EVALUATION OF THE ACCEPTABILITY AND VALIDITY OF THE SERIOUS ILLNESS CONVERSATION GUIDE AMONGST HEALTHCARE PROFESSIONALS IN AN ONCOLOGY SETTING IN SOUTH AFRICA

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DISSERTATION IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE MPHIL IN PALLIATIVE MEDICINE

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ACKNOWLEDGEMENTS

I would like to express my sincere gratitude for the continued support and guidance that I have received form my supervisor, Dr Rene Krause, throughout this journey.

I would like to thank the healthcare professionals who volunteered their time to take part in this study and my research assistant, Nokuzola Williams, who made it easy for the participants to be authentic in their contributions.

I would have been able to complete this work without the support and sacrifices of my husband, Hendrik Burger, my children and my family.

This research study was made possible by a grant from the Harry Crossley foundation.

ACRONYMS AND ABBREVIATIONS

ACP: Advance Care Planning

EBSCO: Elton B. Stephens Company

EOL: End-of-life

GSH: Groote Schuur Hospital

HCP: Healthcare professionals

HIV: Human Immunodeficiency Virus

HPCA: Hospice Palliative Care Association of South Africa

HREC: Human Research Ethics Committee

MEDLINE: Medical Literature Analysis and Retrieval System Online

NPFSPC: National Policy Framework and Strategy for Palliative Care

PC: Palliative Care

PALPRAC: Association of Palliative Care Practitioners of South Africa

RCT: Randomised Controlled Trial

SA: South Africa(n)

SICG: Serious Illness Conversation Guide

UCT: University of Cape Town

UK: United Kingdom

USA: United States of America

WHA: World Health Assembly

WHO: World Health Organisation

ABSTRACT

Background: Advance care planning (ACP) is the process through which a health care professional (HCP) guides a patient with a life-threatening illness to better understand their disease and to make value-concordant decisions for their future medical care including their end-of-life (EOL) care. The Serious Illness Conversation Guide (SICG, Ariadne Labs 2017) was developed and validated as a structured guide for HCPs when having ACP conversations with patients. Decision-making near the end of life is influenced by many factors including health status, socio-economic status, culture, ethnicity, and decisional control preferences. To our knowledge no study has explored the acceptability and validity of the SICG (Ariadne Labs) in cancer patients in South Africa (SA).

Objectives: The aims of this study are to explore the local acceptability and validity of an internationally validated serious illness conversation guide for use in advance care planning conversations in South African patients with advanced cancer.

Methods: A mixed-methods study design was used to explore the local acceptability and validity of the SICG using a survey and focus-group discussions (FGD) with healthcare professionals. In the quantitative survey each participant was asked to classify the local acceptability of each SICG prompt according to a 3-tiered system. Further survey questions assessed their practice settings, patterns of ACP, perceptions of cross-cultural acceptability of prompts, and the need for additional questions in the SICG. The FGD transcripts were qualitatively analysed using both inductive and deductive thematic analysis to reflect the research question as well as emerging themes.

Results: Focus group discussions (FGD) were conducted with 17 healthcare workers during 2021. Analysis of the survey and FGD data suggests that several SICG prompt are not cross-culturally acceptable in their current state in the South African setting. Emerging factors influencing acceptability in the SA oncology context included poor illness understanding, the use of complex and incongruent language, health system limitations, the role of the family, and the role of belief systems and culture.

Conclusion: The findings of this study can be used to adapt the Serious Illness Conversation Guide for the South African population to increase uptake of ACP and improve understanding of EOL care preferences for South Africans.

Contents

CHAPTER ONE INTRODUCTION

1.1. Background

Since the publication of the South African National Policy Framework and Strategy for Palliative Care by the National Department of Health in 2017, healthcare workers and policy makers in both the public and private healthcare sector in South Africa, have been working towards the goal of integrating Palliative Care (PC) as part of Universal Health care for all South Africans. In the Lancet Commission's report entitled: "Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage," the authors advocate for access to PC alongside disease directed therapy for all patients with complex chronic or acute, life-threatening, or life-limiting health conditions.(1, 2) In low- and middle-income (LMIC) healthcare settings this ideal of early PC integration is rarely achievable, which has led to the development of indicator tools like the Supportive and Palliative Care Indicators Tool for Low- and Middle-income countries (SPICT-LIS™), to ensure equitable distribution of limited PC resources.(3) In line with this, the South African (SA) adaptation of the SPICT tool recommends PC integration for all cancer patients who are either not amenable to curative treatment, who have symptomatic progressive or metastatic disease, or who are too frail for oncological interventions.(4) Advance care planning (ACP) and discussion of prognosis and goals of care (GOC) is a critical part of providing quality PC.(5-7)

Advance care planning (ACP) is the communication process through which a health care professional (HCP) guides a patient with a life-threatening illness to better understand their prognosis and to make value- and goal-concordant decisions for their future medical care including their end-of-life (EOL) care. Once an HCP determines that the most likely trajectory of their patient's disease or natural life will be that of progressive functional deterioration and that the likelihood of dying from the disease in the next 6-12 months is high, a proactive discussion of that patient's priorities, goals and wishes for care should take place to ensure that the medical care provided is optimally aligned with the patient's values and treatment preferences. It has been shown that engagement in such EOL conversations early in the trajectory of advanced disease is associated with better quality of life, reduced use of life-sustaining treatments near death, reduced EOL expenditure, improved bereavement outcomes for families, earlier hospice referrals and care that is more consistent with patient preferences.(8-11) ACP can be initiated at any time after the diagnosis of a serious illness, but becomes increasingly necessary as the patient's illness progresses and should be revisited at regular intervals.(12) Such conversations may result in the documentation of an individual's care preferences in the form of an advance directive (AD) or living will, and the designation of a surrogate health care decision-maker, which would serve to inform decisions about the patient's medical care when they are not able to speak or make decisions for themselves.(13)

Engaging in EOL conversations requires the patient to understand and acknowledge that their current illness course will result in imminent death. This, in turn, requires the clinician to determine their best estimate of the patient's prognosis and future disease course and share this information with them in a compassionate, but unambiguous way, a construct referred to as truth-telling.(14) This initial step of aligning the HCP and patient's understanding of prognosis has to take place before EOL communication can be taken further. Evidence has shown that a balanced approach to truth-telling by providing honest realistic information whilst supporting appropriate hope, does not lead to hopelessness, depression and anxiety in patients and those close to them.(15) It is however acknowledged that for compassionate truth-telling about prognosis to happen effectively, the patient's baseline prognostic understanding and their informational needs have to be assessed and taken into account when sharing prognostic information.(16)

Once a patient understands that the most likely trajectory of their natural life will be that of progressive functional deterioration and death, a proactive discussion of the patient's priorities, goals and wishes for care should take place to ensure that the medical care provided is optimally aligned with their values and treatment preferences. In the United Kingdom (UK) this concept, named Advance Care Planning (ACP), was detailed in a 2007 UK National Health Service policy entitled Capacity, Care Planning and Advance Care Planning in Life- Limiting Illness (NHS, accessed 9 Dec 2024) and in a professional guidance document entitled Treatment and Care Towards the End of Life, published by the General Medical Council (GMC, accessed 9 Dec 2024). Over time the initial focus of ACP on producing a specific document, called a living will, specifying particular unwanted interventions, has expanded into a broader concept of exploring the patient's priorities and goals, and ultimately their preferences around communication, medical care, place of death, and other end-of-life issues through iterative conversations.(17)

Seminal publications by Fahner et al. and Bernacki et al. exploring the structure and content of EOL and GOC conversations have described key elements or checklist items that need to be covered. This includes i) eliciting the patient's personal views on illness, dying and what constitutes quality of life; ii) assessing the patient's current state of psychosocial well-being; iii) determining the patient's preferences for decision-making and family involvement in their care and; iv) a patient-centred sharing of prognosis.(13, 15) This has led to the publication of a number of tools or conversation guides that assist HCP in structuring the conversation in such a way that causes the least discomfort whilst eliciting the right information about wishes and priorities for care.(2, 15, 18, 19) These conversation guides aid HCP in conducting ACP conversations with their patients and have been shown to be manageable, teachable and well received. One such scripted conversation guide is the Serious Illness Conversation Guide (SICG), first developed by the Serious Illness Care Program team at Ariadne labs, Brigham and Women's Hospital and Harvard T.H. Chan School of Public Health.(20) It specifically explores the patient's views on goals, fears and worries, sources of strength, critical abilities, or trade-offs for gaining more time during the EOL phase.(15, 20) Other sources of ACP communication guides include Five Wishes, The Conversation Starter Kit, and Respecting Choices.(18, 19)

The construct of ACP as it is currently practiced in health care is grounded in the largely western-centric bioethical principles and values of patient autonomy, truth-telling, informed decision-making and the belief that an individual should have some control over their own dying process.(21) Research on cross-cultural differences in EOL decision making is limited to studies originating from western-centric countries where non-western immigrant populations, invariably minority ethnic groups, are compared with western-cultural groups.(21-24) Common outcome differences reported include lower rates of ACP and AD completion, a preference for aggressive interventions at the EOL despite likely futility, and a preference for family-centred decision making amongst the minority groups.(21) When considering possible reasons for these reported differences, an enlarging body of evidence is pointing to the fundamental difference in value assumptions and meanings underpinning the western cultural worldview of ACP versus that of non-western societies.(21) Widely contrasting views on the importance and beneficial effect of respect for autonomy, individual versus collective decision-making, truth-telling and having a degree of control over dying has been demonstrated when comparing typically western societies (USA, UK, Australia, Europe) with that of non-western populations (American-Indian, Mexican American, African American, Australian-aboriginal, east-Asian, middle-eastern, Mediterranean, Asian-Indian Hindus).(21) Further evidence supports the concept that decisional control preferences (DCP) are influenced by age, education level and country of origin.(25, 26) Another factor that could be influencing ACP preferences and the uptake of ACP and ADs in non-western and especially minority groups, is a degree of mistrust in western-centric health care systems and the policies that regulate it.(21, 27) In a recent opinion piece by Ntizimira et al. the urgent need for more inclusive and culturally sensitive EOL care, specifically on the African continent, is advocated for.(28)

To this end, several collaborative projects have resulted in the cultural adaptation of the original Ariadne labs SICG for use in the United Kingdom, in First Nations and indigenous peoples of Canada, and for New Zealanders.(29-31) In the Canadian project feedback from the community members revolved around inclusion of family members in the conversation, asking direct questions, always using plain language, the importance of establishing a trust relationship with the patient, asking for permission and allowing time for storytelling, which is an important element in First Nations community culture.(29) For the UK adaptation suggested changes mainly revolved around simplification and clarification of language use.(30) For the New-Zealanders there was a lack of proper culturally appropriate initiation and closure of the conversation and not enough emphasis on the support of the extended family or community group.(31)

South Africa is a high-middle income country with a population that is culturally diverse in terms of ethnic groups, religious or spiritual affiliation and language. Furthermore, South Africa has been characterized as one of the countries with the highest level of economic disparity in the world and rates of unemployment and HIV infection are high.(32) In the 2022 national census South Africans described their population group as Black African in 81.4% of cases, Coloured (Mixed race) in 8.2%, White in 7.3%, and Indian/Asian in 2.7% of cases.(33) In the Western Cape, the third most populous province in SA and where this study is being conducted, 42.1% of the people described themselves as Coloured, while 38.8% described themselves as Black African, 16.4% as White, and 1.1% as Indian/Asian.(33) Afrikaans is the home language of 41.2% of the province's population. IsiXhosa is the first language of 31.4% of the population, while English is the first language of 22%. In the country, English is the home language of only 8.7% of the population, with isiXhosa or isiZulu being the home language of 40.7%.(33) Furthermore language and ethnic groupings in the Western Cape often do not correlate directly, with Coloured and White people making up the majority of Afrikaans speakers and both Black African, Coloured and White people making up the English speakers. Educational attainment has improved significantly over the past decade with the percentage of adults over the age of 20 completing secondary schooling rising from 40.5% in 2011 to 49.8% in 2022. Similarly, the number of adults over 20 with a primary school education or less dropped from 25.4% to 17.8% over the same time period.(33, 34)

According to the researcher, there is a gap in knowledge about the preferences for EOL communication in patients with life-threatening or life-limiting illnesses in Africa and more specifically in South Africa. A literature review of published data using recognized scholarly databases (EBSCOhost, PUBMED, GOOGLE Scholar, SunScholar, UCT Open) revealed no research studies that have investigated the feasibility, acceptability or validity of ACP conversation guides, including the SICG, amongst African patients. One study was identified that investigated the acceptability of the Five Wishes ACP conversation guide (Standford et al, 2013) amongst healthcare professionals and community members (35) and one study (Shen et al, 2020) reported on the end-of-life care preferences of South African patients.(36)

Because the original SICG was developed in the United States of America (USA) and has not yet been validated in an African setting, nothing is known about the cross-cultural acceptability of the SICG in a South African population. This, along with the fact that cross-cultural review processes of the SICG have been documented for local populations in Canada, New Zealand and the UK, lead to the selection of this ACP tool for the current research project.(29-31) Evaluating a guide that has been previously reviewed is hoped to allow future comparison of validation processes and outcomes.

Along with reliability and responsiveness, validity testing is a well-established part of ensuring the rigour of a health-related measurement instrument.(37) Face validity, or the degree to which a measure appears to test the outcome or construct that it purports to test, is considered the simplest measure of validity. Face validity is determined through subjective assessment by expert developers or non-expert users of the measure.(38) Content validity describes the degree to which a measure tests all the aspects of a particular construct. This can be defined in terms of objective scoring factors or subjectively through expert review.(38)

The Universalist model framework for cross-cultural adaptation of health-related outcome measures (OM), first described by Herdman et al in 1998, describes 6 types of cross-cultural equivalence that need to be evaluated to determine an instrument's validity in a new cultural context namely, conceptual equivalence, item equivalence, semantic equivalence, operational equivalence, measurement equivalence, and functional equivalence.(39) The first of these, conceptual equivalence, arose from the understanding that the concepts contained in an OM may not exist, be constructed similarly, or carry equal relevance in different cultural contexts, a phenomenon that is best evaluated through qualitative research methods. Item and semantic equivalence are seen to relate more to a participant's response to a given OM. Item equivalence represents the degree to which an OM appropriately measures the concept it intends to measure in a different culture, an attribute somewhat related to face validity. Semantic equivalence refers to the nuance or associations the OM may evoke in participants with different language backgrounds, and is more commonly evaluated through quantitative techniques.(39)

The SICG is however not an outcome measuring tool where responses to questions usually take the form of rating scales or Likert scales, and where validity is crucial in ensuring the psychometric properties of the tool and ultimately its reliability and usefulness in statistical analysis.(38) The SICG is an explorative conversation guide in which responses to prompts are expected to be entirely subjective and free, in both content and scope.(15) This, as well as the constraints on in-person research activities imposed by the COVID pandemic during the time data-collection for this study was conducted, led the author to focus the study activities on explorative approaches to the content and face validation of the SICG prompts. Elements of Herdman's cross-cultural validation process, namely conceptual equivalence as well as item and semantic equivalence were therefore explored. A protocol amendment to this effect was approved by the University of Cape Town Human Research Ethics Committee (UCT HREC) in Nov 2021.

This study aims to explore the cross-cultural acceptability and face validity of the Ariadne Labs Serious Illness Conversation Guide amongst healthcare professionals in an oncology setting in South Africa. At the time of designing this research study, the latest version of the SICG, version 7, dated 18 April 2017, was used and will hereafter be referred to as the original SICG or oSICG (Appendix A, Table 1). It should be noted that the oSICG has been updated a number of times since its original publication, based on iterative community-engagement, with the latest version dating from May 2023 (https://www.ariadnelabs.org/resources/downloads/serious-illness-conversation-guide/). Through this research, the author hopes to inform future cross-cultural adaptation of the oSICG for the SA population.

It should be noted that in order to stay within the scope of an MPhil dissertation, this work relates to a subsection of a larger main protocol investigating the local cross-cultural acceptability and validity of the oSICG in oncology healthcare practitioners, patients and caregivers. The lead investigator is the only student involved in this protocol and the rest of the study team, namely the research assistant, and primary supervisor, is the same.

1.2. Rationale

EOL communication can be defined as conversations between health care practitioners (HCP) and patients with an advanced life-limiting illness, about the patient's goals, wishes and priorities for holistic care as it pertains to their quality of life up to their time of death.(13, 15) It has been shown that early engagement in these conversations hold holistic benefit for both patients, families and the healthcare system.(9, 11) The available data on end-of-life communication in the South African context is able to shed some light on the type of EOL communication activities that are conducted, potential barriers to wider acceptance and implementation of such activities, EOL communication preferences, and preferences for EOL care, from the perspective of HCP, patients and the public.(35, 36, 40-46)

The limited number, small cohort sizes, and varying methodologies of publications and studies exploring EOL communication activities in South Africa only give a partial view of how conversations about poor prognosis and discussions on priorities and preferences for EOL care are perceived by the local population. Further research into the reasons for inaccurate perceptions of curability amongst South Africans with serious illnesses, and its role as a barrier to ACP communication is warranted. Qualitative analysis of patients' preferences as it pertains to prognostic sharing and exploration of priorities and preferences is warranted, as it could inform communication skills training for HCP and the design of locally appropriate ACP tools. Deeper qualitative exploration of the cited barriers to ACP conversations and AD promotion could reveal inherent underlying constructs that may offer opportunities to effect change in the uptake of ACP. Further qualitative research on SA patients' EOL care preferences is warranted as it will serve to inform the optimal design of locally appropriate survey tools that can be used in quantitative research.

Further study of the local cross-cultural acceptability of other available ACP and AD tools using a mixed methods approach could provide supporting evidence to close these knowledge gaps.

1.3. Research question

Is there converging evidence that the oSICG is valid and cross-culturally acceptable in a South African oncology setting, in its current form?

CHAPTER TWO LITERATURE REVIEW

1.1. Introduction

This literature review aims to explore published data on end-of-life (EOL) communication in the South African (SA) context, with a focus on currently utilized EOL communication activities and how they are practiced and perceived by health care practitioners, patients and their caregivers. The key elements that need to be included in an advance care planning (ACP) or goals-of-care (GOC) conversation as described by Bernacki et al. in their synthesis of best practice and supported by Fahner et al. in their systematic review of advance care planning interventions, were used as a framework to evaluate the relevance of published materials to the subject.(13, 15)

It should be noted that publications focussed on the initial sharing of a serious illness diagnosis, were not included as this is seen as a communication activity that stands separate from ACP communication both in time and prognostic context.

1.2. Literature review methodology

A literature search of the following academic databases was conducted for the years 1990-2024: EBSCOhost, PUBMED, GOOGLE Scholar, UCT Open, SUNScholar. The search terms and a flow diagram for evidence review are shown in Table 2.1. Table 2.2 represents a summary of the pertinent descriptive aspects of the publications included in this literature review listed by date of publication.

A critical appraisal of the available South African literature will be structured according to the following headings:

- EOL communication activities
- Barriers to EOL communication
- Preferences for ACP communication
- Acceptability of ACP conversation tools and AD tools
- Preferences for EOL care

Table 2.1: Literature search terms and PRISMA flow diagram of included articles

Search terms
• Advance care planning OR Advance directive(s) OR End-of-life (EOL) communication OR End-of-life planning OR Goals of care (GOC) conversation(s) OR Goals of care discussion(s) OR Serious illness conversation(s) OR Serious illness communication

AND

- South Africa(n)

AND

- English language publications

Table 2.2: Characteristics of publications included in literature review

Author	Year of publication	Study design	Size of SA cohort	Participant type
Silbert	2009	Opinion	1	HCP (doctor)
Silbert	2010	Opinion	1	HCP (doctor)
Bull et al.	2012	Qualitative	12	HCP (doctor, nurse)
Stanford et al.	2013	Qualitative	51	HCP (doctor, nurse), Community carer, Lay person
Campbell et al.	2013	Qualitative	13	HCP (nurse)

Graham et al.	2013	Qualitative	21	HCP (traditional healer)
Ganca et al.	2016	Qualitative	14	HCP (doctor)
Yennurajalingam et al.	2018	Quantitative	95	Patients
Shen et al.	2018	Quantitative	221	Patients

HCP=Healthcare practitioners

1.3. EOL communication activities

1.3.1. Assessing prognostic understanding

According to seminal publications by Fahner et al. and Bernacki et al. about the content and structure of EOL conversations, the assessment of a patient's prognostic understanding should precede the sharing of a poor prognosis.(13, 15) Good or high prognostic understanding is present when a person's understanding of the curability of their disease aligns with the currently available medical evidence, or when they have an accurate perception of their life-expectancy as estimated by currently available medical evidence. This concept is seen as distinct from understanding one's diagnosis and disease stage, or the treatment that one is undergoing.(13, 15)

The first study to attempt to quantify illness and prognostic understanding in South African patients was performed by Yennurajalingam et al.(40) The study evaluated illness and prognostic understanding and decisional control preferences in a global cohort of 1390 patients with incurable recurrent or metastatic cancer using linguistically validated surveys in local languages. Amongst this cohort were 95 South African patients receiving palliative care (PC) from an urban hospice in the KwaZulu-Natal (KZN) Province, of which 70.5% understood that their illness was incurable. This is a significantly higher rate of prognostic understanding (PU) than the 49.6% reported for the remainder of the global cohort but still signifies a significant rate of prognostic misunderstanding. Multivariate analysis found that female gender, unemployment, higher education, and being South-African or French predicted for accurate perception of incurability.(40)

In a quantitative study by Shen et al., significantly lower rates of PU were reported in a cohort of 221 patients associated with a dedicated urban public hospital-based palliative care service in Gauteng province.(36) Eligible patients had to have a solid cancer diagnosis for which no further surgery, radiotherapy or chemotherapy was planned, and be deemed to be within the final 6 months of life by their medical team. Only 6% of patients surveyed acknowledged that they were "terminally ill". When asked if they knew how long they had left to live, 84.6% responded in the negative. Of the

15.4% who said they knew, a quarter correctly estimated that they had months left to live, while the rest were not willing to give a time-estimate.

These two quantitative studies give a limited and contradicting view of prognostic understanding rates amongst South African patients with advanced cancer, which limits its generalizability to the wider SA cancer population. Comparison between these 2 studies and international data is also hindered by the varying terminology used when measuring prognostic understanding namely terminally ill, seriously ill, or incurable. These terms are nuanced and can be interpreted in different ways, especially in populations with low health literacy levels and when survey tools are translated into local languages.

1.3.2. Sharing of prognostic information

In the earliest publications on the subject of prognostic sharing in a South African context Silbert describes his personal experiences and insights as a family physician sharing information related to poor prognosis, or what he refers to as “the ultimate prognosis” of a life-limiting illness, with patients in his urban private general practice.(41, 42) The concept of truth-telling in the context of EOL communication is recognized here as a source of moral dilemma for the HCP. On the one hand the HCP recognizes their professional duty to share with the patient all the information they have about their disease course, as it supports patient autonomy in decision-making. On the other hand, they fear that telling the “whole truth” could lead to emotional distress and loss of hope in the patient or those close to them. Silbert also refers to the role of truth-telling in the doctor-patient relationship and how both the withholding of information and the sharing of unwanted information, could lead to breakdown of trust.

These sentiments were echoed in a qualitative study by Campbell et al. in a self-selected sample of 13 nurses and home-based carers affiliated to paediatric PC services in a rural part of SA’s KZN Province.(43) When exploring their attitudes to sharing information about poor prognosis, participants reported experiencing internal conflict when having to share poor prognosis. They equated it to telling the patient that there was nothing more they could do for the child or the family and found it difficult to reconcile this with their role as carer. Even though they understood and advocated for the benefits of truth-telling about poor prognosis, they could also appreciate that it could cause distress.(43)

Graham et al. conducted a cross-sectional qualitative study to explore the views of Xhosa traditional healers in the Eastern Cape Province on requirements for a “good death” in their cultural context.(44) Traditional healers expressed that truth-telling about impending death at the deathbed, was generally not acceptable, but that it sometimes was appropriate to give a person “permission to go” as a form of release.(44)

Ganca et al. conducted a qualitative study exploring the communication practices when conveying a poor prognosis in a cohort of 14 doctors working in an urban training hospital in the Western Cape (WC) Province of SA. The authors reported that participants considered conveying a poor prognosis to be a difficult task.(45) It was considered even harder when a prior relationship existed with the patient, children or young people were involved, when the patient or family had unrealistic expectations, when the doctor was not aware of the expectations of the patient/family, interactions were deemed cross-cultural, and when the doctor lacked formal communication skills training in breaking bad news. They recognized the value of a structured approached to such conversations which included preparation, truth-telling, emotional containment, expressing empathy, and accessing support from other interdisciplinary HCP.(45)

From these studies we can identify some SA HCP's perceptions and attitudes that could be a barrier to EOL communication. However, wider exploration of HCP and patient perceptions and attitudes around the sharing and receiving of information about a poor prognosis is needed.

