04	3.88	4.05
NHS	Patients	100	3.57	0.73	0.07	3.43	3.72
	Community	100	3.68	0.88	0.09	3.51	3.86
	EFARs	93	3.85	0.72	0.07	3.70	3.99
	Total	293	3.70	0.79	0.05	3.61	3.79
FHI	Patients	100	3.71	0.72	0.07	3.56	3.85

	Community	100	3.82	0.78	0.08	3.66	3.97
	EFARs	93	3.88	0.72	0.07	3.73	4.02
	Total	293	3.80	0.74	0.04	3.71	3.88
UHI	Patients	100	4.09	0.61	0.06	3.97	4.21
	Community	100	4.09	0.66	0.07	3.96	4.22
	EFARs	93	4.09	0.60	0.06	3.97	4.21
	Total	293	4.09	0.62	0.04	4.02	4.16

Table 8: Summary of health literacy scores

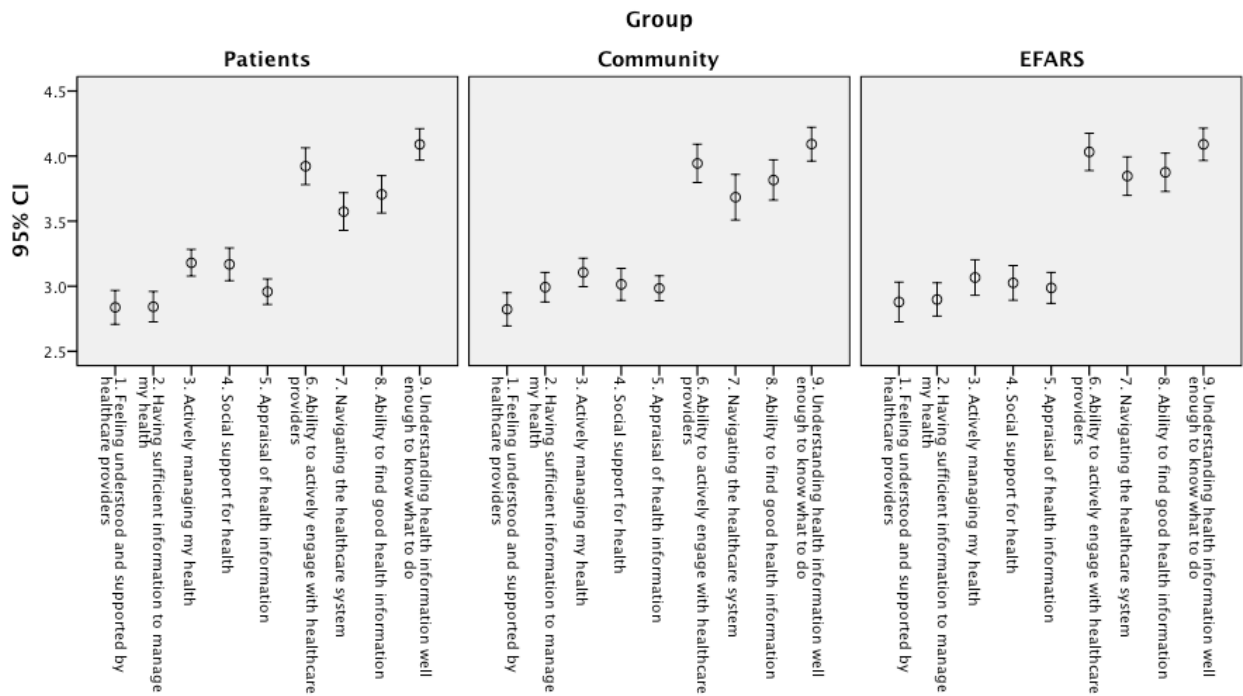


Figure 2: 95% Confidence intervals for nine health literacy scales

Frequency plots for each of the groups and for each of the nine scales are shown below, in Figures 3-11.

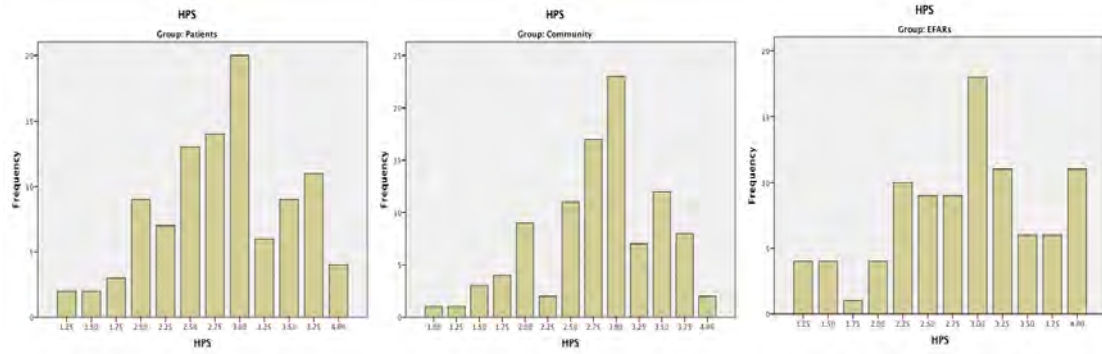


Figure 3: Frequency plots- HPS (Feeling understood and supported by healthcare providers)

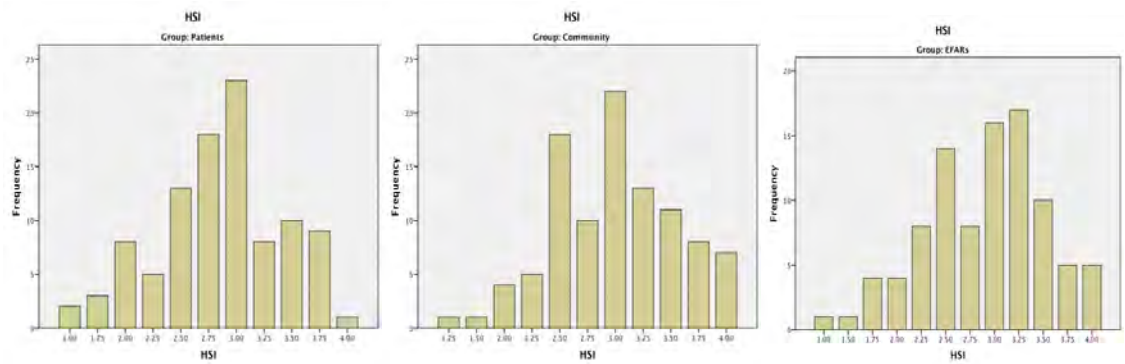


Figure 4: Frequency plots- HSI (Having sufficient information to manage my health)

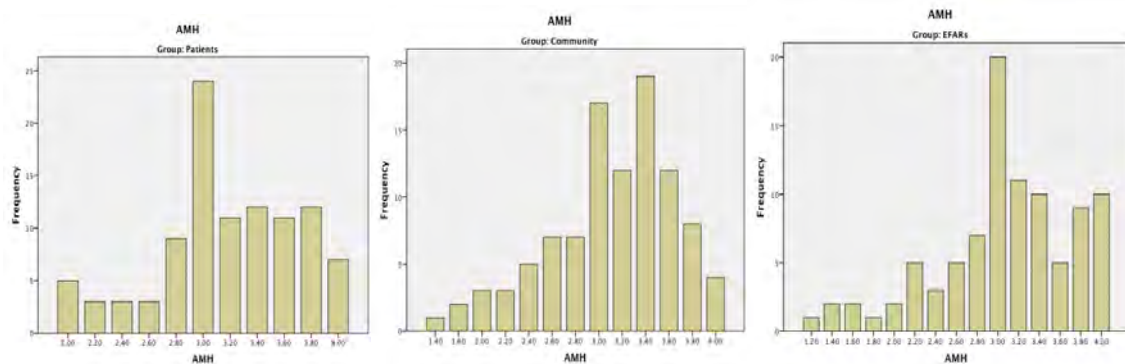


Figure 5: Frequency plots- AMH (Actively managing my health)

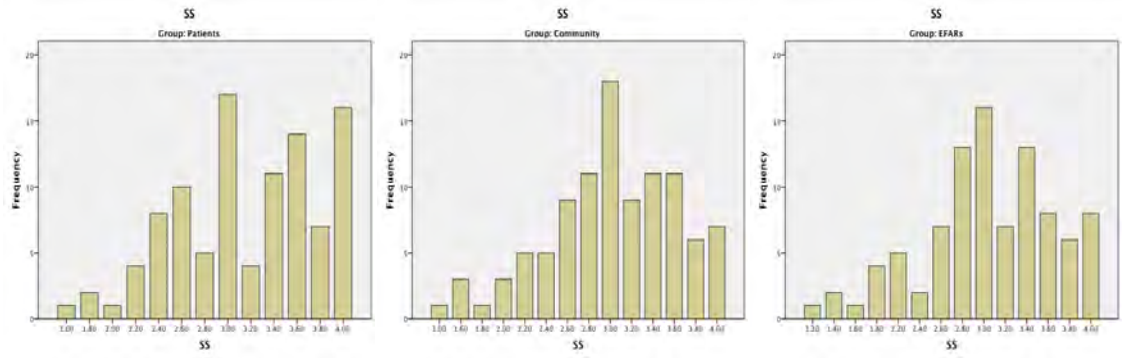


Figure 6: Frequency plots- SS (Social support for health)

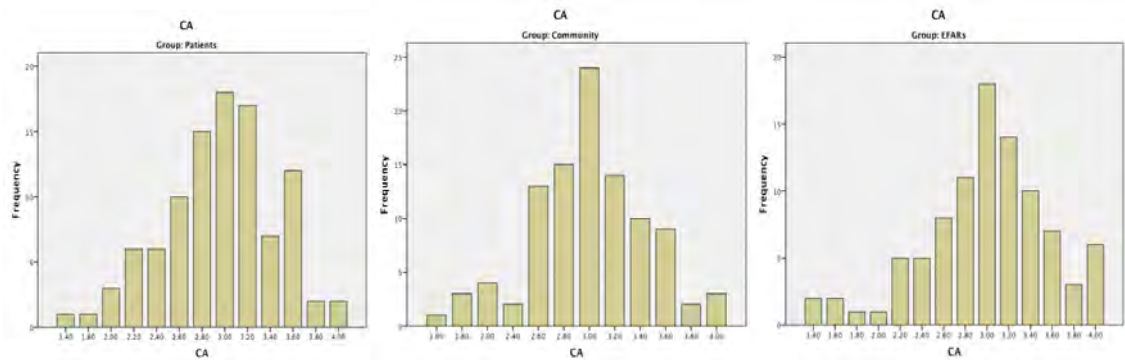


Figure 7: Frequency plots- CA (Appraisal of health information)

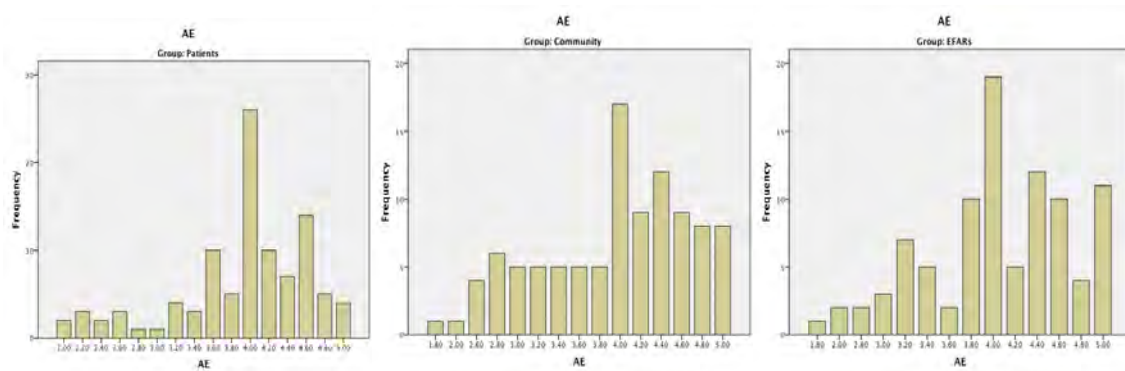


Figure 8: Frequency plots- AE (Ability to actively engage with healthcare providers)

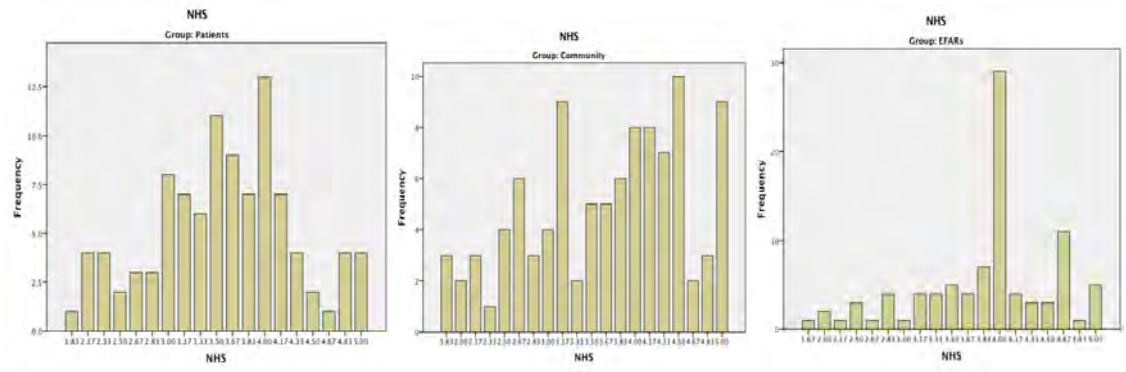


Figure 9: Frequency plots- NHS (Navigating the healthcare system)

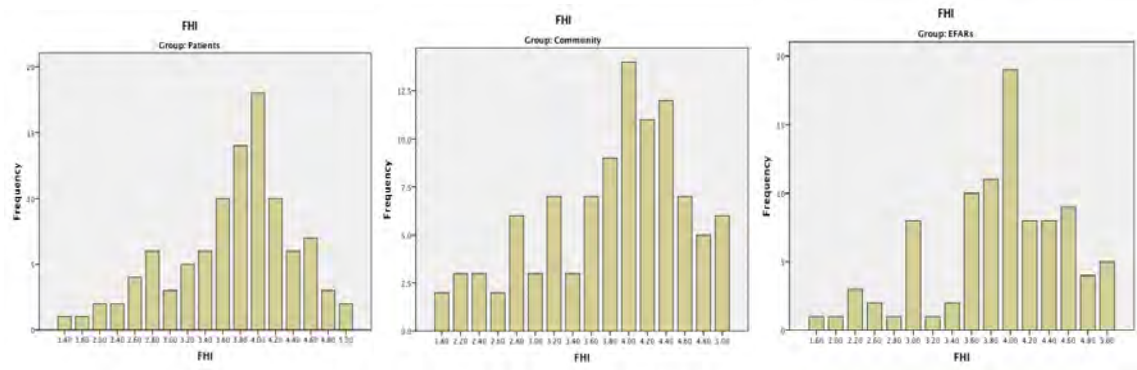


Figure 10: Frequency plots- FHI (Ability to find good health information)

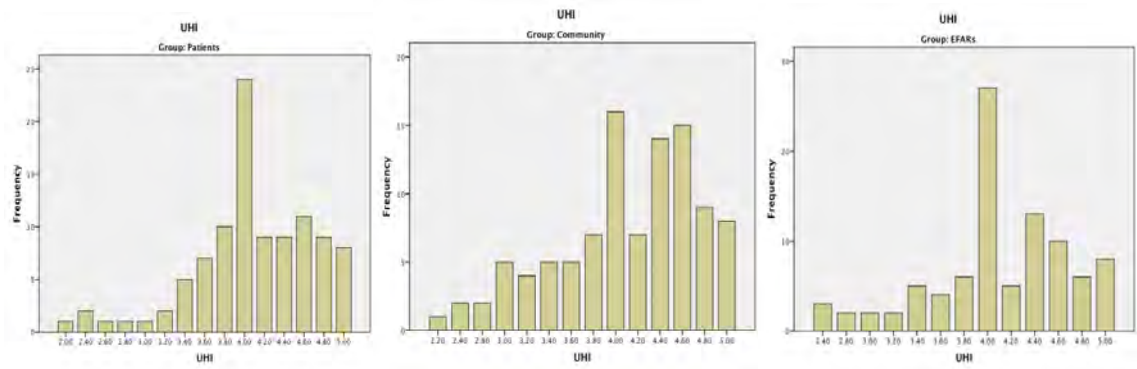


Figure 11: Frequency plots- UHI (Understanding health information well enough to know what to do)

SPSSv21 was used to do a test of homogeneity of variance for all ten scores across all three groups (see Table 9). This revealed a statistically significant Levene statistic (significance at >0.05) for “NHS,” meaning that for the scale “Navigating the healthcare system,” a regular one-way ANOVA could not be used to compare means because the assumptions of normal distribution and variances was violated.

Scale	Levene statistic	df1	df2	Significance
Overall	1.764	2	290	0.173
HPS	1.296	2	290	0.275
HSI	0.720	2	290	0.488
AMH	1.615	2	290	0.201
SS	0.432	2	290	0.650
CA	1.264	2	290	0.284
AE	0.790	2	290	0.455
NHS	5.508	2	290	0.004*
FHI	0.992	2	290	0.372
UHI	0.990	2	290	0.373

*significant at $p < 0.05$

Table 9: Test of homogeneity of variance

SPSSv21 was then used to do a robust ANOVA for the NHS scale using the Brown-Forsythe method, which can be used for data violating the assumptions of normal distribution and variances. Post hoc testing for this scale was then

done using the Games-Howell method of multiple mean comparisons. These tests are presented below, in Tables 10 and 11.

	Statistic	df1	df2	Sig.
Brown-Forsythe	2.963	2	281.771	.053

Table 10: Robust ANOVA of NHS scale using Brown-Forsythe method

Dependent variable: NHS						
Games-Howell						
(I) Group		Mean difference (I-J)	Std. error	Sig.	95% Confidence Interval	
					Lower bound	Upper bound
Patients	Comm	-.11020	.11457	.602	-.3808	.1604
	EFARs	-.27273*	.10450	.026	-.5196	-.0259
Community	Patients	.11020	.11457	.602	-.1604	.3808
	EFARs	-.16253	.11570	.341	-.4359	.1108
EFARs	Patients	.27273*	.10450	.026	.0259	.5196
	Comm	.16253	.11570	.341	-.1108	.4359

* The mean difference is significant at the 0.05 level

Table 11: Post-hoc testing of NHS scale using Games-Howell method

For all of the other scales, a one-way ANOVA was performed for all three groups to examine whether there were significant differences between groups. Post hoc testing for these scales was done using the Gabriel method of multiple mean comparisons, because the group sizes were slightly different. Results of these tests are summarised in Tables 12 and 13.

ANOVA						
		Sum of Squares	df	Mean Square	F	Sig.
Overall	Between Groups	.134	2	.067	.297	.743
	Within Groups	65.241	290	.225		
	Total	65.375	292			
HPS	Between Groups	.164	2	.082	.178	.837
	Within Groups	133.785	290	.461		
	Total	133.949	292			
HSI	Between Groups	1.150	2	.575	1.631	.197
	Within Groups	102.168	290	.352		
	Total	103.318	292			
AMH	Between Groups	.644	2	.322	.959	.384
	Within	97.303	290	.336		

	Groups					
	Total	97.947	292			
SS	Between Groups	1.456	2	.728	1.812	.165
	Within Groups	116.496	290	.402		
	Total	117.952	292			
CA	Between Groups	.050	2	.025	.093	.911
	Within Groups	78.543	290	.271		
	Total	78.593	292			
AE	Between Groups	.650	2	.325	.631	.533
	Within Groups	149.301	290	.515		
	Total	149.951	292			
FHI	Between Groups	1.434	2	.717	1.305	.273
	Within Groups	159.364	290	.550		
	Total	160.798	292			
UHI	Between Groups	.000	2	.000	.000	1.000
	Within Groups	112.825	290	.389		
	Total	112.825	292			

Table 12: One-way ANOVA for all scales besides NHS

Dependent Variable			Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
						Lower Bound	Upper Bound
Overall	Patients	Community	-.01960	.06708	.988	-.1807	.1415
		EFARs	-.05225	.06833	.828	-.2163	.1118
	Community	Patients	.01960	.06708	.988	-.1415	.1807
		EFARs	-.03265	.06833	.950	-.1967	.1314
	EFARs	Patients	.05225	.06833	.828	-.1118	.2163
		Community	.03265	.06833	.950	-.1314	.1967
HPS	Patients	Community	.01500	.09606	.998	-.2156	.2456
		EFARs	-.04153	.09785	.964	-.2764	.1934
	Community	Patients	-.01500	.09606	.998	-.2456	.2156
		EFARs	-.05653	.09785	.917	-.2914	.1784
	EFARs	Patients	.04153	.09785	.964	-.1934	.2764
		Community	.05653	.09785	.917	-.1784	.2914
HSI	Patients	Community	-.15000	.08394	.208	-.3516	.0516
		EFARs	-.05535	.08551	.887	-.2606	.1499
	Community	Patients	.15000	.08394	.208	-.0516	.3516
		EFARs	.09465	.08551	.609	-.1106	.2999
	EFARs	Patients	.05535	.08551	.887	-.1499	.2606
		Community	-.09465	.08551	.609	-.2999	.1106
AMH	Patients	Community	.07400	.08192	.746	-.1227	.2707
		EFARs	.11333	.08345	.438	-.0870	.3137

	Community	Patients	-.07400	.08192	.746	-.2707	.1227
		EFARs	.03933	.08345	.952	-.1610	.2397
	EFARs	Patients	-.11333	.08345	.438	-.3137	.0870
		Community	-.03933	.08345	.952	-.2397	.1610
SS	Patients	Community	.15400	.08963	.238	-.0612	.3692
		EFARs	.14219	.09130	.319	-.0770	.3614
	Community	Patients	-.15400	.08963	.238	-.3692	.0612
		EFARs	-.01181	.09130	.999	-.2310	.2074
	EFARs	Patients	-.14219	.09130	.319	-.3614	.0770
		Community	.01181	.09130	.999	-.2074	.2310
CA	Patients	Community	-.02600	.07360	.979	-.2027	.1507
		EFARs	-.02910	.07497	.972	-.2091	.1509
	Community	Patients	.02600	.07360	.979	-.1507	.2027
		EFARs	-.00310	.07497	1.000	-.1831	.1769
	EFARs	Patients	.02910	.07497	.972	-.1509	.2091
		Community	.00310	.07497	1.000	-.1769	.1831
AE	Patients	Community	-.02200	.10147	.995	-.2656	.2216
		EFARs	-.11026	.10336	.637	-.3584	.1379
	Community	Patients	.02200	.10147	.995	-.2216	.2656
		EFARs	-.08826	.10336	.777	-.3364	.1599
	EFARs	Patients	.11026	.10336	.637	-.1379	.3584
		Community	.08826	.10336	.777	-.1599	.3364
FHI	Patients	Community	-.11000	.10484	.649	-.3617	.1417
		EFARs	-.16927	.10679	.304	-.4256	.0871

	Community	Patients	.11000	.10484	.649	-.1417	.3617
		EFARs	-.05927	.10679	.925	-.3156	.1971
	EFARs	Patients	.16927	.10679	.304	-.0871	.4256
		Community	.05927	.10679	.925	-.1971	.3156
UHI	Patients	Community	-.00200	.08821	1.000	-.2138	.2098
		EFARs	-.00032	.08985	1.000	-.2160	.2154
	Community	Patients	.00200	.08821	1.000	-.2098	.2138
		EFARs	.00168	.08985	1.000	-.2140	.2174
	EFARs	Patients	.00032	.08985	1.000	-.2154	.2160
		Community	-.00168	.08985	1.000	-.2174	.2140

Table 13: Post hoc testing of all scales besides NHS using Gabriel method

4.3.3 Cluster analysis

Cluster analysis was performed on each of the groups. The final cluster solutions comprised 11 clusters for the community member group, 10 clusters for the EFAR group, and 11 clusters for the patient group. Summary sheets listing each of these clusters by their numbers, short cluster names, and mean health literacy scale scores are attached (Appendices 7-9).

To help organise the discussion of these cluster results, each group's clusters were divided into categories of either High, Moderate, Mixed, or Low health literacy. Clusters in the High health literacy category demonstrated consistently high scores across all nine domains. Clusters in the Moderate health literacy category had middle, moderate scores consistently across all domains, and Low health literacy clusters had consistently low scores. Mixed clusters had varying scores and therefore did not fit into any of the other categories. The clusters that fell into each of these groups are displayed in Table 14.

Group	High	Moderate	Mixed	Low
Community	3, 7, 4	1, 2	5, 8, 10, 11	6, 9
EFARs	5, 6, 3, 8	1, 4	9, 2	10, 7
Patients	3, 11, 6	8	7, 10, 4, 1, 2, 9	5

Table 14: Identification of clusters into high, moderate, mixed, and low categories

After these clusters had been identified, narrative vignettes were written to give a more meaningful representation of what each cluster represents.

4.3.4 Vignettes

To facilitate the discussion of clusters and intervention ideas to address health literacy needs evident from the HLQ scores, vignettes were developed to represent each of the clusters. These scenarios were fictional characters inspired both by the profile of HLQ scores for the particular cluster, and where available, interviews with participants from that group.

Vignettes for each of the clusters are attached (Appendices 10-12). Vignettes and the rest of the HLQ data was discussed in a feedback workshop, as described in the next section.

4.4 Feedback workshop

The feedback workshop was well attended, with approximately equal representation from health services, community groups, and EFAR leaders. The overall format of the workshop adequately allowed for participants to become acquainted (or reintroduced) to the research project, discuss several relevant vignettes, and discuss two of the nine health literacy domain scales. This all led to the formation of proposed areas for intervention in response to identified health literacy needs.

4.4.1 Overview

There were 18 attendees at the feedback workshop:

Principal Investigator of present study

Cosupervisor of present study

EFAR Coordinator (for all Western Cape EFAR branches)

EFAR Administrative clerk (for all Western Cape EFAR branches)

2 Provincial administrators for Western Cape/Department of Health (1 a

Family Medicine doctor at Retreat CHC)

Emergency medicine physician at Victoria Hospital

Health promotion officer for Southern Sub District

Clinic manager for Lavender Hill/Muizenberg CHC

Emergency medicine registrar

Clinic manager for Seawinds CHC

Mothers Unite director (also a Mothers Unite EFAR trainer)

2 Mothers Unite EFAR trainers (1 serving as MU EFAR administrator)

Social work intern at Mothers Unite

3 lay community members from the Lavender Hill area

Introduction

The workshop began with introductions and a very brief presentation on the research project. The benefits of this portion of the workshop were to recognise and emphasise the important roles that certain individuals and groups played and to acquaint all parties to the research goals. For this particular workshop, the director of Mothers Unite, the EFAR Coordinator for the Western Cape Province, and a Retreat CHC facility representative were invited to introduce

themselves to the group after a brief introduction by the Principal Investigator. Given that there is a focus on co-creation of health literacy interventions that are driven by local wisdom, it was essential that these parties were properly recognised and thanked for their guidance and participation in the project.

A short presentation followed that discussed a quick background on health literacy, presented the HLQ, described the Ophelia process, and stated what work had been done on the project at that point. The participants were briefed on what their role would be in the workshop and given a few guiding questions to consider when discussing vignettes. The use of sample cases or examples of interventions developed at other workshops was strategically avoided to allow discussions to begin as open-minded and creative.

Vignette discussion

Following the introduction, workshop participants split into two groups to discuss vignettes. In one group, the Patient vignettes were presented, with a goal of developing intervention ideas geared more at the healthcare provider and health services level. The other group discussed both EFAR and Community vignettes, with a goal of developing interventions at a community-based level or through Mothers Unite and its local EFAR branch. After joining back into one group, two volunteer participants (one from each smaller group) presented one of their vignettes to the entire group.

Scale discussion

For the next section of the workshop, all participants discussed two of the nine health literacy scales, what it meant for somebody to be either very high or very low in this area, and what interventions might aid somebody who was low.

A report summarising the workshop in detail is attached (Appendix 13). This report was distributed to all attendees two weeks after the meeting. Additionally, the rest of this section will provide more information about the proceedings during the workshop.

4.4.2 Discussion of vignettes in Patient group

The small group discussing Patient clusters and vignettes was facilitated by Jennifer Bress, Principal Investigator. Other attendees for this small group were:

2 Provincial administrators for Western Cape/Department of Health (1 a

Family Medicine doctor at Retreat CHC)

Emergency medicine physician at Victoria Hospital

Health promotion officer for Southern Sub District

Clinic manager for Lavender Hill/Muizenberg CHC

Emergency medicine registrar

Clinic manager for Seawinds CHC

EFAR trainer for Mothers Unite EFAR branch

Potential strategies that were suggested after discussing the follow Patient clusters are presented below, in Table 15. A more detailed report of these discussions, including the health literacy scores for each cluster and reflections of attendees in response to the vignettes, can be found in the workshop report (Appendix 13).