1.3.3. Exploring wishes and priorities for care

Taking the concept of Advance Care Planning conversations forward in the SA setting, Stanford et al. conducted a qualitative study aimed at exploring perceptions of the relevance of advanced care planning conversations amongst hospice staff and community members in a rural part of the WC, at the hand of the "One Slide" ACP tool.(35) This ACP communication tool asks the user to indicate their preferences for EOL care in relation to place of death and appetite for life-sustaining interventions, then goes on to test if a loved one is aware of these preferences, and concludes with a prompt to complete a living will and appoint a surrogate healthcare decision-maker (Figure 2.1, left column). Focus-group discussions were conducted where issues around the relevance, preferred timing, method of initiation, content, role players and feasibility of ACP conversations were discussed. Attitudes towards the selection of surrogate healthcare decision-makers and contextual barriers to living will adherence were also addressed. Participants were then asked to critically assess the appropriateness of the "One Slide" ACP initiation tool and suggest adaptations for the local setting. Although participants displayed low awareness of, and experience with ACP and living wills, there was consensus that conversations about ACP were useful and necessary. The value of formally writing down wishes and appointing someone to make healthcare decisions on one's behalf in case of incapacitation was acknowledged. The social and professional diversity of the participants in this study allowed rich thematic analysis, which revealed more about participants' attitudes towards ACP conversations and EOL care preferences. Even though the perceptions of patients were not explored directly in this study, the varying points of view of the participants added to the richness of the analysis, with HCPs often representing the views of patients they had cared for, and lay persons representing their own personal views as family members and friends of seriously ill patients.(35)

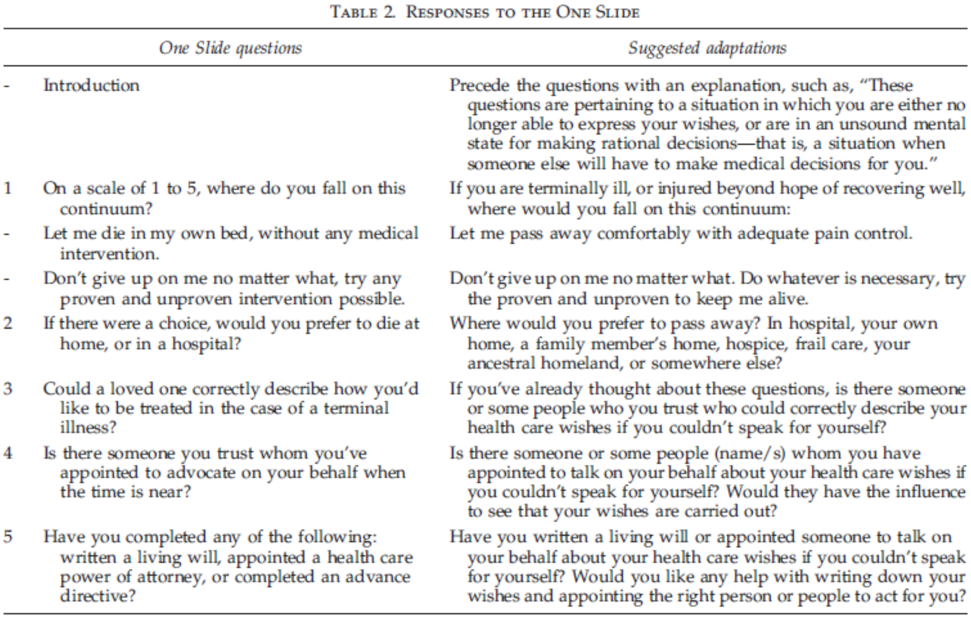

TABLE 2. RESPONSES TO THE ONE SLIDE

	One Slide questions	*Suggested adaptations*
-	Introduction	Precede the questions with an explanation, such as, "These questions are pertaining to a situation in which you are either no longer able to express your wishes, or are in an unsound mental state for making rational decisions—that is, a situation when someone else will have to make medical decisions for you."
1	On a scale of 1 to 5, where do you fall on this continuum?	If you are terminally ill, or injured beyond hope of recovering well, where would you fall on this continuum:
-	Let me die in my own bed, without any medical intervention.	Let me pass away comfortably with adequate pain control.
-	Don't give up on me no matter what, try any proven and unproven intervention possible.	Don't give up on me no matter what. Do whatever is necessary, try the proven and unproven to keep me alive.
2	If there were a choice, would you prefer to die at home, or in a hospital?	Where would you prefer to pass away? In hospital, your own home, a family member's home, hospice, frail care, your ancestral homeland, or somewhere else?
3	Could a loved one correctly describe how you'd like to be treated in the case of a terminal illness?	If you've already thought about these questions, is there someone or some people who you trust who could correctly describe your health care wishes if you couldn't speak for yourself?
4	Is there someone you trust whom you've appointed to advocate on your behalf when the time is near?	Is there someone or some people (name/s) whom you have appointed to talk on your behalf about your health care wishes if you couldn't speak for yourself? Would they have the influence to see that your wishes are carried out?
5	Have you completed any of the following: written a living will, appointed a health care power of attorney, or completed an advance directive?	Have you written a living will or appointed someone to talk on your behalf about your health care wishes if you couldn't speak for yourself? Would you like any help with writing down your wishes and appointing the right person or people to act for you?

Figure 2.1: One slide ACP conversation tool (left) with suggested changes by Stanford et al. (right).

The study by Shen et al. is the only study that directly evaluated preferences for EOL communication and care amongst South African patients.(36) As stated by the authors, "This study was modelled after the United States–based Coping with Cancer 1 and 2 cohort studies and included many of the same measures". The survey was conducted in person in the patient's first language but was not validated or piloted in the target population. Participants were asked about their preferred place of death; whether they would prefer care aimed at relieving pain and discomfort over life-extending care; whether they would want to be kept alive if it required them being on a ventilator or dialysis; and whether they wanted their HCP to do anything possible to keep them alive if they had only days left to live. Due to its quantitative design the potential for exploration of patient perceptions is limited. The rigid construct of the survey questions and suboptimal language use in the survey response options also make it difficult to make inferences about patient perceptions and the motivation for their choices.(36) The findings of this study are reported in section 2.7 of this study.

Further qualitative research is warranted to explore SA patients' attitudes towards conversations aimed at exploring their EOL priorities and preferences, as it will serve to inform the optimal design of locally appropriate ACP tools that can then be validated in the local context.

1.3.4. Documenting wishes and priorities

Although Emanuel et al. describes the iterative ACP process, through which a patient formulates their wishes and preferences for care and quality of life up to their time of death, as a meaningful endpoint of EOL communication in and of itself (17), there are further practical steps that need to be taken to increase the likelihood of these wishes and preferences being followed.(13) This involves communicating the patient's wishes and preferences with the individuals and entities who will be involved in their care or in decision-making around their care. Depending on the individual this could include health care professionals and services, their family or those closest to them, and non-professional caregivers. Communication usually takes the form of verbal or written conversations during which wishes and preferences are expressed, their feasibility assessed amongst all stakeholders, and plans negotiated for their execution.(13)

In its 2019 Ethical Guidelines on Palliative Care the Health Professions Council of South Africa (HPCSA) recommends that HCP encourage their patients to concretize these wishes and priorities for care in the form of a document that could be references in the event that a patient becomes incapacitated and loses the ability to think or speak for themselves.(6) The most commonly used template for documenting EOL care wishes and preferences is the Advance Directive (AD), also referred to as a Living Will (LW). An AD allows a patient to specify elements of care that they do want, but also elements of care that they do not want.(6, 13) A further extension of the ACP process advocated for by the HPCSA, is the designation of a surrogate health care decision-maker through verbal instruction or documentation.(13) Such a person could be asked to relay the patient's wishes and preferences for treatment if they are unable to think or speak for themselves.(6) It is important to note that ADs and documents appointing surrogate health care decision-makers are not considered legally binding by South African law and HCPs are encouraged to, "give effect to the patient's wishes provided that the directive is applicable to the present circumstances and represents the patient's current wishes".(6)

The only original research assessing the knowledge and attitudes of SA HCP on the use of advance directives (AD) or living wills was conducted by Bull et al. in the KZN province of SA.(46) The aim of this qualitative study was to explore general factors that influenced the promotion and use of living wills amongst 12 primary care physicians and frail care nurse coordinators working in a retirement community, with specific reference to an online Advance Directive (AD) template made available by The Living Will Society of South Africa at the time. The study found that all participants where familiar with the concept of a LW and with the proforma LW document, but that they did not see a high rate of uptake amongst their patients. The study participants acknowledged the benefits that having a LW held for patients, families, and themselves as HCP during the EOL care phase. They found living wills to be a particularly valuable source of information regarding patients' preferences <u>against</u> certain treatment options. This aided EOL decision-making and communication with families about withholding or withdrawing treatment.

Further assessment of the local acceptability of the available AD documentation is warranted in the South African population.

1.4. Barriers to EOL communication

A number of barriers to EOL communication in the SA context were identified in the reviewed literature.

1.4.1. Poor prognostic understanding amongst patients

In the two studies by Yennurajalingam et al. and Shen et al. lack of prognostic understanding amongst cancer patients was evaluated as it represents an early stumbling block in effective communication about wishes and priorities for EOL care.(36, 40) These studies represent the only published data on prognostic understanding in advanced cancer patients in South Africa. They were both conducted in dedicated palliative care service settings where one would expect conversations about prognosis and disease course to be commonplace.

Further qualitative research exploring the possible reasons for low PU and inaccurate perceptions of curability amongst South African cancer patients, and its role as a patient barrier to EOL communication is warranted.

1.4.2. HCP's fear of causing emotional distress and taking away hope

The perception amongst HCP that the sharing of information about a poor prognosis will lead to emotional distress and loss of hope in patients and their loved ones is specifically mentioned by Silbert et al., Campbell et al., Ganca et al., Graham et al., and Bull et al. Factors that are reported to increase the likelihood of eliciting emotional distress are having a prior relationship with the patient or when children or young people are involved. HCP are also worried that misunderstandings may arise from the ACP conversation, a risk they relate to patients or family members who are not familiar with the concept of ACP or who have unrealistic expectations for their EOL phase, or when the doctor is not aware of the expectations of the patient or family.(45, 46) HCP tend to avoid ACP conversations because they fear that they are not able or equipped to manage these misunderstandings or emotional reactions of patients or family members optimally, or that the misunderstandings, emotional distress and loss of hope will result in break-down of the HCP-patient relationship.(46) In the study by Graham et al., talking about impending death at the deathbed is seen to cause emotional distress, which will prevent the person from passing on peacefully, something which is seen as a requirement for a “good death”.(44) Ganca et al. introduces the theory that expanding PC and communication skills training amongst HCP could on the one hand reduce the patient distress caused by the sharing of a poor prognosis and ACP conversations, but also impart HCP with the skills to manage it correctly.(45)

1.4.3. HCP’s own perceived lack of knowledge and skill in prognostication and sharing of prognosis

The HCP interviewed by Campbell et al. reports being unsure of when to tell a patient or family that death was near, either due to the fluctuating nature of some illness diagnoses such as AIDS, or due to the PC provider’s lack of clinical experience. This uncertainty relates to the lack of confidence in prognostication ability also described by Silbert et al., and illustrates that both nurses, doctors and home-based carers realize the importance of having prognostication skills, but have inherent doubt in their own ability to prognosticate accurately.(41, 43)

Silbert and Ganca et al. reported that doctors considered conveying a poor prognosis especially difficult when the doctor lacked formal communication skills training.(41, 45) Ganca et al. put forward the theory that doctors who had training in PC, or who had established working relationships with PC practitioners, found conveying a poor prognosis to patients or families less difficult and less emotionally distressing. The authors contend that this is related to their exposure to PC related communication skills and the value placed on palliative and supportive interventions that can still be offered, even though no further curative treatment is available.(45)

Prognostication and prognostic sharing are advanced clinical skills that are not widely taught in undergraduate HCP curricula outside of PC programs.(47) Unfortunately PC teaching and training has only been integrated into undergraduate clinician training programs in the last 15 years.(47) Further evaluation of optimal techniques for teaching prognostication and prognostic sharing in the SA context is needed.

1.4.4. Religious and cultural belief systems

The perceived role of religious and cultural belief systems or a patient’s “worldview” as a barrier to prognostic sharing amongst HCP, is a shared theme in the publications by Silbert, Campbell et al., Stanford et al., and Ganca et al..

Speaking from the point of view of a South African Jewish clinician working in an urban predominantly Jewish community with access to private healthcare, Silbert describes the tendency towards non-disclosure of poor prognosis or impending death amongst clinicians in the SA Jewish community due to their own fear of causing emotional distress or diminishing hope.(41, 42) This distress, and loss of hope is linked to Jewish religious teaching on the sanctity of life and that hope for survival should at no point be abandoned. Silbert goes on to describe that in the Jewish belief system, the sanctity of life is valued above all else. He references the writings of an eminent Jewish scholar, that teaches that it is allowable to “play down or suppress” the truth of a poor prognosis, especially if it is thought that knowing the whole truth will cause distress to the patient, and in order to retain an element of hope. He explores the apparent conflict between Judaic beliefs about death and dying and the modern philosophy of experiencing a “good death” by preparing for the end of life. The author contends that this could prevent doctors caring for Jewish patients at the end of life from disclosing the whole truth about prognosis and life-expectancy, for fear of causing emotional distress, or removing hope. The author however seems to advocate for increased truth-telling by HCP in the Jewish community by pointing out the many negative consequences of such an approach to maintaining hope. In his opinion, this includes disregarding patient autonomy and their role in shared-decision-making, losing professional trust when the poor prognosis becomes a reality, denying the patient the opportunity to share their emotions and thoughts about dying with those close to them, which in his opinion could lead to them not getting needed support, and not being afforded the chance to get their affairs in order, or come to terms with personal relationships. He also asserts that hope can be fostered through other mechanisms like the ability of modern medicines to control symptoms and suffering, and to prolong life. He also points to studies that showed that open communication about impending death does not necessarily have a negative impact on patients and can, in itself, be a source of hope. He suggests that this apparent moral dilemma can be managed by sharing the details about the likely outcome of a serious illness in stages, and by carefully titrating this against the patient’s appetite for information and their ability to process and accept the poor prognosis. Such a compassionate approach would include allowing elements of healthy denial, giving the patient ample time to process information, and to mobilize their sources of strength and support.(41, 42)

In the study by Campbell et al. most of the HCP participants were part of the Zulu culture and belief system, as were the patients they cared for, providing a different cultural setting than that of Silbert.(43) This study elucidated specific beliefs around communicating poor prognosis and talking about death in the Zulu culture. Participants reported that in Zulu culture relaying bad news is interpreted as going against traditional practice and talking about impending death is seen to hasten its coming or “invite death in”. The Zulu belief system, as propagated by traditional healers, also supports the notion that miracles of healing are a possibility. PC providers who try to counsel patients and families about impending death, could therefore be seen as transgressing cultural beliefs. PC providers acknowledged that even though they understood and advocated for the benefits of truth-telling about poor prognosis, they could also appreciate that it could cause distress. They were conflicted between the drive to empower patients with information that would facilitate decision-making, and the traditional way of protecting people from the harsh reality of death, that is supported by the cultural elders, namely avoidance.(43)

Xhosa traditional healers in the study by Graham et al. described a reluctance to get actively involved in the process of dying because of the burden of cultural cleansing rituals that they would have to go through after being involved in a client's death, and the negative association it would bring to their professional reputation, amongst other reasons.(44)

Although it was not explored in detail the cultural taboo of "inviting death" or bringing "bad luck" by talking about impending death was brought up by a number of participants in the study by Stanford et al.(35)

In the study by Ganca et al. doctors considered conveying a poor prognosis especially difficult when interactions were deemed to be cross-cultural.(45) Reported strategies employed to optimize cross-cultural interactions included having cultural diversity in the clinical team, being aware of the cultural, social and religious facets of each interaction, using interpreters, gestures and drawings to enhance communication, and to prioritize communication in a patient's first language where possible.(45)

South Africa is a culturally diverse country where language and religion often bridge racial and socio-economic divides. Although the publications included here do not represent the entire SA population, representation is found from rural and urban settings across the 3 most populous provinces and Jewish and African traditional belief systems are included.

1.4.5. Influences of family and loved ones

One of the underpinning principles of palliative care is extension of care to the family or those close to the patient, both before and after the patient's death. Examples of the influence that family members or loved ones have on prognostic sharing are given by Silbert and Campbell et al..(42, 43)

Silbert lists requests from family members to withhold information about impending death as a barrier to truth-telling.(42) Participants in the study by Campbell et al. described their dilemma when the families of ill children resisted being told of their poor prognosis. In this cohort PC providers related that they were sometimes prevented from providing any care to patients, because the families anticipated that they would try to share a poor prognosis and did not want this.(43)

Family members can also stand in the way of advance directives being followed. Stanford et al. relates this phenomenon to cultural constructs around autonomy within South African family structures where male-dominated decision-making is prevalent.(35)

1.4.6. Lack of awareness of ACP and AD amongst HCP and patients

Although the participants in the study by Stanford displayed low levels of awareness about ACP, they all agreed that there is a need for increased public awareness about ACP and for normalization of ACP conversations.(35)

Lack of awareness about AD and ACP amongst patients was cited as a reason for low uptake of AD completion in the study by Bull and a barrier to the following of AD in the study by Stanford.(35, 46)

1.4.7. Responsibility for promotion and completion of ACP

Opinions on who should take ownership of ACP advocacy and completion varied between studies. Participants in Stanford et al. felt that awareness about ACP could be facilitated by educational institutions, religious establishments, healthcare systems, community groups and in the workplace.(35)

Bull et al. reported that many HCP participants saw themselves as custodians and executors of the completed AD document, but did not consider advocating for, creating awareness about, and initiating AD completion as part of their role or their responsibility.(46) The participants regarded third party organizations or other individuals as more appropriate advocates.(46) This could be a reflection of the fact that up until the middle 2010's PC in South Africa was mainly being provided by Hospices and non-governmental organizations and PC teaching was not integrated into undergraduate HCP training, as described by Burger et al.(47)

Participants in Bull et al. did however not feel that HCPs were responsible for creating awareness around the subject of AD.

1.4.8. The lack of legal status

Bull et al. cites that the lack of legal status that living wills carry in SA discouraged many practitioners from promoting or initiating it. It also illustrates their belief that drawing up a living will without legal authority would be a futile activity. This study introduces the concept that as long as living wills did not have legal status in South Africa, the process of drafting it could be considered a futile, and even harmful exercise, especially if the process leads to emotional distress and takes up valuable consultation time. It is apparent that the HCPs interviewed here attributed the value of the AD or living will to its final execution, and not to the conversations and exploration of goals and preferences for care that form part of its drafting.(46)

1.4.9. Lack of time

Silbert sites limited time to attend to the patient's inevitable emotional needs resulting from receiving the poor prognosis, as a barrier to ACP.(41)

Bull et al. sites "lack of time" to have meaningful discussions as a reason for poor uptake of AD. This suggests that these HCP perceive ACP conversations as being lengthy.(46)

1.4.10. Logistics

Barriers to advance directives being followed sited by Stanford et al. included logistical factors like not having access to the AD document in the acute clinical setting, or when the surrogate decision-maker does not have the most current information, if wishes weren't written down.(35)

1.5. Preferences for ACP communication

The studies by Shen et al. and Stanford et al. provide information on ACP communication preferences in the South African setting but do so through different methodologies.

In the study by Shen et al., cancer patients were directly surveyed on their communication preferences by asking them 2 yes-no questions.(36) When asked if they had had a conversation with their doctor about how long they had left to live, less than 3% responded in the positive. When asked if they would want to know how long they had left to live, if their doctor knew, 77% said no, 21% said yes, and 2% were unsure.(36)

The authors point out that the 21% who wanted to know how long they had left to live, was much lower than cohorts from other LMIC countries such as India, Pakistan and Brazil.(48-50) This comparison could be criticised because of the language used to evaluate prognostic awareness. The participants in the study by Shen et al. might simply be expressing their preference for not having their prognosis expressed in terms of time, not a reluctance for knowing their prognosis. So, in fact, there could be more than 21% of participants who want to know their prognosis, as long as it is not expressed in terms of time. Comparison of preferences for prognostic information across cohorts of patients when there is no consistency in the definitions and phrases used to evaluate it, is likely to introduce bias, especially when survey tools are translated.(36)

The study by Stanford et al. reported on EOL communication preferences in a more indirect way through qualitative analysis of HCP and lay-person focus group conversations.(35) Participants felt that ACP conversations were better received earlier in the disease trajectory and well before the end-of-life phase, when patients were still in relatively good health, but acknowledged that a significant health event often prompted such conversations. These conversations were best conducted in the setting of a trusting relationship. Different views on the best timing and setting for the conversation emerged, as well as differing preferences for whom to involve in such conversations and whom to appoint as surrogate health care decision-makers for example, a family member versus a friend. Some of these differences appeared to relate to cultural differences, but the sample was too small to make any definite deductions on this aspect.(35)

1.6. Acceptability of ACP conversation and AD tools

Despite the wide availability of ACP conversation tools and AD templates, evidence of the evaluation of acceptability was found for only one, namely the “One Slide” ACP conversation tool in the study by Stanford et al.(35) The authors concluded that the “One Slide” ACP conversation tool was not appropriate for the SA setting in its use of language and suggested changes that would clarify complex concepts and align given examples with the SA healthcare and social contexts (Figure 1, right column).(35) Due to their own limited awareness of ACP, and the fact that they felt patients would also have low awareness, study participants also suggested changes aimed at providing context for the conversation in general and certain prompts in particular. Further qualitative analysis of the data to extract common themes resulted in several additional suggested adaptations to the conversation tool to align the content and wording with local preferences. An introductory statement was added to put the conversation into context by explaining that the responses to the questions would pertain to a scenario where the patient is no longer able to speak for themselves or be competent to make decisions about their medical care. Adequate pain control was highlighted as an essential part of comfort care and at the other end of the spectrum the phrase “do whatever is necessary, try proven or unproven interventions to keep me alive”, was added to clarify the implications of aggressive care. Additional options for place of death were incorporated, for example hospice, frail care, family member’s home. Phrases like “loved-one”, “terminal illness”, and “advocate” were rephrased and clarified as “someone or some people who you trust”, “if you couldn’t speak for yourself”, and “talk on your behalf” respectively. The terms “health care power of attorney” and “advance directive” was explained as “writing down your wishes” and “appointing the right person or people to act for you”.(35)

Even though participants in the study by Bull were asked if they were familiar with the proforma living will document promoted by the Living Will Society of South Africa, the study did not include an exploration of the acceptability of the actual document.(46)

1.7. Preferences for EOL care

Data on preferences for EOL care was limited to the studies by Stanford et al., Graham et al., and Shen et al., and dealt mainly with preferences for life-extending care over comfort care, place of death, the presence of family at the deathbed, and aggressiveness of life-sustaining interventions in the last days of life.

A theme that clearly emerged from the study by Stanford et al. was the influence of socio-economic context on preferences for place of death and ultimate place of death. Preference for place of death was pervasively influenced by adequacy judgements of the human (caregivers), healthcare (medication, care, interventions), infrastructural (space, water, lighting), and financial (health insurance, days-off work) resources in the patient’s home, versus the resources available in their local healthcare facility, which is commonly associated with poor quality care, loneliness, and lack of compassion form HCP. Participants acknowledged that families sometimes could not or were not prepared to care for a dying relative in the home. Some patients also preferred to die in hospital to avoid being a burden on their family. Participants highlighted disparities in financial resources to pay for care, in the burden on caregivers, and in the quality of medical care received in different healthcare settings (public hospital, private hospital, home, nursing home, hospice). These differences apply on an individual level, but also on community levels. This indicates the importance of determining each patient’s preferences individually and not basing it on assumptions about family structure and cultural context.(35) Preference for place of dying in the study by Shen et al. was their home in 57.5% of cases, hospital in 23.1%, hospice, nursing home or step-down facility in 2.3%, and some other setting in 17.2% of cases. The authors concluded that most (57.5%) participants preferred to die at home and suggested that the 23.1% who preferred to die in hospital, did so because of not wanting to place a burden on families, especially when socio-economic resources were low, or where medical knowledge of the carer or lack of access to medical care or medications, or basic amenities, would mean they would get inferior comfort care. To support this theory they reference 2 publications detailing lack of resources for general and HIV PC in SSA, and not studies supporting this theory directly.(51, 52) They do, however, acknowledge that the study did not address the possible influence of resource constraints on patient preferences. They also did not correlate preference for place of death with actual place of death, indicating the fulfilment of wishes.(36)

In the study by Graham et al. the presence of family around the deathbed was described as contributing to a “good death”.(44) Participating traditional healers felt that family presence not only comforted the dying patient but also allowed them to share their final wishes with the family, give a verbal will, and restore broken relationships. Within Xhosa families, complying with the final wishes of a dying person is given great importance, as it is believed that the spirits of dead relatives can confer good fortune and protection on these who followed their wishes, whether it be for something before death or after. The authors also highlighted the importance of being aware of psychosocial or spiritual needs unique to the Xhosa culture and belief system that would inform a person’s EOL care preferences. Examples include needing to travel to a specific location to commune with ancestors, or taking a herbal medicine that hold specific meaning for them.(44)

In the study by Shen et al. most participants (73%) chose care aimed primarily at relieving pain and discomfort, even if that meant not living as long (comfort care), while 14% chose a course of treatment that focused on extending life as much as possible, even if it meant more pain and discomfort (life-extending care).(36) One could contend that this represents a methodological flaw, in that the participant is given only 2 choices, namely “comfort care” aimed primarily at relieving pain and discomfort, or “a course of treatment that focused on extending life as much as possible, even if it meant more pain and discomfort”. This emotive reference to pain and discomfort could have led participants to assume that all life-extending treatment would be associated with pain and discomfort. In fact, not all life-extending palliative treatments in the setting of advanced cancer cause more pain and discomfort, an example is oral antioestrogen therapy for breast cancer. The response options are therefore not optimally phrased and do not encompass all scenarios. The authors suggest that patients might choose comfort care because they are not aware of the possibility of life-extending care or accept that the possibility is not there because of resource constraints but does not supply robust supporting evidence for these theories. They cite a publication by Cleary et al. that describes resource constraints, but not people’s reasoning behind preferring comfort care.(51) The reasons for preferring comfort care are not evaluated further in this study. With regards to life-sustaining treatments at the end of life, 81% of participants in the Shen study did not want to be kept alive if it required ventilation or dialysis, and 15% did. When asked whether, if they were going to die in a few days, they would want their doctor to do anything possible to keep them alive, 78% of the participants in the Shen study said no, and 16% said yes.(36) In this study there was a consistent group of approximately 30-34 patients who wanted life-extending and life-sustaining therapy. This consistency indicates that the phrases in this questionnaire “kept alive on a breathing machine or kidney dialysis”, “do anything possible to keep you alive if you were going to die”, “treatment that focused on extending life as much as possible,” were well understood by the cohort. The question arises whether the full complement of palliative treatment options and their potential benefit, outside of the extension of life, are understood by South Africans.

Shen et al. found that most patients had “planned for death by making funeral plans”, although having a funeral plan cannot be equated to “planning for death” or being prepared for death. It is a cultural-economic construct of creating some sense of stability for the family left behind to ensure that they are not ruined by the cost of a traditional African funeral. Because big funerals are expected in the African culture, there is an expectation that the deceased will put insurance in place to cover the cost of a big funeral, and not have it be a financial burden on the family.(36)

The study by Shen et al. is the first to explore EOL care and EOL communication preferences amongst SA patients and gives us valuable information on the subject.(36) Participants were recruited from a palliative care setting and relevant themes were addressed. Due to its quantitative design the potential for exploration of patient perceptions is however limited. The rigid construct and suboptimal language use in the survey responses also make it difficult to make inferences about patient perceptions and the motivation for their choices. When analysing end-of-life care preferences the authors concluded that most patients with advanced cancer did not want life-extending treatment or extreme life-sustaining measures such as ventilation and dialysis but preferred what the authors termed “comfort care”. They also contend that participants are more accepting of death, a conclusion also drawn from a 2011 systematic review on end-of-life care in Sub-Saharan Africa by Gysels et al.(53) They conclude that “care should be taken to ensure that prognoses are communicated, and care provided to patients with advanced cancer in South Africa in ways that are culturally appropriate, ethical, and patient-centred on the basis of South African patient preferences and values, not Western- or other LMIC-based values”.(36)

Further qualitative research is warranted to explore SA patients’ EOL priorities and preferences as it will serve to inform the optimal design of locally appropriate survey tools that can then be used in quantitative research.

1.8. Synthesis of Literature review

When considering the scope of EOL communication activities practiced and studied in the SA population, supporting data was found for the assessment of prognostic understanding amongst patients, sharing of prognostic information, and the exploration and documentation of wishes and priorities for EOL care.