Patient cluster identifiers	Vignette	Individual-level strategies	Organisational level strategies
Patient cluster 8- “Moderate health literacy”	This is a 39 year old male who has struggled with on-going back pain for a while. He has tried to	<i>Patient empowerment and plan making</i> Encourage HPs to spend more time with patient when first	<i>Support groups</i> After initial visits with HP to rule out dangerous causes of pain, encourage patient to

	fix his posture, but is not sure it has helped. He has gone to the CHC for help, and thinks he describes his problem well, but is not sure his doctors understand the pain that he has to deal with. Overall, he does not feel like he has much support from healthcare providers or his family, so he tries to manage his pain on his own. He does not spend too much time looking for information about his health, but feels confident he can follow instructions from the doctor and take tablets when he needs to.	meeting them, to form better patient-physician relationships and to make sure a plan is developed to both rule out dangerous causes of pain and find a way to manage it. If back pain is not priority of visit due to more pressing concerns, help patient book another appointment specifically to address pain. Make sure patient is on board with the plan and takes an active role!	join support group with other patients who have similar problems. - Physio and social worker can team up for consults-- very valuable for these patients <i>Standardise information given to patients, based on evidence</i> Communicate the same, evidence-based information to patients to minimise confusion and encourage best practices and up-to-date knowledge <i>Encourage continuity of care</i> To make sure pain gets addressed and patient does not continue to get worked up by several different providers (or go to EC instead)
Patient	This is a 40 year old	<i>Patient empowerment</i>	<i>Support primary care</i>

Cluster 7- “No control over health, poor information, and no healthcare provider (HP) to rely on”	male. He usually rarely visits the clinic, but has recently been told he has high blood pressure, so he is here to find out more information. He does not feel he has any healthcare providers he knows or can rely on, because he hardly ever visits the clinic, and prefers not to focus on his own health. However, when he does go, he feels that healthcare providers are trustworthy sources of information and feels confident talking to them to learn and to make sure his problems are understood. In general, he has never spent much time finding health information or setting personal goals about health and fitness, because he does not	Encourage HPs to spend a little bit more time with patient when first meeting them, to form better patient-physician relationship. Encourage patient to take actions like booking further appointments with the same HP to follow up. Examine why patient might not be interested in taking a more active role in health management, why he has feelings of no control- address with patient if possible. <i>Assess patient motivation</i> Before advising patient or giving out health information, assess patient's openness to information or willingness to change- give advice better suited to where individual patient is at the moment	<i>follow-up after emergency visits</i> Encourage EC patients to make follow-up appointment with primary care to better manage conditions they came in to EC for. Help them book, if possible. Send them off with a report about what was examined and determined at the visit and tell them to bring it to their primary care provider. <i>Standardise information given to patients</i> Communicate the same, evidence-based information to patients to minimise confusion and encourage best practices and up-to-date knowledge. Perhaps find one common place to disseminate information to patients to try to facilitate this <i>Encourage continuity of care</i> Both by
--	---	--	---

	feel he has that much control over his life. He has a good network of support in his family and at the church.		empowering patient to take more active role, and perhaps developing strategy to work with post-call schedules and booking follow-up appointments
Patient Cluster 2- "Not prioritising health"	This is a 43 year old female with vision issues and some bothersome skin problems. She graduated high school and enrolled in university, but did not end up going. She has to visit an eye doctor every once in a while to make sure she can see, but otherwise, tends to avoid going to the clinic when she is sick unless she is very very ill, because she has other priorities in life. When she does see a healthcare provider, she feels able to discuss her problems and follow their advice. In	<i>Target entire family/group through patients that are leaders/caretakers</i> For example, when educating patient about healthier diet, encourage them to support the same diet for the rest of their family. This is a good place to educate patient about why an intervention works for several people and gives patient an active role managing both their own health and those around them (often who have similar risk factors)	<i>Attempt to streamline process at CHC wherever possible, to lower wait times</i> Potential issues to address here are numerous, including better coverage for unscheduled/sick leave for employees, use of night shift personnel to pull folders for scheduled patients - Would have to address acute patient group most- this group most responsible for backups <i>Emphasize preventive strategies</i> Well visits and parents (healthy parents taking kids to paediatricians) are

	general, health is not that important to her and she doesn't spend much time learning about health or trying to understand her body.		great opportunities to intervene before patient is sick and has to wait for meds and follow-up appointments. Healthier patients who don't need to wait for meds would also contribute to lowering wait times at clinic, and patients may be more likely to come in for follow-up. <i>Disseminate health information in other areas</i> Have healthcare practitioners go to other groups outside of healthcare system to help get health information out in other settings—help reach patients who can't make it to CHC or choose not to go. Example: some groups ask GPs to come give talks about diabetes/blood sugar.
--	---	--	---

HP= Healthcare provider; EC= Emergency centre

Table 15: Summary of discussion of patient vignettes in workshop

4.4.3 Discussion of vignettes in Community/EFAR group

The small group discussing Community and EFAR clusters and vignettes was facilitated by Michele Twomey, Cosupervisor of the study. Other attendees for this small group were:

EFAR Coordinator (for all Western Cape EFAR branches)

EFAR Administrative clerk (for all Western Cape EFAR branches)

Mothers Unite director (also a Mothers Unite EFAR trainer)

Mothers Unite EFAR trainer and administrator

Social work intern at Mothers Unite

3 lay community members from the Lavender Hill area

Potential strategies that were suggested after discussing the follow Community and EFAR clusters are presented below, in Table 16. A more detailed report of these discussions, including the health literacy scores for each cluster and reflections of attendees in response to the vignettes, can be found in the workshop report (Appendix 13).

Comm / EFAR cluster identifiers	Vignette	Individual-level strategies	Organisational level strategies
Community Cluster 5- “Not thinking about health”	This is a 30 year old female with asthma, which causes her to have trouble breathing when she is busy running around	<i>Patient empowerment</i> Ideally want to make it easier for this person to have time to focus on their health and take a more active role	<i>Information groups</i> Gather groups of community members who have the same health concerns, and distribute information to

	to get things done. She is able to get to the clinic and talk to healthcare providers when she needs to, and finds the information that she gets there to be helpful. She has trouble comparing information from different places, so she generally just tries to accept what she hears and reads. She does not make her health a priority, because she is usually too busy taking care of her children to focus on her own problems.	in managing her asthma. Want her to realise that without her health she will not be able to continue properly taking care of her children!	them in a forum where they may compare how they have been managing their own health. EFARs may be good people to lead these groups. This will help give patients a safe place to ask questions about their conditions and ask others for advice- will help address critical appraisal issues <i>Resources for childcare</i> Find organisations that are available to take care of children so that the patient can take time to bring herself to the clinic and focus on herself. Mothers Unite takes care of children after school; need other places where children who are not in school can go during the day, or disabled children can go. Examples- Hope for the Nation, Village Care?
--	--	---	--

			<i>Buddy system for clinic visits</i> To make it easier for patients to get to clinic appointments (particularly those who are busy and forget to keep appointments), have “date club” where patients can book visits, meet up, and walk to the CHC together. This adds security as well.
Community Cluster 8- “Lack of support”	This is a 39 year old male who has diabetes. He lives alone, and has devoted a lot of his time to learning about his condition, and feels confident in his ability to manage his blood sugars and follow instructions from the healthcare providers. He feels able to ask the healthcare providers questions, though he doesn't necessarily think he has one that he can regularly rely on that knows him	<i>Social network support</i> Want to encourage patient to find other places outside of home to get support- lead to groups, clubs.	<i>Social support groups</i> Organise groups (like clubs) for individuals with similar medical conditions, but with smaller numbers of participants and less structure, so patients can make friends and get social support from others who are experiencing similar problems that they can relate to

	well. He sometimes has trouble figuring out what services he is entitled to, and does not have anyone at home he can ask for help.		
Community Cluster 11- “A lot of support but trouble taking actions”	This is a 23 year old male diagnosed with cancer. He has an excellent support network of family and friends in the community, and also feels he can rely upon his cancer specialist. However, in general he is quite passive in Dr appointments, accepting information without questioning it or asking for clarification. He has trouble understanding what to do and how to use the healthcare services to get appropriate care. He struggles to find information on his own, but has learned a lot from having	<i>Patient empowerment in a safe forum</i> Want to encourage patient to feel comfortable asking questions and taking a more active role in his visits so that he can develop skills to manage his health	<i>EFAR Program</i> EFAR program is existing way to uplift community members by educating them, giving them confidence, and providing support sessions where EFARs can discuss questions and experiences relating to health - EFARs often don't attend support sessions- try to expand this part of the program - EFARs themselves may go out into community to provide others with information

	cancer and feels that he has gotten good at comparing information that he has been given over the past year.		
EFAR Cluster 9- “Lacking support”	This is a 20 year old healthy male. He graduated high school and is halfway through his degree at the university. He chooses to do most things on his own, and is confident that he can keep himself healthy and get services if he were to need them. He doesn't have a ton of knowledge about health, but thinks this is OK because he has always been healthy. He does not feel that he has any support from family or friends, and can't rely upon his healthcare providers either.	<i>Encouragement to take health more seriously</i> Want to encourage patient to learn health information and take his health more seriously, so that he addresses health concerns before needing to call ambulance	<i>EFAR Program</i> This patient, who is well educated and independent, may be a good candidate for higher levels of training within the EFAR program. This may help provide health information and encourage interest in healthcare, as well as a more positive picture of healthcare system
EFAR Cluster 7-	This is a 38 year old male with a history of	<i>Target family</i> When encountering these	<i>EFARs as support network</i> Encourage

“Low health literacy”	depression and anxiety. He has trouble dealing with his life on a daily basis, and doesn't feel he can count on family members or doctors to help him. He is greatly confused by the healthcare system, and is not sure how to find information on his own, so he has no confidence in his knowledge about health. He is not sure what to do with new information when he does get it, and struggles to communicate well with healthcare providers to explain what is wrong and understand his options.	types of EFARs, reach out to their families and see how they are coping. Some preventive strategies might help family deal with their depressed loved one - Family members may also help ensure patient complies with medications and clinic visits	EFARs to attend support sessions; expand and market this part of the program. Often, other EFARs will reach out and support EFARs who seem to be struggling with something. EFARs may also serve others by accompanying patients to clinic to help them keep appointments, helping refer depressed patients to psychiatric resources, or visiting family members of affected EFARs to help them cope
-----------------------	--	--	--

Table 16: Summary of discussion of community member and EFAR vignettes in workshop

4.4.4 Discussion of dimensions

All workshop attendees discussed two of the nine HLQ health literacy domains and what they might do for clients who scored low in these domains. The particular scales that are discussed were:

Scale 3: Actively managing my health

People with low levels don't see their health as their responsibility; they are not engaged in their healthcare and regard healthcare as something that is done to them.

Scale 7: Navigating the healthcare system

Somebody who is low is unable to advocate on their own behalf and unable to find someone to help them use the healthcare system to address their health needs. They do not look beyond obvious resources and have a limited understanding of what is available and what they are entitled to.

A summary of these discussions can be seen in the workshop report (Appendix 13).

4.4.5 Summary of workshop recommendations

A short list of areas to target for interventions was developed based on the most important and most common problems that were identified in the workshop.

This included four themes:

1. Use of evidence-based practice and information, made consistently available to patients and community members
 - Reference to up-to-date information consistently by various providers and community-based organisations may minimize confusion and increase patients' understanding of health information
2. Use of groups to facilitate management and support for various conditions
 - Groups in community and in clinic setting for management of chronic conditions- ex back pain, diabetes

- Social support groups- ex “date club” in community to facilitate process of getting to appointments
- These groups can also be places where evidence-based information is distributed
- Should be small enough to function as a source of social/psychological support
- May utilise specialists as needed for various groups (ex physio and social worker for pain)

3. Patient empowerment to increase active management of health

- Healthcare providers can develop specific strategies to do this, and do staff-wide training to encourage similar capacity-building practices across an entire clinical site (ex teach back method, motivational interviewing..)
- Community-based organizations and campaigns may help patients overcome other obstacles so that they may focus on their health (ex childcare)

4. Large-scale campaign to educate patients on how to access healthcare services

- Need this information to get out to as many people as possible, ideally nationally
- Encourage communication across sites serving the same geographic region- continued meeting of interested parties to address on-going health literacy work
- In clinics, use sign posting and education strategies

CHAPTER 5: DISCUSSION

This chapter presents an interpretation of the results that were reported in the previous chapter. The focus is on the integration of the results on a larger scale with background information about health literacy, South Africa, and emergency medicine.

5.1 Importance of addressing health literacy in South Africa

One of the most important questions to answer when reflecting upon this research project is whether health literacy is a topic worth addressing in South Africa at this time. While there have been decades of research done in the developed world, there is a paucity of data regarding health literacy in South Africa. Partly, this may be due to differing ways that the concept of health literacy is understood or defined. There are certainly health promotion campaigns taking place in South Africa, but these campaigns don't directly identify "health literacy" as one of their aims. It could prove difficult to measure health literacy amongst South African populations given that most measurement tools were originally developed and validated for English speakers, and English is only one of 11 official languages spoken in South Africa. In fact, one study tried to use the Rapid Estimate of Adult Literacy in Medicine in a South African population speaking English as a second language, and reported that this test was inappropriate for use even when translators were present ¹¹⁷.

However, South African populations absolutely may benefit from interventions designed to increase health literacy. With approximately a fifth of the population still residing in informal shelter (and the majority of those unemployed and impoverished), most citizens rely upon the overburdened public healthcare system for all medical care. This typically means a patient must wait a minimum of one full day to be evaluated and treated at a community clinic that might be several kilometres away, in an unsafe location. A patient likely will see a different healthcare provider at each visit, and will only have a short window of time to interact with their doctor to make sure their healthcare needs are met.

Traumatic injuries, chronic medical conditions, HIV/AIDS, and tuberculosis are widespread, and there are dramatic health inequalities between patients in the private versus public realm. Empowering a population like this to take better care of their own health, utilise healthcare services and resources, and feel more ownership over their wellbeing has the potential to lead to a higher quality of life, improved health status, decreased health disparities, and increased vitality within these communities.

Additionally, in the absence of data regarding the utility of health literacy research in South Africa, anecdotal experience from the present study suggests there is a need for interventions to improve health literacy in the areas surrounding Cape Town. Nearly all parties involved in this project initially required that the concept of “health literacy” be properly explained and defined. However, immediately upon receiving this information, everyone emphatically agreed that South Africans in Cape Town could benefit from health promotion and health literacy interventions. Some individuals even mentioned other groups they knew of that were developing programs to educate and empower individuals to take more control over their health.

5.2 Language and the Health Literacy Questionnaire

The translation process used during this study was able to successfully create an Afrikaans/English version of the Health Literacy Questionnaire (HLQ) that is likely appropriate for use with populations in the Cape Town metropolis, and potentially with other South African populations.

Importantly, the original translation process was thorough and psychometrically sound. This was achieved by giving all translators a guide to the question and scale intent, having an independent checker for the provisional forward translation, and having a back translator that was blinded to the original English version as well as the document explaining the question and scale intent. Any discrepancies that arose during this process were thoroughly discussed by the Chairperson, Principal Investigator, and two local bilinguals during the first translation teleconference.

Changes that were made after the provisional forward translation was created reflected differences in local dialects, stylistic preferences, or a level of comfort with “formal” Afrikaans that would be appropriate for the presumed HLQ target population; there were no changes that occurred due to errors during the initial translation process.

Following field testing with the first, Afrikaans-only version of the HLQ, it became clear that the test population experienced difficulty answering all of the questions. As a result, during the second translation teleconference, additional changes were made to the Afrikaans translation. The decision was also made to include both the Afrikaans and English versions of each scale and question in the same combined-language HLQ, with the English as a smaller, italicised script directly beneath each corresponding Afrikaans statement. It is important to consider whether these changes weaken the strength of the translation or the appropriateness of using the HLQ for future Afrikaans or English speakers in South Africa.

“Formality” of Afrikaans language

One of the most commonly echoed concerns during the entire translation process was regarding what level of “formality” to use for the Afrikaans translation. In the greater Lavender Hill area, almost all individuals have received some level of formal education in both English and Afrikaans, and no HLQ participant reported attending a strictly Afrikaans-only school. While the preferred, colloquial language spoken in Lavender Hill is more often Afrikaans than English, both languages are spoken frequently. Additionally, some bordering townships speak primarily isiXhosa and English, so English appears to serve as a common language almost as frequently as Afrikaans.

Accordingly, the dialect for the greater Lavender Hill area tends to reflect Afrikaans with English (and occasionally isiXhosa) words and phrases incorporated. Some formal Afrikaans vocabulary words appeared to be infrequently used whenever there was an easier or faster way to speak or conceptualise the same idea. For example, the Afrikaans “kontroleer” for “check

up on” was changed to “maak ek seker,” which simply means “make sure of” (and is more similar in structure to English). The bilinguals who participated in the translation teleconference believed this change reflected a more realistic and common way that a majority of Afrikaans speakers would ask the question, and importantly, this would still retain the same meaning for speakers of a more formal Afrikaans. As presented in Chapter 4, other words or phrases were changed for similar reasons, and one of the measurement scales was changed as well. When an Afrikaans word was somewhat poorly understood but had no substitute that would preserve the same meaning, the Afrikaans word was left in place (for example, “bronne” was used for “sources”).

As a more dramatic example of this, two Anglicisms were incorporated into the final Afrikaans version: “gehalte” was changed to “kwaliteit” (for “quality”) and “doeltreffend” changed to “effektief” (for “effectively”). Again, the changes were accepted because it was believed they would be understood by greater Afrikaans speakers (particularly those with lower education) and reflect the dialect of the townships outside of Cape Town more closely. It is believed that the original intent of the questions was not changed by altering these vocabulary words. However, further work using the finalised Afrikaans/English version of the HLQ should investigate how Afrikaans speakers from other areas of South Africa understand and interpret these items.

Stigma tied to language

It is important to consider whether stigma associated with either of these languages (or their formality) factors into how the HLQ is viewed by participants. Historically, both Afrikaans and English were languages cultivated in South Africa by European colonisers during Apartheid, and in fact were the only two official languages until 2003¹¹⁸. Afrikaans is uniquely South African, giving some South Africans a sense of pride. Additionally, some associate Afrikaans with education because when they attended primary or secondary school, it was the predominant language of instruction. However, others feel that speaking Afrikaans pays tribute to the Dutch colonisers responsible for

much of Apartheid. On the other hand, English has been associated with upward mobility, higher education, government, or commerce, and is recognised by some as a globally-important language¹¹⁸. While English still may be upsetting to South Africans who speak or value indigenous tongues, it does appear to be slightly less emotionally polarising than Afrikaans.

Stigma associated with the language of a questionnaire can certainly alter how a participant views a research project, its relevance to their people, and their willingness to participate. During this study, it was recognised that participants would sometimes request to have an HLQ read to them in one language or the other based upon who was offering to administer it, regardless of what language they ended up saying they felt most comfortable with. Additionally, many participants would attempt to take the questionnaire in one language first, but end up referring back to the other language for most questions. This may reflect an inclination for participants to tailor their responses slightly depending on how they perceive the questionnaire administrator.

Combined language version

The decision to include both Afrikaans and English was therefore strategic in several ways. While these languages are only the third and fourth most commonly spoken first languages (respectively), a majority of South Africans have had some exposure to either or both of these languages through education or interaction with the government or business worlds. Additionally, providing both languages on the same HLQ allows the questionnaire to be given without requiring the participant to identify which language they prefer. This has the dual effect of avoiding some potentially-negative stigma associated with choosing between these languages, as well as allowing participants to refer to either language for clarity if they come across a difficult concept or vocabulary word.

5.3 Validity of the combined-language HLQ

After the translation process was completed, cognitive interviews were performed as another way to assess whether the original intent of each question and scale were understood by the target group. Feedback was also solicited from HLQ administrators regarding their interactions with participants while giving the questionnaires. Cognitive interviews were performed in exclusively Afrikaans, exclusively English, and with the combined Afrikaans/English version of the HLQ. Issues that arose during these processes centred around understanding of the measurement scales, low prevalence of critical appraisal skills, and Afrikaans vocabulary.

Conceptualising the measurement scales

After approximately 50 HLQs had been administered, it became apparent that a small minority of participants had a unique understanding of the measurement scales. This was true more so in the Agree/Disagree scale than the Easy/Difficult scale, but problems were seen conceptualising both.

The problem seemed to be that a participant could not distinguish what all of the gradations on a given measurement scale meant in relation to one another, even though they were aware that at least two answer options were available. For instance, all participants knew what it meant to either “Agree” or “Disagree” with a statement. However, a small percentage of participants did not grasp what it meant to “Agree” versus “Strongly agree”, so they would only check off one of two responses. For example, all answer choices would be marked either “Agree” or “Disagree” only. In some instances, participants would only mark “Strongly disagree” or “Strongly agree” for the same reasons. When HLQs were given in the oral format, this response pattern took the form of a participant either shaking or nodding their head rather than specifying one of four or five response options. To attempt to have these participants make a selection, HLQ administrators were required to ask participants to choose, and did not just mark down an answer choice for them.

Given that the measurement scales determine how each of the health literacy domains are evaluated, problems with these scales can significantly alter how

valid it is to use the HLQ for a target population. It is believed in general that people who have little experience or education in mathematics may struggle to use interval scales like those found in the HLQ. An HLQ administrator who also has experience developing triage scales reported encountering similar difficulties when trying to institute a 1-10 pain measurement scale. Not surprisingly, participants who seemed to have difficulty with the scale gradations tended to be older and have less formal education.

Fortunately, the majority of participants understood the scales quite well and chose a variety of responses. In the study population, the number of individuals who appeared to have difficulty with the scale is likely not high enough to deem the HLQ invalid or unusable for South African populations. However, this concern must be investigated further with any additional studies using the HLQ. It is possible that with time, a more educated population with more formal exposure to mathematics will predominate, eliminating this concern.

Understanding critical appraisal

Some participants appeared to struggle to answer questions in the “Appraisal of health information” scale, both in the Afrikaans-only and English-only versions. However, overall it appeared that most participants understood what the questions in the scale were asking, but were not familiar with all of the concepts raised by the questions. For instance, most participants could accurately describe what it meant to compare and contrast information, but paused when they got to questions asking whether they compare health information because it did not appear to be something the participants had done very often. As another example of this, when participants encountered the statement “I ask healthcare providers about the quality of the health information I find”, they were able to describe what “quality” meant, but most participants did not report actually speaking with a provider about quality of information. Multiple participants ended up justifying their answers for questions on this scale by ultimately saying they were too lazy to critically evaluate information or did not think it was important to do so.

Afrikaans vocabulary concerns

As expected, a small minority of participants had difficulty understanding some Afrikaans vocabulary, including “fiksheid” (fitness), “vergelyk” (compare), “op datum” (up to date), and “bronne” (sources). However, all participants quickly understood the meaning of these words when pointed to the equivalent word in the English version. Additionally, no participants were confused or asked questions about words like “kwaliteit” that had been used in place of more formal Afrikaans during the translation process.

Ultimate success of combined language version

The combined Afrikaans/English overall was successfully understood and used by participants. While there were some difficulties encountered as described above, these cases represented only a small minority of participants out of the nearly 300 that took the HLQ. Essentially no participants asked administrators to define specific words when the text was available in both Afrikaans and English. Importantly, no participants appeared emotionally disturbed by the questionnaire or the presence of Afrikaans and English languages, and having both on the same paper appeared to facilitate a more relaxed, bilingual communication between participants and the HLQ administrators. It is believed this final combined language version is therefore valid for the target population in South Africa, and is likely to be useful for further studies within the country in the future. Of course, it is possible that new issues may arise when the HLQ is used in a different setting. Further successful use of the HLQ in South Africa should take place to strengthen its validity countrywide.

5.4 Comparison of health literacy across participant groups

Overall, there were minimal differences between the Community, Patient, and EFAR group’s health literacy scores. Original predictions about EFARs and Patients scoring higher than the Community members overall and in some scales did not turn out to be confirmed. However, there was one scale where the EFAR group scored significantly higher than the patient group ($p < 0.05$):

“Navigating the healthcare system.” Looking back at the HLQ scales and items document (Appendix 3), the questions that contribute to a score for “Navigating the healthcare system” include:

Find the right health care

Get to see the healthcare providers I need to

Decide which healthcare provider you need to see

Make sure you find the right place to get the healthcare you need

Find out what healthcare services you are entitled to

Work out what is the best care for you

There are several reasons why EFARs may score higher on this domain than patients. EFARs have been exposed to training by paramedics and other EMS providers, possibly allowing them to feel more competent and more comfortable speaking with healthcare providers and staff. A greater level of comfort and familiarity with medical evaluation and treatment, in turn, may help EFARs feel more confident utilising health services. In fact, a study on the psychological effects of the EFAR program demonstrated that community members felt more empowered and more confident in emergency situations after taking the EFAR course ¹¹⁹. It is plausible that this confidence and empowerment extends to other healthcare-related situations.

Follow up on predictions regarding EFARs

Prior to the start of the data collection, it was predicted that EFARs would have the highest overall health literacy scores, as well as higher scores compared to Community in “Having sufficient information to manage my health”, “Actively managing my health”, “Ability to find good health information”, and “Understanding health information well enough to know what to do”. However, EFARs did not vary significantly compared to the Community group for any scales, and the overall health literacy scores for all three groups did not vary either. This may indicate that although EFARs are given health information and

access to a computer at Mothers Unite, the effects of the course and relationship with Mothers Unite are not substantial enough to influence the health literacy of EFARs.

It might be that because EFAR training prepares a volunteer to respond to emergencies that occur to other people in their community, EFARs do not internalise their training as health information that is relevant or usable for their own health. Additionally, part of the reason why it was predicted that EFARs would score highly on “Having sufficient information to manage my health” and “Ability to find good health information” was because Mothers Unite reported that they had a computer library with electronic resources relating to a wide variety of health concerns, and that they informed all EFARs that they were free to use this resource whenever convenient. However, while there was a functioning computer and library at Mothers Unite, it was not clear that EFARs were informed that they had access to it. Many EFARs reported they were unaware of this resource, and many others received their EFAR training prior to this resource being available. In the future, consistent access to and awareness of this resource may change the pattern of responses from EFARs within these scales.

Perhaps most surprising is a lack of significant difference in “Understanding health information well enough to know what to do”, particularly because prior studies suggest EFARs retain part of their training for months after their course and demonstrate increased confidence and initiative to help in an emergency situation^{46,119}. However, this likely relates back to the items that define this measurement scale:

Confidently fill medical forms in the correct way

Accurately follow the instructions from healthcare providers

Read and understand written health information

Read and understand all the information on medication labels

Understand what healthcare providers are asking you to do

While all of these skills (aside from reading information on medication labels) are practiced in EFAR training, it may be that EFARs do not immediately consider this training when they read these questions. During the cognitive interviews that took place with EFARs, in fact, no EFARs described recalling working with paramedics and other healthcare providers to learn and apply skills- they were more prone to recalling interactions with their own healthcare providers when they were seeking care for their own medical problems. If these questions were written in another format (for example, “Know what to do in an emergency”), it is likely that EFARs would indeed have scored higher on this scale.

Finally, it might be that the sample size was too small to demonstrate the predicted effects. It may also be that EFAR training unfortunately does not provide EFARs with enough information or skills to impact their health literacy as measured by the HLQ, and that their knowledge and skills are too specific for emergency situations to significantly alter any of the scales.

Follow up on predictions regarding Patients

Similarly, it was predicted that the Patient overall health literacy score might be higher than the Community group (though not as high as EFARs), and that the patients would have higher scores than Community on “Feeling understood and supported by healthcare providers”, “Actively managing my health”, “Ability to actively engage with healthcare providers”, and “Navigating the healthcare system”. However, none of these predictions were confirmed. Once again, it might be that the sample size was too small to demonstrate the predicted effects. It may also be true that patients do not differ significantly from community members. It was originally thought that patients may be more likely to have experience with the healthcare system, more likely to have health problems, and more likely to have an active role in their healthcare, given that they were encountered in the clinic rather than in the community. However, this does not appear to be the case.

Further, it may be that even among patients who have historically spent more time at the clinic, their experiences have failed to improve their health literacy as measured by the HLQ. This would occur if patients failed to improve upon the items measured by each of these scales, which include:

Feeling understood and supported by healthcare providers

I have at least one healthcare provider who knows me well

I have at least one healthcare provider I can discuss my health problems with

I have the healthcare providers I need to help me work out what I need to do

I can rely on at least one healthcare provider

Actively managing my health

I spend quite a lot of time actively managing my health

I make plans for what I need to do to be healthy

Despite other things in my life, I make time to be healthy

I set my own goals about health and fitness

There are things that I do regularly to make myself more healthy

Ability to actively engage with healthcare providers

Make sure that healthcare providers understand your problems properly

Feel able to discuss your health concerns with a healthcare provider

Have good discussions about your health with doctors

Discuss things with healthcare providers until you understand all
you need to

Ask healthcare providers questions to get the health information
you need

Navigating the healthcare system

Find the right health care

Get to see the healthcare providers I need to

Decide which healthcare provider you need to see

Make sure you find the right place to get the healthcare you need

Find out what healthcare services you are entitled to

Work out what is the best care for you

Regarding the scale “Actively managing my health,” it was predicted that patients who have chosen to spend the day at a clinic seeking care would be more likely to devote time and energy to other activities to support their health. However, patients did not score differently on this scale compared to EFARs or community members. This may highlight that all of these groups may not possess enough knowledge about health to be actively involved in healthy activities outside of the clinic environment. For example, individuals may not know how diet or exercise can contribute to things like diabetes and hypertension. Or, they might not know exactly what a “healthy diet” looks like. They also may lack enough self esteem or sense of self worth to prioritise their health, or have their time preoccupied by other concerns relating to basic survival.

Most of the other three scales involve a majority of questions related to interactions with healthcare providers and services. Improvement in these

realms of health literacy thus depends on providers and health systems as much as it does on the capacities of individual patients. Failure of patients to demonstrate higher scores in these scales may therefore reveal issues with the Retreat CHC services. In support of this idea, when vignettes were discussed with health department employees and physicians in the feedback workshop, it was often echoed that there were known problems with patient access to a consistent provider. It makes sense that patients without at least one identifiable provider to learn to rely upon or become comfortable interacting with would score lower than expected on these scales.

It was surprising that no other differences emerged when comparing the groups. Additionally, overall health literacy scores were higher than expected. It is important to consider whether there are biases that have affected all or part of the data in a way that minimises differences between groups. This may be the case if scores tend to be higher than would be expected if health literacy was a normally-distributed variable in the population. There are several factors to consider regarding these results, including the Dunning-Kruger effect, ceiling effect, overconfidence effect, sampling bias, observer-expectancy effects, and demand characteristics.

Dunning-Kruger effect

The Dunning-Kruger effect is a well-described cognitive bias wherein unskilled individuals mistakenly overestimate their abilities and are unable to fully recognise their inadequacies¹²⁰. Incompetence causes poor performance as well as an inability to realise that performance is poor due to a lack of metacognitive skills among less skilled individuals.

It is quite possible that individuals residing in the greater Lavender Hill are prone to this type of bias. Public health services for this population are overcrowded, underfunded, and therefore inefficient. Access to health-related education and materials is extremely limited, leaving people relying more on their social network, personal experiences, and traditional rituals and healers for information. Additionally, the country is still emerging from Apartheid, during

which time all of these limitations were even more pronounced. In this type of environment, it would not be surprising to have widespread inadequacies in multiple areas of health literacy. Such inadequacies should be interpreted not as a reflection of the intrinsic capacities of individuals living in the Cape Flats, but as an inevitable result of decades of oppression, poor health services, and neglected education.

If it is indeed true that a large proportion of the study population has overestimated their abilities, one would expect certain patterns to emerge in the data. Overall health literacy scores (as well as scores within each of the nine domains) would likely be relatively high. There may be a negative skew to the pattern of responses within each scale, reflecting a tendency for more participants to choose higher marks than would occur if health literacy domains were all normally distributed. Indeed, both of these patterns are seen within the data: overall health literacy and domain scores are fairly high, and some (though not all) of the frequency plots for the nine health literacy scales have a slight negative skew.

Importantly, there is a critical additional aspect to the Dunning-Kruger effect: when these unskilled individuals are exposed to training for a given skill, they are typically then able to acknowledge their previous lack of that skill ¹²⁰. This would mean that individuals with greater experience with the field of health and healthcare might tend to score lower on their HLQ domains. Interestingly, anecdotally the researchers for this study recognised that there appeared to be a bit of a response shift among EFARs taking the HLQ. EFARs with more advanced levels of training (including the seven level-3 EFARs as well as numerous level-1 EFARs) tended to score much lower than their Basic EFAR counterparts. While the number of participants from each EFAR training level was not high enough to formally statistically measure this effect, it does suggest that some type of response shift might exist. This may be unique to EFAR training or simply further support the possibility that the Dunning-Kruger effect is relevant in this population.

Of note, if present, this response shift would contribute towards EFAR scores overall not being as high as originally predicted. In support of this, the overall health literacy score for the EFAR group was the highest (though not statistically significantly), but this group also had the highest standard deviation. This may indicate that while most EFARs scored high overall, there were several participants that scored further away from the mean (most likely the few advanced EFARs, demonstrating the response shift). Overall, it is very likely that the Dunning-Kruger effect is responsible for some part of the relatively high scoring overall that occurred in all three groups.

Reality, ceiling effect, overconfidence effect

Of course, there are several other reasons why overall health literacy scores may be higher than the actual health literacy of the study population, as well as reasons for some of the nine scales to have a slight negative skew. The study population may indeed have overall high health literacy, though with widespread high health literacy one would expect a population that is more empowered and engaged in health. Even more likely is that some particular scales truly are not evenly distributed in the population. For example, “Social support for health” might even be expected to have a fairly high average score in this population, where social networks are extensive and often necessary for survival and wellbeing.

Another possibility to consider is that there is a ceiling effect that is causing some difficulty measuring the actual central tendency of data. This might be the case if individuals in the study population do not view the extremes of the two measurement scales (“Strongly disagree/Strongly agree” and “Cannot do it/Very easy”) as the actual extremes of response options. While this effect may exist in this study, it is slightly less likely given the extensive translation and validation processes that took place before using the HLQ to collect data. However, to investigate this in the future, it might be helpful to ask individuals how they might express how intensely they agree or disagree with a statement (or how

difficult or easy it is to do a task), without providing a measurement scale to refer to.

Another possibility for relatively high health literacy scores and a slightly negatively skewed distribution of scale scores is overconfidence effect, where some or all groups of participants tended to have more confidence in their abilities and beliefs than might be warranted. Confidence in one's abilities and knowledge may be an important aspect of self-esteem or self-preservation for some participants.

Another possible cause for the observed pattern of mean health literacy scores is participants' emotions or self image preventing honest responses. For instance, a participant may be too proud or embarrassed to openly state to a stranger that they have no social support. Similarly, they might not want to admit if they don't understand a question or the concept of the questionnaire at all, so they just check off boxes or provide answers without fully understanding the implications of their responses. This is particularly important to consider given possible issues with a few Afrikaans vocabulary words.

Sampling bias

It is important to consider whether sampling bias is responsible for some of the patterns observed in the data- or lack thereof.

For safety reasons, community members were recruited almost entirely through contact with Mothers Unite staff members. Some community participants were parents of children who attended Mothers Unite for after-school care. Others were family members, friends, or acquaintances of staff members. Some happened to be passing by the grounds when HLQs were being given out to willing passers-by. This pattern of recruiting connects most participants fairly closely to Mothers Unite.

EFARs were recruited in several ways. EFARs that were close family or friends with staff EFARs from Mothers Unite were personally offered HLQs. In addition, several mass messages were sent out to all current EFARs who had provided

phone numbers (approximately 300), using a web-based communication program that is in development. All EFARs attending a Mothers Unite training or support session were offered voluntary, anonymous participation as well. EFARs who chose to participate may be those that are more interested and involved in first responder training, health, or education, which may skew their responses overall as a group and not accurately represent the health literacy of all EFARs in Lavender Hill. However, this is not very likely to have had a significant effect in this particular population. Nearly all EFARs that were offered HLQs after training or a support session participated and only 10% of responses were from volunteers who responded to the phone messages, so the data is likely a good reflection of EFARs as a group overall.

Patients were recruited over four different days at the Retreat Community Health Centre. Between three and seven different HLQ administrators (all certified EFARs and staff members at Mothers Unite) were present and dispersed spatially throughout the waiting areas of the clinic. Patients were approached at random and invited to participate. The patients who chose to participate may represent a different population than if all patients at the CHC over the same time period were sampled.

In the future, randomisation and alternative sampling strategies may be used to try to mitigate potential sampling bias that resulted during this study.

Observer-expectancy effect, demand characteristics

A majority of participants preferred to have the HLQ read aloud to them. This means that a majority of HLQ responses were obtained by having one of about nine HLQ administrators give the questionnaire. This type of arrangement predisposes responses to an observer-expectancy effect, where administrators may subtly be phrasing or presenting questions in a way that elicits particular responses more often. Additionally, demand characteristics may influence the data, particularly for groups like the EFARs that might believe their scores will affect their standing as a trained responder.

In anticipation of the risk for these effects, a training session was conducted with all HLQ administrators prior to beginning data collection. Among other topics, the training session taught administrators why it was important to avoid phrasing questions a particular way or providing supplemental information to some participants. Each administrator practiced giving an HLQ with the Principal Investigator of the study prior to interacting with study participants. However, this training session alone can not eliminate the risk for significant observer-expectancy effects or demand characteristics.

5.5 Formation and use of vignettes

After the HLQ data was collected and statistically analysed, narrative vignettes were developed to facilitate the discussion of clusters during the feedback workshop. The intended purpose for these vignettes was to provide meaningful, more tangible, realistic portraits of people that workshop participants already interact with on a regular basis. This allows the workshop participant to recollect what strategies they have used successfully already in the past to help these people. This empiric knowledge could then be shared with the group, so that others may benefit from that experience.

The vignettes successfully painted portraits of common community members, EFARs, or patients that workshop participants encounter frequently.

Participants endorsed all of the vignettes discussed in the workshop as seeming familiar and realistic, and many participants shared stories from when they have interacted with those types of cases in the past.

A few techniques were used to create these vignettes. One or a couple of a cluster's highest-scoring scales were included in each vignette, with the hope that this might help facilitate the creation of targeted interventions for the lower-scoring scales. For example, if a cluster scored very high in Social Support, the vignette would mention that the person had a powerful, trusting relationship with their family in order to identify a strength that future interventions could take advantage of. Lower-scoring scales were included to reveal areas of need. Demographics were taken from the statistical questions. Some of these

vignettes were based roughly off casual interviews with HLQ participants, while others were imagined. Workshop participants did not appear to distinguish whether a vignette was based off of an interview or fabricated.

Originally, one of the goals of this research project was to establish a database of these vignettes for reference in the future. Accordingly, all workshop participants were provided a full list of all 32 vignettes, along with their associated health literacy scores and demographics. These vignettes will remain available for use if researchers in the future request them. However, a formal database has not been created at this time. The somewhat small numbers of participants in each cluster and use of several recent interviews as a basis for the vignettes made these profiles fairly unique. In the future, a similar strategy for the new set of HLQ participants will be more likely to produce appropriate vignettes for the new study population than referencing those created for this project.

5.6 Reflections on the feedback workshop

Following are reflections specific to portions of the workshop.

Vignette discussion groups

The most successful strategy used in the vignette section of the workshop was splitting into two separate, smaller focus groups to discuss vignettes, with participants free to choose which group to attend. Ultimately, participants from all three areas were found in both groups. Performing the vignette focus groups in this way appeared to have the effect of emphasising that input from all three areas was essential to the project, and community members and healthcare staff both had valuable information for one another.

Sample case presentation

One effective strategy that helped reunite the group after the vignette discussions was to ask a volunteer from each focus group to present a brief overview of one case they discussed. This revealed that while both groups

underwent a similar process of recognising the vignette, identifying the problems, and brainstorming solutions, the intervention ideas differed in their approach based on their setting. However, it was clear that having interventions at multiple levels simultaneously could be a more powerful way to address an identified health literacy need.

Scale discussion

One strategy that helped make this part of the discussion a success was choosing the two scales right before the discussion actually took place. The decision was made by the two facilitators that had guided each of the focus groups, who jointly identified which scales the groups had seemed most interested and concerned about. Interestingly, the two scales that were picked had been quite commonly echoed and identified as problematic for the study population. The two scales that were discussed in this section were “Actively managing my health” and “Navigating the healthcare system”.

Having the discussion about these scales as a larger group was quite beneficial. Participants had already had some time in their smaller groups to talk about what to do for individuals who scored poorly on these scales. Discussing the issue again in a more isolated format with the entire workshop group allowed for collaboration to occur across the community, EFAR, and health services realms. After the workshop ended, participants even stayed behind to continue to discuss how they could officially work together in the future on the identified problems.

5.7 Identified health literacy needs and early interventions

As presented in the workshop report, there were numerous ideas for interventions developed in response to identified health literacy needs. Specific strategies were proposed for intervening at an individual level (for example, patient empowerment techniques and a need for healthcare providers to assess patient motivation) as well as at an organisational level (such as standardising care based on evidence or a buddy system for clinic visits).

Based on the most repeated sentiments from the workshop, a short list was created of the most important themes to focus interventions on. The four most common concerns were 1) the need for evidence based medicine, 2) use of groups to facilitate management of conditions, 3) patient empowerment, and 4) education about how to access health services.

Evidence-based practice and information

Both health services staff and community/EFAR members felt there was a need to make health care and information consistent and based upon current evidence. This would involve practitioners using a more standard treatment plan for common conditions like asthma and chronic pain. It would also involve making the same evidence and other up-to-date health information available to EFARs and community members. Several individuals at the workshop expressed concern that there is diversity in medical practices amongst healthcare providers, which makes it hard for patients to gain a better understanding of their condition and what proper management entails. For instance, one physician might state that chronic low back pain is caused by muscle spasms and is treated best with stretching, while another informs patients that this pain is due to chronic inflammation and improves when the patient takes routine anti-inflammatories. This situation is even more problematic considering that there are system-wide difficulties maintaining continuity of care within the CHC, so patients typically see different doctors every time they visit. Workshop participants also felt it was important for these practices and updated health information to be more easily reached by both doctors and patients/community members. This workshop theme highlights how the needs of individuals at a community level are often similar to the needs of providers. If there is a systematic lack of available, updated health information causing problems at both of these levels, it is likely that a systematic intervention like increasing the availability of evidence-based medicine will serve the entire community well.

Use of groups to facilitate management and support

All workshop participants felt that the use of groups could address several identified health literacy needs. For example, groups of patients with diabetes could meet in the community as well as with specialists and social workers through the clinics. This would facilitate the distribution of current, evidence-based information and practices for management of these chronic conditions. Additionally, they would function as social and psychological support. Having a group of patients with similar conditions could alleviate some of the burden off of providers at the clinics that would otherwise need to see each patient individually. This theme emphasizes how strategies that work in one setting may also work well in another, and also points out a practical way that an intervention can involve collaboration between health services and community-based organisations.

Patient empowerment

Over the course of the workshop, it was often stressed that one way to improve the health of the community would be to empower individuals to take more ownership over their health. Several strategies to support this were proposed, including staff training for healthcare providers in patient empowerment techniques as well as community-based campaigns to help individuals overcome obstacles to managing their health. This theme highlighted how a particular health literacy need may be addressed by separate interventions that function through a particular organisation or service. A lack of patient empowerment is likely a problem with numerous contributing factors, so there are several different areas where interventions may work to address the problem.

Campaign to educate patients on how to access health services

Finally, it was commonly echoed that patients and community members are often not aware of how to properly access health services, which contributes to overcrowding and time delays in care. There are some local strategies that were proposed to address this need, including sign posting/education strategies and meetings of providers in geographical proximity to standardise access.

However, it was felt that the need was so great and so common that the best way to intervene would be to launch a large-scale (provincial or country level) campaign to educate patients how to access services, most likely using multiple forms of national media. This discussion emphasises how the use of this health literacy framework can lead to large-scale, systematically applied interventions that have the potential to benefit an entire country.

5.8 Relationship to Ophelia process and Public Health Innovation (PHI)

Overall, this project has had a mutually beneficial relationship with PHI. An exchange of ideas and feedback has taken place about both the HLQ and some of the principles of the Ophelia process. Additionally, a relationship has been forged that hopefully can continue into the future.

The HLQ in Cape Town

One major success of the collaboration between PHI and the principal investigator of this study was to translate and validate the Afrikaans version of the HLQ for use in South Africa. To our knowledge, this is the first comprehensive health literacy assessment tool available for use in South Africa or with Afrikaans speakers. This opens up endless possibilities for further health literacy research in this region.

Additionally, the successful validation of the HLQ in this new population strengthens the overall validity of the questionnaire. Publishing this study may help encourage more widespread use and cultural adaptation/validation of the HLQ. This may, in turn, lead to a new body of literature relating to the use of the HLQ in health literacy research across the globe.

The Ophelia process in South Africa

There were several important differences to consider when comparing this study with the Ophelia protocol as recently published. This project was much more limited than the systematic approach seen in Victoria, with only one principal investigator driving the project on the ground. There were three

participant groups and only one geographical location, as opposed to eight organisations collaborating with two universities and the local government. At the present time, the project has gone so far as to hold a workshop to develop early intervention ideas, but has not piloted these interventions or run Plan-Do-Study-Act cycles to refine them. A community of practice would be difficult to establish at this point given limitations in the numbers and types of participants.

In addition, this project was unique from the rest of the Ophelia process in that community members and a volunteer layperson first responder program were included in the study population, and the study required collaboration with a pre-existing community based organisation. The feedback workshop was unique in bringing together participants from these distinct, yet closely related groups within the Lavender Hill area. Accordingly, interventions reflect the importance of these groups within the community and a proposed role for them in improving health disparities.

However, as for the HLQ, collaboration between PHI and this project has been mutually beneficial. The researchers using the Ophelia protocol in parallel in Victoria were able to advise us about successful techniques or potential pitfalls when collecting, analysing, and presenting data, and also provided statistical expertise. In addition, our project provides a case study for PHI in how the Ophelia process might be adapted and used in different settings. As for the HLQ, this may lead to other research being carried out across the globe. Further research and experience with the HLQ and Ophelia principles can continue to provide validation or feedback about how these tools can best be used to improve health outcomes and health inequalities.

5.9 Using the EFAR program to address health literacy

Finally, there is the question of whether the primary aim of this study has been achieved: the creation of a framework that uses EFARs to help identify and respond to health literacy needs.

There are several core concepts and values that are honoured by the EFAR program, the Ophelia process, and this project. Most importantly, all place extremely high value on the communities they serve, and believe community members and leaders possess critically relevant and useful knowledge about their people. This knowledge comes from years of experience living and/or working successfully in their own neighbourhood, and simply can not be learned easily by visiting researchers. Involving community leaders in the co-creation or co-ownership of key aspects of the project is essential for the success of any program or intervention.

Additionally, involving community leaders and the EFAR program as key players in this project led to unique intervention ideas that reflect the culture of the greater Lavender Hill community and depend upon its strengths. For instance, the large percentage of proposed interventions that include groups and collaboration reflect the interdependence of individuals and organisations that is an inherent part of this community.

Shared belief in reliance upon and coordination with community leaders allowed the pieces of two seemingly unrelated parallel programs to flow seamlessly together: the EFAR program and the Ophelia process. Given their experience and training within the EFAR program, Head EFARs and the director of Mothers Unite were quite familiar with the processes of recruiting participants, discussing research, and participating in formal and informal feedback. They were already familiar with the principle of co-ownership of the project and knew what undertaking a commitment to the health literacy project would entail. Also, because they were Head EFARs at a respected, well-known community based organisation, they had access to an extensive network of EFARs and community members within the greater Lavender Hill area. EFARs were quite familiar with the Retreat CHC and were able to anticipate and plan around barriers to completing data collection on site.

Further, EFARs had contacts within the community, at the EFAR governing body level, and through healthcare services at local clinics that they were able

to reach out to and invite to participate in the feedback workshop. EFARs are also perfectly situated as an intermediate party between community members and health services, making them valuable for several health promotion interventions. This may even represent a pathway for EFARs interested in research or health promotion to become more involved in these areas. Similarly, one of the reasons the Head EFAR level of training was created was to provide additional levels of education, experience, and integration with health services to individuals who chose to pursue this.

Finally, on a more practical note, EFARs already operated from a central location within the Lavender Hill area and had access to a meeting space that could be used to base future community- or EFAR-based health literacy interventions. This space was normally used for EFAR training courses and support sessions.

In short, this project would have been exceedingly difficult (if not impossible) without the dedication and co-ownership of the EFARs at Mothers Unite. The EFAR program is therefore an excellent resource to build upon in the creation of a health literacy framework.

5.10 A model for identifying and responding to health literacy needs using the EFAR program

An outline of the general steps involved in the framework is provided below:

1. Research coordinator (RC) identifies and meets with EFAR-associated community-based organization (CBO) to discuss interest and feasibility of conducting health literacy project in their community
2. If CBO is interested, they may provide anticipatory guidance about unique local context that might influence the study
3. CBO invites EFARs to participate in study
4. RC gives training to willing EFARs on how to administer HLQs
5. EFARs administer HLQs to target population. During this time, they provide feedback to the RC about the process. CBO will securely and

confidentially store HLQs until RC can collect them, and may also provide a safe place for HLQ administration to occur.

6. RC performs data analysis
7. EFARs and leaders of CBO invited to participate in feedback workshop, as well as help identify other local leaders and healthcare providers to invite.
8. Feedback workshop facilitated by RC. May take place at CBO, but not required.
9. Interventions initially proposed in the workshop further developed by RC in conjunction with EFAR, CBO, or other local participant that wishes to lead pilot testing of an intervention.
10. Interventions tested.

An overview of the roles for each involved party are discussed further below.

Community-based organisation (CBO)

Co-ownership of the project by a CBO operating an EFAR branch is essential to the success of this framework. CBO involvement will likely increase EFAR and community member buy-in and can provide valuable local context that will be useful in adapting and executing the project, as well as properly interpreting the results. The CBO may store HLQs in a confidential manner until they handed over to the RC, and may also choose to offer their grounds as a safe place for EFARs to administer HLQs. The CBO may also choose whether or not to host the feedback workshop, but should have representation in the workshop. The CBO may decide to undertake a community-level health literacy intervention that is identified in the workshop, though this is not required.

Emergency First Aid Responders (EFARs)

EFAR involvement will also likely increase community member buy-in, and EFARs are another valuable source of information about local context and potential need for adaptation of the framework. EFARs will administer HLQs to the target population and provide feedback on the reception and any difficulties

encountered with the HLQ. They may choose to participate in the feedback workshop and may also help identify other candidates for participation. EFARs, like CBOs, may decide to get involved in a health literacy intervention that is identified in the workshop, but this is not required.

Research coordinator (RC)

The RC will initially contact an EFAR branch CBO and introduce the project. The RC will continue to serve as the contact person for all issues related to the study. The RC will run a training session on how to properly administer HLQs, and will be responsible for data analysis once all HLQs are administered. Finally, the RC will serve as the facilitator of the feedback workshop and will help guide the refinement and early implementation of interventions. Further testing of interventions will likely involve the RC, but may vary depending on who ends up taking a primary leadership role for a particular intervention. Importantly, the RC may be any person who is familiar with the EFAR program, the field of health literacy, and principles related to conducting research. The RC may therefore even be an EFAR, CBO leader, or member of the EFAR governing body.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

6.1 Conclusions

This study adds significantly to the body of knowledge and experience studying health literacy in South Africa. It also provides valuable experience with both the EFAR program and the Ophelia process.

6.1.1 Utility of studying health literacy in South Africa

South Africans are currently subject to dramatic health inequalities and a heavy burden of both disease and injury. This population is likely to benefit from interventions designed to increase health literacy through patient empowerment, improved patient outcomes, and decreased health disparities. Interventions may reach many individuals with low health literacy through emergency centres or pre-hospital emergency medical services.

6.1.2 Validity of the English, Afrikaans, and combined language HLQ for use in South Africa

The translation process used during this study was able to successfully create an Afrikaans version of the Health Literacy Questionnaire (HLQ). The combined Afrikaans/English version was used most successfully. This version is likely appropriate for use with other English and/or Afrikaans-speaking populations in the Cape Town metropolis, and potentially with other South African populations. Further testing should be performed regarding the validity of the HLQ in other South African populations.

6.1.3 Health literacy data from Lavender Hill

EFARs appear to be slightly better than the average Lavender Hill resident at navigating healthcare services. This may reflect an increase in confidence or knowledge about healthcare access as a result of EFAR training.

A failure of health literacy scores to improve amongst patients with potentially more exposure to healthcare providers may be due more to healthcare providers and services than individual patients. This may be a reflection of known difficulties with continuity of care and access to preferred providers at Retreat CHC.

The Dunning-Kruger effect is a well-described cognitive bias wherein unskilled individuals mistakenly overestimate their abilities and are unable to fully recognise their inadequacies¹²⁰. It is quite possible that individuals residing in the greater Lavender Hill are prone to this type of bias, mostly secondary to widespread poor health literacy skills from years of oppression and poverty.

6.1.4 Workshop

Important themes emerged from the workshop to support the idea that collaborations between community and healthcare realms can be mutually beneficial when addressing health literacy. The needs of individuals at a community level are often similar to the needs of providers, and some strategies that work well in one setting may also work well in another (for example, reliance upon groups). A particular health literacy need may be addressed by separate interventions that function through isolated organisations or services or through collaboration between health services and community-based organisations.

6.1.5 Collaborations with the Ophelia research team and the EFAR program

Overall, this project has enjoyed mutually beneficial relationships with both PHI and the EFAR program. Core concepts and values that are honoured by the EFAR program, the Ophelia process, and this project have been mutually reinforced within these three realms.

Constructive and reinforcing feedback has taken place regarding the HLQ, some of the principles of the Ophelia process, and the strengths of the EFAR program that extend beyond first responder care. Involving community leaders and the EFAR program as main players in this project led to unique intervention ideas that reflect the culture of the greater Lavender Hill community and depend upon its strengths. Relationships have been forged that hopefully can continue into the future.

6.2 Limitations

This study took place in only one small section of the Cape Town metropolis in the Western Cape Province, where the demographic profile is slightly different from the rest of the country. For example, more people in Cape Town speak Afrikaans and English than in other provinces.

As alluded to earlier, it is possible that such biases as the Dunning-Kruger effect, ceiling effect, overconfidence effect, observer-expectancy effect, demand characteristics, and sampling bias affected the results of the HLQ data, which would in turn influence how workshop attendees learned about the health literacy needs of their community members and patients.

In this particular study, sampling bias may be responsible for some of the patterns observed in the data- or lack there of. Non-probability, convenience sampling strategies were used for all three groups of participants. Many participants had a close connection to the Mothers Unite staff. Repeated studies may obtain differing results with a different sampling strategy.

6.3 Recommendations

Recommendations in response to this study fall into two broad categories. It is important that work initiated during this study continues, if possible, to achieve the greatest benefit from the work that has been done. For example, intervention ideas from the feedback workshop should be tested.

It is also important that this project makes a sustainable contribution. Contribution to the EFAR program will be sustainable if a reusable framework is created that allows for replication of the health literacy program. Additionally, contributions to the Ophelia project will be more beneficial if further steps of the process are completed, such as refining and testing interventions.

6.3.1 Further work

As mentioned previously, further testing should be performed regarding the validity of the HLQ in other South African populations. Special attention may be paid to issues highlighted during our translation, cultural adaptation, and validation processes. If the HLQ appears to be very well understood, cognitive interviewing may not be required.

Intervention ideas that were proposed in the workshop should be refined, compared to health promotion literature, and piloted to discover whether such targeted health literacy interventions are effective.

The EFAR health literacy model (presented in section 5.10) should undergo testing at a new EFAR branch site to examine whether the proposed framework is achievable in a

new setting. A few more details regarding how this could be accomplished are provided below.

6.3.2 *Implementation of the EFAR health literacy model*

Implementation of the EFAR health literacy model should take place in a new EFAR branch site. As explained in 5.10, this requires a willing community-based organisation as well as a motivated research coordinator. A CBO interested in becoming involved in health literacy may choose to seek out a RC to lead the project. Conversely, it is also possible for an interested RC to contact an accessible EFAR branch CBO, introduce the project, and gauge the interest of the CBO in partnering to execute it.

If the new branch site is located outside of the Cape Town metropolis, experience with HLQ administration in the new site can provide valuable information about the validity of the HLQ in other South African populations.

REFERENCES

1. The barriers and challenges to Health Promotion in Africa [Internet]. [cited 2014 Aug 8];Available from: http://reference.sabinet.co.za/webx/access/electronic_journals/mp_saftp/mp_saftp_v47_n10_a8.pdf
2. Kickbusch IS. Health literacy: addressing the health and education divide. *Health Promot Int* 2001;16:289–97.
3. The economic and social cost of illiteracy: a snapshot of illiteracy in a global context [Internet]. [cited 2014 May 5];Available from: http://www.worldliteracyfoundation.org/The_Economic_&_Social_Cost_of_Illiteracy.pdf
4. Sentell TL, Halpin HA. Importance of adult literacy in understanding health disparities. *J Gen Intern Med* [Internet] 2006 [cited 2014 May 5];21(8):862–6. Available from: [/pmc/articles/PMC1831569/?report=abstract](http://pmc/articles/PMC1831569/?report=abstract)
5. Perlow E. Accessibility: global gateway to health literacy. *Health Promot Pract* 2010;11:123–31.
6. Sørensen K, Van den Broucke S, Fullam J, et al. Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health*. 2012;12:80.
7. Osborne RH, Batterham RW, Elsworth GR, Hawkins M, Buchbinder R. The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). *BMC Public Health* [Internet] 2013 [cited 2014 May 5];13(1):658. Available from: <http://www.biomedcentral.com/1471-2458/13/658>
8. Buchbinder R, Batterham ROY, Ciciriello S, et al. Health Literacy : What Is It and Why Is It Important to Measure ? 2011;38(8).
9. Nielsen-Bohlman L, Panzer AM, Kindig D a. Health Literacy: A Prescription to End Confusion. *Heal San Fr* [Internet] 2004;;368. Available from: http://www.nap.edu/catalog.php?record_id=10883#toc
10. Peterson PN, Shetterly SM, Clarke CL, et al. Health literacy and outcomes among patients with heart failure. *JAMA* 2011;305:1695–701.
11. Sudore RL, Yaffe K, Satterfield S, et al. Limited literacy and mortality in the elderly: the health, aging, and body composition study. *J Gen Intern Med* 2006;21:806–12.

12. Baker DW, Wolf MS, Feinglass J, Thompson JA, Gazmararian JA, Huang J. Health literacy and mortality among elderly persons. *Arch Intern Med* 2007;167:1503–9.
13. Baker DW, Wolf MS, Feinglass J, Thompson JA. Health literacy, cognitive abilities, and mortality among elderly persons. *J Gen Intern Med* 2008;23:723–6.
14. Howard DH, Gazmararian J, Parker RM. The impact of low health literacy on the medical costs of Medicare managed care enrollees.[erratum appears in *Am J Med*. 2005 Aug;118(8):933]. *Am J Med* 2005;118:371–7.
15. Cho YI, Lee SY, Arozullah AM, Crittenden KS. Effects of health literacy on health status and health service utilization amongst the elderly. *Soc Sci Med* [Internet] 2008;66:1809–16. Available from: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=18295949
16. Paasche-Orlow MK, Riekert KA, Bilderback A, et al. Tailored education may reduce health literacy disparities in asthma self-management. *Am J Respir Crit Care Med* 2005;172:980–6.
17. DeWalt DA, Dilling MH, Rosenthal MS, Pignone MP. Low Parental Literacy Is Associated With Worse Asthma Care Measures in Children. *Ambul Pediatr* 2007;7:25–31.
18. Murray MD, Tu W, Wu J, Morrow D, Smith F, Brater DC. Factors associated with exacerbation of heart failure include treatment adherence and health literacy skills. *Clin Pharmacol Ther* 2009;85:651–8.
19. White S, Chen J, Atchison R, White S, Chen J, Atchison R. Relationship of preventive health practices and health literacy: a national study. *Am J Health Behav* 2008;32:227–42.
20. Garbers S, Chiasson MA. Inadequate functional health literacy in Spanish as a barrier to cervical cancer screening among immigrant Latinas in New York City. *Prev Chronic Dis* 2004;1:A07.
21. Bennett IM, Chen J, Soroui JS, White S. The Contribution of Health Literacy to Disparities in Self-Rated Health Status and Preventive Health Behaviors in Older Adults. *Ann Fam Med* 2009;7:204–11.
22. Guerra CE, Krumholz M, Shea JA. Literacy and knowledge, attitudes and behavior about mammography in Latinas. *J Health Care Poor Underserved* 2005;16:152–66.