Contradicting quantitative evidence for levels of prognostic understanding amongst local patients were reported, with Yennurajalingam et al. reporting high levels and Shen et al. reporting low levels.(36, 40) The varying terminology used to measure prognostic understanding in the two studies and the high likelihood of misinterpretation of these terms by local participants with low health literacy levels raise concerns about the generalizability of the findings.

The predominant view of HCP on conveying poor prognosis to a patient, was that it was a difficult task that was often associated with internal conflict. HCP felt conflicted between their belief that patients should know the truth about their disease trajectory, and their fear of causing distress or losing the trust of their patients by talking about poor prognosis.(41-45)

The study by Stanford et al. showed that although the participating HCP and lay persons were unfamiliar with ACP tools and living wills, they agreed that they were useful and necessary. The concept of appointing a proxy healthcare decision-maker was also supported.(35) Even though the study by Shen et al. provides valuable data on the EOL care preferences of local patients, its quantitative design and rigid survey construct does not allow inferences about the perceptions and attitudes of local patients towards conversation exploring their priorities and preferences for EOL care.(36)

Bull et al. reported that local HCP were familiar with advance directives (AD) or living wills, but did not see a high level of uptake amongst their patients. They acknowledged the value of AD in EOL decision-making, especially when supporting families in decisions about withholding or withdrawing treatment at the EOL.(46)

From the assimilated literature it appears that HCPs consider a wide range of factors to be barriers to the routine use of ACP conversations in their daily practice. There is a lack of knowledge about ACP amongst HCP and in communities and a perceived sensitivity around the subject in patients.(35, 46) In the studies by Stanford et al. and Campbell et al., talking about death is said to be labelled as a taboo in certain African cultures.(35, 43) HCP express the fear that ACP conversations could lead to a breakdown in the doctor patient relationship. This fear that the delivery of poor prognosis or the discussion of impending death will cause emotional distress or remove hope, or hasten death, based on the patient's religious, social, or cultural belief systems is described in the setting of the Jewish community by Silbert, and in two traditional African communities by Campbell et al. and Graham et al.(41-44) The differences in cultural constructs around autonomy within family structures also stopped some HCP from pursuing the subject.(35) Silbert and Ganca et al highlighted HCP's perceived or actual lack of training in communicating poor prognosis, as a barrier to initiating these conversations.(41, 45) Their own uncertainty about accurate prognostication and accurate timing of the conversation also played a role.(41, 43) Silbert and Bull et al. reported the concern amongst HCP that they would not have adequate time to attend to the patient's emotional needs resulting from receiving a poor prognosis.(41, 46) Bull et al further reported that the fact that living wills do not have legal status in SA made some HCP question its value while other clinicians and nurses did not see it as their role to advocate for the drafting of living wills.(46) Implementation factors around the availability of ACP documents at the bedside and concerns that wishes would not be respected, were also seen to be a barrier to implementation.(35) Other reasons for avoiding ACP conversations included having a prior relationship with the patient, when patients are children or young people, when the patient or family have unrealistic expectations, when the doctor is not aware of the expectations of the patient or family, and family members obstructing delivery of poor prognosis.(41, 43, 45)

The study by Shen et al. suggests that local patients are not having discussions with their HCP about how long they have left to live, and have a low desire to know their prognosis in terms of time.(36) Reasons for this preference or their desire to discuss prognosis without referring to time, was not studied.(36) Participants in the study by Stanford et al. agreed that ACP conversations should be had early in the disease trajectory and in the setting of a trusting relationship. They however had differing opinions on who should participate in EOL conversations, the optimal time and place for it, and on who they would appoint as proxy healthcare decision-makers.(35)

The only ACP tool that has been evaluated for acceptability in the SA setting is the "One Slide" ACP conversation tool. Stanford et al found that the tool was not locally appropriate in its use of complex language, and in the locally inappropriate examples used to illustrate concepts.(35) Given the low levels of awareness of ACP in the local population, the need to provide adequate context for the conversation was also highlighted.(35)

On the topic of EOL priorities and preferences, the studies by Shen et al. and Stanford et al. suggested that local patients preferred to die at home versus in health facilities. Both studies however highlighted the major influence of local socio-economic and healthcare resource limitation on the ultimate place of death.(35, 36) Due to the poor living conditions of many South Africans, EOL care at home is often not safe or feasible. Unfortunately due to inequalities in healthcare access this same segment of the population is dependent on the public healthcare service, where palliative care is not widely available.(35)

Graham et al. reported that South-Africans belonging to the Xhosa culture value the presence of their family and loved ones around their deathbed, and that care should be taken to enquire about emotional and spiritual needs in the EOL phase that relate specifically to their cultural belief systems.(44)

The only data available on local preferences for aggressiveness of medical interventions at the EOL comes from Shen et al. who reports that the vast majority of patients preferred care aimed primarily at relieving pain and discomfort, even if that meant not living as long, or what the study team called "comfort care".

1.9. Concepts and constructs emerging from literature review

Based on this literature review and a detailed study of the Serious Illness Care Program's Clinician's Reference Guide (CRG) (12 Oct 2017 Revision)(54), the following concepts and constructs emerged as relevant to the content of the oSICG and were used to evaluate conceptual equivalence in the individual prompts.

1. Perception of advanced Illness trajectory (Illness understanding [diagnosis, stage, palliative treatment intent], Deteriorating functional ability [dependence], Increasing symptom burden, Death)
2. Prognostic uncertainty (Deteriorating functional ability, Life-expectancy)
3. Patient autonomy (Informational preferences, decision-making preferences)
4. Life-expectancy
5. Quality of life (Living well, Critical abilities)
6. Priorities and preferences (Goals)
7. Goal-concordant care
8. Treatment burden versus benefit or “trade-offs”
9. Fears and worries
10. Resilience
11. Family as unit of care
12. Commitment to care

CHAPTER THREE AIM AND OBJECTIVES

1.1. Aim

To explore the local validity and cross-cultural acceptability of the 2017 version of the internationally validated Ariadne Labs Serious Illness Conversation Guide (Appendix A, Table 1), for use in advance care planning conversations in South African oncology healthcare practitioners (HCP).

1.2. Objectives

1.2.1. Primary objectives

1.2.1.1. To explore the cross-cultural acceptability of each of the 16 Serious Illness Conversation Guide (oSICG) prompts for South African oncology healthcare practitioners.

1.2.1.2. To explore the content and face validity of each of the 16 oSICG prompts for South African oncology healthcare practitioners.

1.2.2. **Secondary objectives**

1.2.2.1. To explore emerging themes related to the use of the oSICG by South African oncology healthcare practitioners.

CHAPTER FOUR METHODOLOGY

1.1. Study design

This study made use of a mixed methods research design combining quantitative data that was collected through a survey and qualitative data that was collected through structured focus group discussions (FGD).(55) Including a qualitative component ensured the greatest chance of eliciting in-depth and subjective descriptions of participants' understanding of the complex and emotive issues surrounding discussions about poor prognosis, and wishes for EOL care.(56) It also allows the researcher wider scope to explore, interpret, and make sense of the collected data.(57)

Primary objective 1 was achieved through analysis of the survey data on acceptability (Appendix E, Questions 9-43) as well as deductive thematic analysis of FGD data. Primary objective 2 was achieved through deductive thematic analysis of FGD data. The secondary objective was achieved through inductive thematic analysis of FGD data.

1.2. Study sites

The study was conducted at the two centres offering specialist oncology services in the public health sector of the WCP, namely Tygerberg Academic Hospital (TAH) and Groote Schuur Hospital (GSH). Both facilities offer secondary and tertiary clinical services and are situated in the Cape Town Metro area. TAH is a 1384-bed training hospital affiliated with Stellenbosch University (SU) and GSH an 893-bed training hospital affiliated with the University of Cape Town. The oncology divisions in both hospitals offer chemotherapy and radiotherapy services alongside routine diagnostic, supportive and palliative oncology services to an ethnically diverse, mostly adult population.

1.3. Study team

To ensure effective and continuous data collection and management the study employed a research assistant (RA) to assist the lead investigator with recruitment of participants, data collection and data management. The RA contributed to the design of the FGD discussion prompts and was present at all the FGD.

1.4. Study population

The study population consisted of healthcare professional that satisfied the below inclusion and exclusion criteria. This population was chosen to represent the cultural worldviews of South Africa and to have a high likelihood of engaging in discussions about poor prognosis or advance care planning conversations due to the inherent nature of their daily work with advanced cancer patients and would therefore possess expert knowledge on the issue under study. It is acknowledged that obtaining the views of cancer patients and caregivers would allow for deeper exploration of the study aims, but the scope of this MPhil did not allow for this.

Inclusion criteria:

1. Healthcare professionals who care for oncology patients as part of their day-to-day work.
2. Primary location of practice in the Western Cape
3. South African citizens or foreign citizens who had worked in SA for the last 10 years
4. Consenting to volunteer to attend the FG meetings in person or online
5. Conversant in English or Afrikaans.

Exclusion criteria

1. Younger than 18 years of age.
2. Unable to attend the FG meetings due to time or logistical constraints

1.5. Sampling method and sample size

The participants for the study were purposively sampled. A flyer describing the goals and procedures of the study as well as the inclusion and exclusion criteria (Appendix D) was distributed through local multidisciplinary oncology and palliative care networks, inviting volunteers. The study team approached potential participants who expressed an interest, and who met the inclusion and exclusion criteria, and proceeded to recruited them for the study.

To ensure richness of qualitative data analysis, the aim was to recruit approximately 12 participants from different healthcare disciplines including doctors, nurses, social workers, and spiritual counsellors. Twelve is also the recommended sample size associated with theoretical data saturation, the point at which no new information is expected to result from thematically analysing data from additional participants.(56)

1.6. Data collection tools

Three data collection tools were developed namely: 1) Participant demographic data collection sheet. 2) SICG acceptability survey, 3) Focus group discussion (FGD) prompts.

1.6.1. Participant demographic data collection sheet

An Excel spreadsheet was designed to collect the demographic details (e.g. profession, age, language, ethnicity, gender) of consenting participants. A detailed list of these descriptive data variables can be found in Appendix A, Table 3.

1.6.2. SICG acceptability Survey

Prior to attending the FGD each enrolled participant was asked to complete an online oSICG acceptability assessment survey. The first set of questions in the survey focussed on the participant's occupational experience, clinical practice setting, and patterns of oSICG use (Appendix E, Questions 2-8). The survey then listed each of the 13 prompts in the oSICG and required the participant to assign an acceptability rating to each prompt individually (Appendix E, Questions 9-43). To assign acceptability rating, this survey utilized a colour-coding system first described by Beddard-Huber et al (2021) and successfully used before in the culturally appropriate oSICG adaptation process for indigenous communities in New Zealand and Canada.(29) In this system participants are asked to rate the acceptability of each individual oSICG prompt according to the colour codes described below:

Green—This question is acceptable as it is.
Orange—This question needs work.
Red—This question is not acceptable.
Blue—Is there another question that needs to be asked?

This approach is believed to stimulate discussion in a non-threatening collaborative setting. It was felt to be both feasible and culturally appropriate for the South African population by the study team. If a participant labelled a prompt as red (This question is not acceptable), they were asked to describe what they considered to be unacceptable about the prompt in an open text format.

The survey included 3 further questions about the oSICG asking the participant which member of the healthcare team they believe is most suitable to initiate serious illness conversations with patients, whether they found any of the oSICG prompts inappropriate, disrespectful or offensive when considering the cultural, ethnic, and spiritual backgrounds of the people they cared for, and lastly whether they wanted to add any questions or statements to the oSICG to enhance it. (Appendix E, Questions 44-47)

1.6.3. Focus group discussion prompts

In order to ensure a high yield of data to meet the objectives of the study, the lead investigator, research assistant and primary supervisor created a set of prompts that would stimulate discussion in the focus groups around the topics of face and content validity, item and semantic equivalence, and conceptual equivalence. All prompts were formulated in English.

To develop prompts that would explore face and content validity, the definitions described by DiIorio et al, were studied.(38) Face validity is defined as the degree to which a measure appears to test the outcome or construct that it purports to test. Content validity describes the degree to which a measure tests all the aspects of a particular construct.(38)

Prompts aimed at exploring item and semantic equivalence were derived from the Universalist model framework for cross-cultural adaptation of health-related outcome measures (OM), first described by Herdman et al in 1998, where item equivalence represents the degree to which an OM appropriately measures the concept it intends to measure in a different culture, and semantic equivalence refers to the nuance or associations the OM may evoke in participants with different language backgrounds.(39)

Evaluating conceptual equivalence involves appraising and clarifying the constructs assessed by each prompt in the oSICG to ensure they would be recognized as equivalent in the target language and culture.(58) Conceptual definition of key constructs in the oSICG were identified firstly by a brief review of the literature on EOL communication practices and preferences in the South African population. This helped the study team to identify what is already known about preferences and patterns of practice for EOL communication as well as barriers to promotion and uptake of EOL communication, specific to the target population. The results of this literature review are described in Chapter 2 of this dissertation. In addition, the lead investigator made a detailed study of the Serious Illness Care Program's Clinician's Reference Guide (12 Oct 2017 Revision), to ensure a clear understanding of the intended meaning of the prompts in the oSICG.(54) By defining the concepts used in the oSICG beforehand, the study team were better acquainted with the prompt they were working with and became aware of some concepts that would possibly not be seen as equivalent by the target population.(58)

The prompts focussed on the following areas: i) defining the meaning of concepts, terms and constructs in each prompt; ii) describing how the information elicited by the prompt could be used to direct patient management and care; iii) expressing their opinions on the clarity, understandability, and local acceptability of each prompt; iv) and suggestions for equivalent or suitable alternative language if the oSICG language was judged to be unclear, ambiguous or unsuited to the local context. A list of the prompts can be found in Appendix A, Table 2. The discussion prompts were not formally piloted or validated prior to use.

1.7. Data collection process

1.7.1. Recruitment and training of research assistant

As the study took place in a multi-cultural setting with participants from diverse socio-cultural backgrounds the research assistant was selected for their multilingualism (able to speak Afrikaans, English and isiXhosa) and congruence with the ethnic and gender diversity of the WCP. The research assistant was trained by the study team on the following topics: ethical research practices, administration of the oSICG, how to identify distressed participants during the conduct of the FGD and how to refer such patients appropriately for support. The research assistant had frequent feedback sessions with the lead investigator during the data collection phase to discuss any issues that arose with patient recruitment, data collection or data management.

1.7.2. Recruitment of participants and informed consent

The participants for the FGDs with palliative healthcare professionals were purposively recruited. Care was taken to include professionals with and without formal palliative care training, and have representation of the primary gender, ethnic and language groups in the Western Cape population to minimize sampling bias.(34) All participants gave written consent for participation in their first language. The recruitment process progressed very slowly. This could be attributed to the reluctance of people to participate in clinical research or speak openly about impending death but could have been affected by the 2020-2021 South African COVID lockdowns, quarantine periods of potential participants, increased workload, restriction of movement in hospitals and the resultant reluctance of the public to attend any gatherings for non-essential purposes.

1.7.3. Collection of participant characteristics

Self-reported demographic data on participants' profession, age, language preferences, ethnicity and gender were collected in person on the day of the FGD. Responses were captured in an Excel spreadsheet.

1.7.4. Process of data collection

In preparation for the HCP FG meetings and the completion of the survey, each HCP was asked to watch a 5-minute introductory video on The Conversation Project, an example of an APC tool, watch a 17-minute presentation and simulated serious illness conversation published on the PALPRAC website, and read through the oSICG (Ariadne Labs, Version 7; 18 April 2017) and 2 background documents that form part of the PALPRAC Advance Care Planning (ACP) tool kit (Appendix E, Page 1). The survey document was electronically distributed to consenting participants in the form of an online Google form (Appendix E). Responses were captured in an Excel spreadsheet.

During the FG discussions lead investigator and research assistant used the discussion prompts described in section 2.5 (Appendix A, Table 2) to facilitate an HCP discussion of each oSICG prompt in a sequential fashion. All focus group meetings were hosted in person at the 2 study sites or online using Microsoft TEAMS. Discussions were primarily conducted in English and Afrikaans to enable cost- and time-efficiency. If any HCP participants required clarification of prompts, the research assistant (native isiXhosa speaker), and the lead investigator (native Afrikaans speaker) provided translation and explanation. Online FG discussions were video- and audio-recorded and face-to face FG discussions were audio-recorded only. All recordings were transcribed verbatim by an accredited transcription service and reviewed by the lead investigator before analysis commenced. Any comments in a language other than English was translated by the study team. Member checking was not performed due to logistical challenges. During all FGDs, the lead investigator made detailed field notes of conceptual definitions as well as any problematic or culturally discordant concepts or language identified in each prompt of the oSICG. Regular communication with the heads of the divisions in which the study was conducted to discuss any issues arising from the conduct of the study in their units occurred to resolve problems promptly.

1.7.5. Distress protocol

If an HCP participant became physically or emotionally distressed during the conduct of study activities, the participant was given the option of leaving the discussion, either temporarily or permanently, and was immediately referred to an appropriate counselling and support service through the HPCA.

1.8. Data storage and confidentiality

The quantitative survey data and demographic data was entered and stored in a password protected Excel Spreadsheet. Each participant was assigned a study number that was correlated to their name and surname. The PI allocated these study numbers and the master list linking participant names with study numbers was kept in a password protected document on the PI’s personal computer which was password secured. All further participant data was de-identified and only linked to the study number. The study database was password protected and stored on a secure server hosted by SU. Qualitative data and focus group recordings and transcripts were stored on a password-protected document cloud and on password protected NVivo software. Only the PI, who is GCP trained, RA and supervisors had access to the database and interview data. The RA signed a patient confidentiality agreement prior to conducting any study-related activities or getting access to study records, FG discussion data and the database.

1.9. Data analysis

1.9.1. Demographic data

Participant characteristics were reported using quantitative continuous and categorical descriptive variables and descriptive statistics.

1.9.2. Survey data

Survey responses on participant's occupational experience, clinical practice setting, and patterns of oSICG use (Appendix E, Questions 2-8) were reported using quantitative descriptive statistics.
To meet primary objective 1, acceptability data derived from the HCP applying the colour-coding assessment system described by Beddard-Huber et al during the pre-FGD online survey (Appendix E, Questions 9-43), was reported using quantitative descriptive statistics, and basic graphs.(29) Responses to the 3 additional survey questions (Appendix E, Questions 44-47) were reported using quantitative descriptive statistics and tables, to meet primary objective 1.

1.9.3. Focus group discussion data

Thematic analysis using both deductive and inductive techniques, as described by Braun & Clarke, was performed on the FGD transcript data.(59) Deductive thematic analysis was used to meet the 2 primary objectives and to reflect the research question and followed the six-step process of data familiarisation, identifying codes, finding themes, reviewing themes, defining and naming themes, and report writing.(59) Inductive thematic analysis was employed to meet the secondary objective. The supervisors supported the primary researcher in the process of data familiarization and immersion with the goal of identifying themes and subthemes. Negative cases or outliers were included and discussed. NVivo software was used to code and analyse data.

The FGD transcript data were analysed using deductive coding to identify themes related to the face and content validity as well as the cross-cultural acceptability of the oSICG prompts. A 5-point framework evaluating face validity, content validity, item equivalence, conceptual equivalence and semantic equivalence, based on the work done by DiIorio and Herdman, was used to thematically analyse the data.(38, 39) Deductive coding was performed at the hand of the following queries: i) Does the prompt appear to elicit/communicate what it intends to elicit/communicate (face validity); ii) Does the prompt address all aspects of the construct/concept it intends to address (content validity); iii) Does the prompt appear to elicit/communicate what it intends to elicit/communicate in the target culture (item equivalence); iv) Do the concepts/constructs exist, are they constructed in the same way, and do they have relevance in the target culture (conceptual equivalence); and v)

Does the prompt evoke unique associations and nuances when interpreted by people with other native languages or from the target culture (semantic equivalence). The results are reported in Chapter 4 of this dissertation alongside the inferences reached by the study team regarding the research question.

Emerging conceptual themes relevant to use of the SICG in the local context were identified through the inductive coding process of reflexive thematic analysis (TA), as described by Braun & Clarke. This method of TA allowed the researcher to adapt codes as their own interpretation of themes and concepts arising from the data deepens and evolves.(59, 60) Themes and sub-themes that emerged from the inductive analysis of the FGD data were coded. Codes and analyses were discussed with the supervisor. Codes were also discussed with advisors to check for bias of the researcher. Codes were applied, and data was charted across all the FGD data sources in the study. Finally, data were collated.

Key themes arising from the FGDs along with selected quotes to illustrate them, are reported in detail in Chapter 5 of this dissertation.

1.10. Ethical considerations

Approval to conduct the study was obtained from the Human Research Ethics Committees of the UCT Faculty of Health Sciences, the SU Faculty of Medicine and Health Sciences (UCT HREC reference number 439.2020, Appendix B) and the respective hospital managers at the 2 sites. The study was conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice (61, 62). Written informed consent for focus group participation was obtained from all HCP participants.

The conduct and findings of this study were managed in such a way so as not to infringe on the rights of any participants or affect or change the healthcare management of any patients in any way (justice). Participants were not excluded from participation in this study based on gender, ethnicity or language.

It is believed that patient autonomy is promoted through the conduct of serious illness conversations by empowering patients to take an active part in decision making about their healthcare. Patients are guided towards clarifying their own preferences for EOL care and towards sharing these preferences with their healthcare team and those closest to them. Engaging HCP on their views around EOL communication is believed to benefit the patients they may consult with in the future by increasing the chance of ACP communication which is hoped to lead to receiving care that is aligned with their wishes. All efforts were made to ensure participant comfort, privacy, and anonymity during the conduct of the study (non-maleficence).

1.11. Study timeline

Due to the 2020-2021 South African COVID lockdowns, quarantine periods of researchers and participants, restriction of movement in hospitals and the resultant reluctance of the public to attend any gatherings for non-essential purposes, significant delays occurred in the recruitment of FG participants. Although some FG meetings were held online, many participants did not have access to online meeting platforms and had to attend face-to-face meetings. The financial limitations caused by COVID on South African health research funders also delayed the securing of funds for the study. Despite these challenges, a total of 32 participants were recruited to the main study (17 HCP, 15 public) and data collection through FG discussions commenced in May 2021 and were concluded in July 2021 (Figure 5.1). These delays, and the uncertainties of how COVID would affect face-to-face research activities in the future, prompted the study team to review the feasibility of the original study protocol in September 2021. The field notes and preliminary thematic analysis of the HCP FG data were reviewed by the lead investigator and supervisor and were felt to be sufficiently rich to allow in-depth qualitative thematic analysis that would allow for the effective exploration of the acceptability as well as the face and content validity of the oSICG. A protocol amendment detailing these changes was submitted to the UCT HREC and was approved in November 2021.

1.12. Dissemination of findings

Feedback on the study findings will be given to the participating sites through written reports and presentations. Participants will receive written feedback on the study findings in the form of a one-page summary. The findings of this study will be described in a mini thesis that will be submitted to the University of Cape Town Faculty of Medicine and Health Sciences towards obtaining a Master's degree in Palliative Medicine and will be accessible through the OpenUCT database. The findings of this study will also be submitted for publication in the form of a journal article to an accredited peer reviewed journal. The preliminary findings of the study were presented at the 2023 SACO National conference held in Cape Town during September. It is the intention of the PI to submit the final results of the study for presentation at relevant national and international conferences.

CHAPTER FIVE RESULTS: Validity and cross-cultural acceptability exploration

1.1. Characteristics of HCP Focus Group Participants

Of the 21 healthcare professionals (HCP) purposively recruited to participate, 17 agreed to participate in focus group (FG) discussions (Figure 5.1). Work pressure and travelling distance were the main reason given for non-participation. Between May and July 2021, the lead-investigator conducted 4 focus group discussions. Due to logistical challenges one healthcare professional was interviewed alone. Each healthcare professional only attended 1 session. The FG sizes ranged from 3 to 5 participants. A total of 9.8 hours of conversation were recorded and transcribed. The demographic and practice setting characteristics of the healthcare professional FG participants are shown in Table 5.1 and Table 5.2. Although the HCP cohort was predominantly female (97.2%), it was more balanced in terms of profession, home language, ethnicity, and practice setting. The group was very experienced (median years in practice = 16) and the majority practiced in a predominantly cross-cultural setting. Just under half of survey respondents were familiar with the SICG, with most using it on a regular basis.

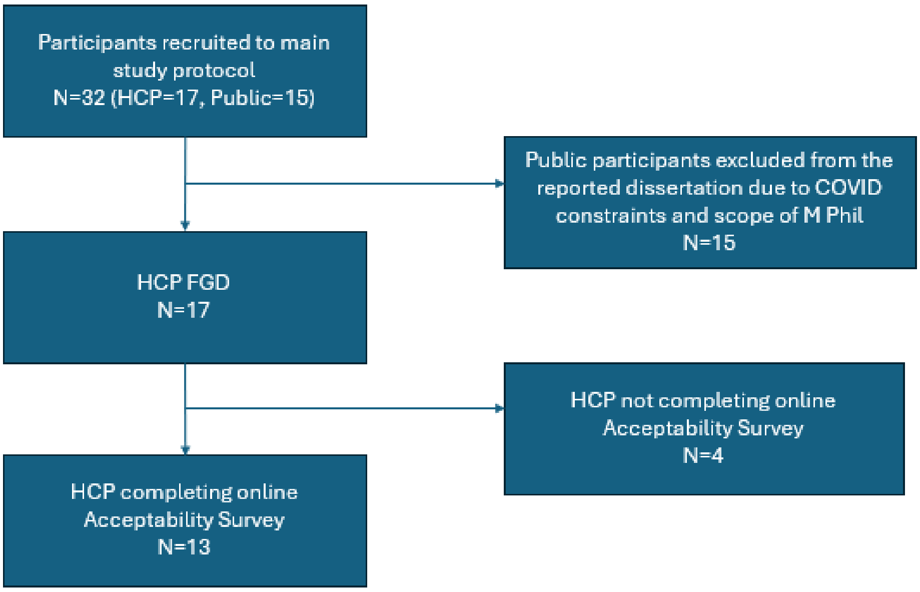

Figure 5.1: Diagram of included participants in main and current study

Table 5.1: Demographics of study participants

Focus Group code	***Male***	***Female***	***Home language*** ***(A=Afrikaans, E=English, X=African language)***	***Race*** ***(B=Black, C=Coloured, W=White)***	***Profession*** ***(C=Counsellor, D=Doctor, N=Nurse, S=Social worker)***
A (n=4)	*0*	*4*	*A2, E2*	*W4*	*D2, N1, S1*
B (n=5)	*1*	*4*	*E4, X1*	*B1, C1, W3*	*C1, D3, N1*
C (n=3)	*0*	*3*	*A2, E1*	*C2, W1*	*D1, N1, S1*
D (n=4)	*0*	*4*	*A1, E1, X2*	*B2, C2*	*N2, S2*
E (n=1)	*1*	*0*	*X1*	*B1*	*D1*
Totals (%)	*2 (11.8%)*	*15 (97.2%)*	*A5 (29.4%), E8 (47.1%), X4 (23.5%)*	*B4 (23.5%), C5 (29.4%), W8 (47.1%)*	*C1 (5.9%), D7 (41.2%), N5 (29.4%), S4 (23.5%)*

Table 5.2: Practice characteristics of participants

Characteristic	**N**
Age in yrs (median, range)	47 (31-80)
Practice setting (n=17)	
Hospital	6
State health centre or clinic	5
Hospice (with or without home visits)	3
General or specialist private practice (Consulting rooms with or without home visits)	1
Home care/ Home visits only (including care homes)	1
Private Nurse Practitioner PHC Clinic	1
Life-limiting diagnosis managed (more than 1 response allowed) (n=13)	
Cancer	13
End-stage organ failure	9
People with multiple chronic illnesses or frailty	9
Chronic infectious diseases (HIV, DR-TB)	5
Dementia	4
Degenerative neurological conditions (e.g., Multiple Sclerosis, AML)	3
Number of years in clinical practice, Median (range) (n=13)	16 (7-33)
Cross-cultural clinical case load (n=13)	
Less than a third (<33%)	1
1 to 2 thirds (33-66%)	4
More than 2 thirds (>66%)	8

Prior use of oSICG (n=13)	
Yes	6
No	7
Frequency of use per month	
1	2
2-4	1
>4	3
Reasons for not using oSICG in past (more than 1 response allowed)	
I was not aware of the SICG before now.	6
I think the SICG is too time-consuming.	2
I think the questions in the SICG will not be acceptable to my patients.	1
I prefer to use a different advance care planning conversation guide.	1
I have the serious conversation but not using the guide. I may use the guide now that I am more aware of it	1

1.2. HCP pre-FG acceptability assessment results

Thirteen healthcare professional participants completed the voluntary online pre-meeting Acceptability Survey in which they were asked to classify each of the 16 SICG prompts (Appendix A) as either “This question is acceptable as it is”, “This question needs work”, or “This question is not acceptable” (Appendix E). They were also asked if there were additional questions that they felt needed to be asked, and if they considered any of the prompts to be culturally inappropriate in the South African setting. The acceptability assessment data are shown graphically in Figure 5.2 below.