23. Fortenberry JD, McFarlane MM, Hennessy M, et al. Relation of health literacy to gonorrhoea related care. *Sex Transm Infect* 2001;77:206–11.
24. Howard DH, Sentell T, Gazmararian JA. Impact of Health Literacy on Socioeconomic and Racial Differences in Health in an Elderly Population. *J Gen Intern Med* 2006;21:857–61.
25. Sudore RL, Mehta KM, Simonsick EM, et al. Limited literacy in older people and disparities in health and healthcare access. *J Am Geriatr Soc* 2006;54:770–6.
26. Williams M V, Baker DW, Parker RM, Nurss JR. Relationship of functional health literacy to patients' knowledge of their chronic disease. A study of patients with hypertension and diabetes. *Arch Intern Med* 1998;158:166–72.
27. Gazmararian JA, Williams M V., Peel J, Baker DW. Health literacy and knowledge of chronic disease. *Patient Educ Couns* 2003;51:267–75.
28. Schillinger D, Grumbach K, Piette J, et al. Association of health literacy with diabetes outcomes. *JAMA [Internet]* [cited 2014 Apr 28];288(4):475–82. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/12132978>
29. Yin HS, Johnson M, Mendelsohn AL, Abrams MA, Sanders LM, Dreyer BP. The health literacy of parents in the United States: a nationally representative study. *Pediatrics* 2009;124 Suppl :S289–S298.
30. Baker DW, Gazmararian JA, Williams M V., et al. Health literacy and use of outpatient physician services by medicare managed care enrollees. *J Gen Intern Med [Internet]* 2004 [cited 2014 May 5];19(3):215–20. Available from: [/pmc/articles/PMC1492157/?report=abstract](http://pmc/articles/PMC1492157/?report=abstract)
31. Hope CJ, Wu J, Tu W, Young J, Murray MD. Association of medication adherence, knowledge, and skills with emergency department visits by adults 50 years or older with congestive heart failure. *Am J Health Syst Pharm* 2004;61:2043–9.
32. Schumacher JR, Hall AG, Davis TC, et al. Potentially preventable use of emergency services: the role of low health literacy. *Med Care [Internet]* 2013;51:654–8. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/23703649>
33. Carpenter CR, Kaphingst KA, Goodman MS, Lin MJ, Melson AT, Griffey RT. Feasibility and Diagnostic Accuracy of Brief Health Literacy and Numeracy Screening Instruments in an Urban Emergency Department.

Acad Emerg Med [Internet] 2014 [cited 2014 May 5];21(2):137–46.
Available from: <http://www.ncbi.nlm.nih.gov/pubmed/24673669>

34. McNaughton C, Wallston KA, Rothman RL, Marcovitz DE, Storrow AB. Short, subjective measures of numeracy and general health literacy in an adult emergency department. Acad Emerg Med [Internet] 2011 [cited 2014 May 5];18(11):1148–55. Available from: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3886121&tool=pmcentrez&rendertype=abstract>
35. Hubley J. Patient education in the developing world--a discipline comes of age. Patient Educ Couns 2006;61:161–4.
36. Jafar TH, Hatcher J, Poulter N, et al. Community-based interventions to promote blood pressure control in a developing country: a cluster randomized trial. Ann Intern Med 2009;151:593–601.
37. Thiam S, LeFevre AM, Hane F, et al. Effectiveness of a strategy to improve adherence to tuberculosis treatment in a resource-poor setting: a cluster randomized controlled trial. JAMA 2007;297:380–6.
38. Jiang C, Driscoll P, Woodford M, Wang Z, Yates D. Trauma care in China: challenge and development. Injury [Internet] 1996 [cited 2014 Aug 8];27(7):471–5. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/8977831>
39. Sun JH, Wallis LA. The emergency first aid responder system model: using community members to assist life-threatening emergencies in violent, developing areas of need. Emerg. Med. J. 2012;29:673–8.
40. Crime, Violence, and Development: Trends, Costs, and Policy Options in the Caribbean [Internet]. [cited 2014 Aug 8]; Available from: <http://siteresources.worldbank.org/INTHAITI/Resources/CandVfrontandacknowledgments.pdf>
41. More Slums Equals More Violence: Reviewing Armed Violence and Urbanization in Africa [Internet]. [cited 2014 Aug 8]; Available from: <http://www.genevadeclaration.org/fileadmin/docs/regional-publications/Armed-Violence-and-Urbanization-in-Africa.pdf>
42. Nantulya VM, Reich MR. The neglected epidemic: road traffic injuries in developing countries. BMJ [Internet] 2002 [cited 2014 Aug 8];324(7346):1139–41. Available from: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1123095&tool=pmcentrez&rendertype=abstract>

43. Smith GS, Barss P. Unintentional injuries in developing countries: the epidemiology of a neglected problem. *Epidemiol Rev* [Internet] 1991 [cited 2014 Aug 8];13:228–66. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/1765113>
44. Holliman CJ, Kirsch TD, Green GB, Wolfson AB, Tom PA. Guidelines for Evaluation of International Emergency Medicine Assistance and Development Projects. *Ann Emerg Med* [Internet] 1997 [cited 2014 Aug 8];30(6):811–5. Available from: <http://www.annemergmed.com/article/S0196064497700544/fulltext>
45. Krug EG, Sharma GK, Lozano R. The global burden of injuries. *Am J Public Health* 2000;90:523–6.
46. Sun JH, Wallis LA. Learning and retention of emergency first aid skills in a violent, developing South African township. *Emerg. Med. J.* 2012;
47. Jordan JE, Osborne RH, Buchbinder R. Critical appraisal of health literacy indices revealed variable underlying constructs, narrow content and psychometric weaknesses. *J Clin Epidemiol* [Internet] 2011 [cited 2014 May 5];64(4):366–79. Available from: <http://www.sciencedirect.com/science/article/pii/S0895435610001435>
48. Jordan JE, Buchbinder R, Osborne RH. Conceptualising health literacy from the patient perspective. *Patient Educ Couns* [Internet] 2010 [cited 2014 May 5];79(1):36–42. Available from: <http://www.sciencedirect.com/science/article/pii/S0738399109004601>
49. Braveman P, Egerter S, Williams DR. The social determinants of health: coming of age. *Annu Rev Public Health* [Internet] 2011 [cited 2014 May 1];32:381–98. Available from: <http://www.annualreviews.org.ezproxy.library.tufts.edu/doi/full/10.1146/annurev-publhealth-031210-101218>
50. World Health Organization Health Promotion Glossary [Internet]. [cited 2014 May 9]; Available from: [http://www.who.int/healthpromotion/about/HPR Glossary 1998.pdf](http://www.who.int/healthpromotion/about/HPR%20Glossary%201998.pdf)
51. Parker RM. Health literacy: report of the Council on Scientific Affairs. Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association. *JAMA* [Internet] 1999;281:552–7. Available from: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=10022112

52. Freedman DA, Bess KD, Tucker HA, Boyd DL, Tuchman AM, Wallston KA. Public Health Literacy Defined. *Am. J. Prev. Med.* 2009;36:446–51.
53. Health Literacy Interventions and Outcomes: An Updated Systematic Review [Internet]. [cited 2014 May 9];Available from: <http://www.ahrq.gov/research/findings/evidence-based-reports/literacyup-evidence-report.pdf>
54. Kalichman SC, Benotsch E, Suarez T, Catz S, Miller J, Rompa D. Health literacy and health-related knowledge among persons living with HIV/AIDS. *Am J Prev Med* 2000;18:325–31.
55. Wolf MS, Gazmararian JA, Baker DW. Health Literacy and Health Risk Behaviors Among Older Adults. *Am J Prev Med* 2007;32:19–24.
56. Kalichman SC, Pope H, White D, et al. Association between health literacy and HIV treatment adherence: further evidence from objectively measured medication adherence. *J Int Assoc Physicians AIDS Care (Chic)* [Internet] 2008;7:317–23. Available from: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3015090&tool=pmcentrez&rendertype=abstract>
57. Osborn CY, Paasche-Orlow MK, Davis TC, Wolf MS. Health Literacy. An Overlooked Factor in Understanding HIV Health Disparities. *Am J Prev Med* 2007;33:374–8.
58. Osborn CY, Davis TC, Bailey SC, Wolf MS. Health literacy in the context of HIV treatment: introducing the Brief Estimate of Health Knowledge and Action (BEHKA)-HIV version. *AIDS Behav* 2010;14:181–8.
59. Wolf MS, Davis TC, Osborn CY, Skripkauskas S, Bennett CL, Makoul G. Literacy, self-efficacy, and HIV medication adherence. *Patient Educ Couns* 2007;65:253–60.
60. Waite KR, Paasche-Orlow M, Rintamaki LS, Davis TC, Wolf MS. Literacy, social stigma, and HIV medication adherence. *J Gen Intern Med* 2008;23:1367–72.
61. Murphy DA, Lam P, Naar-King S, Robert Harris D, Parsons JT, Muenz LR. Health literacy and antiretroviral adherence among HIV-infected adolescents. *Patient Educ Couns* 2010;79:25–9.
62. Graham J, Bennett IM, Holmes WC, Gross R. Medication beliefs as mediators of the health literacy-antiretroviral adherence relationship in HIV-infected individuals. *AIDS Behav* 2007;11:385–92.

63. Paasche-Orlow MK, Cheng DM, Palepu A, Meli S, Faber V, Samet JH. Health literacy, antiretroviral adherence, and HIV-RNA suppression: a longitudinal perspective. *J Gen Intern Med* 2006;21:835–40.
64. Johnson VR, Jacobson KL, Gazmararian JA, Blake SC. Does social support help limited-literacy patients with medication adherence?. A mixed methods study of patients in the Pharmacy Intervention for Limited Literacy (PILL) Study. *Patient Educ Couns* 2010;79:14–24.
65. Lincoln A, Paasche-Orlow MK, Cheng DM, et al. Impact of health literacy on depressive symptoms and mental health-related: quality of life among adults with addiction. *J Gen Intern Med* 2006;21:818–22.
66. Nokes KM, Coleman CL, Cashen M, et al. Health literacy and health outcomes in HIV seropositive persons. *Res Nurs Health* 2007;30:620–7.
67. Bennett IM, Culhane JF, McCollum KF, Mathew L, Elo IT. Literacy and depressive symptomatology among pregnant Latinas with limited English proficiency. *Am J Orthopsychiatry* 2007;77:243–8.
68. Walker D, Adebajo A, Heslop P, et al. Patient education in rheumatoid arthritis: the effectiveness of the ARC booklet and the mind map. *Rheumatology (Oxford)* 2007;46:1593–6.
69. Morris NS, MacLean CD, Littenberg B. Literacy and health outcomes: a cross-sectional study in 1002 adults with diabetes. *BMC Fam Pract* 2006;7:49.
70. Coffman MJ, Norton CK. Demands of Immigration, Health Literacy, and Depression in Recent Latino Immigrants. *Home Health Care Manag. Pract.* 2010;22:116–22.
71. Laramée AS, Morris N, Littenberg B. Relationship of literacy and heart failure in adults with diabetes. *BMC Health Serv Res* 2007;7:98.
72. Wolf MS, Gazmararian JA, Baker DW. Health literacy and functional health status among older adults. *Arch Intern Med* [Internet] 2005;165:1946–52. Available from: <Go to ISI>://WOS:000232112800002\nhttp://archinte.jamanetwork.com/data/Journals/INTEMED/12036/oi50059.pdf
73. Kim SH. Health literacy and functional health status in Korean older adults. *J Clin Nurs* [Internet] 2009;18:2337–43. Available from: <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=emed9&AN=19583664\nhttp://nhs5195535.resolver.library.nhs.uk/?sid=OVID:embase&id=pmid:&id=doi:10.1111/j.1365->

2702.2008.02739.x&issn=0962-1067&isbn=&volume=18&issue=16&spage=2337&pages=2337-2343&date=2009&title=Journal+of+Clinical+Nursing&atitle=Health+literacy+and+functional+health+status+in+Korean+older+adults&aulast=Kim&pid=<author>Kim+S.H.</author><AN>19583664</AN><DT>Journal:+Article</DT>

74. Lee SD, Arozullah AM, Cho YI, Crittenden K, Vicencio D. Health Literacy, Social Support, and Health Status Among Older Adults. *Educ Gerontol* 2009;35:191–201.
75. Schillinger D, Bindman A, Wang F, Stewart A, Piette J. Functional health literacy and the quality of physician-patient communication among diabetes patients. *Patient Educ Couns* [Internet] 2004 [cited 2014 May 9];52(3):315–23. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/14998602>
76. National Academy on an Aging Society [Internet]. [cited 2014 May 9]; Available from: http://www.agingsociety.org/agingsociety/publications/fact/fact_low.html
77. Weiss BD, Palmer R. Relationship between health care costs and very low literacy skills in a medically needy and indigent Medicaid population. *J Am Board Fam Pract* [Internet] [cited 2014 May 9];17(1):44–7. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/15014052>
78. Morrison AK, Myrvik MP, Brousseau DC, Hoffmann RG, Stanley RM. The relationship between parent health literacy and pediatric emergency department utilization: A systematic review. *Acad. Pediatr.* 2013;13:421–9.
79. Morrison AK, Schapira MM, Gorelick MH, Hoffmann RG, Brousseau DC. Low caregiver health literacy is associated with higher pediatric emergency department use and nonurgent visits. *Acad Pediatr* [Internet] 2014;14:309–14. Available from: <http://www.sciencedirect.com/science/article/pii/S1876285914000060>
80. Gignon M, Ammirati C, Mercier R, Detave M. Compliance with emergency department discharge instructions. *J Emerg Nurs* 2014;40:51–5.
81. Clarke C, Friedman SM, Shi K, Arenovich T, Monzon J, Culligan C. Emergency department discharge instructions comprehension and compliance study. *CJEM Can J Emerg Med care = JCMU J Can soins médicaux d'urgence* 2005;7:5–11.

82. Herndon JB, Chaney M, Carden D. Health literacy and emergency department outcomes: A systematic review. *Ann. Emerg. Med.* 2011;57:334–45.
83. Karsenty C, Landau M, Ferguson R. Assessment of medical resident's attention to the health literacy level of newly admitted patients. *J community Hosp Intern Med Perspect* [Internet] 2013 [cited 2014 Aug 8];3(3-4). Available from: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3879518&tool=pmcentrez&rendertype=abstract>
84. Wickline M, Sellnow TL. Expanding the concept of significant choice through consideration of health literacy during crises. *Health Promot Pract* [Internet] 2013;14:809–15. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/23975797>
85. Cawthon C, Mion LC, Willens DE, Roumie CL, Kripalani S. Implementing routine health literacy assessment in hospital and primary care patients. *Jt Comm J Qual Patient Saf* [Internet] 2014 [cited 2014 Aug 8];40(2):68–76. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/24716329>
86. Barber MN, Staples M, Osborne RH, Clerehan R, Elder C, Buchbinder R. Up to a quarter of the Australian population may have suboptimal health literacy depending upon the measurement tool: results from a population-based survey. *Health Promot Int* 2009;24:252–61.
87. Adams RJ, Stocks NP, Wilson DH, et al. Health literacy--a new concept for general practice? *Aust Fam Physician* 2009;38:144–7.
88. Health Literacy Around the World [Internet]. [cited 2014 May 9];Available from: <http://www.iom.edu/~media/Files/ActivityFiles/PublicHealth/HealthLiteracy/2012-SEP-24/WorldHealthLit.pdf>
89. Bridging the International Divide for Health Literacy Research [Internet]. [cited 2014 May 9];Available from: http://ac.els-cdn.com.ezproxy.library.tufts.edu/S0738399109001645/1-s2.0-S0738399109001645-main.pdf?_tid=5f0dd1ac-d7bc-11e3-b973-00000aab0f6c&acdnat=1399669160_7cc0c7fa06d2898f1bcf47011861f460
90. Von Wühlisch FS, Pascoe M. Maximizing health literacy and client recall in a developing context: speech-language therapist and client perspectives. *Int J Lang Commun Disord* [Internet] [cited 2014 Aug 11];46(5):592–607. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/21899675>

91. Keikelame MJ, Swartz L. Lost opportunities to improve health literacy: observations in a chronic illness clinic providing care for patients with epilepsy in Cape Town South Africa. *Epilepsy Behav* [Internet] 2013 [cited 2014 Aug 12];26(1):36–41. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/23207515>
92. Robins S. Foot soldiers of global health: teaching and preaching AIDS science and modern medicine on the frontline. *Med Anthropol* [Internet] [cited 2014 Aug 8];28(1):81–107. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/19184757>
93. Desclaux A, Alfieri C. Counseling and choosing between infant-feeding options: overall limits and local interpretations by health care providers and women living with HIV in resource-poor countries (Burkina Faso, Cambodia, Cameroon). *Soc Sci Med* [Internet] 2009 [cited 2014 Aug 8];69(6):821–9. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/19559512>
94. Nachega JB, Morroni C, Zuniga JM, et al. HIV Treatment Adherence, Patient Health Literacy, and Health Care Provider-Patient Communication: Results from the 2010 AIDS Treatment for Life International Survey. *J. Int. Assoc. Physicians AIDS Care*. 2012;11:128–33.
95. Mugusi F, Mugusi S, Bakari M, et al. Enhancing adherence to antiretroviral therapy at the HIV clinic in resource constrained countries; the Tanzanian experience. *Trop Med Int Health* [Internet] 2009 [cited 2014 Aug 8];14(10):1226–32. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/19732408>
96. Davis TC, Crouch MA, Long SW, et al. Rapid assessment of literacy levels of adult primary care patients. *Fam Med* 1991;23:433–5.
97. Parker RM, Baker DW, Williams M V, Nurss JR. The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. *J Gen Intern Med* 1995;10:537–41.
98. Weiss BD, Mays MZ, Martz W, et al. Quick Assessment of Literacy in Primary Care: The Newest Vital Sign. *Ann Fam Med* 2005;3:514–22.
99. Public Health Innovation [Internet]. [cited 2014 Aug 7];Available from: <http://www.deakin.edu.au/health/research/phi/index.php>
100. Jordan JE, Buchbinder R, Briggs AM, et al. The Health Literacy Management Scale (HeLMS): A measure of an individual's capacity to

seek, understand and use health information within the healthcare setting. *Patient Educ Couns* 2013;91:228–35.

101. Batterham RW, Buchbinder R, Beauchamp A, Dodson S, Elsworth GR, Osborne RH. The OPTimising HEalth LIterAcy (Ophelia) process: study protocol for using health literacy profiling and community engagement to create and implement health reform. *BMC Public Health* [Internet] 2014;14:694. Available from: <http://www.biomedcentral.com/1471-2458/14/694>
102. 2011 Census in brief [Internet]. [cited 2014 Aug 11];Available from: http://www.statssa.gov.za/census2011/Products/Census_2011_Census_in_brief.pdf
103. Study on the social profile of residents in three selected informal settlements in Cape Town [Internet]. [cited 2014 Aug 11];Available from: http://www.capetown.gov.za/en/stats/CityReports/Documents/InformalSettlements/Main_Report_2722006113759_359.pdf
104. Integrated Annual Report 2012/13 [Internet]. [cited 2014 Aug 11];Available from: https://www.capetown.gov.za/en/IDP/Documents/2012-2013_int_annual.pdf
105. Cause of death and premature mortality in Cape Town, 2001-2006 [Internet]. [cited 2014 Aug 11];Available from: http://www.mrc.ac.za/bod/premort_cpt.pdf
106. Rowe K, Moodley K. Patients as consumers of health care in South Africa: the ethical and legal implications. *BMC Med Ethics* [Internet] 2013 [cited 2014 Aug 12];14(1):15. Available from: <http://www.biomedcentral.com/1472-6939/14/15>
107. Surender R, Van Niekerk R, Hannah B, Allan L, Shung-King M. The drive for universal healthcare in South Africa: views from private general practitioners. *Health Policy Plan* [Internet] 2014 [cited 2014 Aug 12];:czu053–. Available from: <http://heapol.oxfordjournals.org.ezproxy.library.tufts.edu/content/early/2014/06/25/heapol.czu053.long>
108. Moosa S, Mash B, Derese A, Peersman W. The views of key leaders in South Africa on implementation of family medicine: critical role in the district health system. *BMC Fam Pract* [Internet] 2014 [cited 2014 Aug 12];15(1):125. Available from: <http://www.biomedcentral.com/1471-2296/15/125>

109. Wallis LA, Garach SR, Kropman A. State of emergency medicine in South Africa. *Int J Emerg Med* 2008;1:69–71.
110. Wen LS, Geduld HI, Nagurney JT, Wallis LA. Africa's first emergency medicine training program at the University of Cape Town/Stellenbosch University: history, progress, and lessons learned. *Acad Emerg Med [Internet]* 2011 [cited 2014 Aug 12];18(8):868–71. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/21843223>
111. MacFarlane C, van Loggerenberg C, Kloeck W. International EMS systems in South Africa--past, present, and future. *Resuscitation* 2005;64:145–8.
112. Resuscitation and transport by emergency care workers: resuscitation update [Internet]. [cited 2014 Aug 12]; Available from: http://reference.sabinet.co.za/sa_epublication_article/medsajaa_v16_n1_a35
113. Murray CJ, Lopez AD. Evidence-based health policy--lessons from the Global Burden of Disease Study. *Science [Internet]* 1996 [cited 2014 Aug 8];274(5288):740–3. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/8966556>
114. VanRooyen MJ, Thomas TL, Clem KJ. International emergency medical services: assessment of developing prehospital systems abroad. *J Emerg Med [Internet]* [cited 2014 Aug 8];17(4):691–6. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/10431962>
115. Sun JH, Shing R, Twomey M, Wallis LA. A strategy to implement and support pre-hospital emergency medical systems in developing, resource-constrained areas of South Africa. *Injury*. 2012;
116. Osborne R. (HLQ TM) Translation and cultural adaptation procedure. 2012;
117. Dowse R, Lecoko L, Ehlers MS. Applicability of the REALM health literacy test to an English second-language South African population. *Pharm World Sci* 2010;32:464–71.
118. Language Systems in South Africa and Their Parallels to the Linguistic Struggle of Blacks in the U.S. [Internet]. [cited 2014 Aug 7]; Available from: http://web.stanford.edu/~jbaugh/saw/Tracy_Language_&_Ebonics.html

119. Sun JH, Wallis LA. The psychological effects of widespread emergencies and a first responder training course on a violent, developing community. *African J Emerg Med* 2011;1:166–73.
120. Kruger J, Dunning D. Unskilled and unaware of it: how difficulties in recognizing one's own incompetence lead to inflated self-assessments. *J Pers Soc Psychol* 1999;77:1121–34.

Appendix 1: Participant information and consent form

PARTICIPANT INFORMATION AND CONSENT FORM

Client keeps this

Date:

Full Project Title: Developing a framework to identify and respond to health literacy needs using community-based emergency first aid responders in the greater Lavender Hill area

Principal Researcher: Jennifer Bress

As someone living in the greater Lavender Hill area, you are invited to be in a research study.

What the research is about

The main reason for the study is to help your health service, the Emergency First Aid Responder (EFAR) program, and community leaders at Mothers Unite to understand your needs so that they can improve the way they give you information and services. The results, which won't be able to identify you in any way, will be discussed with head EFARs, community leaders and facilitators at Mothers Unite, and local healthcare providers. These groups will then share ideas for the services they provide to you.

The study uses a survey called the Health Literacy Questionnaire (HLQ). The HLQ survey looks at how people find, understand and use health information. It asks questions about how you use health services, talk with doctors and other health workers, and manage your health.

For most people it takes 10 to 20 minutes to complete.

Some people will also be asked to do a telephone or in-person interview to talk about your responses or to find out your ideas for helping people get the health information they need.

What does being in the study involve?

Being in the study involves filling in the consent form and HLQ survey.

If you like, someone can read the questions to you. That person could be:

- A family member or friend
- A different EFAR or staff member from Mothers Unite

If you are willing to do a phone or in-person interview please tick the box on the consent form that says "I consent to being interviewed by a researcher about my HLQ answers". You may or may not be asked for an interview.

If you agree to an interview, you will need to provide your name and phone number so that we can call you. After the interview your name and phone number will be removed from your HLQ survey and from the interview records.

If you agree to an interview, you can stop the interview at any time, without giving a reason. Even if you do **not** want to be interviewed, it would still be very helpful if you could complete the HLQ survey.

Risks and potential benefits of being in the study

We do not expect there will be any risks or direct benefits to you from being in this study. By being in the study, you will be helping your health service and EFAR program leaders to better understand your needs.

How your privacy and confidentiality will be protected

Your privacy and confidentiality will be fully protected. Your name will not be included in anything that is written about the study. Records will be stored on secured computers and in locked filing cabinets. This study has been approved by University of Cape Town.

How the study's findings will be published

A report will be given to local healthcare providers, the EFAR program, and leaders at Mothers Unite, and you will be able to get a copy. If you would like a copy, please email jennybress@gmail.com or call/SMS 0791166311. Conference and journal papers will also be published. You will not be identified in any of these papers.

Withdrawing from the study

If you have given your contact information for an interview in the future, you may withdraw this information at any point in the future by contacting Jennifer Bress at 0791166311 or jennybress@gmail.com. If you are contacted for an interview in the future and do not wish to participate, your contact information will be deleted.

If you decide not to be in the study or if you choose to withdraw from the study it will not affect your relationship with the EFAR program, Mothers Unite, or University of Cape Town in any way.

Researcher's contact details

If you have any questions about this study, please contact the principal researcher **Jennifer Bress** at University of Cape Town: Phone: 079 116 6311. Email: jennybress@gmail.com.

Complaints

If you have any complaints about any aspect of the project, the way it is being conducted, or any questions about your rights as a participant, please contact: UCT Human Research Ethics Committee, Old Main Building of Groote Schuur Hospital, Floor E52, Room 23, Observatory 7925. Phone: 021 406 6338. Email: shuretta.thomas@uct.ac.za.

Study ID _____

1. I have read and understood the attached Participant Information and freely agree to participate in this project according to the conditions outlined in the Participant Information.

I have the Participant Information Form to keep.

I understand that the researchers have agreed not to reveal my identity in any report, publication, or presentation.

I understand that my decision to participate or not to participate or to withdraw WILL NOT affect my relationship with health services, the EFAR program, Mothers Unite, or the University of Cape Town in any way

Yes No

2. I consent to being interviewed by a researcher about my HLQ survey answers.

Yes No If yes, my phone number is:

If you do not wish to sign the form you can get Jennifer Bress or another witness to sign that you have agreed.

Participant's Name (printed)

Signature Date

OR

Witnesses name: Role:

Signature Date

Appendix 2: Demographic form

N Paar ekstra inligting oor jouself *Some details about yourself*

Beantwoord van die volgende vrae is opsioneel. Inligting wat hier versamel word sal nie gekoppel word aan jou naam nie. Dit sal slegs gebruik word vir statiese doeleindes en moontlik om jou te help uit vind wat die beste manier is om die gesondheidsgeletterheid behoeftes van mense soos jy aan te spreek.

Answering the following questions is optional. Information collected here will not be connected to your name. It will only be used for statistical purposes, and possibly to help figure out how best to address the health literacy needs of people like you.

Persoon administrasie van u HLQ: _____
Person administering your HLQ

Wat is jou ouderdom of geboortedatum? _____
What is your age or date of birth?

Wat is jou geslag? ☐ Vroulik ☐ Manlik
What is your sex? Female Male

Bly jy alleen? ☐ Ja ☐ Nee
Do you live alone? Yes No

In watter land is jy gebore? _____
In which country were you born?

In watter area woon jy nou in? _____
What area do you live in now?

Watter taal is jy mees gemaklikste met? _____
What language are you most comfortable with?

Wat is die hoogste vlak van opleiding wat jy bygewoon het? (Kies net een)
What is the highest level of education you have attended? (Tick one only)

- ☐ Primêre skool of minder *Primary school or less*
- ☐ Hoërskool (ontvoltooid) *High school (not completed)*
- ☐ Hoërskool (voltooi) *High school (completed)*
- ☐ Universiteit *University*

Het jy n jarelange siekte of ongeskiktheid? Maak seker jy kies al van toepassing.
Do you have a long standing illness or disability? Please check all that apply

- ☐ Artritis *Arthritis*
- ☐ Rug pyn *Back pain*
- ☐ Hart problem *Heart problems*
- ☐ Asma *Asthma*
- ☐ Kanker *Cancer*
- ☐ Depressie of ang *Depression or anxiety*
- ☐ Diabetes
- ☐ Anvalle *Seizures*
- ☐ Beroerte *Stroke*

- ☐ Ander, spesifiseer asseblief: *Other, please specify* _____
- ☐ Nie een van die bogenoemde *None of the above*

Hey jy n privaat gesondsheids versekering? ☐ Ja ☐ Nee
Do you have private health insurance? Yes No

Het iemand jou gehelp om hierdie vraelys te voltooi? ☐ Ja ☐ Nee
Did someone help you complete this questionnaire? Yes No

Indien ja, beskryf asseblief hoe was jy gehelp _____
If yes, please describe in what way you were helped

Baie dankie!

Thank you!

Appendix 3: HLQ scales and item intent

The Health Literacy Questionnaire (HLQ™)

Not for distribution

Scales 1 to 5: How strongly you disagree or agree with the following statements
(Strongly disagree/disagree/Agree/Strongly agree)

1. Feeling understood and supported by healthcare providers		
Item #	High: Has an established relationship with at least one healthcare provider who knows them well and who they trust to provide useful advice and information and to assist them to understand information and make decisions about their health. Low: People who are low on this domain are unable to engage with doctors and other healthcare providers. They don't have a regular healthcare provider and/or have difficulty trusting healthcare providers as a source of information and/or advice.	QN in HLQ
11	I have at least one healthcare provider who knows me well	2
14	I have at least one healthcare provider I can discuss my health problems with	8
26	I have the healthcare providers I need to help me work out what I need to do	17
32	I can rely on at least one healthcare provider	22
2. Having sufficient information to manage my health		
Item #	High: Feels confident that they have all the information that they need to live with and manage their condition and to make decisions Low: Feels that there are many gaps in their knowledge and that they don't have the information they need to live with and manage their health concerns	QN in HLQ
4	I feel I have good information about health	1
17	I have enough information to help me deal with my health problems	10
23	I am sure I have all the information I need to manage my health effectively	14
34	I have all the information I need to look after my health	23
3. Actively managing my health		
Item #	High: Recognise the importance of and are able to take responsibility for their own health. They proactively engage in their own care and make their own decisions about their health. Low: People with low levels don't see their health as their responsibility, they are not engaged in their healthcare and regard healthcare as something that is done to them.	QN in HLQ
8	I spend quite a lot of time actively managing my health	6
16	I make plans for what I need to do to be healthy	9
21	Despite other things in my life, I make time to be healthy	13
27	I set my own goals about health and fitness	18
31	There are things that I do regularly to make myself more healthy	21
4. Social support for health		
Item #	High: A person's social system provides them with all the support they want or need Low: Completely alone and unsupported	QN in HLQ
3	I can get access to several people who understand and support me	3
6	When I feel ill, the people around me really understand what I am going through	5
19	If I need help, I have plenty of people I can rely on	11
24	I have at least one person who can come to medical appointments with me	15
29	I have strong support from family or friends	19

HLQ™: Health Literacy Questionnaire. ©Richard Osborne, Rachelle Buchbinder, Roy Batterham and Gerald Elsworth 2012.
The HLQ can only be used under license. Information: Richard.Osborne@Deakin.edu.au or Rachelle.buchbinder@monash.edu

5. Appraisal of health information		
Item #	High: Able to identify good information and reliable sources of information. They can resolve conflicting information by themselves or with help from others Low: No matter how hard they try, they cannot understand most health information and get confused when there is conflicting information	QN in HLQ
2	I compare health information from different sources	4
10	When I see new information about health, I check up on whether it is true or not	7
20	I always compare health information from different sources and decide what is best for me	12
25	I know how to find out if the health information I receive is right or not	16
30	I ask healthcare providers about the quality of the health information I find	20

Scales 6 to 9: How easy or difficult the following tasks are for you to do now

(Cannot do/Very difficult/Quite difficult/Quite easy/Very easy)

6. Ability to actively engagement with healthcare providers		
Item #	High: Is proactive about their health and feels in control of relationships with healthcare providers. Is able to seek advice from additional health care providers when necessary. They keep going until they get what they want. Empowered. Low: Is passive in their approach to health care, i.e., they do not proactively seek or clarify information and advice and/or service options. They accept information without question. Unable to ask questions to get information or to clarify what they don't understand. They accept what is offered without seeking to ensure that it meets their needs. Feel unable to share concerns.	QN in HLQ
36	Make sure that healthcare providers understand your problems properly	2pt2
38	Feel able to discuss your health concerns with a healthcare provider	4pt2
41	Have good discussions about your health with doctors	7pt2
49	Discuss things with healthcare providers until you understand all you need to	15pt2
54	Ask healthcare providers questions to get the health information you need	20pt2
7. Navigating the healthcare system		
Item #	High: Able to find out about services and supports so they get all their needs met. Able to advocate on their own behalf at the system and service level. Low: Unable to advocate on their own behalf and unable to find someone who can help them use the healthcare system to address their health needs. Do not look beyond obvious resources and have a limited understanding of what is available and what they are entitled to.	QN in HLQ
39	Find the right health care	1pt2
42	Get to see the healthcare providers I need to	8pt2
45	Decide which healthcare provider you need to see	11pt2
47	Make sure you find the right place to get the healthcare you need	13pt2
50	Find out what healthcare services you are entitled to	16pt2
53	Work out what the best care is for you	19pt2

The Health Literacy Questionnaire (HLQ™)

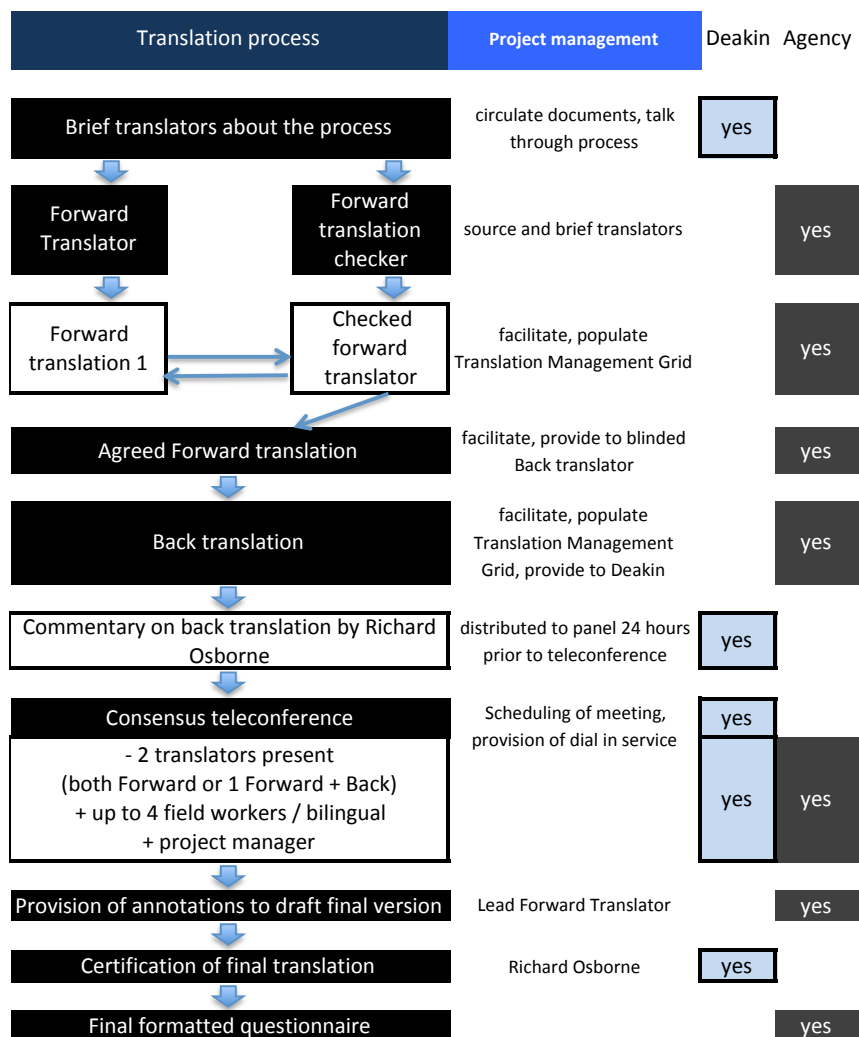
Not for distribution

8. Ability to find good health information		
Item #	High: Is an 'information explorer'. Actively uses a diverse range of sources to find information and is up to date.	QN in HLQ
	Low: Cannot access health information when required. Is dependent on others to offer information.	
37	Find information about health problems	3pt2
40	Find health information from several different places	6pt2
44	Get information about health so you are up to date with the best information	10pt2
48	Get health information in words you understand	14pt2
52	Get health information by yourself	18pt2
9. Understanding health information well enough to know what to do		
Item #	High: Is able to understand all written information (including numerical information) in relation to their health and able to write appropriately on forms where required	QN in HLQ
	Low: Has problems understanding any written health information or instructions about treatments or medications. Unable to read or write well enough to complete medical forms	
39	Confidently fill medical forms in the correct way	5pt2
43	Accurately follow the instructions from healthcare providers	9pt2
46	Read and understand written health information	12pt2
51	Read and understand all the information on medication labels	17pt2
55	Understand what healthcare providers are asking you to do	21pt2

Appendix 4: HLQ Item intent and translation management

HLQ™ Item intent and translation management document

Prepared by Richard Osborne. 25th February 2013



Translation consensus teleconference – participants

Participants	Name	Role	Country	Time zone / phone numbers	Local time
1 Developer*	<i>Dr Richard Osborne</i>	<i>Chairperson</i>	<i>Australia</i>	<i>EST</i>	
2 Forward translator 1*	<i>Folio staff (Henk)</i>	<i>Primary spokesperson, responsible scribe</i>	<i>South Africa</i>		
3 Forward translator 2**	<i>Folio staff member</i>	<i>Secondary spokesperson</i>	<i>South Africa</i>		
4 Local bilingual 1*	<i>F Lunar</i>	<i>Discussant</i>	<i>South Africa</i>		
5 Local bilingual 2**	<i>S. De Vos</i>	<i>Discussant</i>	<i>South Africa</i>		
6 Study management	<i>Jennifer Bress</i>	<i>Observer</i>	<i>South Africa</i>		
7 Other local bilingual or local language representative		<i>Discussant</i>			
8 Other local bilingual or local language representative		<i>Discussant</i>			
9 Add others as needed					

* mandatory participants

** highly recommended participants

Understanding this grid and who does what?

Guidance for translation process.			
eg	Eng.	Original English version of the question.	Description of the intent of the item, including synonyms
	Fwd	The two forward translators agreed version is inserted here by translation agency	Comments: Any major difficulties experienced, potential problems, alternate words or phrases for difficult concepts, synonyms for words that may only be used in some regions.
	Back	The back translators translation, blind to the original English version, is inserted here by translation agency	Comments: Same as for Fwd.
	Chair	Chairperson, usually one of the developers (authors)	Comments: Commentary on the back translation provided by Richard Osborne 24 hours prior to the teleconference
	Cons.	Consensus: Final agreed target language version. Lead Forward translator writes commentary	If necessary, write a description of what was decided during the consensus meeting, which included Chair, Fwd, Back, bilingual health workers. Confirm that each item: ☐ has the same 'strength' as the English version, i.e., the combination of words in an item conveys precisely the same tendency to answer the same response option if they were answering in English or the target language if they objectively had exactly the same level of the trait. This needs to account for local cultural tendencies, e.g., in English saying that one has plenty of people to talk to is reasonable, but the word 'plenty' is problematic in some languages because it might be regarded as bragging or boasting. ☐ works well for all people with low education ☐ works well for people using different dialects ☐ has no words that are too 'academic' ☐ is as efficient as possible, i.e., least number of words to convey meaning ☐ matches all the response options (high and low, and the sentence structure of the item naturally fits with all the response options) ☐ can be understood in full on the first read through

Translation management document grid

Guidance for translation process.		Health Literacy Questionnaire (HLQ™)	
		For each scale, descriptions of high and low levels of traits within the constructs are presented. It is the construct that we seek to measure but it cannot be measured directly because it is conceptually complex. So each scale comprises tangible questions about aspects of (traits within) the construct and, together, the answers to these questions provide the means by which the whole construct can be measured. The response options for the questions allow for the capture of the full breadth of the construct – from very low levels of the traits to very high levels of the traits. Each question must be translated such that it makes perfect sense for it to be answered using the <i>agree/disagree</i> (scales 1 to 5) or <i>cannot do/very easy</i> (scales 6 to 9) response options. Years of careful research using qualitative and quantitative methods have led the way to the development of these items. Please see the template below to guide the translation process, and to track comments from the forward and back translators, and the chairperson.	
		Descriptor High: A vignette of a high level of the trait. If a person responded strongly agree/very easy to all items, they would be well described by this vignette.	
		Descriptor Low: A vignette of a low level of the trait. If a person responded strongly disagree/cannot do to all items, they would be well described by this vignette	
eg	Eng.	Original English version of the question.	Description of the intent of the item, including synonyms
	Fwd	The two forward translators agreed version	Comments: any major difficulties experienced, potential problems, alternate words or phrases for very difficult concepts, synonyms for words that may only be used in some regions.
	Back	The back translator, blind to the original English version, inserts their translation of the target language translation back to English.	Comments: same as for Fwd.
	Chair	Chair person, usually one of the developers (authors)	Comments: Commentary on the back translation
	Cons.	Consensus: Final agreed target language version	If necessary, write a description of what was decided during the consensus meeting, which included Chair, Fwd, Back, bilingual health workers. Confirm that each item: ☐ has the same 'strength' as the English version, i.e., the combination of words in an item conveys precisely the same tendency to answer the same response option if they were answering in English or the target language if they objectively had exactly the same level of the trait. This needs to account for local cultural tendencies, e.g., in English saying that one has plenty of people to talk to is reasonable, but the word 'plenty' is problematic in Danish because it might be regarded as bragging or boasting. ☐ works well for people with low education ☐ works well for people using different dialects ☐ has no words that are too 'academic' ☐ is as efficient as possible, i.e., least number of words to convey meaning ☐ matches all the response options (high and low, and the sentence structure of the item naturally fits with all the response options) ☐ can be understood in full on the first read through

Response option set 1. Disagree / Agree scale			
	Eng.	Strongly disagree	<i>For a person to tick this option they need to be very clear that they hold the position. 'Strongly' means certainty in their stand, and they are quite convinced. It does not mean absolutely. The term strongly is not the full end of the scale of how intensely a person might agree.</i>
	Fwd	Verskil ten sterkste	<i>Comments:</i>
	Back	Disagree strongly	<i>Comments:</i>
	Chair		<i>Comments: discuss the strength of 'strongly' Why 3 words?</i>
	Cons.	Verskil ten sterkste	<i>Decision:</i>
	Eng.	Disagree	<i>Differ, oppose the concept in the question, the content of the item does not match their thinking or approach.</i>
	Fwd	Verskil	<i>Comments:</i>
	Back	Disagree	<i>Comments:</i>
	Chair		<i>Comments:</i>
	Cons.	Verskil	<i>Decision:</i>
	Eng.	Agree	<i>Concur, matches their position, have the same view.</i>
	Fwd	Stem saam	<i>Comments:</i>
	Back	Agree	<i>Comments:</i>
	Chair		<i>Comments:</i>
	Cons.	Stem saam	<i>Decision:</i>
	Eng.	Strongly agree	<i>The 'strongly' descriptor is same as above for Strongly disagree.</i>
	Fwd	Stem ten sterkste saam	<i>Comments:</i>
	Back	Agree strongly	<i>Comments:</i>
	Chair		<i>Comments: discuss the strength of 'strongly' Why 4 words?</i>
	Cons.	Stem ten sterkste saam	<i>Decision:</i>

Scale 1. Healthcare provider support			
High: Has an established relationship with at least one health provider who knows them well and who they trust to provide useful advice and information and to assist them to understand information and make decisions about their health.			
Low: People who are low on this domain are unable to engage with doctors and other healthcare providers. They don't have a regular health provider and/or have difficulty trusting health providers as a source of information and/or advice.			
11	Eng.	I have at least one healthcare provider who knows me well	Explores if respondent has very few healthcare providers (HCPs - see front instructions for definition of HCP) (one or more). 'Knows me well' means the respondent feels their HCP properly understands them and understands their situation and problems. Healthcare providers include doctors, psychologists, nurses, social workers, physical therapists i.e., doctors and any allied health professional providing advice, care or support.
	Fwd	Ek het ten minste een gesondheidsorgverskaffer wat my goed ken	Comments:
	Back	I have at least one health care provider who knows me well	Comments:
	Chair		Comments: discuss 'healthcare provider'
	Cons.	Ek het ten minste een gesondheidswerker wat my goed ken	Decision: "health care provider" changed to "health worker"
14	Eng.	I have at least one healthcare provider I can discuss my health problems with	Explores if respondent has very few (one or more) HCP who they can talk with about their health. 'Discuss' means talk with HCP in a meaningful way, i.e., two-way dialogue.
	Fwd	Ek het ten minste een gesondheidsorgverskaffer met wie ek my gesondheidsprobleme kan bespreek	Comments:
	Back	I have at least one health care provider with whom I can discuss my health problems.	Comments:
	Chair		Comments: seems OK
	Cons.	Ek het ten minste een gesondheidswerker met wie ek my gesondheidsprobleme kan bespreek	Decision: "health care provider" changed to "health worker"
26	Eng.	I have the healthcare providers I need to help me work out what I need to do	The question seeks to ascertain whether the respondent has sufficient or adequate healthcare providers given their needs regarding them determining what actions they ought to take. 'Work out' means think through, decide, understand the required steps – 'work out' to be facilitated
	Fwd	Ek het die gesondheidsorgverskaffers wat ek nodig het om my te help uitwerk wat ek moet doen	Comments:
	Back	I have the health care providers I need to help me work out what I should do.	Comments: 'Moet' literally = 'must' but also used for 'should', 'ought to', 'need to' etc. (Applies throughout where 'moet' is used.)
	Chair		Comments: many words, Check healthcare provider
	Cons.	Ek het die	Decision: "health care provider" changed to "health worker"

		gesondheidswerkers wat ek nodig het om my te help uitwerk wat ek moet doen	
32	Eng.	I can rely on at least one healthcare provider	<i>This question is related to the trust question (q18). 'Rely on' means depend on, bank on, count on, or be sure of. A person with a high level of this concept will feel that they can depend on or have faith in their doctor or other allied health professional. The question seeks to find out whether they have one such person in their healthcare team. 'Rely' implies 'count on' the healthcare professional</i>
	Fwd	Ek kan op ten minste een gesondheidsorgverskaffer staatmaak	Comments:
	Back	I can depend on at least one health care provider	Comments: Or 'rely on' or 'count on'.
	Chair		Comments:
	Cons.	Ek kan op ten minste een gesondheidswerker staatmaak	Decision: "health care provider" changed to "health worker"

Scale 2. Having sufficient information			
High: Feels confident that they have all the information that they need to live with and manage their condition and to make decisions.			
Low: Feels that there are many gaps in their knowledge and that they don't have the information they need to live with and manage their health concerns.			
4		I feel I have good information about health	<i>The respondent has a sense that the information they identified from what they read, or hear, is 'good' or adequate or suitable. Not outstanding. It is not about whether they are informed (the could be well- or poorly-informed) but a question. I feel that the information that is available to me is good. It is not about the volume, it covers the quality. Adequate</i>
	Fwd	Ek voel ek het goeie inligting oor gesondheid	Comments:
	Back	I feel that I have good information about health	Comments:
	Chair		Comments: all the back translations are very impressive in this section.
	Cons.	Ek voel ek het goeie inligting oor gesondheid	Decision:
17		I have enough information to help me deal with my health problems	<i>This question seeks to find out whether the volume of information that they have is enough for them to do what they need to with their health problems. 'Deal with' is a somewhat idiomatic – it means cope with, manage, handle, take care of. The item implies that they have enough of the right kind or quality of information to assist them to manage their health.</i>
	Fwd	Ek het genoeg inligting om my te help om my gesondheidsprobleme te hanteer	Comments:
	Back	I have enough information to help me deal with my health problems	Comments: 'Hanteer' also = 'handle' or 'cope with'.
	Chair		Comments:
	Cons.	Ek het genoeg inligting om my te help om my gesondheidsprobleme te hanteer	Decision:
23		I am sure I have all the information I need to manage my health effectively	<i>This item covers a respondent's confidence in that they have all the information required for them to properly help themselves (manage) their health. 'Manage' means take care of, able to do what is required, organise appropriately. Being 'sure' means being certain, convinced (a bit stronger), definite (a little stronger) or in no doubt.</i>
	Fwd	Ek is seker ek het al die inligting wat ek nodig het om my gesondheid doeltreffend te bestuur	Comments:
	Back	I am sure that I have all the information I need to manage my health effectively	Comments:
	Chair		Comments:
	Cons.	Ek is seker ek het al die inligting wat ek nodig het om my gesondheid doeltreffend te bestuur	Decision:

34		I have all the information I need to look after my health	<i>This question is an alternate to q28 but rather than manage, which is a little more involved (harder), it is somewhat softer/easier in that it has the words 'look after'. The question captures whether the respondent has all the data (information) that they need to enable them to care for themselves. 'Look after' is self care, self-manage or do the things needed to keep oneself healthy.</i>
	Fwd	Ek het al die inligting wat ek nodig het om na my gesondheid om te sien	Comments:
	Back	I have all the information I need to look after my health	Comments:
	Chair		Comments:
	Cons.	Ek het al die inligting wat ek nodig het om na my gesondheid om te sien	Decision:

Scale 3. Actively managing health			
Descriptor High : People can recognise the importance and are able to take responsibility for their own health. They proactively engage in their own care and make their own decisions about their health.			
Descriptor Low : People with low levels don't see their health as their responsibility. They are not engaged in their healthcare and see that healthcare is something that is done to them.			
8		I spend quite a lot of time actively managing my health	<i>A person who agrees with this statement is busy with dealing with their health. They put deliberate time into the process. The phrase 'quite a lot' can mean much, substantial, a fair bit; it is much more than a trivial amount, it is specific time deliberately applied each day or so. 'Actively managing' means that they are putting deliberate and thoughtful effort into the process. They decide what needs to be done, plan it and execute it.</i>
	Fwd	Ek spandeer nogal baie tyd om my gesondheid aktief te bestuur	Comments:
	Back	I spend quite a lot of time actively managing my health	Comments:
	Chair		Comments: check strength of 'quite a lot' 'actively managing' – where is the word 'manage' from?
	Cons.	Ek spandeer nogal baie tyd om my gesondheid aktief te bestuur	Decision:
16		I make plans for what I need to do to be healthy	<i>This item taps into the deliberate processes around planning. The person has a sense of what they need to be healthy, and are proactive about getting it done. 'I make plans' embodies self-motivating, self-attributed action. It doesn't necessarily mean they carry the plans through – but they are at least making plans.</i>
	Fwd	Ek beplan vir wat ek moet doen om gesond te wees	Comments:
	Back	I plan for what I need to do to be healthy	Comments:
	Chair		Comments: 'make' is missing. Makes sentence less active.
	Cons.	Ek beplan vir wat ek moet doen om gesond te wees	Decision:
21		Despite other things in my life, I make time to be healthy	<i>In this item, the respondent acknowledges that life has a range of components, and can be quite busy, but nonetheless they engage in healthy activities. The person inserts activities / time / processes into their life to promote or support their health. They prioritise some time for health even though they can be quite busy.</i>
	Fwd	Ten spyte van ander dinge in my lewe maak ek tyd om gesond te wees	Comments:
	Back	Notwithstanding other things in my life, I make time to be healthy	Comments:
	Chair		Comments: seems OK – is the word / concept of 'despite' common?
	Cons.	Ten spyte van ander dinge in my lewe maak ek tyd om gesond te wees	Decision:
27		I set my own goals about health and fitness	<i>This is a very active statement – the person is thoughtful in that they establish and create plans (goals) about their wellbeing. The words 'health' and 'fitness' go together in English, as does 'wellbeing'. The person is proactive about planning for their health and fitness.</i>
	Fwd	Ek stel my eie doelwitte oor gesondheid en fiksheid	Comments:

	Back	I set my own goals in health and fitness	<i>Comments:</i>
	Chair		<i>Comments: about/in??</i>
	Cons.	Ek stel my eie doelwitte oor gesondheid en fiksheid	<i>Decision:</i>
31		There are things that I do regularly to make myself more healthy	<i>This item taps into whether or not the respondent is currently active in their daily lives with the intention to improve their health. 'More healthy' states that they are actively seeking to become even fitter/stronger/healthier than they currently are. They have routine things in place to achieve better health.</i>
	Fwd	Ek doen gereeld dinge om myself gesonder te maak	<i>Comments:</i>
	Back	I regularly do things to make myself healthier	<i>Comments:</i>
	Chair		<i>Comments: not sure about the concept reorder – might be fine. The English implies there are set entities, and these are done regularly. The BT might imply I do bits and pieces, not well defined entities.</i>
	Cons.	Daar is dinge wat ek gereeld doen om myself gesonder te maak	<i>Decision:</i>

Scale 4. Social support

High: A person's social system provides them with all the support they want or need.

Low: Completely alone and unsupported.

3		I can get access to many people who understand and support me	<i>This item asks about whether a person has supportive and caring people around them who are empathetic to their situation. It asks whether they can find and engage with such people, not just one or a few, but several – more than they need and they could choose between them. The 'understand and support' aspect implies not just physical care, but emotional and intellectual help as well.</i>
	Fwd	Ek kan toegang tot baie mense kry wat my verstaan en ondersteun	<i>Comments:</i>
	Back	I can get access to many people who understand and support me	<i>Comments:</i>
	Chair		<i>Comments: great</i>
	Cons.	Ek kan toegang kry tot baie mense wat my verstaan en ondersteun	<i>Decision:</i>
6		When I feel ill, the people around me really understand what I am going through	<i>This is a strong statement about having social support from multiple people who are deeply empathetic to their situation. The 'people around me' aspect refers to family, friends, professionals and others – it is non-specific about who these people are. The context of the sense of being understood is defined as when the person is unwell.</i>
	Fwd	Wanneer ek siek voel, verstaan die mense rondom my werklik waardeur ek gaan	<i>Comments:</i>
	Back	When I feel sick , the people around me genuinely understand what I am going through	<i>Comments:</i>
	Chair		<i>Comments: check strength of 'sick' 'genuinely' seems complex</i>
	Cons.	Wanneer ek siek voel, verstaan die mense rondom	<i>Decision:</i>

		my werklik waardeur ek gaan	
19		If I need help, I have plenty of people I can rely on	<i>This item refers to the amount of help and support a person perceives that they have. If a person feels that they have to have some help, then they know they not only have sufficient help, but there are multiple people most able to assist them in a clear and trustworthy manner. They feel that they can depend on these people without problems arising. To answer 'strongly agree' the person would need to have a large number of people they can draw on for help.</i>
	Fwd	Indien ek hulp benodig, het ek baie mense waarop ek kan staatmaak	<i>Comments:</i>
	Back	If I need help, I have many people I can depend on	<i>Comments: Or 'rely on' or 'count on'.</i>
	Chair		<i>Comments: check magnitude of 'many' vs plenty</i>
	Cons.	Indien ek hulp benodig, het ek baie mense waarop ek kan staatmaak	<i>Decision:</i>
24		I have at least one person who can come to medical appointments with me	<i>This item is a direct question covering whether or not they have anyone who is willing and able to go to a doctor or other medical appointment with them. To mark "strongly agree" the person must have more than one person they could take.</i>
	Fwd	Ek het ten minste een persoon wat saam met my na mediese afsprake kan kom	<i>Comments:</i>
	Back	I have at least one person who can come with me to medical appointments	<i>Comments:</i>
	Chair		<i>Comments:</i>
	Cons.	Ek het ten minste een persoon wat saam met my na mediese afsprake kan kom	<i>Decision:</i>
29		I have strong support from family or friends	<i>This item asks a person whether they feel they have solid, sound or clear-cut support from either family or friends. The support people are clearly helpful, reassuring or understanding.</i>
	Fwd	Ek ontvang sterk ondersteuning deur familie of vriende	<i>Comments:</i>
	Back	I receive strong support from family or friends	<i>Comments:</i>
	Chair		<i>Comments: might be OK 'have' vs 'receive'</i>
	Cons.	Ek kry sterk ondersteuning van familie of vriende	<i>Decision:</i>

Scale 5. Critical appraisal

High: Able to distinguish good information & resolve conflicting information by themselves or with help from others.

Low: No matter how hard they try, they cannot understand most health information and get confused when there is conflicting information.