In the survey seven prompts (1, 4a, 4b, 5, 9, 12, 13) were considered unacceptable (coded as red) by at least one participant. Fourteen prompts were considered in need of some changes (coded as orange) by at least one participant. Nine SICG prompts were considered to be “acceptable as it is” (coded as green) by more than 75% of participants (2, 3, 4c, 6, 7, 8, 10, 11, 12). One participant labelled prompts 4b, 9, and 10 as culturally inappropriate.

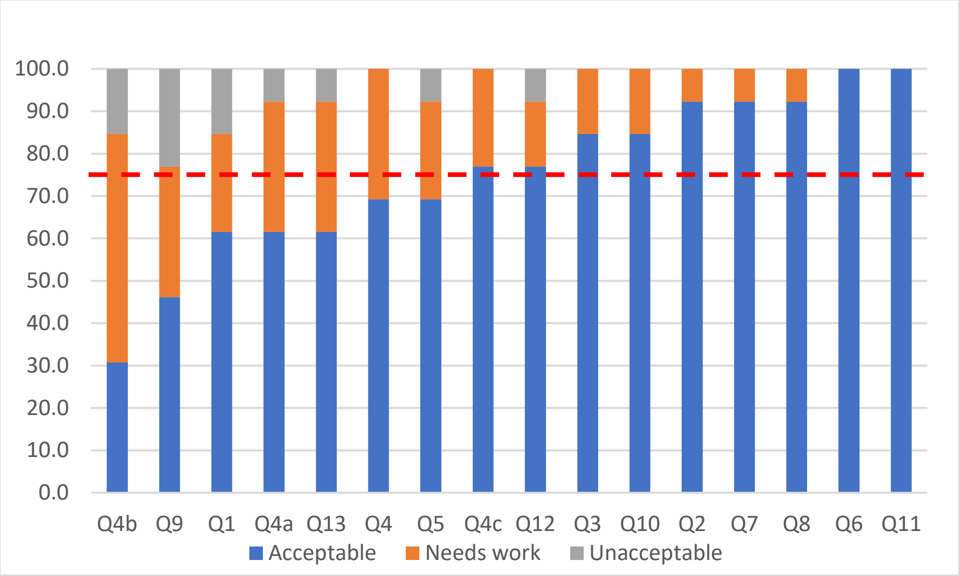

Figure 5.2: Graph of acceptability rating of individual SICG prompts in order of acceptability. (Acceptability rate considered high if >75% Acceptable, Acceptability rate considered low if <50% Acceptable)

1.3. HCP Validity and Cross-cultural acceptability results

In the following section the results of deductive thematic analysis of the face and content validity as well as the cross-cultural acceptability of each oSICG prompt are described at the hand of a 5-point framework evaluating face validity, content validity, item equivalence, conceptual equivalence, and semantic equivalence. Deductive coding was performed at the hand of the following queries: i) Does the prompt appear to elicit/communicate what it intends to elicit/communicate (face validity); ii) Does the prompt address all aspects of the construct/concept it intends to address (content validity); iii) Does the prompt appear to elicit/communicate what it intends to elicit/communicate in the target culture (item equivalence); iv) Do the concepts/constructs exist, are they constructed in the same way, and do they have relevance in the target culture (conceptual equivalence); and v) Does the prompt evoke unique associations and nuances when interpreted by people with other native languages or from the target culture (semantic equivalence). A detailed description of the results by each individual metric can be found in Appendix C.

1.3.1. PROMPT 1

"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want. Is this OK?"

Prompt properties		
Survey results with comments on unacceptable aspects	61.5% Acceptable as is 23.1% Needs work 15.4% Not acceptable	• HW16: Words "ahead" and "advance" (HCP16) • HW17: The use of the phrase "ahead of your illness"

Inference	The discussion revealed moderate **face validity**, in that there were multiple interpretations of the meaning of the prompt, many of which were not aligned with the intended meaning namely prompting the patient to think and talk now about what is important to them, so that when treatment or care decision have to be made in the future, they and the care team are clear about the patient's priorities and preferences. *HW16: Ja. "Thinking in advance" is also like explaining to a person [who is] going …for chemo, …what will be the side effects. Ja, you put the patient's mind in "thinking in advance [mode]," if [you say], "You may expect this, you may expect to be nauseous or you may expect to have no hair".* *HW15: I think also when we say, "What is ahead about your illness", I think, "How far has your illness… progressed".* *HW09: It's sort of like planning ahead, isn't it? Giving some thought to what might be coming so that we could plan or map a way forward from here to there.* The discussion revealed moderate **content validity** as many felt that the request for permission, "Is this OK?" should also include reference to timing and accompanying people. *HW09: …but perhaps we could ask them, "Is now a good time?", rather than, "Is it OK, yes, or no?". They could say, "Well, no, actually it's not a good time, because I'm actually in a lot of pain", or …"I'm not thinking clearly at the moment because I'm on medication and my thoughts are not clear," or "I don't have so and so with me today".* Survey results indicated a moderate level of **local acceptability**, and the discussion showed moderate **conceptual equivalence**, due to differences in the perceived relevance of goal-concordant care at the end of life in a limited resource setting, and the construct of patient autonomy as it relates to shared decision-making in a predominantly paternalistic healthcare setting. *HW02: I don't think the patient always have the… I mean, you can't always get the care you want. It sounds very pie in the sky...*

	HW06: I think also, my experience is that we very seldom ask the patient what they want. And now suddenly we're asking them what do they want. And it's like, "Why are you asking me this, you're just [going to] tell me. The whole way along in my illness people have told me what's going to happen, and now suddenly you are giving me the power?" The discussion revealed low **item equivalence** due to complex, abstract language that could easily be misinterpreted in the target culture. *HW02: Because I think you could easily break this down into …lots of short [questions]. Because it's so broad, if you want to get all the information that we're thinking about from the patient, I don't think you could just ask one question and expect them to answer immediately.* *HW13: …the words "ahead with your illness", it's almost like a euphemism that we are using to try and …get the patient to understand that there is a process happening. …I don't know if they'd actually understand it that way.* **Semantic equivalence** was low due to lack of patient-centredness in the local setting of low illness understanding, diverse cultural beliefs, and low trust in the healthcare system. HCP felt that patients might feel distressed by the seriousness of the language, coerced into the conversation, or not comfortable about talking about dying. *HW05: But I also agree with the previous speaker that said the building of trust. Definitely, this whole question for me, you can't just ask it out of the blue when it's your first visit to the doctor. And I don't know if that is practical in our state setup, health setup.* *HW09: …They should know that it can be "not OK". I don't know, it's difficult, we are so limited with our time with our patients. There is not often another time that we can use. But to me, the answer to that is always going to be: "Yes, doctor. Whatever you say, doctor." And I don't know whether the rest will flow honestly…* *HW16: Ja, and also, in religious people, they believe in speaking positive not negative. So, they will …say, "No, I'm not going to speak about this now. I know what God has in store for me."*

	There is lack of evidence for the validity of this prompt, with compelling evidence suggesting that the prompt is not valid in its current format. There is lack of converging (diverging) evidence for the cross-cultural acceptability of this prompt, with compelling evidence suggesting that the prompt is not cross-culturally acceptable in its current format.

1.3.2. PROMPT 2

"What is your understanding now of where you are with your illness?"

Prompt properties		
Survey results	92% Acceptable as is 7.7% Needs work 0% Not acceptable	
Inference	The discussion revealed high **face validity** and **content validity** for checking understanding of advanced illness trajectories. *HW01: …we want to hear what the patients understand, and how they describe, information wise, where they are.* *HW09: I think it's [understanding] a good word. It might be quite broad, because it might relate to the course of the illness, it might relate to the impact of the illness, it might relate to the social aspect of their illness. But it's good that it's open, because the patient's response to that is going to lead you into where they need to go.* Survey results indicated a high level of **local acceptability**, and the discussion showed high **conceptual equivalence** for advanced illness trajectories, including local relevance in the setting of poor illness understanding. *HW13: No, I think it is clear enough. And I think that last sentence, "The doctors have said that there's nothing that they can do to cure me," that answers the question. That means that they understand that there's a process happening and there's timing involved and there's deterioration...* *HW15: …So, although the doctor told her, "You have cancer", and she understands, "Okay, I have cancer", she has that hope, "I'll be cured". She [does not] know that it's actually an incurable sickness that she [has]. So, it's a relevant question to ask her, "Do you understand?"*	

	However, the discussion revealed that **item equivalence** in the target culture was low with a high likelihood of misunderstanding due to abstract language, which is likely to be interpreted literally by non-English first language speakers with limited education. *HW12: But I don't think that the patients can… all the patients can understand, "where you are with the illness". It's like you [the HCP] understand because you're working there. But a patient, I don't think she will [understand] "where am I with my illness," when you ask that question, [and] you don't explain to her.* **Semantic equivalence** was moderate due to concerns that patients with low illness understanding would not know what their illness status was, which would prevent the conversation from proceeding. *HW13: But yes, the new patients that are referred [to oncology] we hardly… yes, that's [that nobody has told them anything] usually the answer that we get from them and then we have to start working down…* There is evidence for the validity of this prompt. There is lack of converging (diverging) evidence for the cross-cultural acceptability of this prompt with some evidence suggesting that it is not cross-culturally acceptable in its current format.

1.3.3. PROMPT 3

"How much information about what is likely to be ahead with your illness would you like from me?"

Prompt properties		
Survey results	84.6% Acceptable as is 15.4% Needs work 0% Not acceptable	
Inference	The discussion revealed high **face validity** but low **content validity** in that more should be assessed than amount of information.	

	HW09: Ask what information, replace "how much" with the word "what". "What information about what's likely to happen." It's simpler too, and maybe a bit clearer. *HW16: …Some people [do not] want to hear the information. They will say, "Tell my children." Or the children will say, "Don't tell my mother. We want to keep that from her."* Survey results indicated a high level of **local acceptability**, however the discussion revealed moderate **conceptual equivalence** for informational preferences as an expression of patient autonomy, as it was not a familiar concept in the target culture. *HW18: …the patients have, in terms of our relationships with our doctors, we've been, …pummelled into that [paternalistic] way. Then it's revolutionary. I mean, then it feels weird. But there are many other different ways in which we interact. So, there's something... it will bring a familiarity with a different, other, outside of this [healthcare] space, way of interacting, that would be moving. I mean, this question always feels moving too. It feels like… when I hear it, I feel…. after feeling thrown off, I also feel a sense of awakening.* **Item equivalence** in the target culture was low with a high likelihood of misunderstanding due to complex, abstract language use. *HW05: …I'm not sure that the patients will understand it that way, but if you should ask me that question, I would think of, "How much detail do you want?* *HW13: When you say, "likely to be ahead with your illness," are you asking the patient, "How do you see your illness progress in the next six months?" Is that what the question is asking? …Would our patients understand that question like that?* **Semantic equivalence** was moderate due to quite a few instances of inequivalence related to poor illness understanding, lack of patient centredness, spiritual belief systems and the fear amongst HCP of causing distress.

	HW06: And if they don't know how much there is to tell, it's quite a strange way of asking it. Because, you know, are you [going to] tell me two facts, …or are there ten things coming I didn't know about? And to "how much of that do I want to know?", I don't know, how much can I handle? *HW06: Yes, I've had that [a patient asserting that it is not for us to decide what the future holds]. [There are] some patients who just want to live one day at a time. And they probably can't deal with thinking about how it's going to …be.* There is lack of evidence for the validity of this prompt with compelling evidence suggesting that it is not valid in its current format. There is lack of converging (diverging) evidence for the cross-cultural acceptability of this prompt with some evidence suggesting that it is not cross-culturally acceptable in its current format.

1.3.4. PROMPT 4

"I want to share with you my understanding of where things are with your illness..."

Prompt properties		
Survey results	69.2% Acceptable as is 30.8% Needs work 0% Not acceptable	
Inference	The discussion revealed low **face validity** due to incongruence with the language of prompts 3 and 4a-c where the HCP clearly communicates information about what might lie ahead in the patient's advanced illness trajectories, and not what the current status is, as is suggested by the phrase, "where things are." Most HCP found it difficult to make sense of this prompt. *HW12: "Things" that could be, like, we did the CT, we did all the investigations. …We did the biopsy, and then… This is the results of the things that we did [for] you, so cancer is stage four.* Due to low face validity, **content validity** could not be assessed.	

	Survey results indicated a moderate level of **local acceptability**, and the discussion showed high **conceptual equivalence** for perception of advanced illness trajectories. *HW14: Normally patients do appreciate [it] if you want to say your view.* However, the discussion revealed low **item equivalence** in the target culture due to abstract and incongruent language that creates a high likelihood of misunderstanding, just as it did for the HCP. *HW16: It's like I said, "Where things…", what things? …They will ask, "What things now, Sister? What things are you talking about?" …So, "I want to share with you where you are with your illness." If "things" can be removed, …out of that sentence…* **Semantic equivalence** was moderate due to language that is not patient-centred and appears to push the agenda of the HCP. *HW11: I will put it in the form of a question. I wouldn't say, "I want to share with you." I would ask, "If I may share with you my understanding." For that person who is not ready, who wouldn't want to know by now.* There is lack of evidence for the validity of this prompt with compelling evidence suggesting that it is not valid in its current format. There is lack of converging (diverging) evidence for the cross-cultural acceptability of this prompt, with some evidence suggesting that it is not cross-culturally acceptable in its current format.

1.3.5. PROMPT 4A

Uncertainty: “It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I’m worried that you could get sick quickly, and I think it is important to prepare for that possibility.”

Prompt properties		
Survey results	61.5% Acceptable as is 30.8% Needs work 7.7% Not acceptable	- HW17: We cannot predict the time of death. Suggested alternative language: “We don't know what the future holds, but you need to prepare yourself.”
Inference	The discussion revealed high **content validity. Face validity** was moderate, due to the phrase, “and I think it is important to prepare for that possibility,” which was misunderstood by some participants to refer to drafting a care plan and not the exploration of priorities and preferences (moderate). *HW04: …when I start this [prompt] I say, “…We are in a very unpredictable situation. Things are very uncertain, and therefore we do need to plan for the worst-case scenario and then, …once that's done, we can put it aside and we know that we have a plan, and then we implement that when we get there. And that's why I want to discuss with you the following…"* Survey results indicated a moderate level of **local acceptability**, and the discussion showed moderate **conceptual equivalence** due to the perceived lack of relevance of maintaining quality of life in patients with incurable illness or a significant symptom burden. *HW06: The word “continue” implies that they currently are living well. I'm not so sure they are.* *HW13: Yes, that might be setting ourselves up for failure. …Like, that wouldn’t work on, for example, a breast cancer patient …with brain [metastases], where you say, “I hope you will continue to live for a long time.”* The discussion revealed low **item equivalence** related to abstract language that would be difficult to understand in the local context of low illness understanding.	

	HW16: "I hope you will live…" No, isn't that to give false hope? …That is false hope and uncertainty… …also now he thinks he will live long, like the doctor said. "Let us hope that the doctor say that I will live long." This is how patients react on what the doctor is saying. The discussion revealed low **semantic equivalence** related to language that could be seen as distressing in the local context of low illness understanding, low trust in the healthcare system, and religious belief systems. *HW16: Oh dear! He was just "living long" and now he's going to get sick quickly! But also, doesn't that put fear in the patient, and also a distrust in the doctor, if the doctor can't tell me?* *HW05: …the patients …and the nurses would like to say something like, "We don't decide." You know, in a Christian perspective. "It is not for us to predict". …they would say, "Only God decides".* There is lack of evidence for the validity of this prompt with some evidence suggesting that it is not valid in its current format. There is lack of converging (diverging) evidence for the cross-cultural acceptability of this prompt with compelling evidence suggesting that the prompt is not cross-culturally acceptable in its current format.

1.3.6. PROMPT 4B

Time: "I wish we were not in this situation, but I am worried that time may be as short as ___ (express as a range, e.g. days to weeks, weeks to months, months to a year)."

Prompt properties		
Survey results	30.8% Acceptable as is 53.8% Needs work 15.4% Not acceptable	• HW09: I don't feel that giving a prognostic time is helpful unless the patient has specifically asked for it in prompt 3. We can so often be very wrong. Prompt is culturally inappropriate. • HW17: We cannot determine the time. Suggested alternative language: "I wish...but I am worried that... we may not have as much

		time as you might like.” “We don't know what the future holds, but we need to be prepared.”
Inference	The discussion revealed high **face validity**, but moderate **content validity**, because the concepts of pace of deterioration and preparing for what lies ahead are not included. *HW02: What I sometimes say is, “We don't know the future, but I'm worried that often, if you deteriorate quickly, it means …that your lifespan is shorter than if you deteriorate slowly, and therefore I'm concerned, because it seems to me you have deteriorated quite quickly.* *HW10: Or I would just say, "While we have time now to discuss this, let’s get a plan of action before things get more difficult or before we don’t have time to talk.” …That at least, when push comes to shove, I know what we planned already, rather than saying weeks or days, because I always tell them nobody can predict the future* Survey results indicated a low level of **local acceptability**, but the discussion showed high **conceptual equivalence** and moderate **item equivalence** due to the phrase “I wish we were not in this situation” which was seen as abstract and could be misinterpreted as insincere or unrealistic. *HW13: …A lot of our patients in our clinic, though, do ask us, "Doctor, how long do I have?" …We can’t tell them exactly how much time they have. But the months to years and weeks to months, does help us just to give them some form of answer.* *HW13: I don’t really like that part of the sentence. And the reason for that is because you’re putting yourself as part of being in a situation that you… And patients can perceive that as offensive, and they can say that you are not in the situation.* The discussion revealed low **semantic equivalence** related to language that is not patient-centred, that could cause distress, or that is discordant with local belief systems.	

	HW09: And I think, only if they have asked, when you said, "What information do you want?" and they said, "I want to know how much time I've got left." I think, then it's appropriate to bring in a timeline. *HW16: The patient may not die in that quick timeframe, right? And you stop living or you stop having hope in yourself, or you just stop working with the people [caregivers]. You just want to lay there and wait for that time to come.* HW17: Doctor can't predict. He's not God. He's just a human being. There is lack of evidence for the validity of this prompt with some evidence suggesting that it is not valid in its current format. There is lack of converging (diverging) evidence for the cross-cultural acceptability of this prompt with some evidence suggesting that the prompt is not cross-culturally acceptable in its current format.

1.3.7. PROMPT 4C

Function: "I hope that this is not the case, but I'm worried that this may be as strong as you will feel, and things are likely to get more difficult."

Prompt properties	
Survey results	76.9% Acceptable as is 23.1% Needs work 0% Not acceptable
Inference	The discussion revealed high **face validity** and moderate **content validity** as some HCPs wanted more direct references to likely disease complications and loss of independence, and more focus on the family. *HW08: "Get more difficult", is probably …saying, …your care needs may be increased or your ability for independent function, …might be… not really likely to… You may become less independently functional.* *HW18: But here, it is important to point the patient's gaze a bit outwards now. …so we are vague with "things," but we broaden the landscape at which those things can exist by saying, "You and the people around you."*

	Survey results indicated a high level of **local acceptability**, and the discussion showed high **conceptual equivalence**. However the discussion revealed low **item equivalence** related to abstract language that would be difficult to understand. *HW06: “As strong as you feel”, is a strange term.* *HW10: I think that is too verbose. I would make it much simpler by saying, “You know, things can only get harder from here on forward.”* **Semantic equivalence** was moderate as the prompt could be seen as distressing or insincere in the local context of low illness understanding, and low trust in the healthcare system. *HW02: I think it also depends on the type of patient, if the family is still trying to accept the diagnosis, and you say, “Things aren’t going to get better,” they might get a bit of a shock, and you might lose that trust. They might say that this doctor does not have any hope, and they don't think anything is going to change.* There is lack of evidence for the validity of this prompt with some evidence suggesting that it is not valid in its current format. There is lack of converging (diverging) evidence for the cross-cultural acceptability of this prompt, with some evidence that the prompt is not cross-culturally acceptable in its current format.

1.3.8. PROMPT 5

“What are your most important goals if your health situation worsens?”

Prompt properties	
Survey results	69.2% Acceptable as is 23.1% Needs work 7.7% Not acceptable
Inference	The discussion revealed moderate **face validity**, in that there were two distinct interpretations of the intended meaning of the word “goals,” with

	some seeing it as activities to complete before dying, and others seeing it as preferences for medical care. *HW02: I think of goals, like, if I was a mom and I want to see my son finish matric. Or my goal would be to just be able to do some gardening every day. More about… maybe also time things, like see my son finish matric, or be able to go to a certain function, or see my daughter finish varsity.* *HW13: But what do you want to know when you ask "goals"? …So, what I think this question is asking is regarding treatment planning. Do you want to prolong your life as long possible?* The discussion showed moderate **conceptual equivalence** due to differences in the perceived relevance of goal-concordant care at the end of life in the setting of limited resources. The discussion showed moderate **content validity**, in that healthcare needs and tasks of dying were not included. *HW10: I would replace goals. I would rather ask about needs, "What are your needs when you become sicker?" Rather than goals for things that I won't be able to necessarily assist the patient with. It lies more with the social worker perhaps.* *HW03: I think, for me, there's also a practical aspect to it. And my own approach would be, "There are some things that we need to look at because they're important. For instance, do you have a will in place? Have you discussed with your family your wishes for the future? What you would like and would not like", introducing that, because those are important.* Survey results indicated a moderate level of **local acceptability**, but the discussion revealed low **item equivalence** related to language that would be difficult to understand or misunderstood in the local context. High **semantic equivalence** was noted. *HW08: Yeah, you need to define goals, in a way, which is hard, because at the same time you don't want to lead someone as to what their goals might be.*

	HW08: Yes, it implies that you didn't reach your goal. …because these are now goals that you're setting. And if you don't get to the goal, there is an element, perhaps, of failure. There is lack of evidence for the validity of this prompt with compelling evidence suggesting that it is not valid in its current format. There is lack of converging (diverging) evidence for the cross-cultural acceptability of this prompt with some evidence suggesting that the prompt is not cross-culturally acceptable in its current format.

1.3.9. PROMPT 6

"What are your biggest fears and worries about the future with your health?"

Prompt properties	
Survey results	100% Acceptable as is 0% Needs work 0% Not acceptable
Inference	The discussion revealed high **face validity** and **content validity** for fears and worries as it relates to the perception of advanced illness trajectories. Survey results indicated a high level of **local acceptability**, and the discussion showed high **conceptual equivalence** and high **semantic equivalence** in the target culture. *HW08: I kind of get the impression that a fear is something that you are afraid of, where a worry is something that bothers you. So, you know, a fear might be, having uncontrolled pain, but a worry might be, where will your daughter go and live, who lives with you. Whereas the fear is, perhaps, something that genuinely ...scares you.* However, the discussion revealed moderate **item equivalence** with a high likelihood of misunderstanding in the target culture due to incongruent and abstract language use in the phrases "The future with your health." *HW04: The fears are about your deteriorating condition. It's not about "your health" really.* There is evidence for the validity of this prompt.

	There is converging evidence for the cross-cultural acceptability of this prompt, but some evidence suggests that the phrase “the future with your health,” should be adapted to be less abstract and more congruent with the language used in other prompts, to reduce the risk of misunderstanding in the target culture.

1.3.10. PROMPT 7

“What gives you strength as you think about the future with your illness?”

Prompt properties	
Survey results	92% Acceptable as is 7.7% Needs work 0% Not acceptable
Inference	The discussion revealed high **face validity** and high **content validity** for resilience and support as it relates to the perception of advanced illness trajectories. *HW06: I think it also gives an opening… that strength can also be, where you get your support from. Your strength could come from your family. It could come from the support …structures that you have. So, what gets you up in the morning? What helps you, what supports you? Which might be faith, and it might be your kids, your mother, your friends.* Survey results indicated a high level of **local acceptability**, and the discussion showed high **conceptual equivalence** and high **item equivalence** in the target culture. **Semantic equivalence** was regarded as moderate due to the foreboding connotation with the phrase “the future with your illness.” *HW04: But I don’t think it’s necessary to bring in ‘the future of your illness’. You can just say, ‘what gives you strength?’ ‘What inspires you?’, “what keeps you going?”* There is evidence for the validity of this prompt.

	There is converging evidence for the cross-cultural acceptability of this prompt, but some evidence suggests that the phrase “the future with your illness,” could be omitted.

1.3.11. PROMPT 8

“What abilities are so critical to your life that you can’t imagine living without them?”