2		I compare health information from different sources	<i>This item asks the respondent whether they evaluate, compare, and contrast information they get. The wording also demands that the person is getting information from more than one place, i.e., a person might look health information up in the internet then talk with their doctor about it. They might also check what is said on two internet sites, or discuss what their general practitioner said with their specialist.</i>
	Fwd	Ek vergelyk gesondheidsinligting van	<i>Comments:</i>

		verskillende bronne	
	Back	I compare health information from different sources	Comments:
	Chair		Comments:
	Cons.	Ek vergelyk gesondheidsinligting van verskillende bronne	Decision:
10		When I see new information about health, I check up on whether it is true or not	<i>This item specifically focuses on the situation when a person finds new or different information, and then considers how they regard this information. It implies that they think about the reliability of the information, and question its integrity – i.e., whether the source is trustworthy. They actively find a way to test its integrity (truth).</i>
	Fwd	Wanneer ek nuwe inligting oor gesondheid sien, kontroleer ek of dit waar is of nie	Comments:
	Back	When I see new information on health, I check [up on] whether it is true or not	Comments:
	Chair		Comments: seems OK - discuss
	Cons.	Wanneer ek nuwe inligting oor gesondheid sien, maak ek seker of dit waar is of nie	Decision:
20		I always compare health information from different sources and decide what is best for me	<i>This is a strong statement that starts with 'I always compare', which is a hard test to fully endorse (i.e., mark 'strongly agree') and implies a constant or vigilant approach to information seeking. This is followed by a second strong task – 'decide what is best', which indicates the person thinks about a variety of information options and uses critical appraisal skills.</i>
	Fwd	Ek vergelyk altyd gesondheidsinligting van verskillende bronne en besluit wat die beste vir my is	Comments:
	Back	I always compare health information from different sources and decide what is best for me	Comments:
	Chair		Comments:
	Cons.	Ek vergelyk altyd gesondheidsinligting van verskillende bronne en besluit wat die beste vir my is	Decision:
25		I know how to find out if the health information I receive is right or not	<i>As for q15 above, this item starts with 'I know' but asks about the person's process of working out if the information is what they need and will be helpful for them. It doesn't ask about the quality of information, but asks whether they can say with conviction that they can determine if the information they get will support them.</i>
	Fwd	Ek weet hoe om uit te vind of die gesondheidsinligting wat ek ontvang, reg is of nie	Comments:
	Back	I know how to find out	Comments:

		whether the health information I receive is right or not	
	Chair		Comments:
	Cons.	Ek weet hoe om uit te vind of die gesondheidsinligting wat ek ontvang, reg is of nie	Decision:
30		I ask healthcare providers about the quality of the health information I find	<i>This item tests whether the respondent makes direct enquiries to healthcare providers regarding health information they find. The item makes clear that the respondent does seek and find health information. Such information includes material from magazines, TV, books, internet and other sources. The item also highlights that the person recognises 'quality' information and makes judgements about its integrity and value.</i>
	Fwd	Ek vra gesondheidsorgverskaffers oor die gehalte van die gesondheidsinligting wat ek vind	Comments:
	Back	I ask health care providers about the quality of the health information that I find	Comments:
	Chair		Comments:
	Cons.	Ek vra gesondheidswerkers oor die gehalte van die gesondheidsinligting wat ek vind	Decision:

Response option set 2.			
	Eng.	Cannot do	<i>For a person to tick this option they are completed unable to the activity.</i>
	Fwd	Kan dit nie doen nie	Comments:
	Back	Cannot do it	Comments:
	Chair		Comments:
	Cons.	Kan dit nie doen nie	Decision:
	Eng.	Very difficult	<i>The respondent is able to do the task but with great trouble.</i>
		Baie moeilik	
		Very difficult	
			<i>Discuss 'very' strength</i>
		Baie moeilik	
	Eng.	Quite difficult	<i>The respondent is able to do the task, but with moderate difficulty.</i>
		Taamlik moeilik	
		Quite difficult	
			<i>Discuss 'quite'</i>
		Taamlik moeilik	

	Eng.	Quite easy	<i>The respondent can to the task with confidence and some fluency.</i>
	Fwd	Taamlík maklík	<i>Comments:</i>
	Back	Quite easy	<i>Comments:</i>
	Chair		<i>Comments:</i>
	Cons.	Taamlík maklík	<i>Decision:</i>
	Eng.	Very easy	<i>The respondent can to the task with full confidence and with great fluency.</i>
	Fwd	Baie maklík	<i>Comments:</i>
	Back	Very easy	<i>Comments:</i>
	Chair		<i>Comments:</i>
	Cons.	Baie maklík	<i>Decision:</i>

Scale 6. Active engagement with healthcare providers			
High: Is proactive about their health and feels in control in relationships with healthcare providers. Is able to seek advice from additional healthcare providers when necessary. They keep going until they get what they want. Low: Is passive in their approach to health care, inactive, i.e., they do not proactively seek or clarify information and advice and/or service options. They accept information without question. Unable to ask questions to get information or to clarify what they don't understand. They accept what is offered without seeking to ensure that it meets their needs. Unable to share concerns or get a second opinion. They feel that they have very little agency.			
2		Make sure that healthcare providers understand your problems properly	<i>This is the first item using the 'cannot do—very easy' scale. This item covers the respondent's ability to communicate clearly with healthcare providers. Their communication skills help them 'make sure' (take care to validate, perhaps check) that the healthcare provider fully understands the respondents problems (issues, health concerns). In this item, 'healthcare providers' is plural, so the item indicates they do this with every provider. To understand something 'properly' means to fully comprehend the history, context and cause of the issue. The content of this question calls for very high competencies to be able to endorse 'strongly agree'.</i>
	Fwd	Om seker te maak dat gesondheidsorgverskaffers jou probleme behoorlik verstaan	Comments:
	Back	To make sure that health care providers understand your problems properly	Comments:
	Chair		Comments: what word is used for 'properly'?
	Cons.	Om seker te maak dat gesondheidswerkers jou probleme behoorlik verstaan	Decision:
4		Feel able to discuss your health concerns with a healthcare provider	<i>The item explores the degree to which the respondent believes they can talk with their healthcare provider about their health problems. The term 'feel' seeks an affective (emotive) response, one that relates to their subjective view of their ability to discuss issues with their doctor and other healthcare providers. This is a core element of the construct, which is embodied in the term 'agency', i.e., the capacity of the person to act in the world, or whether they feel it is permissible for them to speak up for themselves in the face of an authority.</i>
	Fwd	Om in staat te voel om jou gesondheidsorge met 'n gesondheidsorgverskaffer te bespreek	Comments:
	Back	To feel able to discuss your health concerns with a health care provider	Comments:
	Chair		Comments: what word is used for 'discuss'?
	Cons.	Om in staat te voel om jou gesondheidsorge met 'n gesondheidswerker te bespreek	Decision:
7		Have good discussions about your health with doctors	<i>This item is a test of a respondent's view on the quality of the discussions (two-way conversations) with doctors. 'Good' implies more than satisfactory or reasonable; rather, the word conveys beneficial and rewarding conversations. A 'good discussion' is one where the issues were aired and fulfilling interchange achieved.</i>
	Fwd	Om goeie gesprekke oor jou gesondheid met dokters te hê	Comments:
	Back	To have good conversations with doctors about your	Comments:

		health	
	Chair		<i>Comments: 'discussion' is different to 'conversation'</i>
	Cons.	Om goeie gesprekke oor jou gesondheid met dokters te hê	<i>Decision:</i>
15		Discuss things with healthcare providers until you understand all you need to	<i>When a respondent marks 'very easy' on this item, it means the respondent has substantial tenacity to talk with the healthcare provider until all the issues are sufficiently covered such that they feel they understand the key things they need know. The 'all' in 'all you need to' implies that the respondent is conscious of their own information needs, and actively persists with discussions with their doctor until they have their information needs met.</i>
	Fwd	Om goed met gesondheidsorgverskaffers te bespreek totdat jy alles verstaan wat jy moet	<i>Comments:</i>
	Back	To discuss things with health care providers until you understand everything you need to	<i>Comments:</i>
	Chair		<i>Comments:</i>
	Cons.	Om dinge met gesondheidswerkers te bespreek totdat jy alles verstaan wat jy moet	<i>Decision:</i>
20		Ask healthcare providers questions to get the health information you need	<i>This question asks the respondent about the difficulty or ease they have in asking healthcare providers questions to get the information they need. The question does presume the respondent has information needs.</i>
	Fwd	Om vir gesondheidsorgverskaffers vrae te vra om al die gesondheidsinligting te kry wat jy nodig het	<i>Comments:</i>
	Back	To ask health care providers questions in order to get all the health information you need	<i>Comments:</i>
	Chair		<i>Comments: this the translation stronger with 'all'?</i>
	Cons.	Om vir gesondheidswerkers vrae te vra om die gesondheidsinligting te kry wat jy nodig het	<i>Decision:</i>

Scale 7. Navigating the healthcare system			
High: Able to find out about services and supports so they get all their needs met. Able to advocate on their own behalf at the system and service level.			
Low: Unable to advocate on their own behalf and unable to find someone who can help them use the healthcare system to address their health needs. Do not look beyond obvious resources and have a limited understanding of what is available and what they are entitled to.			
1		Find the right healthcare	<i>This is a straightforward question asking about competency to find the 'right' healthcare. 'Right' mean appropriate, suitable or the needed healthcare. 'Healthcare' is the services provided by doctors and related professionals, and may also include a range of community health services including pharmacy, social work, counselling, and various outreach services.</i>
	Fwd	Om die regte gesondheidsorg te vind	Comments:
	Back	To find the right health care	Comments:
	Chair		Comments:
	Cons.	Om die regte gesondheidsorg te vind	Decision:
8		Get to see the healthcare providers I need to	<i>This question asks about the person's competency to make a time with a healthcare provider for a consultation. The focus of the question is on how difficult/easy it is for them to 'work out how' to make an appointment. 'Work out' relates to the processes of identifying the service, and setting the appointment through phone, face-to-face, internet or other mechanisms.</i>
	Fwd	Om die gesondheidsorgverskaffers te sien wat ek moet	Comments:
	Back	To see the health care providers that I should	Comments:
	Chair		Comments: 'get' is missing. Missing the active intent 'need to' maybe different to 'should' -
	Cons.	Om die gesondheidswerkers te kan sien wat ek moet	Decision:
11		Decide which healthcare provider you need to see	<i>This question asks about the respondent's decision-making ability to choose the type of healthcare provider they require, given their problems. For example, it might be about deciding to see their GP or a specialist or another type of other allied health professional.</i>
	Fwd	Om te besluit watter gesondheidsorgverskaffer jy moet sien	Comments:
	Back	To decide what health care provider you should see	Comments:
	Chair		Comments: ?'should'
	Cons.	Om te besluit watter gesondheidswerker jy moet sien	Decision:
13		Make sure you find the right place to get the health care you need	<i>This question asks about the respondent's navigation competency and the related planning required for them to get to the 'right' or correct place (in addition to finding the right type of care for themselves). The term 'make sure' implies that they consciously plan the journey.</i>
	Fwd	Om seker te maak dat jy die regte plek vind om die gesondheidsorg te kry wat jy nodig het	Comments:
	Back	To make sure that you find	Comments:

		the right place to get the health care you need	
	Chair		<i>Comments:</i>
	Cons.	Om seker te maak dat jy die regte plek vind om die gesondheidsorg te kry wat jy nodig het	<i>Decision:</i>
16		Find out what healthcare services you are entitled to	<i>This question asks about the respondent's competency to seek ('find out') the services they have a right to receive.</i>
	Fwd	Om uit te vind op watter gesondheidsorgdienste jy geregtig is	<i>Comments:</i>
	Back	To find out what health care services you are entitled to	<i>Comments:</i>
	Chair		<i>Comments: what word is used or 'entitled'?</i>
	Cons.	Om uit te vind op watter gesondheidsdienste jy geregtig is	<i>Decision:</i>
19		Work out what is the best care for you	<i>This question asks about the respondent's competency to deduct what is optimal ('best') care for them. It implies that they scope the options and then decide which services would be most beneficial to them.</i>
	Fwd	Om uit te werk wat die beste sorg vir jou is	<i>Comments:</i>
	Back	To work out what is the best care for you	<i>Comments:</i>
	Chair		<i>Comments:</i>
	Cons.	Om uit te werk wat die beste sorg vir jou is	<i>Decision:</i>

Scale 8. Ability to find good health information			
High: This describes a person who is an 'information explorer'. Actively uses a diverse range of sources to find information.			
Low: Does not access required health information. Is dependent on others to offer information.			
3		Find information about health problems	<i>A straightforward question about competency to 'find' (identify, locate, and obtain) information about health problems in general. There is no attribution to their own health problems. The type of information could be in any format (digital, written, oral).</i>
	Fwd	Om inligting oor gesondheidsprobleme te vind	<i>Comments:</i>
	Back	To find information about health problems	<i>Comments:</i>
	Chair		<i>Comments:</i>
	Cons.	Om inligting oor gesondheidsprobleme te vind	<i>Decision:</i>
6		Find health information from several different places	<i>A general question about seeking health information, and asks about whether or not they can find information from several places. The types of places could be internet, friends, doctors, community services, TV, or public lectures. 'Several' implies more than two but fewer than many.</i>
	Fwd	Om gesondheidsinligting by heelwat, verskillende plekke te vind	<i>Comments:</i>
	Back	To find health information in a considerable number of different places	<i>Comments:</i>
	Chair		<i>Comments: discuss</i>
	Cons.	Om gesondheidsinligting by verskeie ander plekke te vind	<i>Decision:</i>
10		Get information about health so you are up to date with the best information	<i>This question covers the respondent's competency to access information in a way that ensures the person is up to date with information. The question is qualified by the 'best' information. To mark high (very easy) the respondent needs to be confident that they have the highest quality information, i.e., the 'best' information for them.</i>
	Fwd	Om inligting oor gesondheid te kry sodat jy op datum is met die beste inligting	<i>Comments:</i>
	Back	To get information about health so that you are up to date with the best information	<i>Comments:</i>
	Chair		<i>Comments:</i>
	Cons.	Om inligting oor gesondheid te kry sodat jy op datum is met die beste inligting	<i>Decision:</i>
14		Get health information in words you understand	<i>A simple question about competency to obtain information that is understandable. The 'words' may not be understandable because the text is too technical, or it is in a language they don't understand. Responding to this question with 'cannot do' or 'with great difficulty' could be related to their own access challenges (e.g., poor health, isolation, confidence, low literacy) or due to the formats in which information is available (e.g., type face, cost, language)</i>
	Fwd	Om gesondheidsinligting in woorde te kry wat jy verstaan	<i>Comments:</i>

	Back	To get health information in words that you understand	<i>Comments:</i>
	Chair		<i>Comments:</i>
	Cons.	Om gesondheidsinligting in woorde te kry wat jy verstaan	<i>Decision:</i>
18		Get health information by yourself	<i>This item asks about the respondent's competency to source ('get') health information without assistance from others.</i>
	Fwd	Om op jou eie gesondheidsinligting te kry	<i>Comments:</i>
	Back	To get health information on your own	<i>Comments:</i>
	Chair		<i>Comments:</i>
	Cons.	Om op jou eie gesondheidsinligting te kry	<i>Decision:</i>

Scale 9. Reading and understanding health information			
High: Is able to understand all written information (including numerical information) in relation to their health and able to write appropriately on forms where required.			
Low: Has problems understanding any written health information or instructions about treatments or medications. Unable to read or write well enough to complete medical forms.			
5		Confidently fill medical forms in the correct way	<i>This item assesses the respondent's perceived ability to complete the written information in forms or surveys. The types of forms could relate to health insurance, reimbursement, consent and other forms completed when registering at a clinic. The item asks for the respondent to assess their 'confidence' to complete the forms, i.e., their self-efficacy, or how sure they are that they have done it properly and accurately.</i>
	Fwd	Om mediese vorms met vertroue op die regte manier te voltooi	Comments:
	Back	To fill in medical forms in the correct way with confidence	Comments:
	Chair		Comments: discuss
	Cons.	Om mediese vorms met vertroue op die regte manier te voltooi	Decision:
9		Accurately follow the instructions from healthcare providers	<i>This item asks the respondent about their difficulty/ease in understanding and accurately executing the instructions given to them by healthcare providers.</i>
	Fwd	Om gesondheidsorgveskaffers se instruksies akkuraat te volg	Comments:
	Back	To follow the instructions of health care providers accurately	Comments:
	Chair		Comments:
	Cons.	Om gesondheidswerkers se instruksies akkuraat te volg	Decision:
12		Read and understand written health information	<i>This item asks the respondent about their difficulty/ease in both reading and understanding written information about health.</i>
	Fwd	Om geskrewe gesondheidsinligting te lees en verstaan	Comments:
	Back	To read and understand written health information	Comments:
	Chair		Comments:
	Cons.	Om geskrewe gesondheidsinligting te lees en verstaan	Decision:
17		Read and understand all the information on medication labels	<i>As for Q46, but more specific about information on medication labels.</i>
	Fwd	Om al die inligting op medikasie-etiket te lees en verstaan	Comments:
	Back	To read and understand all the information on medicine labels	Comments:
	Chair		Comments:
	Cons.	Om al die inligting op	Decision: changed "label" to "packaging"

		medikasie-verpakking te lees en verstaan	
21		Understand what healthcare providers are asking you to do	<i>This item asks the respondent about their competency in comprehending what healthcare providers are telling them to do.</i>
	Fwd	Om te verstaan wat gesondheidsorgverskaffers jou vra om te doen	<i>Comments:</i>
	Back	To understand what health care providers ask you to do	<i>Comments:</i>
	Chair		<i>Comments: 'are asking' implies 'here and now'</i>
	Cons.	Om te verstaan wat gesondheidswerkers jou vra om te doen	<i>Decision:</i>

Appendix 5: Early Afrikaans HLQ

Byvoorbeeld:

Dui asseblief aan hoe sterk jy verskil of saamstem met die volgende stellings deur die kruising van die reaksie wat jou die beste beskryf

Mev. Jane het hierdie vrae in die volgende manier beantwoord:

Merk 'n boks af me 'n kruis:

☐ ☐ ☐ ☒

	Verskil ten sterkste	Verskil	Stem saam	Stem ten sterkste saam
1. Ek doen 'n paar van my stokperdjies	☐	☐	☒	☐
2. Ek het 'n plan om sommige fisiese aktiwiteit	☐	☒	☐	☐

Vraag 1, Jane se antwoord toon dat sy saam stem dat sy was besig om sommige van haar stokperdjies te doen.

Vraag 2, Jane stem nie saam met die stelling dat sy nou 'n plan het nie, om sommige fisiese aktiwiteit te doen.

Dui asseblief aan hoe sterk jy verskil of saamstem met die volgende stellings deur die kruising van die reaksie wat jou die beste beskryf

	Verskil ten sterkste	Verskil	Stem saam	Stem ten sterkste saam
1. Ek voel ek het goeie inligting oor gesondheid	☐	☐	☐	☐
2. Ek het ten minste een gesondheidswerker wat my goed ken	☐	☐	☐	☐
3. Ek kan toegang kry tot baie mense wat my verstaan en ondersteun	☐	☐	☐	☐
4. Ek vergelyk gesondheidsinligting van verskillende bronne	☐	☐	☐	☐
5. Wanneer ek siek voel, verstaan die mense rondom my werklik waardeur ek gaan	☐	☐	☐	☐
6. Ek spandeer nogal baie tyd om my gesondheid aktief te bestuur	☐	☐	☐	☐

Dui asseblief aan hoe sterk jy verskil of saamstem met die volgende stellings deur die kruising van die reaksie wat jou die beste beskryf

	Verskil ten sterkste	Verskil	Stem saam	Stem ten sterkste saam
7. Wanneer ek nuwe inligting oor gesondheid sien, maak ek seker of dit waar is of nie	☐	☐	☐	☐
8. Ek het ten minste een gesondheidswerker met wie ek my gesondheidsprobleme kan bespreek	☐	☐	☐	☐
9. Ek beplan vir wat ek moet doen om gesond te wees	☐	☐	☐	☐
10. Ek het genoeg inligting om my te help om my gesondheidsprobleme te hanteer	☐	☐	☐	☐
11. Indien ek hulp benodig, het ek baie mense waarop ek kan staatmaak	☐	☐	☐	☐
12. Ek vergelyk altyd gesondheidsinligting van verskillende bronne en besluit wat die beste vir my is	☐	☐	☐	☐
13. Ten spyte van ander dinge in my lewe maak ek tyd om gesond te wees	☐	☐	☐	☐
14. Ek is seker ek het al die inligting wat ek nodig het om my gesondheid doeltreffend te bestuur	☐	☐	☐	☐
15. Ek het ten minste een persoon wat saam met my na mediese afsprake kan kom	☐	☐	☐	☐
16. Ek weet hoe om uit te vind of die gesondheidsinligting wat ek ontvang, reg is of nie	☐	☐	☐	☐
17. Ek het die gesondheidswerkers wat ek nodig het om my te help uitwerk wat ek moet doen	☐	☐	☐	☐
18. Ek stel my eie doelwitte oor gesondheid en fiksheid	☐	☐	☐	☐
19. Ek kry sterk ondersteuning van familie of vriende	☐	☐	☐	☐
20. Ek vra gesondheidswerkers oor die gehalte van die gesondheidsinligting wat ek vind	☐	☐	☐	☐
21. Daar is dinge wat ek gereeld doen om myself gesonder te maak	☐	☐	☐	☐
22. Ek kan op ten minste een gesondheidswerker staatmaak	☐	☐	☐	☐
23. Ek het al die inligting wat ek nodig het om na my gesondheid om te sien	☐	☐	☐	☐

Byvoorbeeld:

Dui asseblief aan hoe maklik of moeilik die volgende take is om nou te doen

Mev. Jane het hierdie vrae in die volgende manier beantwoord:

Merk 'n boks af me 'n kruis:

☐ ☐ ☐ ☒ ☐

Kan dit nie doen nie
Baie moeilik
Taamlik moeilik
Taamlik maklik
Baie maklik

1. Ry 'n kar	☒	☐	☐	☐	☐
2. Lees 'n boek	☐	☐	☐	☒	☐

Vraag 1, Jane se antwoord verwys dat op die oomblik kan sy nie 'n kar ry nie.

Vraag 2, Jane toon dat op die oomblik kan sy 'n boek maklik lees.

Dui asseblief aan hoe maklik of moeilik die volgende take is om nou te doen

Kan dit nie doen nie
Baie moeilik
Taamlik moeilik
Taamlik maklik
Baie maklik

1. Om die regte gesondheidsorg te vind	☐	☐	☐	☐	☐
2. Om seker te maak dat gesondheidswerkers jou probleme behoorlik verstaan	☐	☐	☐	☐	☐
3. Om inligting oor gesondheidsprobleme te vind	☐	☐	☐	☐	☐
4. Om in staat te voel om jou gesondheidsorge met 'n gesondheidswerker te bespreek	☐	☐	☐	☐	☐
5. Om mediese vorms met vertroue op die regte manier te voltooi	☐	☐	☐	☐	☐
6. Om gesondheidsinligting by verskeie ander plekke te vind	☐	☐	☐	☐	☐
7. Om goeie gesprekke oor jou gesondheid met dokters te hê	☐	☐	☐	☐	☐
8. Om die gesondheidswerkers te kan sien wat ek moet	☐	☐	☐	☐	☐
9. Om gesondheidswerkers se instruksies akkuraat te volg	☐	☐	☐	☐	☐

Dui asseblief aan hoe maklik of moeilik die volgende take is om nou te doen

	Kan dit nie doen nie	Baie moeilik	Taamlik moeilik	Taamlik maklik	Baie maklik
10. Om inligting oor gesondheid te kry sodat jy op datum is met die beste inligting	☐	☐	☐	☐	☐
11. Om te besluit watter gesondheidswerker jy moet sien	☐	☐	☐	☐	☐
12. Om geskrewe gesondheidsinligting te lees en verstaan	☐	☐	☐	☐	☐
13. Om seker te maak dat jy die regte plek vind om die gesondheidsorg te kry wat jy nodig het	☐	☐	☐	☐	☐
14. Om gesondheidsinligting in woorde te kry wat jy verstaan	☐	☐	☐	☐	☐
15. Om dinge met gesondheidswerkers te bespreek totdat jy alles verstaan wat jy moet	☐	☐	☐	☐	☐
16. Om uit te vind op watter gesondheidsdienste jy geregtig is	☐	☐	☐	☐	☐
17. Om al die inligting op medikasie-verpakking te lees en verstaan	☐	☐	☐	☐	☐
18. Om op jou eie gesondheidsinligting te kry	☐	☐	☐	☐	☐
19. Om uit te werk wat die beste sorg vir jou is	☐	☐	☐	☐	☐
20. Om vir gesondheidswerkers vrae te vra om die gesondheidsinligting te kry wat jy nodig het	☐	☐	☐	☐	☐
21. Om te verstaan wat gesondheidswerkers jou vra om te doen	☐	☐	☐	☐	☐

Begrip oor gesondheid en gesondheidsorg vraelys

Understanding health and healthcare questionnaire

Dankie vir die tyd wat jy nou neem om die vraelys te voltooi oor gesondheid en gesondheidsorg.

Thank you for taking the time to complete this questionnaire about health and healthcare.

- Daar is geen reg of verkeerde antwoord nie. Beantwoord asseblief elke vraag op grond van eie ervaring, en dink oor wat jy doen of kan doen, as jy siek is.

There are no right or wrong answers, so please answer every question based on your own experience and thinking about what you do, or might do, if you get sick.

- Voltooiing van hierdie vraelys is vrywillig. Hierdie vraelys is vertroulik.

Completing this questionnaire is voluntary. This questionnaire is confidential.

In hierdie vraelys, oorweeg asseblief **gesondheidswerkers** as dokters en ander verwante professionele **gesondheids professionele**.

*In this questionnaire, please consider **healthcare providers** as doctors and any other allied health professional.*

Studie ID _____

Byvoorbeeld:**Example:**

Dui asseblief aan hoe sterk jy verskil of saamstem met die volgende stellings deur die kruising van die reaksie wat jou die beste beskryf.

Please indicate how strongly you disagree or agree with the following statements by crossing the response that best describes you now.

Mev. Jane het hierdie vrae in die volgende manier beantwoord:

Ms. Jane Citizen has answered these questions in the following way:

Merk 'n boks af me 'n kruis:

Check a box by crossing it:

☐ ☐ ☐ ☒

1. Ek doen 'n paar van my stokperdjies

I am doing some of my hobbies

Stem glad nie saam nie <i>Strongly disagree</i>	Stem nie saam nie <i>Disagree</i>	Stem saam <i>Agree</i>	Stem baie sterk saam <i>Strongly agree</i>
☐	☐	☒	☐

2. Ek het 'n plan om sommige fisiese aktiwiteit

I have a plan to do some physical activity

☐	☒	☐	☐
--------------------------	-------------------------------------	--------------------------	--------------------------

Vraag 1, Jane se antwoord toon dat sy saam stem dat sy was besig om sommige van haar stokperdjies te doen.

Question 1, Jane's answer shows that right now she agrees that she has been doing some of her hobbies.

Vraag 2, Jane stem nie saam met die stelling dat sy nou 'n plan het nie, om sommige fisiese aktiwiteit te doen.

Question 2, Jane disagrees with the statement that right now she has a plan to do some physical activity.

Dui asseblief aan hoe sterk jy verskil of saamstem met die volgende stellings deur die kruising van die reaksie wat jou die beste beskryf.

Please indicate how strongly you disagree or agree with the following statements by crossing the response that best describes you now.

		Stem glad nie saam nie <i>Strongly disagree</i>	Stem nie saam nie <i>Disagree</i>	Stem saam <i>Agree</i>	Stem baie sterk saam <i>Strongly agree</i>
1	Ek voel ek het goeie inligting oor gesondheid <i>I feel I have good information about health</i>	☐	☐	☐	☐
2	Ek het ten minste een gesondheidswerker wat my goed ken <i>I have at least one healthcare provider who knows me well</i>	☐	☐	☐	☐
3	Ek kan toegang kry tot baie mense wat my verstaan en ondersteun <i>I can get access to several people who understand and support me</i>	☐	☐	☐	☐
4	Ek vergelyk gesondheidsinligting van verskillende bronne <i>I compare health information from different sources</i>	☐	☐	☐	☐
5	Wanneer ek siek voel, verstaan die mense rondom my werklik waardeur ek gaan <i>When I feel ill, the people around me really understand what I am going through</i>	☐	☐	☐	☐
6	Ek spandeer nogal baie tyd om my gesondheid aktief te bestuur <i>I spend quite a lot of time actively managing my health</i>	☐	☐	☐	☐
7	Wanneer ek nuwe inligting oor gesondheid sien, maak ek seker of dit waar is of nie <i>When I see new information about health, I check up on whether it is true or not</i>	☐	☐	☐	☐

Dui asseblief aan hoe sterk jy verskil of saamstem met die volgende stellings deur die kruising van die reaksie wat jou die beste beskryf. Please indicate how strongly you disagree or agree with the following statements by crossing the response that best describes you now.

Stem glad nie saam
nie Strongly disagree
Stem nie saam nie
Disagree
Stem saam Agree
Stem baie sterk
saam Strongly agree

8	Ek het ten minste een gesondheidswerker met wie ek my gesondheidsprobleme kan bespreek <i>I have at least one healthcare provider I can discuss my health problems with</i>	☐	☐	☐	☐
9	Ek beplan vir wat ek moet doen om gesond te wees <i>I make plans for what I need to do to be healthy</i>	☐	☐	☐	☐
10	Ek het genoeg inligting om my te help om my gesondheidsprobleme te hanteer <i>I have enough information to help me deal with my health problems</i>	☐	☐	☐	☐
11	Indien ek hulp benodig, het ek baie mense waarop ek kan staatmaak <i>If I need help, I have plenty of people I can rely on</i>	☐	☐	☐	☐
12	Ek vergelyk altyd gesondheidsinligting van verskillende bronne en besluit wat die beste vir my is <i>I always compare health information from different sources and decide what is best for me</i>	☐	☐	☐	☐
13	Ten spyte van ander dinge in my lewe maak ek tyd om gesond te wees <i>Despite other things in my life, I make time to be healthy</i>	☐	☐	☐	☐
14	Ek is seker ek het al die inligting wat ek benodig om my gesondheid effektief te bestuur <i>I am sure I have all the information I need to manage my health effectively</i>	☐	☐	☐	☐
15	Ek het ten minste een persoon wat saam met my na mediese afsprake toe kan gaan <i>I have at least one person who can come to medical appointments with me</i>	☐	☐	☐	☐
16	Ek weet hoe om uit te vind of die gesondheidsinligting wat ek ontvang, reg is of nie <i>I know how to find out if the health information I receive is right or not</i>	☐	☐	☐	☐
17	Ek het die gesondheidswerkers wat ek benodig om my te help uitwerk wat ek moet doen <i>I have the healthcare providers I need to help me work out what I need to do</i>	☐	☐	☐	☐
18	Ek stel my eie doelwitte oor gesondheid en fiksheid <i>I set my own goals about health and fitness</i>	☐	☐	☐	☐
19	Ek kry sterk ondersteuning van familie of vriende <i>I have strong support from family or friends</i>	☐	☐	☐	☐
20	Ek vra gesondheidswerkers oor die kwaliteit van die gesondheidsinligting wat ek vind <i>I ask healthcare providers about the quality of the health information I find</i>	☐	☐	☐	☐
21	Daar is dinge wat ek gereeld doen om myself meer gesond te maak <i>There are things that I do regularly to make myself more healthy</i>	☐	☐	☐	☐
22	Ek kan op ten minste een gesondheidswerker staatmaak <i>I can rely on at least one healthcare provider</i>	☐	☐	☐	☐
23	Ek het al die inligting wat ek nodig het om na my gesondheid om te sien <i>I have all the information I need to look after my health</i>	☐	☐	☐	☐

Part 2

Byvoorbeeld:

Example:

Dui asseblief aan hoe maklik of moeilik die volgende take is om nou te doen

Please indicate how easy or difficult the following tasks are for you to do now.

Mev. Jane het hierdie vrae in die volgende manier beantwoord:

Ms. Jane Citizen has answered these questions in the following way:

		Kan dit nie doen nie	Cannot do	Baie moeilik Very difficult	Taamlik moeilik Quite difficult	Taamlik maklik Quite easy	Baie maklik Very easy
1	Ry 'n kar Drive a car	☒		☐	☐	☐	☐
2	Lees 'n boek Read a book	☐	☐	☐	☒	☐	☐

Vraag 1, Jane se antwoord verwys dat op die oomblik kan sy nie 'n kar ry nie.

Question 1, Jane's answer shows that right now she cannot drive a car

Vraag 2, Jane toon dat op die oomblik kan sy 'n boek maklik lees.

Question 2, Jane shows that right now she can read a book quite easily

Dui asseblief aan hoe maklik of moeilik die volgende take is om nou te doen

Please indicate how easy or difficult the following tasks are for you to do now.