Prompt properties	
Survey results	92% Acceptable as is 7.7% Needs work 0% Not acceptable
Inference	The discussion revealed high **face validity.** *HW01: It would add to your suffering. If you were to lose certain abilities, you would suffer more. So, if possible, could we lessen the suffering by helping with the choices that you make? What are the things that you really would… would cause immense suffering? More suffering than others.* *HW12: To do things on your own. Not be able to walk again, or... And you won’t be able to go back to work, provide for the family.* It also showed moderate **content validity**, in that a number of other aspects of functioning e.g. emotional or social abilities, were not included. *HW06: So, …for some people, …being a mother might be so critical to someone's life that they, if they can't be a mother, and that might be that my kid can get into bed with me and cuddle, then I can still do that. If I'm paralyzed from the neck down, I can't do it anymore, and that's a problem. What makes you, who you are? And that's very personal. Being part of the family, not being admitted to the hospital. But “abilities” is quite …limited, I think. …the intention of the question …could be, more broad.* Survey results indicated a high level of **local acceptability**, but the discussion showed low **conceptual equivalence**, due to the perceived lack of relevance of weighing up quality of life against the

	potential benefit of palliative treatment interventions in end-of-life care. *HW04: This is actually a discussion for earlier on, not in the palliative phase where we are having this discussion a year before this patient might be dying.* *HW05: Yes, I also don’t like this question, because what are you going to do with the answer? Because that what the patient fears, is most probably going to happen.* The discussion revealed low **item equivalence** related to abstract language that would be difficult to understand in the local context. *HW13: I don’t understand that question. “What abilities?“ The word “abilities.” “What abilities are so critical?” I mean, if I must ask that to one of our patients, I don’t think they will understand what I’m trying to ask.* If further revealed moderate **semantic equivalence** related to abstract language that could be seen as threatening in the local context of low illness understanding. *HW02: And I don't think it should be, like, a blanket question. Because some people might get a bit of a surprise and think …when it comes out of the blue, “Why are you suddenly asking about abilities I can’t live without. What are you going to take away from me? What are you about to do to me that…?"* There is lack of evidence for the validity of this prompt with some evidence suggesting that it is not valid in its current format. There is lack of converging (diverging) evidence for the cross-cultural acceptability of this prompt with compelling evidence suggesting that the prompt is not cross-culturally acceptable in its current format.

1.3.12. PROMPT 9

“If you become sicker, how much are you willing to go through for the possibility of gaining more time?”

Prompt properties		
Survey results	46.2% Acceptable as is 30.8% Needs work 23.1% Not acceptable	• HW10: I am unsure if patients will understand the question. • HW16: Giving false hope that there is more that can be done. • HW17: This question puts more strain and trauma on the patient. (HW09: Culturally inappropriate)
Inference	The discussion revealed high **face validity** and moderate **content validity**, in that the concepts of trade-offs to achieve one’s goals, as opposed to only gaining time, and preferences for life-sustaining treatment were not included. *HW09: I think it is an important question to ask when it comes to advanced care planning. You know, if I can gain myself three months, and live to see my daughter's wedding, I'll go through any amount of hospitalization during those three months. … So, it's planning around their goals, ahead of time.* Survey results indicated a low level of **local acceptability**, and the discussion showed low **conceptual equivalence**, due to differences in the underlying construct of patient autonomy and lack of relevance and weighing up the benefits and burdens of treatment option in the local context of limited resources and poor illness understanding. *HW02: The second point …maybe also in the government sector is that... sometimes there aren't that many treatments. So, it's saying, “How much are you willing to go through,” like, there actually might not be that many treatment options.* *HW06: I think I’m battling with that… I’m not sure if my patients can cope with this kind of question. Maybe I'm being too authoritarian or too dismissive. But in a population that is trusting the doctor, it's quite a difficult question to ask them.*	

	HW01: Some patients have said to me, “They told me that I would live… that this would give me six months longer, but then they didn't tell me what the quality of my life would be in those six months. And six months of this, post-chemo, has been hell. …I would still want to clarify what they mean by “more time.” Because more time as currently now, right now, this moment, in this condition of health or disease, or more time, but very sick with more time. The discussion revealed moderate **item equivalence** related to abstract language that would be difficult to understand in the local setting. *HW01: No, no, it [“How much are you willing to go through”] doesn't sound right for me either. No, it doesn’t feel good at all, this one. This is a scary one. This sounds very scary.* The discussion revealed low **semantic equivalence** related to language that could be seen as threatening or unfamiliar in the local context of low illness understanding and low uptake of shared healthcare decision-making. *HW17: Ja, but if people… most people now, if they hear they’ve got cancer, they know I’m going to die. So, what is the use of doing the surgery or whatever.* There is lack of evidence for the validity of this prompt with some evidence suggesting that it is not valid in its current format. There is lack of converging (diverging) evidence for the cross-cultural acceptability of this prompt with compelling evidence suggesting that the prompt is not cross-culturally acceptable in its current format.

1.3.13. PROMPT 10

“How much does your family know about your priorities and wishes?”

Prompt properties	
Survey results	85% Acceptable as is

	15.4% Needs work 0% Not acceptable
Inference	The discussion revealed high **face validity** but low **content validity** with multiple aspects that should be added to make this prompt more appropriate and meaningful in the target culture. The prompt should be preceded by an assessment of what the family knows about the patient's diagnosis and prognosis, and what the patient would like their family to know about their priorities and preferences. *HW10: Because you don't want to fall into the trap of saying something in front of a family member and then they actually don't even know, but you think they know. So, "What did you tell your family about your situation?"* *HW11: Maybe one can say, "Is there anything that you want your family to know regarding your priorities and your wishes?"* The HCP should also offer to support the patient in sharing their priorities and wishes with their families, ascertain if the family accepts and agrees with their priorities and wishes, and enquire about a healthcare proxy and/or a family contact person. *HW02: Are they on board? Do they agree with your wishes? Because sometimes the family might want something different to what the patient wants.* *HW10: I often ask them, which family member would you like me to communicate with, then they can spread the news to the other family members.* *HW16: We do that [ask the patient who will speak for them when they cannot]. We do it regular, yes* Survey results indicated a high level of **local acceptability**, and the discussion showed high **conceptual equivalence** for the family as unit of care.

	HW18: Yes [it is an important question], I think even more so because family networks are so much more… play such a bigger roll [in the local context]. Although **item equivalence** was high, the discussion revealed low **semantic equivalence** due to contextual differences in the target culture relating to cultural norms, family structures, lack of patient centredness, and the fear amongst HCP that discussion about poor prognosis will cause harm or conflict in families. *HW12: I am speaking about my own experience, my people… (African) "family know about priorities and wishes?" [No], it's only few of them that they know what it is, only few of them that will know what [are] my wishes. But most of them, they don't. I think because we are not opened up [about] what will happen. …So, we don't discuss about... we're avoiding. We don't want to talk about death and dying, honestly. I think it's because we're scared about it?* *HW04: I think in our community there's a lot of conflict between family members, often times. …oftentimes in low- and middle-income families. You do have a lot of conflict about money and debt and loans and all sorts of things that can really be a big deterrent in terms of palliative care planning.* *HW05: Yes, that's often true. And we often find that the families don't want to talk about it. So, it leaves the patient feeling alone.* There is lack of evidence for the validity of this prompt with compelling evidence suggesting that it is not valid in its current format. There is converging evidence for the cross-cultural acceptability of this prompt, but some evidence that local cultural and belief systems will cause patients to have a nuanced response to this prompt.

1.3.14. PROMPT 11

"I've heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we ___. This will help us make sure that your treatment plans reflect what's important to you."

Prompt properties	
Survey results	100% Acceptable as is 0% Needs work 0% Not acceptable
Inference	The discussion revealed high **face and content validity.** The HCP is checking in that their interpretation of the patient's responses is correct and making recommendations to support future individualized and goal-concordant decision-making. *HW14: This question will also give the patient the confirmation that he was actually listened to. And that somebody is going to try and assist him as best as possible. The summary, that is always very helpful. And you can also get clarity if that what you've heard is what the patient really wants.* *HW10: It's a personalized thing, it's an individualized thing. It's your plan, not a one-size-fits-all kind of thing. It's a personalized thing for you as an individual.* Survey results indicated a high level of **local acceptability.** The discussion showed moderate **item equivalence** in the target culture due to the possibility that the recommendation could be interpreted narrowly as only referring to treatment plans. *HW01: This is really at the time when you're wanting to… there are still options for treatment perhaps, and we're saying that we are recommending the next step. So, it's almost like 'what's the next step now?' Is it like that?* **Conceptual equivalence** for priorities and preferences for EOL care and goal-concordant care was moderate due to its perceived lack of relevance in the setting of limited resources and low illness understanding.

	HW04: …So, people that are educated, they would be able to voice their needs very clearly. But people that are [less educated], they would not have an idea of what they could ask for. And the resources in those communities are less, and then the planning becomes more difficult. **Semantic equivalence** was deemed to be moderate due to an important instance of semantic inequivalence in the second sentence related to language that is not considered patient centred enough. *HW02: "How would you feel about discussing some short- and long-term plans?" Instead of saying, "I recommend that...".* There is evidence for the validity of this prompt. There is lack of converging (diverging) evidence for the cross-cultural acceptability of this prompt with compelling evidence suggesting that it is not cross-culturally acceptable in its current format.

1.3.15. Prompt 12

"How does this plan seem to you?"

Prompt properties		
Survey results	76.9% Acceptable as is 15.4% Needs work 7.7% Not acceptable	• The plan is worked out before discussing with the patient (HW16)
Inference	The discussion revealed high **face and content validity** for the prompt as a whole. *HW04: "Do you feel comfortable with it?" "Does this really reflect your thoughts? How would you like to change it, or personalize it?"* Survey results indicated a high level of **local acceptability** for the prompt in its entirety. **Conceptual equivalence** is high for patient	

	autonomy as it relates to shared decision-making and is seen as relevant. *HW04: I think consensus [about the plan] is important, to reach consensus of some degree.* **Semantic equivalence** was high. The discussion showed moderate **item equivalence** in the target culture, because of the risk of patients misunderstanding the phrase "this plan," as referring to a treatment or care plan. *HW05: Well, I think maybe with the last slide, slide twenty-four, you would write down that care plan. So, that when the next [prompt] comes, it's something that is written, and then you would ask the patient, "is this what you want?"* There is evidence for the validity of this prompt. There is converging evidence for the cross-cultural acceptability of this prompt, but some evidence suggests that the phrase "the plan" should be adapted to reduce the risk of misunderstanding in the target culture.

1.3.16. Prompt 13

"I will do everything I can to help you through this."

Prompt properties		
Survey results	61.5% Acceptable as is 30.8% Needs work 7.7% Not acceptable	• It is over-promising to say "everything" as it may not be possible to do everything possible. There are other phrases to use to ensure the feeling of security and hope. (HW02)
Inference	The discussion revealed high face validity for the phrase "I will do everything I can to help you…" *HW12: We always say that. And we make sure that…"We will do everything to assist you"*	

	It however revealed low face validity for the phrase "…through this." There appears to be a misinterpretation of the intended meaning of this phrase. "Through this" is not intended to refer to the patient's entire EOL journey. It pertains to the exploration of priorities and preferences and not to exhaustive planning for medical care for all potential future eventualities. Due to the misinterpretation of the intended meaning item equivalence was not commented on for "through this." Overall **face validity** was therefore moderate. *HW12: Make sure that you are pain free. Make sure that you've got the support, make sure that you have the discharge plan, care continues… If your morphine runs out, you know, you must copy the discharge letter to the day hospital. You can also contact us.* *HW10: I would maybe say, "I will be available, should you have a specific need" or "You can contact me when you need something." In our situation maybe, "I'm not always on call, but one of my colleagues will be available should you need something after hours." Practical things like that.* **Content validity** was low because the team was not incorporated in the commitment to care. *HW01: And [the principle here is] that it's a team effort. It's a team. It's not a singular support.* Survey results indicated a moderate level of **local acceptability** for the prompt in its entirety. Conceptual equivalence for commitment to care was high in terms of construct and relevance, but the local feasibility of delivering on such a promise in the setting of limited healthcare resources was questioned. Overall the **conceptual equivalence** was therefore moderate. *HW02: Because you can't do everything, you're overcommitting yourself completely and it's making out as if it is just you, not a team. It's me, and I am going to do absolutely everything in my power to help you. That's not…*

	Semantic equivalence was low due to inequivalence in the local setting related to low illness understanding, limitations of the local healthcare service, and insincerity. *HW05: And yes, I definitely don't like the "everything I can", but also, "to help you through this" dying? If you put it that way, it seems as if there's going to be… it's a problem that can be solved in the end.* *HW18: To say, "To walk along with you through this," when you are actually not. Even though you are in a professional relationship with the client, but because of the circumstances, you know that there are some moments where you will not be available. …So, it will be false and fake to say I would do that. "I'm walking along with you," that's, I'm not walking along with you.* There is lack of evidence for the validity of this prompt with compelling evidence suggesting that it is not valid in its current format. There is lack of converging (diverging) evidence for the cross-cultural acceptability of this prompt as a whole, with some evidence suggesting that it is not cross-culturally acceptable in its current format.

1.4. Summary of results

1.4.1. Primary objective 1

The face validity was found to be high for 11 prompts (2,3,4b,4c,6,7,8,9,10,11,12), which suggests that the participating healthcare professionals (HCP) found it easy to understand the intended meaning and the intent of these prompts. Only prompt 4 showed low face validity, with most participants misunderstanding the intended meaning of the prompt. This is ascribed to the incongruence of the phrase "where things are" with the language of prompts 3 and 4a-c in which the HCP clearly communicate information about what might lie ahead in the patient's advanced illness trajectories, and not their current status. This is a major error in the logical flow of the conversation and can lead to misunderstanding in a setting of low health literacy and illness understanding. Content validity was found to be lower than face validity, with only 6 prompts (2,4a,6,7,11,12) showing high content validity. HCP felt that many locally relevant aspects of the concepts addressed in the SICG prompt were not included, which reduced their validity in the local context. They recommended that prompts should be expanded to elaborate more on different aspects of the constructs being explored i.e. informational preference, critical abilities, future functional deterioration. They caution that HCP should not assume that local patients will grasp the full scope of the construct under discussion and therefore should be prompted to ensure that important aspects are not left unaddressed. Another conceptual gap identified by the HCP relates to the scope of involvement of local families in ACP. They recommended that prompt 10 should be preceded by an assessment of what the family already knows and what the patient would like their family to know about their diagnosis and prognosis. They caution that many patients in the local setting have not and do not wish to share this information with others. It should also be preceded by an assessment of what the patient would like their family to know about their priorities and preferences. Furthermore HCP should ascertain if the family accepts and agrees with the patient's wishes and priorities, as family members are often primary caregivers in the local setting, and conflict around wishes and priorities could negatively influence care relationships. Due to the low levels of familiarity with and uptake of ACP and AD in the local population, HCP recommended that the conversation guide should include more direct references to preferences for healthcare and life-sustaining treatment, and the naming of a healthcare proxy and/or a family contact person. The HCP also pointed out that in the local healthcare setting where PC resources are limited, the concept of including the team in commitments to care should be added.

Overall 5 prompts (2,6,7,11,12) showed both high face and content validity and were therefore considered to be valid in the local context in their current format. For 11 prompts (1,3,4,4a,4b,4c,5,8,9,10,13) there was lack of converging evidence of local validity.

1.4.2. Primary objective 2

The cross-cultural acceptability assessment in the pre-FGD survey revealed that 9 prompts (2,3,4c,6,7,8,10,11,12) were considered "acceptable as it is" by >75% of participants. Three prompts (4b,9,10) were labelled as culturally inappropriate, notably by only one of the 17 participants. Analysis of the FGD data for item, semantic and content equivalence showed that at least 2 of the 3 local equivalence metrics were high for 4 prompts (6,7,10,12). When considered together, only 4 prompts (6,7,10,12) had high acceptability in at least 3 out of 4 acceptability metrics. The remaining

12 prompts (1,2,3,4,4a,4b,4c,5,8,9,11,13) lacked converging evidence for cross-cultural acceptability in the local context.

CHAPTER SIX RESULTS: Emerging themes and subthemes of serious illness conversation guide (oSICG) acceptability from HCP Focus Group discussions

Through inductive thematic analysis 3 themes and 8 sub-themes emerged from the HCP FG discussion data as factors influencing the conduct of SIC in the South African context (Table 6.1).

Table 6.1: Emerging themes, and subthemes

Themes	Sub-themes
Patient factors	Poor individual Illness understanding
	Low English language literacy
HCP factors	Avoidance of prognostic sharing
	Misplaced emphasis on putting plans in place and making decisions
Context of care	Historical power imbalances in the healthcare system
	Health system resource limitations
	Local belief systems and culture
	Role of family

1.1. Poor individual illness understanding

The theme of poor individual illness understanding amongst local patients, that is, not understanding their cancer diagnosis, stage, treatment modalities, treatment outcomes and disease trajectory, and its influence on the SIC process, was identified with high prevalence throughout the HCP focus group discussions.

> *HW11: And I do get patients who have been to hospital and they're coming to me, "I was at the hospital, I was sick, and I was operated on and I'm on this medication." And you ask, "What was the cause of your operation, what were you operated for?" The patient has no clue. The patient doesn't know what was wrong with [them], but [they were] operated on.*
>
> *HW04: And then sometimes they would say, "The doctor says that there's nothing more that they can do, but I don't understand that. I've got questions."*

1.1.1. Underlying causes of poor illness understanding

1.1.1.1. Local conceptualization of disease

HCP suggested that the poor understanding of general disease pathology in the local population, of which many have limited formal education, contributed to poor individual illness understanding. Many patients conceptualise illness and healing in terms of their cultural and spiritual belief systems, whereby disease can be attributed to malicious or supernatural causes and conversely, that even serious illnesses can be healed supernaturally.

> *HW15: So, although the doctor told her, "You have cancer," and she understands, "Okay, I have cancer," she has that hope, "I'll be cured." She don't know that it's actually an incurable sickness that she have. … Or maybe one of their friends or neighbours that came to [hospital X] early and then she was referred, and she was cured.*
>
> *HW15: They will say, …"No, God is going to heal me. He's got plans for me. I'm still young. I'm still active. So, I can't be dying now."*
>
> *HW15: …he said, "Now I know …why I'm sick. The ancestors are calling me. So, if I can accept the calling, then I will be healed." But, in a few weeks he was dead. They believe that it's a calling. It's not a cancer. So, as soon as they accept the calling, they'll be healed. …It stops the conversation, because he hopes that he'll be cured.*

1.1.1.2. Systemic barriers to HCP-patient communication

HCPs acknowledged the role that the limitations of the local health system play in poor illness understanding in patients. Due to systemic factors HCP often do not succeed in establishing good illness understanding in their patients. This could be due to limited consultation time, a language barrier, excessive workload, or lack of clinical knowledge or advanced communication skills. The public healthcare service also suffers from a lack of continuity, in that a patient might be seen by a different HCP at each visit. This inhibits the development of a trust relationship between HCP and patients.

> *HW09: They should know that it can be "not OK". And perhaps one needs to then step back and find another time. I don't know, it's difficult, we are so limited with our time with our patients. There is not often another time that we can use.*
>
> *HW05: …the building of trust. Definitely, this whole question for me, you can't just ask it out of the blue when it's your first visit to the doctor. And I don't know if that is practical in our state …health setup.*

There was evidence to suggest that some patients lacked illness understanding, because they did not feel comfortable asking HCP for more information or for clarification of things they did not understand. This mainly related to conversations they had had with HCP prior to the SIC about their diagnosis and disease status. There was a sense that patients felt intimidated by HCP, or by the healthcare encounter.

> *HW11: …So, I'm not blaming healthcare workers in saying nothing was explained. I don't think that happened. But I think because of the situation and the surroundings and… our people are scared of healthcare workers, are scared of hospitals, are scared of theatres, are scared of everything. And they are scared to ask questions.*
>
> *HW12: Because I had an Afrikaans patient, and they also, the doctor was speaking to him in English, until I came in. And then …I asked him [if he understood], I called the sister, shame, they were talking English, and his language is Afrikaans.*

1.1.2. Effect on SIC process

Lack of illness understanding has the potential to interrupt the flow and even prevent the continuation of the SIC at multiple points.

In prompt 1, the concept of "your illness" may not be clearly understood by local patients, especially when they have multiple comorbid diagnoses. The HCP suggested naming the patient's illness, for instance, *"I want to talk to you about your cancer."*

Many local patients would find it difficult to respond to prompt 2, where they are asked to relay their own understanding of their current illness situation, if they have poor illness understanding.

> *HW05: But we do find… It is a straightforward question, but this is the question where people would usually say, "Nobody has told me," or "I don't have any idea".*

If the patient's response to prompt 2 reveals significant gaps in knowledge, understanding or acceptance of their diagnosis, incurable disease status and shortened life-expectancy, the conversation cannot proceed to prompt 3 and a discussion of "what is likely to be ahead". In such cases the aim of the conversation effectively changes from exploring priorities and preferences, to that of breaking bad news. Information needs to be shared, and time and support given for the patient to process and accept it.

The HCP felt that local patients would be unfamiliar with the concept of informational preference, as introduced in prompt 3, which asks them to decide how much and what information they want from the HCP about their likely disease trajectory. Having a baseline of poor illness understanding would compound this. It would be difficult knowing how much there is to know.

> *HW06: And if they don't know how much there is to tell, it's quite a strange way of asking it. Because are you [going to] tell me two facts, …or are there ten things coming I didn't know*

> *about? And to "how much of that do I want to know?", "I don't know, how much can I handle?"*

Poor illness understanding would influence their acceptance and response to the HCP sharing information about poor prognosis, as in prompts 4 to 4c. Participants related experiences were patients rejected the sharing of a poor prognosis or "what might be ahead," by insisting that the HCP cannot know the future, that a miracle could still happen, that divine healing is possible, that a curse could be lifted, or that a positive attitude could improve their functional level.

> *HW16: …in religious people, they believe in speaking positive not negative. So, they will say… "No, I'm not going to speak about this now. I know what God has in store for me. God has good plans for me, not to die now."*

Similarly, poor understanding of their likely disease trajectory and the benefits and burdens of treatment interventions would make it very difficult to move forward with prompts 5 to 9 of the SICG, in which priorities and preferences are explored. Complex questions about critical abilities and trade-offs could lead to confusion and distress, especially for patients who have incorrect information or misconceptions about the potential benefits and toxicities of palliative treatments.

> *HW02: …some people might get a bit of a surprise and think, when it comes out of the blue, "Why are you suddenly asking about abilities I can't live without. What are you going to take away from me? What are you about to do to me…?"*

> *HW17: …most people, …if they hear they've got cancer, they know, "I'm going to die". So, what is the use of doing the surgery or whatever.*

Many patients might not be used to being asked how aggressively they want to be treated. They might not be comfortable with the idea of the HCP not "doing everything that can be done." Conversely it would be difficult for patients to define care preferences in terms of support and intervention if they are not aware of what is available or possible.

> *HW06: I think I'm battling with that… I'm not sure if my patients can cope with this kind of question. Maybe I'm being too authoritarian or too dismissive. But in a population that is, sort of, trusting the doctor, it's quite a difficult question to ask them.*

> *HW04: But again, here, there's also a cultural thing. So, people that are educated, they would be able to voice their needs very clearly. But people that are [less educated], they would not have an idea of what they could ask for.*

1.1.3. Response of HCP to poor illness understanding

Throughout the FGDs there was evidence that healthcare professionals (HCP) believe it is in the patient's interest to have a better understanding of their illness and prognosis. They actively work to improve illness and prognostic understanding in their patients through the following techniques: i) asking them to relay their individual illness understanding in their own words; ii) probing and exploring patients' proffered perceptions further; iii) support for open-ended questions; iv) offering information and explanation where gaps in patients' knowledge or understanding are identified; and v) encouraging questions.

> *HW04: "What would you like to know? Is there something specific that you would like to ask a question about? Is there something specific that you are worried about or that you don't understand?".*

The HCP expressed strong rejection of any language that could create false hope in the local patient population. This mainly involved language that could lead a patient, who might not have accepted or understood the serious nature of their illness, to think that they could still be cured, including the recurring motive of "I wish/hope…, but I am worried that…" They identified this risk when language seemed to be speculative, unrealistic, euphemistic, or contradictory.

> *HW01: But we know they're not going to get better ["I hope that this is not the case, but I'm worried that… things are likely to get more difficult"]. So, for me, we should say …that. We know they're not going to… as things are now, it's not looking like they are going to get better'.*
>
> *HW16: Oh dear! He was just "living long" and now he's going to "get sick quickly"! But also, doesn't that put fear in the patient, and also a distrust in the doctor, if the doctor can't tell me?*

1.2. Low English language literacy.

1.2.1. Complex or abstract language use

HCP rejected multiple examples of words or phrases that they deemed too complex or abstract to be clearly understood by the patients they care for. Local patients are mostly non-English first-language speakers and tend to interpret these phrases more literally. These language elements were highlighted as potential sources of misunderstanding, which could negatively impact the flow and outcome of the SIC.

- “what is ahead with your illness”
- “thinking in advance” misinterpreted to mean planning ahead
- “where things are with your illness”
- “as strong as you will feel”
- “things are likely to get more difficult”
- “What gives you strength”
- “critical abilities… can’t imagine living without them”
- “for the possibility of gaining more time”

> *HW12: They won’t understand. I also don’t understand “critical to your life”.*

> *HW13: I don’t understand that question. “What abilities?“ The word “abilities”. “What abilities are so critical?” …I mean, if I must ask that to one of our patients, I don’t think they will understand what I’m trying to ask.*

The term “goals” was felt to be ambiguous and could be interpreted as putting unrealistic pressure on the patient to achieve something.

> *HW08: …because these are now goals that you’re setting. And if you don't get to the goal, there is an element, perhaps, of failure.*

The tendency of HCP to give patients examples of goals indicates the abstract nature of the concept, or that the term is too open to interpretation.

> *HW18: I mean, depending on who’s listening… because people will hear… and depending on what language they speak, they’ll hear the word “goals”, even if you’re saying it in English, they’ll hear it in different ways.*

1.2.2. Incongruent language

Similar to abstract and complex language, incongruencies in language can also lead to confusion and disruption in the flow and outcome of the SIC. Two examples of incongruencies were identified during the focus group discussions.

Firstly the phrase “where things are” in prompt 4 is incongruent with prompt 1, prompt 3 and prompts 4a-c where the discussion is about what could be expected in the future, and not about the current situation, as in prompt 2. This is a major error in the logical flow of the conversation. In a setting of low health literacy and illness understanding, such an incongruency, along with the abstract nature of the phrase could leave patients confused. The permission obtained in prompt 3 relates to information about the future course of the disease. Prompt 4 then changes direction and leads the patient to expect an explanation of their diagnosis, stage, and current disease status.