		Kan dit nie doen nie Cannot do	Baie moeilik Very difficult	Taamlik moeilik Quite difficult	Taamlik maklik Quite easy	Baie maklik Very easy
1	Om die regte gesondheidsorg te vind Find the right health care	☐	☐	☐	☐	☐
2	Om seker te maak dat gesondheidswerkers jou probleme behoorlik verstaan Make sure that healthcare providers understand your problems properly	☐	☐	☐	☐	☐
3	Om inligting oor gesondheidsprobleme te vind Find information about health problems	☐	☐	☐	☐	☐
4	Om in staat te voel om jou gesondheidsorge met 'n gesondheidswerker te bespreek Feel able to discuss your health concerns with a healthcare provider	☐	☐	☐	☐	☐
5	Om mediese vorms met vertroue op die regte manier te voltooi Confidently fill medical forms in the correct way	☐	☐	☐	☐	☐
6	Om gesondheidsinligting by verskeie ander plekke te vind Find health information from several different places	☐	☐	☐	☐	☐
7	Om goeie gesprekke oor jou gesondheid met dokters te hê Have good discussions about your health with doctors	☐	☐	☐	☐	☐
8	Om die gesondheidswerkers te kan sien wat ek moet Get to see the healthcare providers I need to	☐	☐	☐	☐	☐
9	Om gesondheidswerkers se instruksies akkuraat te volg Accurately follow the instructions from healthcare providers	☐	☐	☐	☐	☐

Dui asseblief aan hoe <u>maklik</u> of <u>moeilik</u> die volgende take is om nou te doen <i>Please indicate how <u>easy</u> or <u>difficult</u> the following tasks are for you to do <u>now</u>.</i>		Kan dit nie doen nie	Cannot do Bale moeilik Very difficult	Taamlk moeilik Quite difficult	Taamlk maklik Quite easy	Bale maklik Very easy
10	Om inligting oor gesondheid te kry sodat jy op datum is met die beste inligting <i>Get information about health so you are up to date with the best information</i>	☐	☐	☐	☐	☐
11	Om te besluit watter gesondheidswerker jy moet sien <i>Decide which healthcare provider you need to see</i>	☐	☐	☐	☐	☐
12	Om geskrewe gesondheidsinligting te lees en verstaan <i>Read and understand written health information</i>	☐	☐	☐	☐	☐
13	Om seker te maak dat jy die regte plek vind om die gesondheidsorg te kry wat jy nodig het <i>Make sure you find the right place to get the health care you need</i>	☐	☐	☐	☐	☐
14	Om gesondheidsinligting in woorde te kry wat jy verstaan <i>Get health information in words you understand</i>	☐	☐	☐	☐	☐
15	Om dinge met gesondheidswerkers te bespreek totdat jy alles verstaan wat jy moet <i>Discuss things with healthcare providers until you understand all you need to</i>	☐	☐	☐	☐	☐
16	Om uit te vind op watter gesondheidsdienste jy geregtig is <i>Find out what healthcare services you are entitled to</i>	☐	☐	☐	☐	☐
17	Om al die inligting op medikasie-verpakking te lees en verstaan <i>Read and understand all the information on medication labels</i>	☐	☐	☐	☐	☐
18	Om op jou eie gesondheidsinligting te kry <i>Get health information by yourself</i>	☐	☐	☐	☐	☐
19	Om uit te werk wat die beste sorg vir jou is <i>Work out what is the best care for you</i>	☐	☐	☐	☐	☐
20	Om vir gesondheidswerkers vrae te vra om die gesondheidsinligting te kry wat jy nodig het <i>Ask healthcare providers questions to get the health information you need</i>	☐	☐	☐	☐	☐
21	Om te verstaan wat gesondheidswerkers jou vra om te doen <i>Understand what healthcare providers are asking you to do</i>	☐	☐	☐	☐	☐

Appendix 7: Community cluster summary sheet

Cluster #	Cluster nick name	# of people	Avg age	Avg overall	Healthcare provider support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
3	High health literacy	23	44.5	3.98	3.53	3.57	3.51	3.46	3.44	4.60	4.44	4.41	4.59
7	High health literacy, motivated to learn	5	34.0	3.97	2.90	2.85	3.32	3.28	3.36	4.80	4.90	4.80	4.92
5	Not thinking about health	5	30.3	3.60	2.65	3.30	1.96	3.32	2.76	4.48	4.60	4.36	4.52
4	Takes responsibility for health, but sometimes confused	14	42.0	3.58	3.13	3.04	3.46	3.11	3.10	4.11	4.02	4.09	3.86
8	Lack of support	3	39.0	3.48	2.42	3.58	3.33	1.80	3.00	4.13	3.61	4.80	4.40
1	Moderate, no perceived health needs	15	34.9	3.36	2.58	2.83	2.87	2.97	2.92	3.89	3.80	3.92	4.11
2	Moderate, passive about health	15	35.6	3.04	2.73	2.70	2.71	2.89	2.63	3.53	3.06	3.28	3.73
10	Difficulty getting information and services	6	40.5	2.92	2.21	2.79	3.33	2.80	2.63	3.30	2.22	2.33	4.63
6	Low health literacy but trying to stay healthy	9	34.9	2.71	2.08	2.50	3.07	2.58	2.60	2.91	2.70	2.91	2.91
11	A lot of support but trouble taking actions	2	23.0	2.69	3.00	2.88	3.00	3.40	3.30	1.90	2.00	2.50	2.50
9	Low health literacy, no support, but can follow instructions	3	39.7	2.63	1.50	1.75	2.60	1.67	2.40	3.67	2.33	3.20	4.20

Cluster #	Cluster nick name	# of people	Avg Age	Avg # conditions	% Female	Avg ed level
3	High health literacy	23	44.5	0.8	57%	2.10
7	High health literacy, motivated to learn	5	34.0	0.8	60%	2.40
5	Not thinking about health	5	30.3	0.6	80%	2.20
4	Takes responsibility for health, but sometimes confused	14	42.0	0.6	64%	2.00
8	Lack of support	3	39.0	0.7	33%	2.33
1	Moderate, no perceived health needs	15	34.9	0.5	47%	2.43
2	Moderate, passive about health	15	35.6	0.4	53%	2.08
10	Difficulty getting information and services	6	40.5	0.8	50%	2.33
6	Low health literacy but trying to stay healthy	9	34.9	0.7	67%	2.13
11	A lot of support but trouble taking actions	2	23.0	0.5	50%	3.00
9	Low health literacy, no support, but can follow instructions	3	39.7	0.7	67%	2.33

Appendix 8: EFAR cluster summary sheet

Cluster #	Cluster nick name	# of people	Avg age	Avg overall	Healthcare provider support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
5	High health literacy	11	35.1	4.08	3.77	3.57	3.56	3.45	3.53	4.69	4.64	4.64	4.56
6	High health literacy, some trouble getting info and services	8	46.0	3.95	3.78	3.59	3.93	3.90	3.63	4.25	4.00	3.95	4.40
3	High overall, though not always confident	12	36.9	3.77	2.77	3.02	3.25	3.03	3.32	4.60	4.44	4.45	4.60
8	Passive about health, good social support + relationship w/ HPs	7	27.7	3.77	3.54	3.11	2.83	3.66	3.17	4.66	4.17	4.29	4.23
9	Lacking support	2	20.0	3.53	1.63	2.75	3.40	1.60	2.90	4.60	4.83	4.70	4.60
1	Moderate health literacy, sufficient right now	25	35.1	3.45	2.87	2.86	3.10	3.08	2.88	4.01	3.91	3.86	4.14
2	Low support and information, but spends time staying healthy	2	36.5	3.10	3.13	1.88	3.80	1.90	3.30	3.10	2.92	3.30	4.40
4	Moderate/low health literacy despite having resources	6	33.6	3.04	2.79	2.79	2.97	3.03	2.90	3.33	3.42	2.90	3.03
10	Low health literacy, not much experience with health problems	14	32.9	2.98	2.14	2.59	2.43	2.56	2.57	3.66	3.20	3.64	3.76
7	Low health literacy	6	38.3	2.14	1.67	1.63	2.00	2.03	1.70	2.47	2.25	2.27	3.00

Cluster #	Cluster nick name	# of people	Avg age	Avg # conditions	% Female	Avg ed level
5	High health literacy	11	35.1	1.4	73%	2.45
6	High health literacy, some trouble getting info and services	8	46.0	0.8	75%	2.00
3	High overall, though not always confident	12	36.9	0.4	42%	2.27
8	Passive about health, good social support + relationship w/ HPs	7	27.7	0.6	29%	2.57
9	Lacking support	2	20.0	0.5	50%	3.00
1	Moderate health literacy, sufficient right now	25	35.1	0.5	52%	2.35
2	Low support and information, but spends time staying healthy	2	36.5	1.0	50%	3.50
4	Moderate/low health literacy despite having resources	6	33.6	1.3	67%	3.40
10	Low health literacy, not much experience with health problems	14	32.9	0.4	50%	2.36
7	Low health literacy	6	38.3	0.3	33%	2.50

EFARS

Appendix 9: Patient cluster summary sheet

Cluster #	Cluster nick name	# of people	Avg age	Avg overall	Healthcare provider support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
3	High health literacy	13	47.3	4.03	3.63	3.60	3.63	3.80	3.31	4.58	4.29	4.51	4.71
11	High overall, slightly less engaged w/ less information	11	41.7	3.71	3.55	3.23	3.56	3.58	3.44	3.91	4.03	4.07	3.80
6	High overall, less confident about support and info	21	41.0	3.62	2.90	2.88	3.09	3.15	3.17	4.35	4.10	4.16	4.38
7	No control over health, poor information and no HP to rely upon	3	40.3	3.27	1.50	1.75	2.87	3.27	3.07	4.93	3.06	3.53	4.87
8	Moderate health literacy	15	38.7	3.24	2.68	2.93	3.08	2.72	3.00	3.63	3.40	3.60	3.93
10	Responsible w/ good social support, but otherwise low	10	39.6	3.21	2.38	2.68	3.58	3.74	2.42	4.04	2.73	3.20	3.94
4	Low confidence	10	39.1	3.20	2.63	2.20	2.82	2.64	2.46	3.98	3.83	3.52	4.30
1	Confident but struggles w/ taking action	3	50.0	3.09	2.92	3.25	3.33	3.40	3.47	2.40	3.00	2.73	3.33
2	Not prioritizing health	5	43.3	3.01	3.05	2.40	2.12	3.20	2.56	3.92	2.87	2.92	4.00
9	Low health literacy and unhappy with healthcare providers	4	45.0	2.83	1.88	2.50	3.00	2.65	2.60	2.40	2.58	3.70	3.95
5	Low health literacy	5	43.4	2.37	2.05	2.35	3.08	2.12	2.36	2.48	2.33	2.08	2.44

Patients

Cluster #	Cluster nick name	# of people	Avg Age	Avg # conditions	% Female	Avg ed level
3	High health literacy	13	47.3	1.8	62%	1.85
11	High overall, slightly less engaged w/ less information	11	41.7	0.6	64%	1.55
6	High overall, less confident about support and info	21	41.0	1.1	76%	2.05
7	No control over health, poor information and no HP to rely upon	3	40.3	1.3	33%	2.00
8	Moderate health literacy	15	38.7	1.3	53%	2.00
10	Responsible w/ good social support, but otherwise low	10	39.6	1.2	50%	1.60
4	Low confidence	10	39.1	0.9	70%	2.56
1	Confident but struggles w/ taking action	3	50.0	2.3	0%	2.33
2	Not prioritizing health	5	43.3	1.4	100%	3.00
9	Low health literacy and unhappy with healthcare providers	4	45.0	2.8	75%	2.25
5	Low health literacy	5	43.4	1.2	60%	2.00

Appendix 10: Community vignettes

COMMUNITY vignettes

	Healthcare prov support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
3	3.53	3.57	3.51	3.46	3.44	4.60	4.44	4.41	4.59
HIGH	This is a 45 year old male who has arthritis but is otherwise pretty healthy. He feels confident in maintaining his own health and tries to stay fit by taking walks and cold showers. He has not had to deal with many health concerns yet in his life, but knows he could find information if he needed to. He is familiar with the health services at the CHC and is comfortable talking to healthcare providers there about his problems. He finds it easy to follow instructions for his pain tablets for his arthritis.								
	Healthcare prov support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
7	2.90	2.85	3.32	3.28	3.36	4.80	4.90	4.80	4.92
HIGH	This is a 34 year old male who is relatively healthy. He is unemployed, and spends time at clinic on behalf of his family members who are unable to go (picking up tablets, taking his niece for a visit, etc). He feels comfortable opening up to healthcare providers and is not shy when discussing his concerns, because doctors have all the education. He is confident in his ability to gather up-to-date information by using the internet and comparing information from different doctors and clinics, and feels motivated to learn more about various health conditions. He thinks that money and time constraints and "what the system allows" are the main limitations on his ability to rely upon a healthcare provider.								
	Healthcare prov support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
5	2.65	3.30	1.96	3.32	2.76	4.48	4.60	4.36	4.52
MIX	This is a 30 year old female with asthma, which causes her to have trouble breathing when she is busy running around to get things done. She is able to get to the clinic and talk to healthcare providers when she needs to, and finds the information that she gets there to be helpful. She has trouble comparing information from different places, so she generally just tries to accept what she hears and reads. She does not make her health a priority, because she is usually too busy taking care of her children to focus on her own problems.								
	Healthcare prov support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
4	3.13	3.04	3.46	3.11	3.10	4.11	4.02	4.09	3.86
HIGH	This is a 42 year old female who is pretty healthy. She works as a maid, so she is fairly active and on her feet most of the day. She believes this helps keep her healthy, and she also tries to eat vegetables and rest when she is not feeling well. She rarely has to visit the clinic, but when she does, she feels confident discussing her problems with the healthcare provider. She sometimes is confused by some of the advice she receives at the clinic, and is not sure what she is supposed to do.								
	Healthcare prov support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
8	2.42	3.58	3.33	1.80	3.00	4.13	3.61	4.80	4.40
MIX	This is a 39 year old male who has diabetes. He lives alone, and has devoted a lot of his time to learning about his condition, and feels confident in his ability to manage his blood sugars and follow instructions from the healthcare providers. He feels able to ask the healthcare providers questions, though he doesn't necessarily think he has one that he can regularly rely on that knows him well. He sometimes has trouble figuring out what services he is entitled to, and does not have anyone at home he can ask for help.								
	Healthcare prov support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
1	2.58	2.83	2.87	2.97	2.92	3.89	3.80	3.92	4.11
MED	This is a 35 year old male who hardly ever visits the clinic, because he has always been pretty healthy. When he does go, he is able to access basic services and list his concerns for his healthcare provider, but doesn't spend too much time dwelling on his illness. If he needed to, he thinks he could find health information on the internet, but right now he doesn't know too much about health because he never really has needed to.								
	Healthcare prov support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
2	2.73	2.70	2.71	2.89	2.63	3.53	3.06	3.28	3.73

MED This is a 36 year old female who is relatively healthy. She does not go to the clinic often, but when she does, she only has a limited understanding of what services she is entitled to and how to advocate for her care. She has some information about health, and is able to present her problems to a Dr, but is mostly passive in office visits and lets the Dr do all the talking. She isn't sure what she should specifically be doing on a regular basis to stay healthy, but she does try to make time to get well when she becomes ill.

	Healthcare prov support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
10	2.21	2.79	3.33	2.80	2.63	3.30	2.22	2.33	4.63

MIX This is a 41 year old female who has great trouble figuring out how to get help for her depression and anxiety. It is always a big ordeal to try to make it to the clinic and get the help she needs. She does not know where to go for information or advice, and has trouble understanding information that she does find on her own. She feels it is important that she takes responsibility for her own care and tries to make her own decisions about healthcare, but has trouble doing so because she does not understand what she must do. When she eventually does get seen by a healthcare provider, she feels very confident following their instructions and taking her medications.

	Healthcare prov support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
6	2.08	2.50	3.07	2.58	2.60	2.91	2.70	2.91	2.91

LOW This is 35 year old female who suffers from seizures. She spends a good amount of time trying to manage her condition and stay healthy, even when she is busy with other things. However, she has difficulty understanding what to do. She struggles to navigate the healthcare system, and has trouble engaging healthcare providers to learn about her condition and how to manage it. She also has a hard time following instructions and advice from healthcare providers, particularly when she has to read brochures or stick to a detailed treatment plan. She stays with a couple family members, but doesn't always feel she has help in the community.

	Healthcare prov support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
11	3.00	2.88	3.00	3.40	3.30	1.90	2.00	2.50	2.50

MIX This is a 23 year old male diagnosed with cancer. He has an excellent support network of family and friends in the community, and also feels he can rely upon his cancer specialist. However, in general he is quite passive in Dr appointments, accepting information without questioning it or asking for clarification. He has trouble understanding what to do and how to use the healthcare services to get appropriate care. He struggles to find information on his own, but has learned a lot from having cancer and feels that he has gotten good at comparing information that he has been given over the past year.

	Healthcare prov support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
9	1.50	1.75	2.60	1.67	2.40	3.67	2.33	3.20	4.20

LOW This is a 40 year old female who gets occasional back pain. She feels very lonely and ignored by both her family and healthcare providers, and has to figure out everything herself. She thinks that she is explaining her problems well in visits, and can ask a few questions to learn from her healthcare provider during an appointment. She generally finds it easy to follow their advice, but doesn't end up devoting too much time to taking care of herself. She lacks information about health and only knows how to get it by asking doctors.

Appendix 11: EFAR vignettes

EFAR vignettes									
	Healthcare prov support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
HIGH	5	3.77	3.57	3.56	3.45	3.53	4.69	4.64	4.56
This is a 35 year old woman who suffers from seizures. She devotes a substantial amount of time to following up in the clinic about her seizures, and feels comfortable using the healthcare system and engaging with healthcare providers. She is confident she has good information about health, and usually compares information from different places to decide what is right.									
HIGH	6	3.78	3.59	3.93	3.90	3.63	4.25	4.00	3.95
This is a 46 year old female who sometimes has back pain but is otherwise healthy. She finished some of high school but left before graduating. She is confident in her ability to take care of herself, and spends time trying to do stretches to help her back. She feels confident that she can rely upon her healthcare providers, but occasionally has trouble using the clinic and other resources to get information or services she needs.									
HIGH	3	2.77	3.02	3.25	3.03	3.32	4.60	4.44	4.45
This is a 37 year old male who sometimes has back or joint pain, but otherwise is quite well. He has a few friends and family members to help him when he needs to, though he can't think of any healthcare providers he could rely on if he really needed help. He is confident that he has at least a basic understanding about health, though he knows he could probably learn more if he put time in to do it, but he is often busy trying to find work. He engages healthcare providers at the clinic and is able to learn from his visits and follow instructions well.									
HIGH	8	3.54	3.11	2.83	3.66	3.17	4.66	4.17	4.29
This is a 28 year old male who has a good support network in the community. He also has good discussions with healthcare providers, whom he trusts. He struggles with feelings of anxiety and depression from time to time, but he tries to not spend too much time dwelling on his health because he doesn't want to think there is something wrong with him. He can find health information when he needs to, but thinks he has enough information already to try to stay healthy.									
HIGH	9	1.63	2.75	3.40	1.60	2.90	4.60	4.83	4.70
This is a 20 year old healthy male. He graduated high school and is halfway through his degree at the university. He chooses to do most things on his own, and is confident that he can keep himself healthy and get services if he were to need them. He doesn't have a ton of knowledge about health, but thinks this is OK because he has always been healthy. He does not feel that he has any support from family or friends, and can't rely upon his healthcare providers either.									
MIX	1	2.87	2.86	3.10	3.08	2.88	4.01	3.91	3.86
This is a 35 year old female who is pretty healthy besides having back pain every once in a while. She tries to rest when her back aches, but doesn't spend too much time worrying about it. She feels mostly confident in her ability to take care of herself, use healthcare services, and talk to doctors to understand what she needs to do. She doesn't need to rely upon healthcare providers too much since she isn't sick.									
MED	2	3.13	1.88	3.80	1.90	3.30	3.10	2.92	3.30
This is a 36 year old female who is healthy and lives alone. She has a university degree. Despite spending a lot of time as a teacher, she makes sure to stay healthy and takes time to visit the clinic when she needs to, although she has trouble figuring out how the system works and how to make sure that her doctor understands her needs. She feels that she can generally rely upon healthcare providers and follow their instructions well. She does not have much support in the community, and feels that she does not have very good information about health, although it is not too much of a problem yet since she is healthy.									
MIX	4	2.79	2.79	2.97	3.03	2.90	3.33	3.42	2.90

	This is a 34 year old female who has asthma and problems with her vision. She graduated university and has medical aid and a good job to help cover her inhalers and follow-up visits, but she does not always have time to devote to her health because she is busy at work. She feels that she can use healthcare services when she needs to, but is sometimes confused by how things work. She knows a couple things about her asthma, but wishes she knew how to find out more or felt more comfortable asking the doctor to explain things to her.									
MED		Healthcare prov support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
	10	2.14	2.59	2.43	2.56	2.57	3.66	3.20	3.64	3.76
	This is a 33 year old healthy male. He does not spend a great deal of time on health because he feels he is pretty healthy already, though he tries to drink water because he read in a magazine that it is good for you. He doesn't go to the clinic very often, and thinks it would be somewhat difficult to find his way around and use services. He has support from his wife, but doesn't have too many friends in the community.									
LOW		Healthcare prov support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
	7	1.67	1.63	2.00	2.03	1.70	2.47	2.25	2.27	3.00
	This is a 38 year old male with a history of depression and anxiety. He has trouble dealing with his life on a daily basis, and doesn't feel he can count on family members or doctors to help him. He is greatly confused by the healthcare system, and is not sure how to find information on his own, so he has no confidence in his knowledge about health. He is not sure what to do with new information when he does get it, and struggles to communicate well with healthcare providers to explain what is wrong and understand his options.									
LOW										

Appendix 12: Patient vignettes

PATIENT vignettes									
	Healthcare prov support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
3	3.63	3.60	3.63	3.80	3.31	4.58	4.29	4.51	4.71
HIGH	This is a 47 year old female who has been managing diabetes and high blood pressure for many years. She never attended high school, but did complete primary school. She is familiar with local health services and feels confident overall in managing her conditions. She gets most of her information from healthcare providers that she has visited over time, as well as by chatting with others from the community that have similar conditions. She feels confident engaging doctors and making sure her problems are understood. When presented with new health information, she sometimes finds it difficult to figure out if it is correct or would be useful for her, so she just follows instructions from her doctors.								
11	3.55	3.23	3.56	3.58	3.44	3.91	4.03	4.07	3.80
HIGH	This is a 42 year old female. She completed primary school. She is pretty healthy, and has not had to visit the clinic as often as some of her friends. She only occasionally gets pain in her joints from arthritis. She feels confident that she keeps herself healthy by walking and drinking plenty of water. She is not always sure how to find health information when she gets sick, and sometimes has difficulty making sure her questions are answered when she does have to see a doctor. She tries her best to follow instructions from doctors, but sometimes has trouble understanding what she is supposed to do or why.								
6	2.90	2.88	3.09	3.15	3.17	4.35	4.10	4.16	4.38
HIGH	This is a 41 year old female who struggles with back pain and sometimes trouble breathing. She works as home health aide, so she has some information in general about health, but is unsure that she has enough information about her own health problems to manage them properly. When she hears new or confusing information, she talks to other people to help figure out what she thinks is right. She feels very comfortable talking to healthcare providers and other people about health information and concerns, and feels able to follow instructions and advice that she receives. She tries to eat a healthy diet and set some goals about health and fitness, but finds that she is quite busy and does not always have time to focus on them. She does not feel that she can rely upon any particular healthcare provider because the doctors in the clinic change every 6 months, and each time she goes in she has to explain her background from the start to a new person.								
7	1.50	1.75	2.87	3.27	3.07	4.93	3.06	3.53	4.87
MIX	This is a 40 year old male. He usually rarely visits the clinic, but has recently been told he has high blood pressure, so he is here to find out more information. He does not feel he has any healthcare providers he knows or can rely on, because he hardly ever visits the clinic, and prefers not to focus on his own health. However, when he does go, he feels that healthcare providers are trustworthy sources of information and feels confident talking to them to learn and to make sure his problems are understood. In general, he has never spent much time finding health information or setting personal goals about health and fitness, because he does not feel he has that much control over his life. He has a good network of support in his family and at the church.								
8	2.68	2.93	3.08	2.72	3.00	3.63	3.40	3.60	3.93
MED	This is a 39 year old male who has struggled with ongoing back pain for a while. Has tried to fix his posture, but is not sure it has helped. He has gone to the CHC for help, and thinks he describes his problem well, but is not sure his doctors understand the pain that he has to deal with. Overall, he does not feel like he has much support from healthcare providers or his family, so he tries to manage his pain on his own. He does not spend too much time looking for information about his health, but feels confident he can follow instructions from the doctor and take tablets when he needs to.								
10	2.38	2.68	3.58	3.74	2.42	4.04	2.73	3.20	3.94

MIX	This is a 40 year old male with heart problems. He did not get very far in school, only making it part of the way through primary school. He feels lucky to have an excellent, supportive group of family and friends in the community. He is confident making his own decisions about his health and knows it is his responsibility to do so. He thinks most of the healthcare providers he sees are kind and competent, but he is unsure how to ask questions to learn about his condition. He struggles to find information on his own, and when he does hear new information, is unsure what exactly it means for him. He does not feel confident that he truly understands his heart problem, but generally follows instructions from doctors the best he can and hopes that it is working for him.								
	Healthcare prov support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
4	2.63	2.20	2.82	2.64	2.46	3.98	3.83	3.52	4.30
MIX	This is a 39 year old female who is mostly healthy, though sometimes she has pain in her joints that she thinks could be arthritis. She graduated high school and now has a day job working at a shop nearby. She is quite busy, and does not feel she has enough time to devote to her health, although she takes a multivitamin and knows she should get more exercise. She feels able to get some health information from the internet and by asking her GP, who she has a good relationship with. However, she has great trouble deciding what information is correct, and wishes other doctors and the CHC would provide more health information to patients in a way they could understand more easily. She relies upon her GP to help her navigate health services through referrals when she needs them. When she does get specific, written instructions from a Dr, she finds it easy to follow.								
	Healthcare prov support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
1	2.92	3.25	3.33	3.40	3.47	2.40	3.00	2.73	3.33
MIX	This is a 50 year old male who has chronic back pain and problems with his cholesterol. He has had these conditions a while, and they are poorly controlled. He thinks that he generally knows enough about his health, and just relies upon others to give him more information if he needs it. He gets confused and frustrated by some of the processes at the CHC. He is not very proactive about his health, and is not sure how to ask healthcare providers for advice or information that fits his needs.								
	Healthcare prov support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
2	3.05	2.40	2.12	3.20	2.56	3.92	2.87	2.92	4.00
MIX	This is a 43 year old female with vision issues and some bothersome skin problems. She graduated high school and enrolled in university, but did not end up going. She has to visit an eye doctor every once in a while to make sure she can see, but otherwise, tends to avoid going to the clinic when she is sick unless she is very very ill, because she has other priorities in life. When she does see a healthcare provider, she feels able to discuss her problems and follow their advice. In general, health is not that important to her and she doesn't spend much time learning about health or trying to understand her body.								
	Healthcare prov support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
9	1.88	2.50	3.00	2.65	2.60	2.40	2.58	3.70	3.95
MIX	This is a 45 year old female with arthritis and heart problems. Sometimes, she struggles with feelings of anxiety and depression. She feels mostly confident in her own ability to find and read health information, so she learns about health on her own, but her only resource is a book about health that her sister has. She does not understand what services she is entitled to, and feels she does not have much of an influence on her own healthcare. She would prefer to go to another hospital nearby, but because of financial reasons, must come to this health centre. She does not feel she has an ongoing relationship with any doctor because every time she visits, she sees new ones. She feels confident in her own ability to describe her health concerns and ask questions, but feels that most doctors don't listen to her or understand her problems, and does not feel like her questions get answered. When she does get instructions from a Dr or tablets to take, she finds it pretty easy to follow.								
	Healthcare prov support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
5	2.05	2.35	3.08	2.12	2.36	2.48	2.33	2.08	2.44
LOW	This is a 43 year old male who has struggled with mental illness since his 20s. He lives alone. He feels somewhat confident in his own abilities to care for himself, and does things like yoga and showering in cold water that he believes are healthy. He thinks he knows most of the policies of the local clinic, but he does not believe adequate resources for patients with psychiatric illness exist. He often feels frustrated by the lack of support and resources specifically for patients with mental illness. He struggles to engage healthcare providers and feels he has no support during clinic visits because the healthcare providers don't have enough time to spend with him. He finds health information from places like encyclopedias and adverts, but does not think doctors give him enough health information, and is unsure about how to find out if what he learns is right or not, so he only relies on his own mind and whether he believes the information makes sense.								

Appendix 13: Workshop report



Health Literacy Interventions

Workshop 20th February 2014 - feedback of data from HLQ and generation of intervention ideas

Attendees:

Jennifer Bress (UCT, principal investigator), Michéle Twomey (EMS/EM), Simonay De Vos (EFAR Admin clerk), Marcus Slingers (EFAR coordinator), Angela de Sa (PAWC- DOH), Carol Kleinhans (PAWC- DOH), Phillip Cloete (VHW), Ann Albrecht (CCT- HPO), Esther Carolus (Lavender Hill), Simphiwe (EM registrar), Tessa Carolissen (Seawinds clinic), Gerry Gordon (Mothers Unite director), Julia Peters (Mothers Unite EFAR Admin), Jocelyne Hoste (Mothers Unite), Sadija Camiedren (Mothers Unite), Margie Fritz (Mothers Unite), Kathelyn (Mothers Unite), Elois (Mothers Unite)

Background

Results presented at the workshop are based on the collection of data from 100 lay community members, 93 Emergency First Aid Responders (EFARs) trained through Mothers Unite, and 100 patients at Retreat Community Health Clinic (CHC). All participants reside in the greater Lavender Hill area. Data was collected using the Health Literacy Questionnaire between October 2013 and February 2014.

Demographic data	Note: [#] denotes missing data			
	Overall	Community	EFAR	Patient
Age (mean)	38.6 yrs	38.4 yrs [9]	35.1 yrs [12]	41.9 yrs [7]
Female (percent of total sample)	59%	57 (59%) [4]	49 (53%) [1]	64 (66%) [3]
Lives alone	8%	4 (4%) [10]	5 (6%) [7]	12 (12%) [2]
South African born	98%	90 (97%) [7]	85 (98%) [6]	96 (100%) [4]
Part high school or less	68%	64 (70%) [8]	54 (61%) [4]	70 (73%) [4]
Private insurance or medical aid	10%	8 (9%) [8]	11 (13%) [5]	6 (7%) [8]

Health conditions	Note: [#] denotes missing data			
	Overall	Community	EFAR	Patient
Arthritis	12%	15 (18%)	4 (5%)	13 (13%)
Back pain	21%	13 (16%)	17 (21%)	23 (24%)
Heart problems	5%	3 (4%)	2 (3%)	8 (8%)
Asthma	14%	8 (10%)	8 (10%)	20 (21%)
Cancer	1%	2 (2%)	0 (0%)	1 (1%)
Depression/anxiety	9%	4 (5%)	6 (8%)	12 (12%)
Seizures	4%	2 (2%)	2 (3%)	6 (6%)
Diabetes	13%	8 (10%)	9 (11%)	16 (16%)
Stroke	1%	0 (0%)	1 (1%)	1 (1%)
Other health condition	20%	8 (10%)	11 (14%)	33 (34%)
Reports no conditions	41%	40 (49%)	40 (50%)	25 (26%)
Did not answer about conditions	12%	18 (18%)	13 (14%)	3 (3%)

Health Literacy Scenarios

Health Literacy Questionnaire (HLQ) data from 100 community members, 93 EFARs, and 100 patients at Retreat CHC were analysed using cluster analysis, a statistical technique to identify groups of people with similar health literacy profiles. Cluster analysis of the data resulted in the identification of 11 groups (or clusters) within the community group, 10 groups within the EFARs, and 11 groups within patients from Retreat CHC, with each cluster displaying a distinct pattern in the way participants answered the HLQ. These groups, their health literacy profiles, and their demographic characteristics were discussed during a 3-hour workshop with community members, local leaders, healthcare providers, and health service employees serving the greater Lavender Hill area.

To facilitate the discussion of clusters and the identification of intervention ideas to address health literacy needs evident from the HLQ scores, scenarios were developed to represent key clusters. These scenarios were fictional characters inspired both by the profile of HLQ scores for the particular cluster, and where available, interviews with participants from that group. The cluster groups are described in turn, in the section to follow. Alongside the cluster descriptions, we report the reflections of workshop participants, and the intervention ideas they generated during the group discussion. For these discussions, there were two separate focus groups- one that discussed data from the community members and EFARs, and one that discussed data from the patients.

1. Higher health literacy clusters

Some clusters in each of the three groups demonstrate relatively high health literacy, with consistently moderate to high scores across all nine domains. Three of 11 Community clusters, four of the 10 EFAR clusters, and three of the 11 Patient clusters demonstrate this pattern.

For the purposes of focusing on interventions for individuals with lower health literacy, discussions focused more on moderate, mixed, and low health literacy clusters.

Community

Clust #	Cluster nick name	# of people	Avg age	Avg overall	Healthcare provider support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
3	High health literacy	23	44.5	3.98	3.53	3.57	3.51	3.46	3.44	4.60	4.44	4.41	4.59
7	High health literacy, motivated to learn	5	34.0	3.97	2.90	2.85	3.32	3.28	3.36	4.80	4.90	4.80	4.92
4	Takes responsibility for health, but sometimes confused	14	42.0	3.58	3.13	3.04	3.46	3.11	3.10	4.11	4.02	4.09	3.86

EFARs

Clust #	Cluster nick name	# of people	Avg age	Avg overall	Healthcare provider support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
5	High health literacy	11	35.1	4.08	3.77	3.57	3.56	3.45	3.53	4.69	4.64	4.64	4.56
6	High health literacy, some trouble getting info and services	8	46.0	3.95	3.78	3.59	3.93	3.90	3.63	4.25	4.00	3.95	4.40
3	High overall, though not always confident	12	36.9	3.77	2.77	3.02	3.25	3.03	3.32	4.60	4.44	4.45	4.60
8	Passive about health, good social support + relationship w/ HPs	7	27.7	3.77	3.54	3.11	2.83	3.66	3.17	4.66	4.17	4.29	4.23

Patients

Clust #	Cluster nick name	# of people	Avg age	Avg overall	Healthcare provider support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
3	High health literacy	13	47.3	4.03	3.63	3.60	3.63	3.80	3.31	4.58	4.29	4.51	4.71
11	High overall, slightly less engaged w/ less information	11	41.7	3.71	3.55	3.23	3.56	3.58	3.44	3.91	4.03	4.07	3.80
6	High overall, less confident about support and info	21	41.0	3.62	2.90	2.88	3.09	3.15	3.17	4.35	4.10	4.16	4.38

2. Moderate health literacy clusters

Two of the community clusters, two of the EFAR clusters, and one patient cluster demonstrate moderate health literacy, with moderate scores across all domains. Almost all of these clusters had a moderate or low-moderate score for “Actively managing health,” and many representatives from these groups did not feel they needed any specific help with aspects of their healthcare. Most of them tended to take a more passive role in their health management. However, some of the patients in the moderate cluster had a chronic condition that they tried to manage, but had difficulty doing so.

Community

Clust #	Cluster nick name	# of people	Avg age	Avg overall	Healthcare provider support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
1	Moderate, no perceived health needs	15	34.9	3.36	2.58	2.83	2.87	2.97	2.92	3.89	3.80	3.92	4.11

2	Moderate, passive about health	15	35.6	3.04	2.73	2.70	2.71	2.89	2.63	3.53	3.06	3.28	3.73
---	--------------------------------	----	------	------	------	------	------	------	------	------	------	------	------

EFARs

Clust #	Cluster nick name	# of people	Avg age	Avg overall	Healthcare provider support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
1	Moderate health literacy, sufficient right now	25	35.1	3.45	2.87	2.86	3.10	3.08	2.88	4.01	3.91	3.86	4.14
4	Moderate/low health literacy despite having resources	6	33.6	3.04	2.79	2.79	2.97	3.03	2.90	3.33	3.42	2.90	3.03

Patients

Clust #	Cluster nick name	# of people	Avg age	Avg overall	Healthcare provider support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
8	Moderate health literacy	15	38.7	3.24	2.68	2.93	3.08	2.72	3.00	3.63	3.40	3.60	3.93

Patient Cluster 8 Scenario: Moderate health literacy

This is a 39 year old male who has struggled with ongoing back pain for a while. He has tried to fix his posture, but is not sure it has helped. He has gone to the CHC for help, and thinks he describes his problem well, but is not sure his doctors understand the pain that he has to deal with. Overall, he does not feel like he has much support from healthcare providers or his family, so he tries to manage his pain on his own. He does not spend too much time looking for information about his health, but feels confident he can follow instructions from the doctor and take tablets when he needs to.

Reflections on patient cluster 8 scenario

- First impressions: this is a common type of patient encountered in both primary care and EC settings
- Often, these patients with chronic conditions become disillusioned about the amount of help that can actually be provided by the system and analgesics.
 - Common to find that nobody has ever spent the time to talk to these patients at length about their prognosis and what to expect- patients get frustrated with lack of diagnosis and solution
 - Another problem is that they are often given varying advice that is not evidence based, so patients get frustrated because even when they follow advice it often does not help
- Some healthcare providers are cynical and may think patients like this are malingering
- Sometimes, the chronic pain is a manifestation of mental or social issues, and patients really come to the clinic because they just need somebody to talk to.
- Often there are huge differences between what HP thinks are main problems to focus on in a visit (ex hypertension) vs what bothers patient most (back pain), and back pain gets neglected

- Healthcare worker fatigue as a result of dealing with so many of these patients is common
- These patients tend to visit several different healthcare providers and ECs to try to deal with their problem

Potential strategies in response to patient cluster 8 scenario

Individual-level strategies

- *Patient empowerment and plan making* Encourage HPs to spend more time with patient when first meeting them, to form better patient-physician relationship and to make sure a plan is developed to both rule out dangerous causes of pain and find a way to manage it. If back pain is not priority of visit due to more pressing concerns, help patient book another appointment specifically to address pain. Make sure patient is on board with the plan and takes an active role!

Organisational level strategies

- *Support groups* After initial visits with HP to rule out dangerous causes of pain, encourage patient to join support group with other patients who have similar problems.
 - Physio and social worker can team up for consults-- very valuable for these patients
- *Standardize information given to patients, based on evidence* Communicate the same, **evidence-based** information to patients to minimize confusion and encourage best practices and up-to-date knowledge
- *Encourage continuity of care* To make sure pain gets addressed and patient does not continue to get worked up by several different providers (or go to EC instead)

3. Mixed health literacy groups

Four of the community clusters, two of the EFAR clusters, and six of the patient clusters showed a mixed pattern of responses across the nine health literacy domains. These clusters were interesting to discuss, because most had at least one domain they scored high enough on that it could be considered a good place to target an intervention for some of the domains with lower scores.

Community

Clust #	Cluster nick name	# of people	Avg age	Avg overall	Healthcare provider support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
5	Not thinking about health	5	30.3	3.60	2.65	3.30	1.96	3.32	2.76	4.48	4.60	4.36	4.52
8	Lack of support	3	39.0	3.48	2.42	3.58	3.33	1.80	3.00	4.13	3.61	4.80	4.40
10	Difficulty getting information and services	6	40.5	2.92	2.21	2.79	3.33	2.80	2.63	3.30	2.22	2.33	4.63
11	A lot of support but trouble taking actions	2	23.0	2.69	3.00	2.88	3.00	3.40	3.30	1.90	2.00	2.50	2.50

EFARs

Clust #	Cluster nick name	# of people	Avg age	Avg overall	Healthcare provider support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
9	Lacking support	2	20.0	3.53	1.63	2.75	3.40	1.60	2.90	4.60	4.83	4.70	4.60
2	Low support and information, but spends time staying healthy	2	36.5	3.10	3.13	1.88	3.80	1.90	3.30	3.10	2.92	3.30	4.40

Patients

Clust #	Cluster nick name	# of people	Avg age	Avg overall	Healthcare provider support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
7	No control over health, poor information, and no HP to rely upon	3	40.3	3.27	1.50	1.75	2.87	3.27	3.07	4.93	3.06	3.53	4.87
10	Responsible w/ good social support, but otherwise low	10	39.6	3.21	2.38	2.68	3.58	3.74	2.42	4.04	2.73	3.20	3.94
4	Low confidence	10	39.1	3.20	2.63	2.20	2.82	2.64	2.46	3.98	3.83	3.52	4.30
1	Confident but struggles w/ taking action	3	50.0	3.09	2.92	3.25	3.33	3.40	3.47	2.40	3.00	2.73	3.33
2	Not prioritizing health	5	43.3	3.01	3.05	2.40	2.12	3.20	2.56	3.92	2.87	2.92	4.00
9	Low health literacy and unhappy with healthcare providers	4	45.0	2.83	1.88	2.50	3.00	2.65	2.60	2.40	2.58	3.70	3.95

Community Cluster 5 Scenario: Not thinking about health

This is a 30 year old female with asthma, which causes her to have trouble breathing when she is busy running around to get things done. She is able to get to the clinic and talk to healthcare providers when she needs to, and finds the information that she gets there to be helpful. She has trouble comparing information from different places, so she generally just tries to accept what she hears and reads. She does not make her health a priority, because she is usually too busy taking care of her children to focus on her own problems.

Reflections on community cluster 5 scenario

- First impressions: this is a familiar type of community member; children are her priority rather than her own health, but her asthma is poorly managed and interferes with her ability to take care of children
- She is capable of getting information, particularly from clinic visits and healthcare providers, but is not likely to always make it to her appointments
 - Also, once she has information she is not great at comparing or critically appraising it

- Her most concerning problem is her lack of prioritizing and taking an active role in her healthcare- and seemingly this is related to interfering childcare responsibilities
- Clinic will always take close to a full day, even longer if patient misses appointment and has to come back

Potential strategies in response to community cluster 5 scenario

Individual-level strategies

- *Patient empowerment* Ideally want to make it easier for this person to have time to focus on their health and take a more active role in managing her asthma. Want her to realize that without her health she will not be able to continue properly taking care of her children!

Organisational level strategies

- *Information groups* Gather groups of community members who have the same health concerns, and distribute information to them in a forum where they may compare how they have been managing their own health. EFARs may be good people to lead these groups. This will help give patients a safe place to ask questions about their conditions and ask others for advice- will help address critical appraisal issues
- *Resources for childcare* Find organizations that are available to take care of children so that the patient can take time to bring herself to the clinic and focus on herself. Mothers Unite takes care of children after school; need other places where children who are not in school can go during the day, or disabled children can go. Examples- Hope for the Nation, Village Care?
- *Buddy system for clinic visits* To make it easier for patients to get to clinic appointments (particularly those who are busy and forget to keep appointments), have “date club” where patients can book visits, meet up, and walk to the CHC together. This adds security as well.

Community Cluster 8 Scenario: Lack of support

This is a 39 year old male who has diabetes. He lives alone, and has devoted a lot of his time to learning about his condition, and feels confident in his ability to manage his blood sugars and follow instructions from the healthcare providers. He feels able to ask the healthcare providers questions, though he doesn't necessarily think he has one that he can regularly rely on that knows him well. He sometimes has trouble figuring out what services he is entitled to, and does not have anyone at home he can ask for help.

Reflections on community cluster 8 scenario

- First impressions: this is a familiar type of community member, and one possibly prone to depression. Biggest concern is the lack of support
- This patient might benefit from groups/clubs focused on people with diabetes. Clubs at CHC are too big for patients to get the most out of them as social support- information still ends up getting passed individually from healthcare provider to patient, and there are too many participants for good discussions to take place. They do work well for following up on diabetes management and getting tests done.

Potential strategies in response to community cluster 8 scenario

Individual-level strategies

- *Social network support* Want to encourage patient to find other places outside of home to get support- lead to groups, clubs.

Organisational level strategies

- *Social support groups* Organize groups (like clubs) for individuals with similar medical conditions, but with smaller numbers of participants and less structure, so patients can make friends and get social support from others who are experiencing similar problems that they can relate to

Community Cluster 11 Scenario: A lot of support but trouble taking actions

This is a 23 year old male diagnosed with cancer. He has an excellent support network of family and friends in the community, and also feels he can rely upon his cancer specialist. However, in general he is quite passive in Dr appointments, accepting information without questioning it or asking for clarification. He has trouble understanding what to do and how to use the healthcare services to get appropriate care. He struggles to find information on his own, but has learned a lot from having cancer and feels that he has gotten good at comparing information that he has been given over the past year.

Reflections on community cluster 11 scenario

- Interesting type of profile- moderate to high in first 5 domains, but low confidence with actually taking action, so very low scores in the last 4 domains
- Education plays a big factor in patients like this. Language may also be a huge barrier
- Newspapers and radio stations provide some places to get health information, but don't give people like this the ability to ask questions
 - o These programs can also be boring or dry- would be better if they were audio visually stimulating or more entertaining
- This patient is passive- he relies only on his experience and does not know how to clarify information. He may also spread information that is incorrect or misunderstood.
 - o Often people are afraid to ask questions because they fear looking stupid, so they try to just accept what they hear, whether or not they properly understand

Potential strategies in response to community cluster 11 scenario

Individual-level strategies

- *Patient empowerment in a safe forum* Want to encourage patient to feel comfortable asking questions and taking a more active role in his visits so that he can develop skills to manage his health

Organisational level strategies

- *EFAR Program* EFAR program is existing way to uplift community members by educating them, giving them confidence, and providing support sessions where EFARs can discuss questions and experiences relating to health
 - o EFARs often don't attend support sessions- try to expand this part of the program
 - o EFARs themselves may go out into community to provide others with information

EFAR Cluster 9 Scenario: Lacking support

This is a 20 year old healthy male. He graduated high school and is halfway through his degree at the university. He chooses to do most things on his own, and is confident that he can keep himself healthy and get services if he were to need them. He doesn't have a ton of knowledge about health, but thinks this is OK because he has always been healthy. He does not feel that he has any support from family or friends, and can't rely upon his healthcare providers either.

Reflections on EFAR cluster 9 scenario

- Common to see young people like this that feel somewhat invincible and don't think they need to focus on being healthy or managing health. Doesn't prioritize health and doesn't feel the need to learn health information
- Main problems here are a lack of support from both healthcare providers and socially, but also concern about lack of health information or ability to appraise it. Likely that this is because he lacks motivation to do so, even though he is well educated and has at least obtained EFAR training
- May have a bad perception of the healthcare system, perhaps due to poor experiences in the past- example having to wait a full day at the clinic. He does not want to rely upon the system. Perception might change in the future with more experience
- Difficulty with coming up with an intervention for this type, because he is independent and might not be interested in what is offered
- These people tend to avoid going to healthcare services until they are very sick and need to call an ambulance

Potential strategies in response to EFAR cluster 9 scenario

Individual-level strategies

- *Encouragement to take health more seriously* Want to encourage patient to learn health information and take his health more seriously, so that he addresses health concerns before needing to call ambulance

Organisational level strategies

- *EFAR Program* This patient, who is well educated and independent, may be a good candidate for higher levels of training within the EFAR program. This may help provide health information and encourage interest in healthcare, as well as a more positive picture of healthcare system

Patient Cluster 7 Scenario: No control over health, poor information, and no healthcare provider to rely on

This is a 40 year old male. He usually rarely visits the clinic, but has recently been told he has high blood pressure, so he is here to find out more information. He does not feel he has any healthcare providers he knows or can rely on, because he hardly ever visits the clinic, and prefers not to focus on his own health. However, when he does go, he feels that healthcare providers are trustworthy sources of information and feels confident talking to them to learn and to make sure his problems are understood. In general, he has never spent much time finding health information or setting personal goals about health and fitness, because he does not feel he has that much control over his life. He has a good network of support in his family and at the church.

Reflections on patient cluster 7 scenario

- Several concerning elements of this scenario. The first is that he does not feel he can rely upon HPs, even though he thinks he can engage well with them- brings up a question of whether this is a system failure or whether it relates more to his own ability to trust and rely upon the HPs he engages with.
 - Might be related to issues of continuity of care, which is a huge problem at the CHC
 - HPs need to empower patients to manage their own health. However, post-call schedules and staff turnover (amongst other problems) still make continuity of care very difficult
 - Might also be related to his feeling that he lacks control over his life- if this was the case, HPs could try their best and might still have difficulty helping him

- Another concern is that he says he doesn't have enough info, but feels moderately confident that he can obtain health information.
 - Might point to problems with his ability to understand info, attention issues
 - Might also highlight issues related to disparities in what patients hear from different HPs
 - Also may refer back to his feeling of "no control"; if he doesn't have the motivation to learn or take an active role in his healthcare, it won't matter what the HP says- ex an HP giving smoking cessation and healthy lifestyle advice to somebody who is not yet ready to contemplate quitting.
- From an Emergency Centre physician standpoint, we need patients to take responsibility for their own healthcare, because they will have to make a point of following up after an acute EC visit. Entire healthcare system here is set up around primary care.

Potential strategies in response to patient cluster 7 scenario

Individual-level strategies

- *Patient empowerment* Encourage HPs to spend a little bit more time with patient when first meeting them, to form better patient-physician relationship. Encourage patient to take actions like booking further appointments with the same HP to follow up. Examine why patient might not be interested in taking a more active role in health management, why he has feelings of no control- address with patient if possible.
- *Assess patient motivation* Before advising patient or giving out health information, assess patient's openness to information or willingness to change- give advice better suited to where individual patient is at the moment

Organisational level strategies

- *Support primary care followup after emergency visits* Encourage EC patients to make followup appointment with primary care to better manage conditions they came in to EC for. Help them book, if possible. Send them off with a report about what was examined and determined at the visit and tell them to bring it to their primary care provider.
- *Standardize information given to patients* Communicate the same, evidence-based information to patients to minimize confusion and encourage best practices and up-to-date knowledge. Perhaps find one common place to disseminate information to patients to try to facilitate this
- *Encourage continuity of care* Both by empowering patient to take more active role, and perhaps developing strategy to work with post-call schedules and booking followup appointments

Patient Cluster 2 Scenario: Not prioritizing health

This is a 43 year old female with vision issues and some bothersome skin problems. She graduated high school and enrolled in university, but did not end up going. She has to visit an eye doctor every once in a while to make sure she can see, but otherwise, tends to avoid going to the clinic when she is sick unless she is very very ill, because she has other priorities in life. When she does see a healthcare provider, she feels able to discuss her problems and follow their advice. In general, health is not that important to her and she doesn't spend much time learning about health or trying to understand her body.

Reflections on patient cluster 2 scenario

- Interesting to note that there seems to be a roughly inverse correlation with education levels amongst patient clusters, with higher education levels associated with lower overall health literacy scores. This is the group with the highest education level (average patient graduated high school), but ranked near the bottom of the list for overall health literacy. Would expect more educated persons to prioritize health more

- However, this might not be necessarily related to lack of knowledge- these patients might have other things that are higher priorities in life- ex they have to work to support their family, and don't have any major illnesses that demand attention at the moment. If they did, situation may change.
- These patients might not prioritize health because they have not had major issues, but many may still have poor habits that adversely affect their longevity and health later on (ex poor diet)
- Some of these patients don't spend much time on health because they can not afford to spend entire day at the clinic- and seemingly no feasible way to speed up that process in CHCs right now
 - Often this means patient puts off coming to the clinic until they are VERY sick
 - Healthcare providers don't always have understanding of what patients must go through to get to clinic and pick up meds; this might affect their recommendations if they knew what obstacles were
- Several of these types of people are primary caretakers or leaders in their families- might want to target them as a way to reach an entire group at once with certain interventions, especially preventive strategies

Potential strategies in response to patient cluster 2 scenario

Individual-level strategies

- *Target entire family/group through patients that are leaders/caretakers* For example, when educating patient about healthier diet, encourage them to support the same diet for the rest of their family. This is a good place to educate patient about why an intervention works for several people and gives patient an active role managing both their own health and those around them (often who have similar risk factors)

Organisational level strategies

- *Attempt to streamline process at CHC wherever possible, to lower wait times* Potential issues to address here are numerous, including better coverage for unscheduled/sick leave for employees, use of night shift personnel to pull folders for scheduled patients
 - Would have to address acute patient group most- this group most responsible for backups
- *Emphasize preventive strategies* Well visits and parents (healthy parents taking kids to pediatricians) are great opportunities to intervene before patient is sick and has to wait for meds and followup appointments. Healthier patients who don't need to wait for meds would also contribute to lowering wait times at clinic, and patients may be more likely to come in for followup.
- *Disseminate health information in other areas* Have healthcare practitioners go to other groups outside of healthcare system to help get health information out in other settings—help reach patients who can't make it to CHC or choose not to go. Example: some groups ask GPs to come give talks about diabetes/blood sugar.

4. Lower health literacy groups

Two of the community clusters, two of the EFAR clusters, and one of the patient clusters demonstrated low health literacy, with consistently moderate to low scores across all domains.

Community

Clust #	Cluster nick name	# of people	Avg age	Avg overall	Healthcare provider support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
6	Low health literacy but trying to stay healthy	9	34.9	2.71	2.08	2.50	3.07	2.58	2.60	2.91	2.70	2.91	2.91
9	Low health literacy, no support, but can follow instructions	3	39.7	2.63	1.50	1.75	2.60	1.67	2.40	3.67	2.33	3.20	4.20

EFARs

Clust #	Cluster nick name	# of people	Avg age	Avg overall	Healthcare provider support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
10	Low health literacy, not much experience with health problems	14	32.9	2.98	2.14	2.59	2.43	2.56	2.57	3.66	3.20	3.64	3.76
7	Low health literacy	6	38.3	2.14	1.67	1.63	2.00	2.03	1.70	2.47	2.25	2.27	3.00

Patients

Clust #	Cluster nick name	# of people	Avg age	Avg overall	Healthcare provider support	Having sufficient info	Actively managing health	Social support	Critical appraisal	Active engagement with HP	Navigating health services	Find good health info	Understand health info for action
5	Low health literacy	5	43.4	2.37	2.05	2.35	3.08	2.12	2.36	2.48	2.33	2.08	2.44

EFAR cluster 7 Scenario: Low health literacy

This is a 38 year old male with a history of depression and anxiety. He has trouble dealing with his life on a daily basis, and doesn't feel he can count on family members or doctors to help him. He is greatly confused by the healthcare system, and is not sure how to find information on his own, so he has no confidence in his knowledge about health. He is not sure what to do with new information when he does get it, and struggles to communicate well with healthcare providers to explain what is wrong and understand his options.

Reflections on EFAR cluster 7 scenario

- Very likely that this person's depression is affecting how he scored on all of the questions. For health literacy to improve, patient will most likely need counselling, education and probably medications.
- Sometimes EFARs become depressed or anxious due to experiences they have had as EFARs. Certain triggers can then continue to aggravate the condition
- Often is a very difficult experience for the entire family of somebody struggling with depression or anxiety- may be at risk of having a rippling effect on other family members.

Potential strategies in response to EFAR cluster 7 scenario

Individual-level strategies

- *Target family* When encountering these types of EFARs, reach out to their families and see how they are coping. Some preventive strategies might help family deal with their depressed loved one
 - Family members may also help ensure patient complies with medications and clinic visits

Organisational level strategies

- *EFARs as support network* Encourage EFARs to attend support sessions; expand and market this part of the program. Often, other EFARs will reach out and support EFARs who seem to be struggling with something
 - EFARs may also serve others by accompanying patients to clinic to help them keep appointments, helping refer depressed patients to psychiatric resources, or visiting family members of affected EFARs to help them cope

Responses to low scores in HLQ domains

Attendees were asked – what would you do for clients who were low in these domains? Only two scales were discussed due to time constraints.

Scale 3 – Actively managing my health

People with low levels don't see their health as their responsibility; they are not engaged in their healthcare and regard healthcare as something that is done to them.

- One strategy to help these patients would be to involve the family; this contributes to education as well
 - Or other people in the community
- HPs should clarify w patient what their role is- makes them more likely to take on that responsibility
 - Start by asking where they would like to be with their condition, and what brought them to the clinic that day to address it
 - Then come up with a plan together and state what the HPs will do and what the patient should do
- These patients are in the clinic for a reason- it is a good opportunity to educate patient about preventing future issues. They are often open to it at these visits, especially in the EC setting.
 - Ask patient how they want to move forward- need them to leave with the understanding that it is THEIR responsibility. Make sure you help them leave with a plan for followup.
 - Need to be upfront about expectations for both scenarios, whether they manage their condition or don't
- Sometimes HPs tend to give out the same advice with same goals for everyone with a condition, but would probably be better to set an individual goalpost for each patient depending on where they are at that stage and what their context is. Need to actually ask what is possible for them at the moment
 - Ex: before giving dietary advice, ask them what they ate the day before- then try to modify a bit at a time with that as a starting point

Scale 7- Navigating the healthcare system

Somebody who is low is unable to advocate on their own behalf and unable to find someone to help them use the healthcare system to address their health needs. They do not look beyond obvious resources and have a limited understanding of what is available and what they are entitled to.

- The HPs expect patients to know what the steps are to follow (start at day clinic, work up to university hospital if they are unable to be managed)..but how does this message get conveyed out to the community?
 - o National drive / provincial government needs to spread this knowledge!
 - o Info that is out now about the steps to access healthcare is quite limited, or it is very specific to each particular area
 - o Before this is done, need those in government to communicate with facilities on the ground so that everyone is on the same page and have the exact same expectations for what community members and patients should know
- Often EC patients show up with cases that are not emergencies and don't need to be seen in that setting.
- Things work entirely differently at different facilities- takes a lot of time and experience for HPs at a clinic to know where and how to refer people, and there is no consistency
 - o Might be helpful to continue to have group meetings that focus on health literacy in a particular region, to facilitate communication amongst providers and community-based organizations all serving a geographic area
 - May help reduce workload for health literacy interventions by dividing up amongst different places
 - Would be excellent for patients to see sisters/staff present in multiple locations (demonstrating consistency and communication between different sites).. perhaps do staff exchange
 - o Want to think of ways to make service delivery more consistent!
 - Examples: SIGN POSTING, daily education in the waiting room, national campaign, contact patient families to get them involved, maybe use groups of EFARs to assist navigating the healthcare system and how to share information
- Sometimes there are trust issues or other communication barriers between clinic staff and patients- ex patients might feel intimidated and afraid to talk or ask questions
 - o Sometimes staff have trouble interacting with patients because they are shy or are put off by patients who are angry about having to wait a long time to get care
- Try to continuously provide up to date information about services during the day at the clinics- ex if short staffed with higher wait times, let patients know so they know how long they will wait and can decide if they want to stay
 - o Other ways: make patients aware of triage for higher-acuity patients, number system
- Want to disseminate consistent information about healthcare services and health info as much as possible to reduce confusion and make it easier for patients to get a handle on good info
- Community-based organizations can help give people skills to manage and understand health

Summary of most important areas to target for interventions

-Use of evidence-based practice and information, made consistently available to patients and community members

- Reference to up to date information consistently by various providers and community-based organizations may minimize confusion and increase patients' understanding of health information

-Use of groups to facilitate management and support for various conditions

- Groups in community and in clinic setting for management of chronic conditions- ex back pain, diabetes
- Social support groups- ex "date club" in community to facilitate process of getting to appointments
- These groups can also be places where evidence-based information is distributed
- Should be small enough to function as a source of social/psychological support
- May utilize specialists as needed for various groups (ex physio and social worker for pain)

14

-Patient empowerment to increase active management of health

- HPs can develop specific strategies to do this, and do staff-wide training to encourage similar capacity-building practices across an entire clinical site (ex teach back method, motivational interviewing..)
- Community-based organizations and campaigns may help patients overcome other obstacles so that they may focus on their health (ex childcare)

-Large-scale campaign to educate patients on how to access healthcare services

- Need this information to get out to as many people as possible, ideally nationally
- Encourage communication across sites serving the same geographic region- continued meeting of interested parties to address ongoing health literacy work
- In clinics, utilize sign posting and education strategies