However, what follows in prompts 4a-c again relates to the future state. This incongruence could therefore be experienced as unexpected, jarring, and harsh, because it does not align with the offer made in prompt 4.

Prompt 1: "what is ahead with your illness…"
Prompt 2: "What is your understanding now of where you are with your illness?"
Prompt 3: "how much information about what is likely to be ahead"
Prompt 4 "my understanding of where things are with your illness..."
Prompts 4a-c: 3 versions of what is likely to be ahead

Secondly the phrase in prompt 5 and prompt 6, "your health" differs from the same concept addressed in prompts Q1-4a and prompt 7, where the discussion is about "your illness". In a non-English first language setting maintaining the same term for the same concept can reduce the risk of misunderstanding

Prompt 1-4a: …with your illness
Prompt 5: if your health situation worsens
Prompt 6: the future with your health
Prompt 7: the future with your illness

1.3. HCP avoidance of prognostic sharing in terms of time

Many HCP displayed a reluctance to discuss poor prognosis with patients. They highlighted that giving a time-based estimate of prognosis was the least preferred of the 3 options given in the SICG (uncertainty (4a), time-based (4b), functional deterioration(4c)).

> *HW09: Yeah, I definitely would go with the uncertainty rather than the timeline. In the second [option], where "time may be as short as" …fill in the blank. I don't… I'm not comfortable filling in the blank. And I think, only if they have asked, when you said, "What information do you want?" and they said, "I want to know how much time I've got left." I think, then it's appropriate to bring in a timeline. But otherwise, just not even to go there.*

Reasons given for not preferring a time-based prognosis included: i) the belief that no person, in this case the HCP, can know the exact time of death of another person, or know what will happen in the future, and that any such predictions are therefore interpreted as baseless, and even presumptuous, "*Doctor can't predict [time to death]. He's not God*"; ii) a fear of taking away hope ; iii) lack of certainty about giving the correct time-based prognosis; and iv) the fear that if their estimate was proven wrong, they would lose the trust of the patient and family.

> *HW14: Usually the patients feel that they actually, most of the time, don't want a timeframe connected to their condition. That also puts away some of their hope. And it's always just, I*

> *think, from a palliative care perspective, it’s not a good thing to take away the hope that the patient has, but to be [as] realistic as possible.*

> *HW11: Because I think we all know that even if you give a specific time, some people live longer. And it... if it happens like that, people always feel that, “You know what, doctors like to write people off and say I have 2 days to live, or I have 72 hours to live”. I specifically wouldn't give a specific time. I would end it at saying, “I can’t predict, everyone is different, but I'm hoping, to my experience and according to medical history, this is what normally happens.”.*

1.4. Misplaced emphasis on putting plans in place and making decisions

Many HCP felt less uncomfortable talking about an uncertain prognosis (prompt 4a) or limited time (prompt 4b) when it could be related to putting a plan in place and making decisions for supportive and medical care as the primary outcome of the SIC, versus plans for exploration of priorities and preferences. They were more comfortable sharing a poor prognosis if it could be framed as the motivation for putting a plan in place in the present, that would help patients manage future challenges. It was further supported by the suggestion to add the concept of preparing for eventualities to prompts 4b and 4c, as it appears in prompt 4a.

> *HW10: Or I would just say, “While we have time now to discuss this, let’s get a plan of action before things get more difficult or before we don’t have time to talk”. Not meaning, I’m going to do this because you only have a few weeks left to live, but "while we have time now, and we are relaxed, let’s talk about it and come up with a plan of action”.*

1.5. Historical power imbalances in the healthcare system

1.5.1. Effect on SIC process

There were references made to the power imbalance that exists in the healthcare domain between HCP and patients, largely due to the traditionally hierarchical character of the healthcare system in South Africa. These imbalances influence the way that patients exercise their autonomy in the healthcare space, in that it seems to inhibit shared decision-making and free expression of their thoughts and preferences for care and communication.

> *HW09: That question, “Is this OK?” It can be quite difficult in our setting, because …the patient is always going to say, “Yes, it's OK.” They’re never gonna say to me, “No, no, actually, I'm not ready for this conversation”. … …to me, the answer to that is always going to be, “Yes, doctor. Whatever you say, doctor.”*

> *HW06: I think also, my experience is that we very seldom ask the patient what they want. And now suddenly we're asking them, "what do they want". And it's like, "Why are you asking me this, you're just gonna tell me". There's a difference there. It's sort of, "You tell me. The whole way along in my illness people have told me what's going to happen, and now suddenly you are giving me the power?"*

1.5.2. Response of HCP to systemic healthcare power imbalances

There were many examples of HCP promoting opportunities that allow the patient to determine the direction and depth of the conversation, giving them a sense of control over the conversation. This shows that the HCP do not wish to be the controlling power in the conversation, but desire that the patient also has some control.

They advocated for regularly checking in whether the patient is willing and ready to talk about all the aspects included in the serious illness conversation (SIC); whether it is the appropriate time; whether they want someone to join them or speak on their behalf. They recommend that HCP should accept when the patient declines to have the conversation, and check for acceptance of the recommendation made in prompt 12.

> *HW02: But I think, I think you could still give the option to the patient here, "You know, we don't have to discuss it now if you don't feel comfortable. We can always discuss it at another meeting."*

> *HW04: Many patients will say, "No, speak to my family about this, I don't want to talk about this, I don't want too much information, I just want to be comfortable and not be in pain". …And then you also know, that's what they need.*

Exploring informational preferences, as in prompt 3, is a direct example of giving control over the conversation to the patient. HCP also suggested that more should be explored than just the amount i.e. "how much", but also the type of information. The patient should also be allowed to choose or request a type of prognostic sharing and the HCP should be sensitive to the individual situation before selecting a type.

> *HW14: No, we definitely need to let the patient be the guide in this [sharing prognosis in terms of uncertainty, time, or deterioration]. Yes, we cannot make a decision on behalf of the patient.*

Reflecting the patient's expressed goals and priorities back to them in prompt 11 is supported as a form of active listening (box152, p60), and language that appears to push the HCP's agenda is rejected.

> *HW04: Yeah, I like that. The reflection and highlighting what is important to them, and it is also checking in. Were you right in your interpretation.*
>
> *HW11: I will put it in the form of a question. I wouldn't say, "I want to share with you". I would ask, "if I may share with you my understanding". For that person who is not ready, who wouldn't want to know by now.*

Conversely there was a strong emphasis on rejecting any language that could potentially reduce trust in the HCP or otherwise damage the patient-HCP relationship in the local context. Examples included language that could be interpreted as an indication of professional incompetence in the HCP, insincerity, presumptuousness, or disrespect.

> *HW18: To say, "to walk along with you through this". I mean, when you are actually not. Even though you are in a professional relationship with the client, but because of the circumstances, you know that there are some moments where you will not be available. So, it will be false and fake to say I would do that.*
>
> *HW02: I was going to say, there are two things. I don't really like the, "I wish we were not in this situation", because we aren't in the situation. It's the patient who's in the situation.*

1.6. Health system resource limitations

Participants acknowledged that the concepts dealt with in the SICG could not be disconnected from the resource limitations of the local healthcare systems in which HCP work.

In prompt 1, the feasibility of offering a patient "the care you want" in the local healthcare setting was debated, with some HCP insisting that it was not possible (n18), while others, mostly those working in established PC teams, saw it as achievable.

> *HW01: Yes, I think it's an over investment, to say that [provide you with the care you want]. You can't be sure.*
>
> *HW02: I don't think the patient always have the… I mean, you can't always get the care you want. It sounds very pie in the sky, saying "the care you want".*

In prompt 9 many participants expressed their discomfort with asking a patient, "How much are you willing to go through?" In the lower resource setting, participants felt it would be pointless for patients to consider treatment options that are not even on offer. Difficult decisions about trade-offs are often linked to therapies with limited benefit or high toxicity. The HCP argued that therapies with limited benefit would in fact never be offered in a low resource setting. Conversely in the higher resource setting, HCP were worried that patients could demand futile interventions just because it would be funded.

> *HW02: …in the government sector...sometimes there aren't that many treatments. So, it's saying, "How much are you willing to go through?" Like, there actually might not be that many treatment options. Sometimes the patients don't have the luxury of saying, "I want to try one line of chemo and then stop".*

Many participants stressed that in the local setting, realistic commitment to care, as expressed in prompt 13, should always be linked to a team, and not fall on an individual. Including alternative health practitioners in the team structure was also felt to be contextually relevant.

> *HW02: The one thing with the government that is important maybe, is to make sure the patients are aware that we are in the same team as [Hospice NGO] and [Cancer NGO]. And they are able to see them at home. So, although they might not be able to get seen by their doctors at [Oncology hospital], if they get seen by [Hospice nurse] at home, she's also part of our team. So, that's still a commitment from the health team.*

1.7. Local belief systems and culture

There was wide acknowledgement of spirituality as one of the dimensions of patients' being and expressed support for prompt 7 and other phrases, as meaningful elements in the SICG that could be a lead-in to explore spiritual aspects of being, that are relevant to the local population.

> *HW17: I'm angry with myself, with my illness. I'm angry towards myself, to God, because why is it happening?*

Many participants referred to having a sense of achievement in their lives or imparting a legacy to those who come after them, as a source of strength for local patients.

> *HW15: You'll see those… patient say, "I lived my life. I did everything that I wanted to do, so it's…" That gives them strength.*

References were also made to the avoidance of discussions about death and end-of-life priorities and preferences due to the local African cultural belief systems, as well as some religious belief systems. Many HCP participants see these belief systems as an obstruction to the SIC.

> *HW12: I am speaking about my own experience, my people… …it's only few of them …that will know what is my wishes. But most of them, they don't. I think because we are not opened up [about] what will happen. So, what are my wishes if I'm no more, you see. So, we don't discuss about... we're avoiding. We don't want to talk about death and dying, honestly. I think it's because we're scared about it.* Is that it? *HW15: No. I think it's the way we grow up. We never hear from our families sitting talking about death.*

1.8. Role of family

One of the core tenets of PC is that care should extend to the patient's family, both before and after the patient's passing. Prompt 10 directly focusses on this when asking the patient how much their family knows about their priorities and wishes.

HCP recognize that family plays an important role in the local context and in communication about EOL care.

> *HW18: Yes [it is an important question], I think even more so because family networks are so much more… play such a bigger roll.*

They agree that the patient's illness journey has an impact on their families and the people close to them, including dependent children, as well as their work responsibilities.

> *HW18: But here, it is important to point the patient's gaze a bit outwards now. …so we are vague with "things", but we broaden the landscape at which those things can exist by saying, "you and the people around you." It may be better to say, "the people around you" rather than "family".*

Participants acknowledged that in the local setting caregiving for patients with advanced illness is often done in the home by family members or friends, and less often by paid professionals. This could be due to the lack of structured PC services, the fact that PC services are not covered by all medical aid benefits, lack of finances, Hospice services not covering rural or dangerous areas, and also the cultural expectation that it is the duty of the family to care for the dying patient.

> *HW12: …those grandchildren, they will look after her. And also when the children who is working, maybe their daughters, or what… Before she dies. At least, when she's at home that her grandchildren will also look after grandmother and…*

Family members may have to fulfil the role of proxy-decision makers, often without being prepared for it or knowing the patient's wishes, an aspect that HCP felt was not adequately addressed by the SICG.

> *HW16: We do that [ask the patient who will speak for them when they cannot]. We do it regular, yes. It's always not the person that stays in the house. Ja, it is sometimes someone out of the house. It's also always not the baby [youngest] or the first person [eldest] or the last, it's sometimes the middle person. A middle child. …the one girl was here with the sister. So when we were asking that question about her, and then she said, "No, you can talk to my cousin", but her sister sit next to her. And the sister is like, "And me?" And she said, "No, I don't want to give that trouble to you. I will give you something else to do".*

With reference to the conduct of the SICG, as it relates to family involvement, participants acknowledged that in the local setting, the family are often not fully informed of patient's disease status or prognosis and felt that it would be beneficial to include the family in the SIC from the start. Family members were more likely to ask about prognosis in terms of time than patients themselves. Other times they avoid SIC, due to fear of causing distress for themselves or the patient or due to cultural norms, as reported in Section 6.

> *HW11: I just feel that sometimes patients don't want to make their families anxious about their illnesses. Some people don't want the family to know that they're dying. They always want to give them that hope, and therefore it might not be easy for them to discuss pertinent things that are really important for the family, in case the patient dies.*

Conflict could arise when a family's dynamics or structure oppose or hinder the fulfilment of a patient's goals and priorities. On the other hand, patients' goals and priorities often revolve around family. This could be a positive thing, but it is vital that consideration is given to the impact of honouring the patient's goals and priorities, on the family.

> *HW02: Are they on board? Do they agree with your wishes? Because sometimes the family might want something different to what the patient wants.*

> *HW03: They are happy for her to stay in hospital and for her to be taken there. And she actually wants to go home to die. That often becomes a moment of tension. … That, "No, no, mom's fine, you're doing well. The hospital is looking after you nicely, Mom. They're caring for you". "But I wanna go home and die."*

Participants suggest that HCP should assess the patient's preferences for family involvement in the SIC process at a much earlier point than prompt 10. They should enquire early in the SIC process if the patient would like a family member to be present or whether the conversation should rather be conducted with a family member, instead of with the patient, based on individual family dynamics or culture.

> *HW04: Many patients will say, "No, speak to my family about this, I don't want to talk about this, I don't want too much information, I just want to be comfortable and not be in pain." And they'll take that stance. And then you also know that that's what they need.*

The HCP should ask the patient if the family needs more information and offer to help the patient share their goals and priorities with those close to them. If conflict arises around priorities and wishes or treatment decisions, the HCP should engage in family discussions and advocate on the patient's behalf.

> *HW14: Yes, in many instances, we pick up that the patient is fine with where they're at within their illness, but then it's difficult for family members to accept it. And that's why we,*

> *many times, arrange for family conferences or meetings, just to keep everybody on the same path, the same level.*

Even though there is lack of evidence that local families are engaging in pre-death discussions and decision-making, there is substantial evidence that families are actively involved in what happens after a patient's death. They are also more comfortable speaking about this, than about decisions around pre-death care. There is however acknowledgement that cultural ideas are changing with younger generations.

> *HW12: On that question, "What does your family know about priorities and wishes?" Most of our patients from Eastern Cape, like the [grandmothers] and the [grandfathers], will say, "My children knows [that] I want to be buried in Eastern Cape, I want to go back to Eastern Cape". Even when you speak to the family and they'll say, "Okay, my father said he wants to go back home", so when it came, if something happens, it must be done at home.*
>
> *HW12: So, that is how we grew up, you see. So in the olden days there was no open discussion about death and dying. So, the [older] people knows that one… It's their duty. So, we know that the eldest son or the eldest daughter will continue with the family, looking after the family, whatever. So, we're not talking about death and dying… [or] who's going to be taking care of the kids. It used not to be a worry. But now… because it's changed… People are more… we have money, because we are working, and then they'll be more on your money and then nobody looks after your kids. And then now, most of us, we are educated now, so there's a need for a will. There's a need for the open discussion about death and dying, you see.*

CHAPTER SEVEN DISCUSSION

This study explored the validity and cross-cultural acceptability of the Serious Illness Conversation Guide (oSICG), a communication tool that helps HCP convey information about poor prognosis to patients and explore their priorities and preferences for end-of-life care, in a South African oncology setting.

A synthesis of the quantitative findings of survey data and qualitative analysis of the FGD data, showed lack of evidence for the validity and cross-cultural acceptability for the majority (11 of 16) of the SICG prompts. Content validity was deemed to be lower than face validity and related to the perceived omission of questions and statements that would enhance illness understanding and patient autonomy and assist patients and families on a practical level to prepare themselves for what lies ahead. In addition, multiple aspects of family involvement in the SICG process and EOL care relevant to the local context were felt to be lacking. It was also felt that complex concepts, like 'accepting trade-offs for living longer' or reaching one's goals, needed to have been described in more detail for it to make sense to the local patient population. In the study by Shen et al. broader descriptions and examples of trade-offs were used in their survey on EOL preferences, for example, patients were asked, "Would you want to be kept alive if it required you being on a breathing machine and/or kidney dialysis?"(36) Even though these phrases provide more context for EOL decision-making, they are still quite restrictive when used in quantitative research, and not necessarily relevant to the SA healthcare setting.

The study identified the following local factors that contributed to the cross-cultural unacceptability of the SICG including poor individual illness understanding, low English language literacy, historical health system power imbalances, health system resource limitations, local cultural and spiritual belief systems and family roles. Results suggested that adaptations to the SICG should aim to mitigate these locally relevant barriers to the effectiveness of SICs.

1.1. Improving illness understanding

The study identified poor individual illness understanding amongst local patients as a frequent barrier to the effective conduct of a SIC. For the purposes of this study, the term illness understanding encompasses understanding of one's diagnosis, stage, and treatment as well as understanding of the curability and expected survival from the disease, or prognostic understanding. If a patient displays meaningful deficits in their knowledge, understanding or acceptance of their illness diagnosis, incurable disease status and shortened life-expectancy, the flow of the SIC has to be interrupted to address these gaps.

> *HW11: …when you say, “What is important to you”. You are now focusing on this patient. Maybe it's an opportunity for the patient to actually say, “You know what, I know that I have cancer. I can't remember what you told me about my illness.”*

The available data on prognostic understanding (PU) rates amongst advanced cancer patients with limited life-expectancy in South Africa, reported PU rates ranging from 6-70%.(36, 40) The measures used to quantify PU in these studies were however not directly comparable.(36, 40) The study by Yennurajalingam et al. reported on associations between poor PU and demographic factors, but did not evaluate underlying reasons for poor PU in the PC setting.(40) Our study identified differences in the cultural conceptualization of disease, belief in supernatural healing, limited education, and healthcare system factors preventing HCP from ensuring good individual illness understanding in patients, as potential causes for poor illness understanding in the local setting. Despite global PU rates, as reported by Yennurajalingam et al., were generally lower than those found in SA, low PU or illness understanding was not found to have a major influence in the cross-cultural adaptations of the SICG in Canada, the UK, or New Zealand.(29-31)

In order for the SICG to be more acceptable in the setting of poor illness understanding, the study results suggest that HCP should explore the patient’s understanding of the illness in question at the very start of the conversation, before discussing the future disease trajectory or priorities and preferences for care (prompt 1). Any misinformation, denial, gaps in understanding, and cultural or spiritual beliefs around the illness can then be identified and addressed in a patient-centred and culturally sensitive manner, before the SIC proceeds to introduce the concept of “what is ahead with your illness.”

This approach may have the added benefit of building the trust relationship between HCP and patients, because relaying their narrative of their healthcare journey puts them at ease.

> *HW14: …So, what we usually do is just ask them, what do they understand about their illness, and how do they experience the whole process up to the point where we’re then meeting up with them. It is like the people won’t feel comfortable at first just to start the [serious illness] conversation, but you need to get them to trust you and gain confidence in you.*

Another SICG adaptation that could enhance illness understanding in the local context is to ask the patient what type of information they want about their future disease course, and not just how much information.

> *HW09: Ask what information, replace how much with the word, what. “What information about what's likely to happen...” It's simpler too, and maybe a bit clearer.*

The study suggested that the risk of creating false hope was higher in patients with poor illness understanding, or who have not accepted their incurable disease status, as is commonly found in the SA setting. Athanas et al. described barriers to truth telling in a Tanzanian cohort of terminally ill cancer patients and oncology healthcare workers and warned that failure to tell the truth about poor prognosis robs patients of their autonomy and the opportunity to prepare for death.(63) The SICG should therefore be adapted to prevent this, by not using language that is contradicting, speculative, or euphemistic when describing patients' likely disease trajectory. This includes reducing the use of the recurring "I wish/hope…, but I am worried that…" motive in the oSICG.

In order to make discussions about "critical abilities" and trade-offs less threatening, efforts should be made to educate patients about the benefits and burdens of palliative disease directed treatment options, the concept of futile treatment, and the active role that they can take in the decision-making process, should they wish to.

> *HW14: No, they don't know the difference. Many of them don't know the difference between quality of life, or just the treatment options and the value of it in the long run. So that's why we [hospice staff] are there to explain to them. They can make an informed decision then. … And if they have expectations that they will get better or live a bit longer, like we've explained now, then we clarify that.*

1.2. Simplifying language use

The study identified that abstract, complex or incongruent English phrases and sentences in the SICG were unlikely to be understood, or could be misunderstood by the local population, for whom English is predominantly a second or third language. The resultant incomprehension and confusion amongst patients could lead to distress and disruption in the flow of the conversation. This would compound the difficulty of talking about emotive and serious matters like goals of care and dying.

> *HW13: …the words "ahead with your illness", it's almost like a euphemism… I'm trying to think of whether that is the right way of speaking to the patient or saying it in our setting. Yes, I don't know if they'd actually understand it that way.*

Our results indicate that the complex and abstract phrases and sentences in the English conversation guide should be simplified, so that it does not contain ambiguous or confusing language that could be a barrier to communication in the local population. This supports the findings of Stanford et al. that advocated for the simplification of APC tools and the incorporation of locally relevant examples into prompts.(35) Interestingly the simplification of language was also an important change made in the UK and Canadian adaptations of the SICG.(29, 30)

Furthermore the SICG should be translated into the predominant home languages of South Africans, namely isiXhosa, isiZulu, and Afrikaans, in order to be implemented in the care of a wider group of patients. Such translations should also aim to use unambiguous and concrete language, to ensure optimal understandability and acceptance.

1.3. Patient choice for type of prognostic sharing

The study revealed a strong reluctance amongst HCP for sharing prognosis in terms of time. The reasons given for this related to the spiritual beliefs that HCP cannot know the future, fear of causing the patient distress, and fear of being wrong, which they worry could lead to loss of trust from the patient and family. This sentiment echoes the internal conflict experienced by HCP around the positive and negative effects of truth-telling when sharing news of a poor prognosis, as reported by Silbert and Campbell et al.(41, 43) In the study by Ganca et al. doctors found poor prognostic sharing more difficult when the patient was young, well known to the HCP, had unrealistic or unknown expectations, belonged to a different culture than the HCP, and when they lacked communication training.(45) Graham et al. reports that African traditional healers completely avoid talking about impending death even at the deathbed, as the resultant distress could prevent a peaceful transition to the next life.(44) Our study expands the list of possible reasons for HCP avoiding prognostic sharing.

To manage these concerns, our study suggests that the SICG prompt that explores the patient's appetite for information about their future disease trajectory (prompt 3), should also ask if they would like to be given their prognosis in terms of time. This would give the patient some control over the type of information they receive.

> *HW18: Yes, there's a finality to giving a timeline. Even if you are boxing it, you know, days to weeks. And it's important. But maybe there should still be a door for [the patient] to ask for it before it's given.*

As highlighted by Ganca et al., training in PC, prognostication and communication skills can decrease the distress felt by HCP around prognostication and increase their prognostic confidence. The need for such training in the local context is supported by our results.

1.4. Preparing for death

HCP in the study placed significant emphasis on their responsibility to help the patient and family prepare for future challenges related to practical matters like symptom control, care needs, and getting their affairs in order. The perceived failure to prepare, is cited as one of the few situations when giving a time-based prognosis would be justified. They frequently made reference to phrases like "put things in place", "get a plan of action" and "hoping for the best but preparing for the worst." This is further evidenced by the suggestion from HCP to add the concept of preparing for future eventualities to prompts 4b and 4c, as it appears in prompt 4a. It is the experience of HCP that patients and families in the local setting, are more often than not unprepared for impending death, and invariably only access the right support when in a state of crisis. It is in an attempt to prevent this, that emphasis is placed on preparedness.

> *HW02: …if the patient and their family haven't quite grasped the fact that their loved one, or that the patient is deteriorating really quickly, and there actually do need to be plans that have to be put into place, because you know that the wheels are going to fall off. Then maybe… maybe it would be appropriate to bring in time.*

In his commentary on the value of truth-telling in the Jewish community, Silbert pointed out that the idea that being prepared for death, equates to a "good death," stood in conflict with Judaic doctrine, which emphasises the sanctity of life and reaches its followers to never give up hope of survival.(41) Shen et al. reported that most patients in their study had "planned for death by making funeral plans."(36) In our study HCP from traditional African cultural groups reported that people in their communities avoided talking about death and dying, but were much more comfortable discussion plans for burial.

> *HW12: On that question, "What does your family know about priorities and wishes?" Most of our patients from Eastern Cape, like the [grandmothers] and the [grandfathers], will say, "My children knows I want to be buried in Eastern Cape, I want to go back to Eastern Cape." Even when you speak to the family and they'll say, "Okay, my father said he wants to go back home."*

In terms of the local acceptability of the SICG, care should be applied to not allow this need amongst HCP, to prepare patients for what might lie ahead, to overshadow the intended aim of the SIC namely, to explore priorities and preferences now, that would enable decision-making in the future. The use of the phrases "your treatment plans" in prompt 11, and "how does this plan seem" in prompt 12, could contribute to the HCP's misperception that the SIC should result in the drafting of a care plan. Similarly, there is a misconception that the blank space in prompt 11, where the HCP's recommendation for further exploration and sharing of priorities and preferences should be added, refers to recommendations for a comprehensive care plan. Removing the phrases referring to plans, may help to reduce misunderstanding and the risk of extending the SIC beyond its intended scope.

1.5. Support for patient autonomy

The study results suggest that due to the intrenched power imbalances in the local healthcare system where most clinical conversations follow an instructive style, and decision-making is not truly shared, patients may be unfamiliar with being asked about their informational preferences, priorities and preferences, or to be an equal partner in decision-making. This perception is not supported by the results of a second study by Yennurajalingam et al., in which 88.1% of SA patients with advanced cancer preferred active or shared decision-making.(25) HCP in our study felt that patients might be caught off guard by prompt 3 asking about their informational preferences and might not know how to respond. They worried that the instructive style was so intrenched that any deviation from it may even be seen as indecisiveness or incompetence on the HCP's side. Or that it may be seen as false patient-centredness, because the patient might believe that the HCP is asking them what they want but will not act on their responses.

> *HW06: …my experience is that we very seldom ask the patient what they want. And now suddenly we're asking them, "what do they want". And it's like, "Why are you asking me this, you're just gonna tell me". There's a difference there. It's sort of, "You tell me. The whole way along in my illness people have told me what's going to happen, and now suddenly you are giving me the power?"*

The findings from Yennurajalingam et al. suggest that this interpretation by the HCP in our study may not be generalizable. They go on to advocate for the need to assess each patient's decisional control preferences on an individual basis.(25)

Our study findings further suggest that all opportunities that allow the patient to determine the direction and depth of the conversation should be maximised. This includes expanding the question at the end of prompt 1, to not only ask, "Is this OK?" but also to check whether it is a suitable time, or whether the patient wants others to join the conversation. This aligns with the findings of the Canadian SICG adaptation, where emphasis was placed on asking for permission.(29) In prompt 3, Any language that appears to push the HCP's agenda, or that could potentially reduce trust in the HCP or otherwise damage the patient-HCP relationship in the local context, should also be avoided.

> *HW11: I will put it in the form of a question. I wouldn't say, "I want to share with you". I would ask, "If I may share with you my understanding?"*

In both the studies by Stanford et al. and Bull et al. participants acknowledged the value of advance directives and healthcare proxy decision-makers.(35, 46) It was noted in the current study that the SICG did not contain any direct reference to the selection of a health-care proxy, the completion of an advance directive, or the filling of resuscitation orders, as a logical outflow of the SIC. This was seen as a deficiency or missed opportunity to strengthen patient autonomy and shared decision-making in the SA setting.

1.6. Aligning language with health system resource limitations

The study consistently showed the local unacceptability of phrases that appeared to disregard the realities of local health system resource limitations. South Africa has a dual healthcare system with complete separation between government funded public health services, that care for 85% of the population, and privately funded services, that are utilized by the 15% of the population that can afford medical aid. There is a dire lack of HCP in the public health service and budgetary constraints severely limit the scope of medication, healthcare technology, and supporting services on offer.(64) Phrases like “provide you with the care you want,” “how much are you willing to go through,” and “I will do everything I can to help you through this,” where considered to lack relevance in the local context, and could even been interpreted as insincerity, because levels of care or types of interventions are being discussed that cannot realistic be delivered to all. This can include specific treatment modalities, availability of HCP and services, or a certain quality of care.

> *HW02: …in the government sector…sometimes there aren’t that many treatments. So, it’s saying, “How much are you willing to go through?” Like, there actually might not be that many treatment options.*

Such phrases should be adapted to align better with the limited resource availability in the local public health setting where ethe majority of SA citizens are cared for, especially where patients are expected to make value judgements around quality of life and life-prolonging palliative treatment interventions.

1.7. Respecting local cultural and belief systems

The study showed that spirituality and belief systems are important to the local population and that it finds expression both in religious activities and the desire to have lived a life of meaning, or to leave a lasting legacy. The exact nature of such a legacy, whether it relates to intangible things like final words or lived values and principles, or to more concrete things like possessions, was not elucidated by the study results.

> *HW18: …it’s getting a sense of legacy and getting an understanding of where the patient’s conceptualisation of legacy is. … What needs to be managed in that respect, what the legacy issues are that are important that may be blind spots to family…*

Local belief systems, whether based on cultural tradition or religion, clearly influenced the way people communication about death and dying in this study. This aligns with the findings of Silbert, Campbell et al., Graham et al., Stanford et al., and Ganca et al.(35, 41, 43-45) Many participants from a traditional African background highlighted the avoidance of discussions about imminent death within families of their cultural group. Clear reasons for this avoidance were not apparent from the study results, but it was echoed in the interpretation of phrases referring to what was ahead, as foreboding or threatening, and therefore culturally unacceptable.

Some adherents to traditional African belief systems resisted talking about poor prognosis, because they believe their illness is caused by a curse or ancestral calling and could consequently be cured by a traditional healer or herbalist.

> *HW15: Like other patient who say …they give food poison in the food, that's why the doctor saw that it is cancer. But he knows that they poisoned him. …So, it's difficult to think ahead. Because you know that, after hospital, he will go to …this [traditional healer] and he will treat [him]. So, it's difficult to have that conversation about thinking ahead, about advanced care, because he had that hope, I'm going to go and I'm going to get help. I'm going to be cured as soon as I get out of hospital.*

In parallel to this, people with strong religious belief systems, in this case Christianity, resisted discussion of possible future deterioration in health and death, based on the beliefs that only God can know the future, and that miracle cures are possible. In the SA context it is important to note that these belief systems often coexist, that is Christianity and African Traditional Religion.(65)

Some participants interpreted this behaviour as denial or lack of readiness for a SIC. Their suggested approach in these cases was to break the SIC down into parts and find out from the patient which parts they would be willing to talk about. There is however always a risk that there will not be an opportunity to continue the discussion in the future.

> *HW06: They don't want to face the reality of what's happening. And it's a form of denial. They're obviously not denying the illness, but they're denying what could happen. And it's probably more distressing for them to force a conversation, than to respect their wishes and discuss what they want to discuss today.*

1.8. Incorporating family

The study indicated that family, including unrelated people that are important to the patient, often play an important role in EOL care and communication about EOL care, but that patient preferences around this shows individual variance in the local context. In the study this ranged from withholding information about a diagnosis or not wanting to share priorities and preferences with the family, to preferring that the SIC be conducted with the family instead of with the patient. At the start of the conversation the HCP should therefore firstly determine the patient's preference for sharing information about their diagnosis and prognosis with family, and secondly, for having family involved in the SIC process. This addition would make the SICG more acceptable in the local context.

> *HW10: "What did you tell your family? Did you tell them the truth? Did you try and spare them and not say all the detail? Are they fully informed or are you trying to keep things from*

> *them?" Because you don't want to fall into the trap of saying something in front of a family member and then they actually don't even know, but you think they know.*

Due to resource limitations in the healthcare system and because of local cultural preferences and large family networks, family members often act as caregivers for patients with serious illness.

They are sometimes called upon to act as proxy-decision makers when patients are not able to think or speak for themselves.

> *HW16: So when we were asking that question about her, and then she said, "No, you can talk to my cousin", but her sister sit next to her. And the sister is like, "And me?" And she said, "No, I don't want to give that trouble to you. I will give you something else to do".*

The patient's expressed priorities and preferences may also directly impact the lives of these family members in positive or negative ways, and conflict can arise when these do not align. The study showed that it is therefore important in the local context to not just enquire about the patient's preferences for sharing their priorities and preferences with those closest to them, as in prompt 10, but to be available to facilitate discussion with the family around EOL priorities and preferences, if needed.

> *HW06: I think that that would follow on, "Is there anything you want your family to know about your wishes?" and then, "Can I help you? Can I call them in? Can I be present with you? Would you like me to help you?"*

In the New Zealand adaptation of the SICG the need for greater support of the extended family and community group was seen as a priority.(31) In our study the approach to family involvement in the SIC process and EOL care had a somewhat different nuance, more in keeping with the findings of the Canadian adaptation, namely a bigger focus on providing information and facilitating family discussions around priorities and preferences.(29)

1.9. Study limitations and strengths

The focus group discussion prompts, and acceptability survey tool were designed specifically for this study by the investigating team and were not validated independently. This is however an exploratory study that does not compare results between groups and results should be interpreted with this in mind.

The focus group discussions were facilitated by the primary researcher, an oncologist with advanced PC training. An independent and trained facilitator was not used due to the resource and time constraints imposed by the COVID pandemic. Even though the transcripts were reviewed by the research supervisor and primary researcher for outliers, they were not member checked. These factors could introduce bias in terms of the importance that the primary researcher placed on certain concepts during the FGDs.

The fact that this study was conducted in only 2 academic oncology units in a single province of South Africa limits the generalizability of the findings to the rest of SA, and to the greater SSA.

The fact that the study only included HCP and not patients, gives a one-sided view of the acceptability and validity of the SICG. HCP were allowed to relay their perceptions on how patients would experience and respond to the SICG. The views of patients are therefore not directly captured but represented by a surrogate. The adequate sample size and inclusion of participants from different language groups, ethnic groups, and healthcare professions (doctors, nurses, social workers, counsellors), however serve to mitigate the risk of selection and sampling bias on the results.

At the time of designing this research study, the latest version of the SICG was version 7, dated 18 April 2017. The SICG has been updated a number of times since its original publication, based on iterative community-engagement, with the latest version dating from May 2023 (https://www.ariadnelabs.org/resources/downloads/serious-illness-conversation-guide/). The findings of the current study can only be applied to the 2017 version of the SICG, and not to subsequent versions.

CHAPTER EIGHT CONCLUSION AND RECOMMENDATIONS

1.1. Conclusions

This study indicates that the original SICG (Ariadne Labs, version 7, 2017), is not valid or cross-culturally acceptable in a South African oncology care setting. Despite the multi-cultural composition of the South African population, many of the EOL concepts and constructs addressed in the SICG were found to be familiar and relevant in the local population. In order to expand the implementation of serious illness conversations in the care of South African patients, significant adaptations to the SICG are needed. Local factors that drive the need for these adaptations are poor illness understanding, the use of complex and incongruent language, health system limitations, and differences in local spiritual and cultural belief systems and family interactions. Here we recommend a number of specific adaptations to the SICG that aim to improve the local acceptability and validity of this communication tool.

Communication in the EOL phase plays a vital role in ensuring goal concordant care and needs to be tailored to the local cultural context. The findings from this study can inform local communication teaching and training practices for HCP caring for patient with serious illnesses. It is believed that this will lead to wider uptake and implementation of SICs in care, which will in turn strengthen the integration of palliative care in South Africa as well as support the patient centred principle of having the patient participate actively in their own care planning as a respected and autonomous individual.

1.2. Recommendations

The findings from the current study should be used to inform the design of a cross-culturally adapted version of the SICG for use in SA. This adapted tool should be translated into local languages and undergo validation testing with local patients. The resultant findings could then be used to inform the creation of a cross-culturally acceptable SIC guide for South Africa.

Further quantitative and qualitative research should be done to compare the acceptability of the latest updated version of the SICG (May 2023) with the findings of this study, using the emerging themes from the current study to guide deductive analysis (https://www.ariadnelabs.org/resources/downloads/serious-illness-conversation-guide/).

Further research is also needed to determine the EOL priorities and preferences of SA cancer patients. The findings from the current study could inform the design of locally relevant data collection tools for such studies.

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APPENDIX A

Table 1: Individual SICG prompts (Ariadne Labs, version 7, 2017) as used in FG discussions

NR	**PROMPT**
1	"I'd like to **talk** about **what is ahead with your illness** and do some **thinking in advance** about **what is important to you** so that **I can make sure** we **provide you with the care you want** — **is this okay**?"
2	"What is **your understanding now** of **where you are with your illness**?"
3	"How much **information about what is likely to be ahead with your illness** would you like from me?"
4	**"I want to share with you my understanding of where things are with your illness..."**
4a	Uncertainty: "It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I'm worried that you could get sick quickly, and I think it is important to prepare for that possibility."
	OR
4b	Time: "I wish we were not in this situation, but I am worried that time may be as short as ___ (express as a range, e.g. days to weeks, weeks to months, months to a year)."
	OR
4c	Function: "I hope that this is not the case, but I'm worried that this may be as strong as you will feel, and things are likely to get more difficult."
5	**"What are your most important goals if your health situation worsens?"**
6	**"What are your biggest fears and worries about the future with your health?"**
7	**"What gives you strength as you think about the future with your illness?"**
8	**"What abilities are so critical to your life that you can't imagine living without them?"**
9	**"If you become sicker, how much are you willing to go through for the possibility of gaining more time?"**
10	**"How much does your family know about your priorities and wishes?"**
11	**"I've heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we ___. This will help us make sure that your treatment plans reflect what's important to you."**
12	**"How does this plan seem to you?"**
13	**"I will do everything I can to help you through this."**

Table 2: Prompts used by study team in HCP FG discussions to explore validity and cross-cultural acceptability

Domain tested	Prompts
Meaning	What do we mean? / What does it mean? / What is the meaning of?
	What are we saying? / What are we trying to tell them? / What is it conveying?
	What are we asking? / What is the question asking?
	What is the definition of "…"?
How elicited information will be used to direct care	How will the information affect your behaviour?
	Why are we asking/ saying this?
	What information are you trying to elicit?
Cross-cultural acceptability of prompt	Would that make sense to people?
	Would you/ do you use this phrase in your practice?
	Does it make you uncomfortable? / Would it make people uncomfortable?
	How do you feel about it? / Do you like it? / Are you happy with it?
	Should this prompt be removed or kept in the SICG?
	Does it sit well with you?
Suggested acceptable language	How would you say/ ask this differently? / Is there a different way of saying this?
	Is there a different way to convey the concept?
	Single word substitutions
Acceptability of question order	Should this prompt be placed earlier or later in the guide?
Need for additional questions	Should an additional question be added here?

Table 3: Healthcare practitioner demographic and occupational data variables

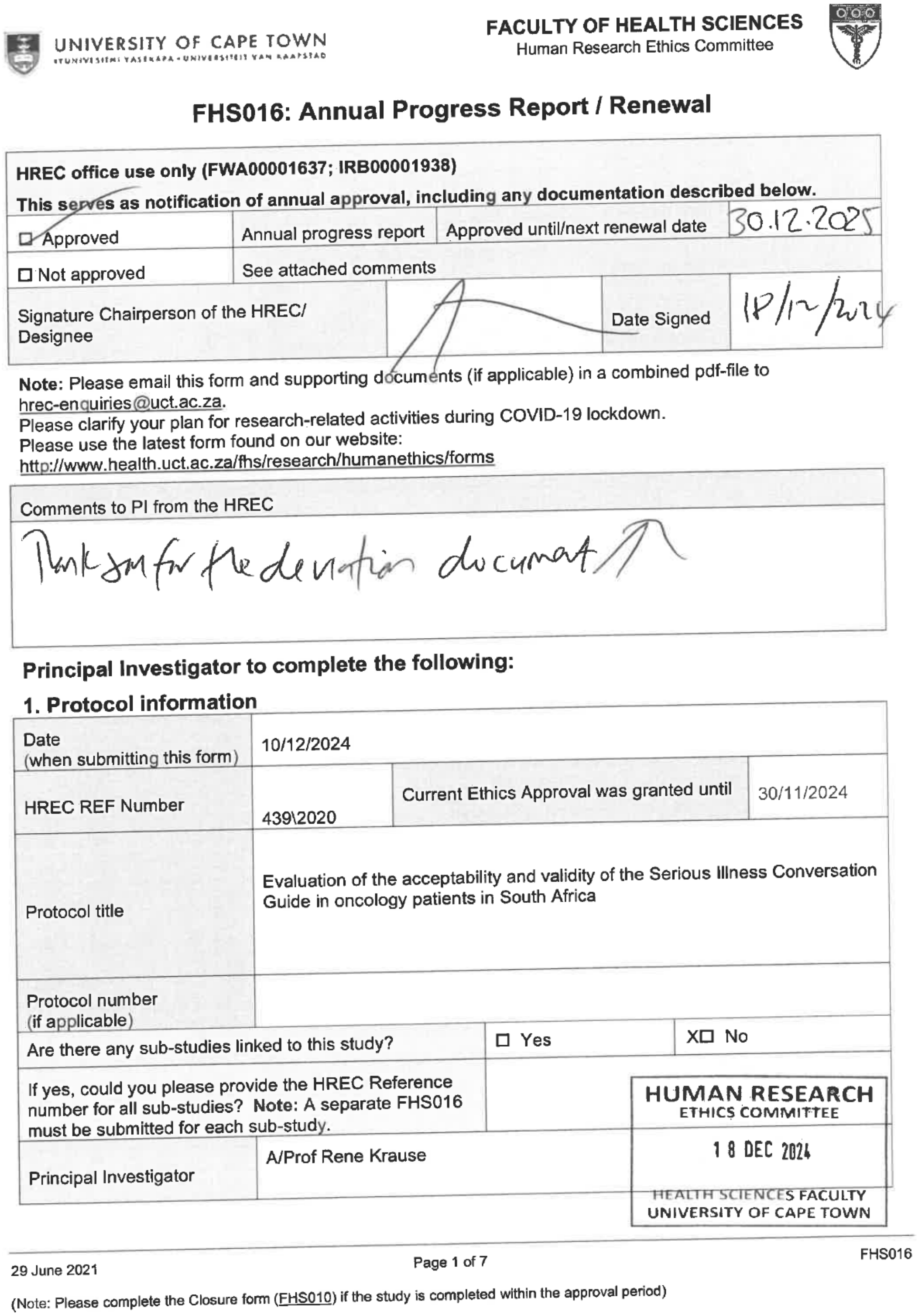
number	Variable name	Description	Values
1.	Age	Age at time of interview in complete years	Continuous number, Range 18-105
2.	Gender	Sexual identification	Male, Female, Other

3.	First language	Primary language spoken at home	Afrikaans, Xhosa, English, Other
4.	Ethnicity	Self-declared identification with one of the racial groups defined by STATSSA South Africa	White, Coloured, Black, Asian
5.	Profession	Discipline of healthcare in which they practice	Doctor, Nurse, Clinical counsellor, Social worker
6.	Practice setting	Site of primary healthcare service provision	Hospital, State health centre or clinic, Hospice (with or without home visits), General or specialist private practice (Consulting rooms with or without home visits), Home care/ Home visits only (including care homes), Private Nurse Practitioner PHC Clinic
7.	Life-limiting diagnoses managed	Types of life-limiting diagnoses managed in practice setting	Cancer, End-stage organ failure, People with multiple chronic illnesses or frailty, Chronic infectious diseases (HIV, DR-TB), Dementia, Degenerative neurological conditions (e.g., Multiple Sclerosis, AML)
8.	Number of years in clinical practice		Continuous number, Range 0-65
9.	Cross-cultural clinical case load	Proportion of clinical case load where a cultural difference exists between the HCP and the patient	Less than a third (<33%), 1 to 2 thirds (33-66%), More than 2 thirds (>66%)
10.	Prior use of oSICG	Has the HCP used the oSICG tool before	Yes, No
11.	Frequency of use per month	Number of times the HCP uses the oSICG per month	1, 2-4, >4

12.	Reasons for not using oSICG in past (more than 1 response allowed)	If responded No to Q9, give reasons for not using oSICG before.	I was not aware of the SICG before now, I think the SICG is too time-consuming, I think the questions in the SICG will not be acceptable to my patients, I prefer to use a different advance care planning conversation guide, I have the serious conversation but not using the guide. I may use the guide now that I am more aware of it

APPENDIX B

HREC and site approvals



UNIVERSITY OF CAPE TOWN
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938)			
This serves as notification of annual approval, including any documentation described below.			
☑ Approved	Annual progress report	Approved until/next renewal date	30.12.2025
☐ Not approved	See attached comments		
Signature Chairperson of the HREC/ Designee		Date Signed	18/12/2024

Note: Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za.
Please clarify your plan for research-related activities during COVID-19 lockdown.
Please use the latest form found on our website:
http://www.health.uct.ac.za/fhs/research/humanethics/forms

Comments to PI from the HREC
Thank you for the deviation document

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	10/12/2024		
HREC REF Number	439\2020	Current Ethics Approval was granted until	30/11/2024
Protocol title	Evaluation of the acceptability and validity of the Serious Illness Conversation Guide in oncology patients in South Africa		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?	☐ Yes	☒ No	
If yes, could you please provide the HREC Reference number for all sub-studies? **Note:** A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	A/Prof Rene Krause		

HUMAN RESEARCH
ETHICS COMMITTEE
18 DEC 2024
HEALTH SCIENCES FACULTY
UNIVERSITY OF CAPE TOWN

29 June 2021 Page 1 of 7 FHS016

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

Western Cape
Government
Health

TYGERBERG HOSPITAL
REFERENCE:
Research Projects
ENQUIRIES: **Dr GG Marinus**
TELEPHONE:**021 938 5752**

Ethics Reference: HREC REF: 439/2020

TITLE: **EVALUATION OF THE ACCEPTABILITY AND VALIDITY OF THE SERIOUS ILLNESS CONVERSATION GUIDE IN ONCOLOGY PATIENTS IN SOUTH AFRICA – M.PHIL. CANDIDATE – DR HENRIETTE BURGER]**

Dear Dr Krause

PERMISSION TO CONDUCT YOUR RESEARCH AT TYGERBERG HOSPITAL.

1. In accordance with the Provincial Research Policy and Tygerberg Hospital Notice No 40/2009, permission is hereby granted for you to conduct the above-mentioned research here at Tygerberg Hospital.

2. Researchers, in accessing Provincial health facilities, are expressing consent to provide the Department with an electronic copy of the final feedback within six months of completion of research. This can be submitted to the Provincial Research Co-Ordinator (Health.Research@westerncape.gov.za).

Dr. G.G. Marinus
MBChB,MPA,
DHM
MP0370665
Manager:Medical Services

DR GG MARINUS
MANAGER: MEDICAL SERVICES

Date: 10/12/2020

Administration Building, Francie van Zilj Avenue, Parow, 7500
tel: +27 21 938-6267 fax: +27 21 938-4890

Private Bag X3, Tygerberg, 7505
www.capegateway.go.v.za

Ethics Reference: HREC REF: 439/2020

TITLE: **EVALUATION OF THE ACCEPTABILITY AND VALIDITY OF THE SERIOUS ILLNESS CONVERSATION GUIDE IN ONCOLOGY PATIENTS IN SOUTH AFRICA – M.PHIL. CANDIDATE – DR HENRIETTE BURGER]**

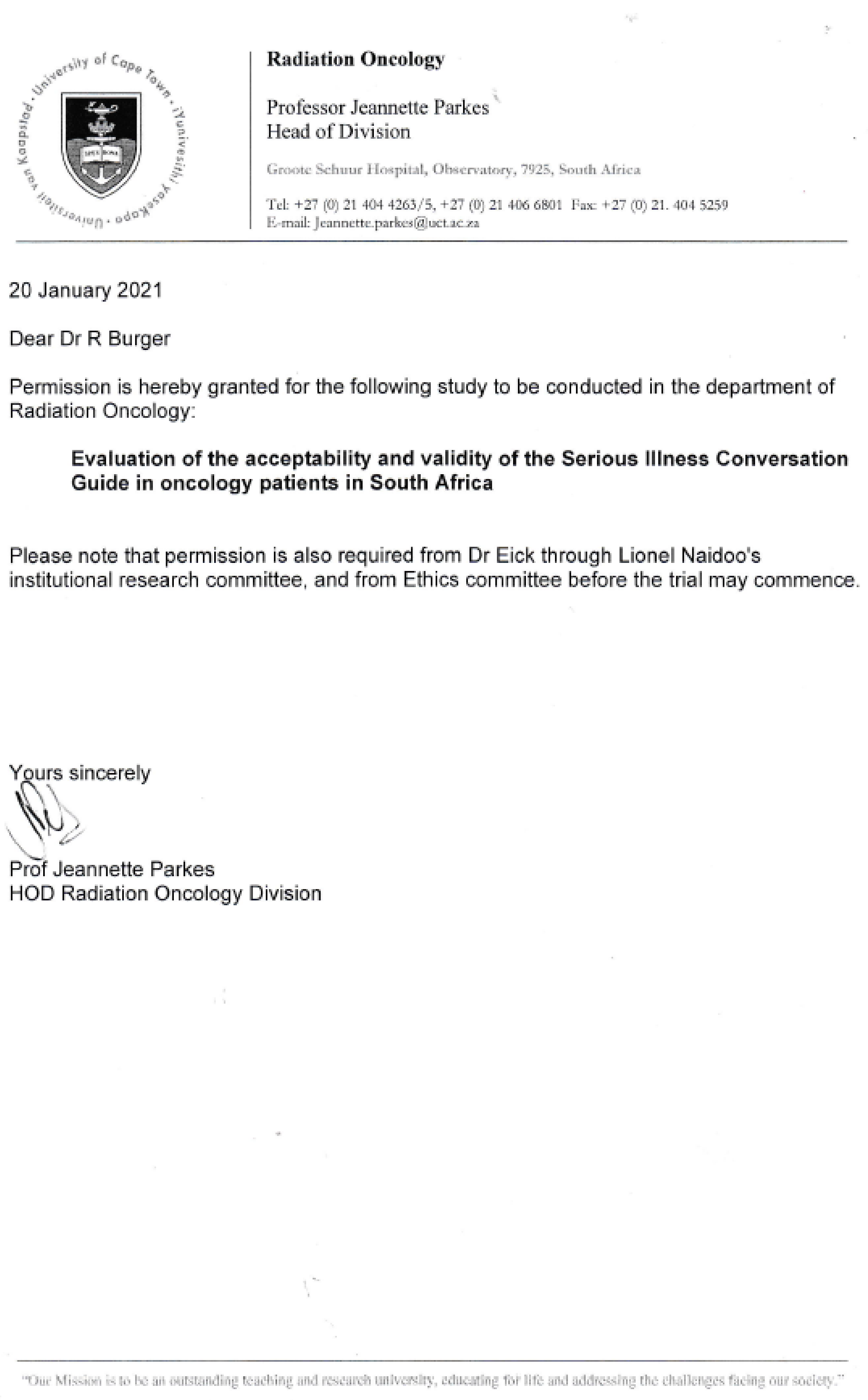
BY ________________________________ [SIGNATURE]

An authorized representative of Tygerberg Hospital

NAME **GRANVILLE MARINUS**

TITLE **MANAGER: MEDICAL SERVICES - RESEARCH**

DATE **12 DECEMBER 2020**



Radiation Oncology

Professor Jeannette Parkes
Head of Division

Groote Schuur Hospital, Observatory, 7925, South Africa

Tel: +27 (0) 21 404 4263/5, +27 (0) 21 406 6801 Fax: +27 (0) 21. 404 5259
E-mail: Jeannette.parkes@uct.ac.za

20 January 2021

Dear Dr R Burger

Permission is hereby granted for the following study to be conducted in the department of Radiation Oncology:

> **Evaluation of the acceptability and validity of the Serious Illness Conversation Guide in oncology patients in South Africa**

Please note that permission is also required from Dr Eick through Lionel Naidoo's institutional research committee, and from Ethics committee before the trial may commence.

Yours sincerely

Prof Jeannette Parkes
HOD Radiation Oncology Division

"Our Mission is to be an outstanding teaching and research university, educating for life and addressing the challenges facing our society."

APPENDIX C

Detailed results of individual metrics used in the validity and cross-cultural acceptability exploration

Prompt 1

"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want. Is this OK?"

Prompt properties	
Face validity:	No, for many. Most understood it as the HCP prompting the patient to engage in a conversation because they have recognized that a critical point has been reached in the patient's illness trajectory. Before proceeding the HCP wants to check that the patient agrees to continue the conversation. However, there were many different interpretations of what the topics and the outcome of the conversation could be. Some interpreted it as an introduction to a discussion about the patient's expected progressive illness trajectory and their priorities and preferences for the EOL phase, which could enable future decision making about care. • *HW05: In other words, we are not now saying that this is now crisis time and… that there's still a future. In other words, you build hope, and you give the idea that this is going to be a journey. So, yes, I like that "thinking in advance".* • *HW13: Yes, I think so. "Important to you" could be "Important to your family, your children". But in this sentence… the way I understand it is… that we can understand what to do in future with regards to the treatment plan.* • *HW04: Because you're setting the stage to have a very deep conversation, and you want to make people safe and you want to make them feel that they can opt out, if they, if they are not comfortable. You don't want to push, push, push, in a sense.* Some focussed on defining a care plan. • *HW09: It's sort of like planning ahead, isn't it? Yeah, giving some thought to what might be coming so that we could plan or map a way forward from here to there.* • *HW04: If I make the appointment, I will say 'I'd like to meet with you so that we can have a discussion about your care plan.* •

	• *HW12: How do you want to be cared for? Some, they say, "I want to be at home with our family". Some, they say, "Okay, I want to be in hospice".* Some focussed on the tasks of dying. • *HW17: What is important to you? Like, your kids, your money. Who's going to take care of you if you go home from… you are being discharged from the hospital? What else is there? Who's [providing] caregiving? Finances? Is there a will put in place? It's basic things, like…. Is it going to be sorted if I should die now? Is the burial sorted? Is the Moneywise [account] sorted? Is the kids?* Some focussed on current illness understanding. • *HW15: I think also when we say, "what is ahead about your illness", I think how far has your illness… progressed.* Some focussed on future treatment options. • *HW16: Ja. "Thinking in advance" is also like explaining to a person who's going on… for chemo, speaking to the patient, what will be the side effects. You see, what you are about to expect. The thinking in advance. Ja, you put the patient's mind in thinking in advance, if, "You may expect this, you may expect to be nauseous or you may expect to have no hair", or…*
Item Equivalence:	No, for most. Overall, the prompt is seen to be too complex and trying to address too many concepts at once. The multiple different interpretations by the HCPs suggest that local patients will also not understand what aspect of their illness you want to talk or think about and will feel uncertain of themselves. • *HW02: Because I think you could easily break this down into 5 or 6 questions or lots of short ones. Because it's so broad, if you want to get all the information that we're thinking about from the patient, I don't think you could just ask one question and expect them to answer immediately.* The phrase, "what is ahead with your illness," is not acceptable in the local context. It is seen as too complex, unfamiliar, vague, and euphemistic. Local patients will not understand it or will not understand what exactly the HCP wants to talk about. • *HW13: So, for me the words "ahead with your illness", it's almost like a euphemism that we are using to try and, you know, get the patient to understand that there is a process happening or, that there's something happening. I'm trying to think of whether that is the right way of*

	speaking to the patient or saying it in our setting. Yes, I don’t know if they’d actually understand it that way, I might be wrong. The phrase, “about what is important to you” is felt to be too vague and will not be understood by local patients. • HW06: Yeah, again, I think it's a bit vague for someone, “what's important to you”. There's lots of things that are important, but what are we talking about? The phrase, “with the care you want” is felt to be ambiguous. • *HW13: For example, like they’re thinking of being hospitalised when they’re sick or, they’re thinking of something else and we’re actually thinking of a treatment plan like, would they want chemotherapy. You know, that is just the difference. It’s the fact that it’s quite ambiguous, like our concept of “care that you want” and their concept might be different*
Content validity:	No, for many. The request for permission, “Is this OK?” should be expanded to give the patient the option to request alternative timing for the conversation, having others present, or that the conversation be conducted with someone other than themselves. • *HW09: but perhaps we could ask them, “Is now a good time?”, rather than, “Is it OK, yes, or no?”. They could say, “Well, no, actually it’s not a good time, because I'm actually in a lot of pain”, or “I don't feel I can think this through clearly,” or, “I'm not thinking clearly at the moment because, you know, I'm on medication and my thoughts are not clear,” or, “I don't have so and so with me today”.*
Conceptual equivalence:	The concept of Perception of advanced illness trajectory exists and is constructed the same way. It has relevance in the target culture. • *HW08: From my perspective, a lot of my patients would like to know. It would make it easier for them to have some sort of idea of what the future had to hold. And often I say to them it would be nice if I knew what that would be like. So, I think, yes, it would be comforting to have a road map, or some sort of, perhaps, looking towards what may be coming in the future.* The concept of Priorities and preferences for EOL care and Goal-concordant care exists and is constructed the same, but it is not considered relevant in the serious illness or palliative context by many. The relevance of exploring it is questioned in the setting of limited health-care resources, where it might not be fulfilled.

	• *HW11: Sometimes we always think we are at the same level of understanding with the patient. You have given the diagnosis, you have explained. Sometimes the patient is not really at the same level as we are. So, now you are saying, "I would like to discuss what is important to you in terms of your illness." So instead of me telling you, for a change, you are the one who's going to tell me. What is it, what is important to you. Instead of me telling you that, this is important, you must take your medication you must do this, you must do this, you must do this. Maybe for this patient, it is not what is important. So I feel that part is quite relevant. At the end of that sentence it says, "so that we make sure that we provide you with the care that you want", not what we think you want* • *HW02: I don't think the patient always have the… I mean, you can't always get the care you want. It sounds very pie in the sky, saying "the care you want".* The concept of Patient autonomy exists in as far as it is recognized in Health policy and legislation. However the extent to which it is applied in healthcare practice differs between healthcare settings and situations and cultural contexts. Shared-decision-making as an expression of patient autonomy is however not widely acknowledged by some HCP and patients, especially in the context of declining, withholding and withdrawing treatment. The construct is therefore not the same. It is however considered to be relevant. • *HW06: I think also, my experience is that we very seldom ask the patient what they want. And now suddenly we're asking them, "what do they want". And it's like, "Why are you asking me this, you're just gonna tell me". The whole way along in my illness people have told me what's going to happen, and now suddenly you are giving me the power?".*
Semantic Equivalence:	No, for most. This prompt is felt to be an inappropriate introduction to a SIC in the local setting. Firstly if the patient has low illness understanding, and secondly where a trust relationship and rapport has not been established between the HCP and the patient over time. In the low resource SA public healthcare setting with limited consultation time and high turn-over of HCPs, the patient is not guaranteed of seeing the same HCP at different visits. Similarly the HCP has no guarantee that they will see this patient again at their next visit, so they often feel pressurized to complete all ACP tasks at once. In the absence of such a trust relationship SA HCPs prefer to start the conversation by asking the patient what they understand about their illness i.e. putting prompt 2 in front of prompt 1. This is felt to build trust and supports the

need of patients to share their personal health narrative as a way of making sense of it, dealing with trauma, and asserting their individual agency.

- *HW05: But I also agree with the previous speaker that said the building of trust. Definitely, this whole question for me, you can’t just ask it out of the blue when it’s your first visit to the doctor. And I don’t know if that is practical in our state setup, health setup.*
- *HW05: What about maybe switching the questions so that you start off, as somebody else said, “What do you know about your illness?”*

The phrase, “I’d like to talk about,” suggests an unequal power-dynamic between the doctor and patient. The HCP is not engaging the patient as an equal partner in the conversation. It is seen to push the agenda of the HCP and not the patient.

- *HW03: I would like to bring in “explore”, “I would like to explore with you what you think and feel and understand about what is happening”. …For me, the emphasis again is on, “I want to hear what you think”.*

The phrases, “what is ahead with your illness,” and “do some thinking in advance,” can sound foreboding and threatening to patients in the local setting and create anxiety and fear of bad things to come, especially when the future outcome is not well understood by the patient yet, or in some cultural or religious settings.

- *HW15: Then the patient will be like that, “How long?” If you say, “Do things”, like, “in advance”, as if now I’m going to die soon, soon.*
- *HW16: Ja, and also, in religious people, they believe in speaking positive not negative. So, they will not, say… “No, I’m not going to speak about this now. I know what God has in store for me. Ja, God has good plans for me, not to die now”, and things. So, this is also where the religion comes in.*

The phrase, “and do some thinking in advance,” could be seen to imply that the patient has not thought about what lies ahead themselves. This is seen as condescending or paternalistic i.e. “I have to think for you”.

- *HW02: I also think, I think “do some thinking in advance” might sound a bit condescending and making out as if the patient hasn't done any thinking in advance. I think if someone said that to me, I would think, “Well, I've actually done a lot of thinking in advance already, and now you're telling me to do some more thinking”.*

	The phrase, “so that I can make sure we provide you with the care you want,” is seen as an unrealistic offer that the HCP cannot fulfil as an individual in the local resource limited healthcare setting. • *HW01: Yes, I think it's an over investment, to say that [provide you with the care you want]. You can’t be sure.* The phrase, “Is this OK?” is not regarded as respectful in the local setting. • *HW18: I’m thinking about the entire question in Sesotho and the translation. We wouldn’t say, “Is this okay”. So, I think, in fact, there isn’t really a term in that sense. I think the term might be, “Is this acceptable to you?”. It just feels more respectful.* The phrase, “Is this OK?” is not seen to effectively allow patient to opt out of taking the conversation further, if they are in fact not ready or in the right frame of mind to have the conversation. This phrase might seem absolutely effective in allowing patient to opt out, but in SA setting where paternalistic dynamics and limited access to HCPs lead to patients i) not speaking their minds, or ii) being afraid of antagonizing the HCP, or iii) believing that the HCP always has their best interest at heart and knows best, or iv) being worried that they will not get a chance to speak to a HCP again after this, or v) being willing to endure a certain degree of discomfort if it means that they will get more clinical attention or information, this prompt is too simplistic. • *HW09: But, I still think it's important at this point, to give them an option to opt out if they're not ready to proceed with this conversation, because it's quite a heavy conversation. They should know that it can be “not OK”. And perhaps one needs to then step back and find another time. I don't know, it's difficult, we are so limited with our time with our patients. There is not often another time that we can use. But to me, the answer to that is always going to be: “Yes, doctor. Whatever you say, doctor.” And I don't know whether the rest will flow honestly if a patient is actually not ready to honestly say yes, at this point.* People from cultures that avoid speaking about death directly and people who had not accepted the serious nature of their illness because of their young age, or because they believe it to be a curse, or people who believe in divine healing, or positive thinking, will not be open to continuing this conversation. They might want to speak about their diagnosis and what they can expect to happen in the future, but not about imminent death. In such

	cases the phrase "Is this OK?" is seen as too simplistic. Permission to discuss each sub-element of the conversation should be sought. - *HW16: Exactly. Cultures. In most cultures they don't want to speak about it. Dying.* - *HW17: "It is not OK, because I haven't accepted this."* - *HW15: They will say, like [HCP] mentioned, that they were saying, "No, God is going to heal me. You see, He's got plans for me. I'm still young. I'm still active. So, I can't be, like, dying now".* - *HW15: Like other patient who say he have… they poison… they give food poison in the food, that's why the doctor saw that it is cancer, but he knows that they poisoned him. He's got poisoning, food poisoning that he had. So, it's difficult to think ahead. Because you know that, after hospital, he will go to somewhere, to this [traditional healer] and he will treat me. So, it's difficult to have that conversation about thinking ahead, about advanced care, because he had that hope, I'm going to go and I'm going to get help. I'm going to be cured as soon as I get out of hospital.* - *HW12: So, with those kinds of patients [who believe that illness was caused by a supernatural force and can be cured supernaturally] you can't ask that question of "thinking ahead", you see. Yes. Because they've got that, "No, it's because of ancestral calling, that I am like this", so…*

Prompt 2

"What is your understanding now of where you are with your illness?"

Prompt properties	
Face validity:	Yes, for most. It elicits the patient's understanding of their current position in their advanced illness trajectory. - *HW01: I think that that one there is clarifying, we want information, we want to hear what the patients understand, and how they describe, information wise, where they are.*
Item Equivalence:	No, for most. The phrase, "where you are with your illness," is seen as too abstract in the context of a population of non-English first language speakers with limited education. - *HW12: But I don't think that the patients can… all the patients can understand, "where you are with the illness". It's like you [HCP] understand because you're working there. But a patient, I don't think she will, "where am I with my illness", when you ask that question, [and] you don't explain to her.* "Your illness," is also thought to be too vague in the setting of multiple chronic illness diagnoses, non-acceptance of one's diagnosis, or poor illness understanding.

	- *HW09: Again, I think, name the illness. Put in the name, like [HCP] said before. Be specific, "Where are you… what is your understanding of where things are with your breast cancer?" Call it what it is.*
Content validity:	Yes, for most. The abstractness of the phrase, "where you are with your illness" is seen to allow for the inclusion of clinical understanding, acceptance, and the patient's physical, emotional, mental or spiritual reaction to illness. - *HW09: I think it's [understanding] a good word. It might be quite broad, because it might relate to the course of the illness, it might relate to the impact of the illness, it might relate to the social aspect of their illness. But it's good that it's open, because the patient's response to that is going to lead you into where they need to go.*
Conceptual equivalence:	The concept of Perception of advanced illness trajectory exists and is constructed the same way. It has relevance in the target culture. - *HW13: No, I think it is clear enough. And I think that last sentence, "the doctors have said that there's nothing that they can do to cure me", that answers the question. That means that they understand that there's a process happening and there's timing involved and there's deterioration and, I think that answers the question.* - *HW15: Even if they know the diagnosis, but they don't understand that it's a serious illness, they thought like, "Okay, I'll be fine". So, although the doctor told her you have cancer and she understands, "Okay, I have cancer", she has that hope, "I'll be cured". She don't know that it's actually an incurable sickness that she have. So, it's a relevant question to ask her, "Do you understand?"*
Semantic Equivalence:	No, for many. The phrase, "where you are with your illness," could elicit fatalistic views in patients which could cause distress. - *HW14: Yes, that is basically what everybody here, yes, 99% of the patients will tell you that, "The doctor told me that there's nothing they can do to cure me."* The phrase, "where you are with your illness," could lead to feelings of inferiority or embarrassment if there is a language barrier. - *HW12: And then also, with the language barrier. So, if he's a Xhosa speaking patient he won't know. And if he's Afrikaans, also. Because I*

	had an Afrikaans patient, and they also, the doctor was speaking to him in English, until I came in, and then I said to him, I asked him [if he understood], I called the sister, shame, they were talking English, and his language is Afrikaans. So, language, there, is also a problem. (Prompt 2, n36) The HCP felt that many patients in the local setting would not be able to respond to this prompt, because of poor illness understanding. If a patient has significant gaps in knowledge, understanding or acceptance of their illness, the conversation cannot proceed to prompt 3. Information needs to be shared, and time given for the patient to process and accept it. This may require time, as sharing of information should be titrated to avoid overwhelming the patient. This represents a major gap in the SICG when applied to the local context of low health literacy and illness understanding. • *HW13: But yes, the new patients that are referred we hardly… yes, that's [that nobody has told them anything] usually the answer that we get from them and then we have to start working down…*

Prompt 3

"How much information about what is likely to be ahead with your illness would you like from me?"

Prompt properties	
Face validity:	Yes, for most. The HCP offers to share information on the patient's likely illness trajectory with them and assesses the patient's appetite for this information. • *HW06: But I think more specifically, "What would you like to know about what could happen to you with your illness, or, what the illness could do to you",*
Item Equivalence:	No, for most. The prompt language is felt to be too abstract and vague and would not be understood by the local population. The phrase, "How much information" is taken literally to mean volume of information, whereas it would be clearer to talk about level of detail. • *HW05: For me, if I read it, and I'm not sure that the patients will understand it that way, but if you should ask me that question, I would think of, "How much detail do you want?*

	The meaning of the phrase: “Likely to be ahead with your illness” is thought to be unclear. • *HW13: That’s what I... When you say, “likely to be ahead with your illness”, are you asking the patient, “How do you see your illness progress in the next six months?” Is that what the question is asking? Okay, would our patients understand that question like that?*
Content validity:	No, for most. More should be assessed than amount of information i.e. types of information, type of prognostic sharing (e.g. time-based, function-based, uncertainty-based), who should be present, and if this is a good time. • *HW09: Ask what information, replace “how much” with the word “what”. “What information about what's likely to happen”. It's simpler too, and maybe a bit clearer. “What information would you like to know?”* • *HW16: “How much information?” Some people doesn’t want to hear the information. They will say, “Tell my children”, you see? Or the children will say, “Don’t tell my mother. We want to keep that from her”.* • *HW02: But I think, I think you could still give the option to the patient here, where you say, “You know, we don't have to discuss it now, if you don’t feel comfortable. We can always discuss it at another meeting”.*
Conceptual equivalence:	The concept of P<u>erception of advanced illness trajectory</u> exists and is familiar to most. It is constructed the same and has relevance in the target culture. The apparent difficulty of the participants and population to understand the phrase “what is likely to lie ahead” is probably more related to the reluctance to discuss future distressing events, than not understanding the meaning of the phrase. The concept of <u>Patient autonomy</u> exists in as far as it is recognized in Health policy and legislation. However the extent to which it is applied in healthcare practice differs between healthcare settings and situations. Informational preference as an expression of patient autonomy is not widely acknowledged but is seen as relevant. • *HW18: …the patients have, in terms of our relationships with our doctors, we’ve been, and it’s global, I suppose, we’ve been pummelled into that [paternalistic] way. Then it’s revolutionary. I mean, then it feels weird. But there are many other different ways in which we interact. So there’s something... it will bring a familiarity with a different, other, outside of this [healthcare] space, way of interacting, that would be moving. I mean, this question always feels moving too. It*

	feels like… when I hear it, I feel…. after feeling thrown off, I also feel a sense of awakening. (Prompt 3, p19) • *HW18: Some don’t want to know anything, and some want to know everything, you know. I think it varies, it varies on the space and the patient. As a doctor I’ve heard, “Tell me everything”, and then also I've heard, “I don’t want to know, I’m not ready”, and then I’ve heard in between.*
Semantic Equivalence:	No, for many. The phrase “How much information” is complex, abstract language. It is taken literally to mean amount of information, which could then inhibit the patient, because with low illness understanding, low trust in the healthcare system, and low awareness of informational preference, they would not know how much information to ask for or could feel like information is being kept from them. *HW06: And if they don't know how much there is to tell, it's quite a strange way of asking it. Because, you know, are you gonna tell me 2 facts, you know, or are there 10 things coming I didn't know about? And to “how much of that do I want to know?”, “I don't know”, “how much can I handle?”* The high level of religiosity leads patients to respond with assertions of divine healing or that it is not within the HCP’s power to predict the outcome of their illness trajectory. HCP suggest using the word “might” instead of “likely” could be more acceptable in this context. • *HW06: Yes, I've had that [a patient asserting that it is not for us to decide what the future holds]. They don't want to face the reality of what's happening. There’s some patients who want to know everything. There’s some patients who just want to just live one day at a time. And they probably can't deal with thinking about how it's going to, how it could be.* • *HW03: I would take “likely” out and put in “might”. So, certainly what I’ve suggested here, we might just have to say that there are other possibilities, but this is where we’re standing at the moment.* Some HCP are reluctant to talk about what might lie ahead. They prefer to refer back to “where things are” i.e. diagnosis, stage, treatment modalities, rather than “what is likely to be ahead”. They admit to avoiding sharing poor prognosis for fear of diminishing hope and leave it to the clinician.

	- *HW16: It couldn't. Ja. So, "how much information." I would leave out "about what is likely". "How much information about your illness would you like from me", "will you like?" Ja, something like that. So, it is difficult.* *HCP feel that talking about what might lie ahead could reduce a patient's hope* - *HW04: So, you have to break that… and the language that you use obviously has to be very gentle, and in language that is understandable, so that it doesn't take away all their hope and, and everything.*

Prompt 4

"I want to share with you my understanding of where things are with your illness..."

Prompt properties	
Face validity:	No, for most. Many found it difficult to make sense of this prompt. In view of the language in prompt 3 i.e. "information about what is likely to be ahead with your illness", and what follows in prompt 4a-c i.e. "what is likely to be ahead", the apparent meaning of this prompt i.e. information about current illness status, as referred to in prompt 2, is incongruent and was confusing in the local context. - *HW12: "Things" that could be, like, we did the CT, we did all the investigations. X-Rays. We did the biopsy, and then… This is the results of the things that we did [for] you, so cancer is stage four.*
Item Equivalence:	No, for most. Similar to the face validity, the meaning will be interpreted as referring to the current illness status and not the future illness trajectory as referred to in prompts 3 and 4a-c The phrase, "where things are" is too abstract - *HW16: It's like I said, "where things…", what things? Do you understand? They will ask, "what things now, sister? What things are you talking about?" you see? So, "I want to share with you where you are with your illness." If "things" can be removed, then it's the same, out of that sentence. Unclear "things",*
Content validity:	Due to low face validity, HCP were not able to assess content validity.

	No, it does not include the aspect of future advanced illness trajectory as is referred to in prompt 3 and follows in prompt 4a-c.
Conceptual equivalence:	The concept of perception of advanced illness trajectory exists and is familiar to many. It is constructed the same and has relevance in the target culture. Local patients are hungry for more information. • *HW14: Normally patients do appreciate if you want to say your view. So, I feel that that statement is fairly reasonable, yes.*
Semantic Equivalence:	No, for many. The phrase, "I want to share with you" is seen as too assertive and not aligned with the patient-centred approach of prompt 3 where the patient's informational needs are respected. In a paternalistic health system patients are not likely to exercise their informational preferences when the HCP starts the prompt in this manner. • *HW11: I will put it in the form of a question. I wouldn't say, "I want to share with you". I would ask, "If I may share with you my understanding". For that person who is not ready, who wouldn't want to know by now. HW09: It's coming back to asking permission, like in the first question. "Is it OK? May I?"*

Prompt 4a

Uncertainty: "It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I'm worried that you could get sick quickly, and I think it is important to prepare for that possibility."

Prompt properties	
Face validity:	Yes, for many, for the first part of the prompt, except for the phrase "and I think it is important to prepare for that possibility," which is misunderstood by many. The HCP is prefacing the prognostic sharing by acknowledging that they cannot be exactly sure of the clinical events that will make up the patient's final phase of life, mostly because of the unpredictable nature of certain disease conditions. The current QOL could be maintained for some time, but the general trend is of gradual deterioration in functionality towards death, and there could also be unexpected severe complications at any time point that could result in significant changes in the patient's functionality and care needs.

	• *HW01: But also bringing it very much to the fore that things can change quickly, like it says, things can change quickly, and so if we can be prepared for that.* The phrase “and I think it is important to prepare for that possibility” is misinterpreted as referring to putting a care plan in place to prepare for sudden deterioration, and not to exploring preferences and priorities to prepare for difficult decisions that might need to be made in the future i.e. “consider that possibility”. • *HW04: So then, when I start this [prompt] I say, “Everything is… we are in a very unpredictable situation. Things are very uncertain, and therefore we do need to plan for the worst-case scenario and then… you know, once that's done, we can put it aside and we know that we have a plan and then we implement that when we get there. And that's why I want to discuss with you the following…"* •
Item Equivalence:	No, for most. Some patients might interpret the phrase, “It can be difficult to predict what will happen,” as meaning that there is still a chance of cure. This is particularly seen in patients with poor illness understanding or acceptance or those who believe in divine healing and miracles, or in curses as the cause of disease. • *HW16: It cause so much uncertainty. Will it not cause some uncertainty? That word “predicts” is like you’re guessing, guessing things. So, that means the doctor’s guessing, they are not sure what will happen with my illness.* • *HW05: the patients, and the nurses would like to say something like, “we don’t decide.” You know, in a Christian perspective. “It is not for us to decide,” or “it is not for us to predict”, you know. they would say, "Only God decides". I don’t think it is something good to say if you’re in a palliative setup, because it stops the conversation.* The phrase, “continue to live well for a long time” is strongly regarded as unacceptable by many participants. The abstract language could create false hope, especially for patients with poor illness understanding or acceptance. • *HW16: “I hope you will live…” No, isn’t that [I hope you will continue to live well for a long time] to give false hope? Hope, because is this not a palliative care, end-of-life patient? Also, and that, it’s not, like, uncertain, and the… That is false hope and uncertainty that the patient is… also now he thinks he will live long, like the doctor said. "Let us hope that the doctor say that I will live long." This is how patients react on what the doctor is saying.*

	- *HW17: It's false hope, because there you say, "I hope you continue to live well", but there, the sentence continue, it says, "but I'm worried". So, the doctor's playing guessing games with the patient there. First, he's giving her hope, she's going to live long, and then he turns around and say, "but I'm worried". With what expression on his face is he using? His face is changing there now.* As with the HCPs, the phrase "and I think it is important to prepare for that possibility" could be misinterpreted by patients as well.
Content validity:	Yes, for most. No additional aspects suggested.
Conceptual equivalence:	The concept of Prognostic uncertainty exists and is constructed the same. It has relevance for the implementation of advance care planning. - *HW03: You know, I think, I think, for me, when I handle this situation. My own way of handling it is to say that "Nobody can predict anything for the future in life. I can't, who's not sick, say that. You can't, and you are ill. So, we don't know where it's going to end, but I think we need to be prepared for it."* The concept of Quality of life exists and is constructed in the same way. However, its relevance in patients with incurable illness or a significant symptom burden is not familiar to all. - *HW09: I think everybody's definition of living well is quite different and it depends on your, your goals.* - *HW06: The word 'continue' implies that they currently are living well. I'm not so sure they are.* - *HW01: For me, that [I hope you will continue to live well for a long time] just sounds like the doctors trying to feel …better about this bad news. For me, it's not honest enough.* - *HW13: Yes, that ["I hope you will continue to live well for a long time, but…"] might be setting ourselves up for failure. Especially if it's our patients with brain metastases or something. Yes, like, that wouldn't work on, for example, a breast cancer patient or with metastatic brain [metastases], where you say, "I hope you will continue to live for a long time." Yes, I don't know. That portion might not…yes. It's almost giving false hope, in a sense, I think.*
Semantic Equivalence:	No, for most. The phrase, "It can be difficult to predict what will happen," could be interpreted by some patients to mean that the doctor is guessing or speculating as to what will happen in the future. This could create professional mistrust in the doctor's competence. - *HW16: That word "predicts" is like you're guessing, guessing things. They guess what will happen. They are not sure. So, that means the*

doctor's guessing, they are not sure what will happen with my illness.

The phrase, "continue to live well for a long time," is regarded as unacceptable by many participants. The language is seen as insincere due to the known seriousness of the prognosis. It appears that the HCP wants to make themselves feel better or create a false sense of security. This could lead to professional mistrust.

- *HW01: For me, that [I hope you will continue to live well for a long time] just sounds like the doctors trying to feel good… feel better about this bad news. For me, it's not honest enough.*

It is also not seen as appropriate for the patient who is not experiencing good quality of life at the moment.

- *HW01: They can also say to you, "How can you hope that for me? Do you know what I'm going through?"*

The phrase, "but I'm worried that you could get sick quickly," is regarded as unacceptable by many participants for different reasons. Some see it as a contradiction of what was just said in the "I hope…." phrase. Because the HCPs real belief is that the patient will deteriorate soon. This could create mistrust in the HCP.

- *HW16: Oh dear! He was just "living long" and now he's going to get sick quickly! But also, doesn't that put fear in the patient, and also a distrust in the doctor, if the doctor can't tell me?*

One HCP reports her impression that when the phrase "I worry that…" is used, patients believe that the HCP has given up on them. Other's also felt that hearing your doctor say they are "worried" about you, can create anxiety.

- *HW11: But I would, I would remove that "I'm worried" I would rephrase it and remove the "I'm worried", because it makes me anxious. …Because remember, we see doctors as people who know it all, you know. And this is my doctor, and my doctor knows what is happening with me. I wouldn't be worried, I wouldn't be that worried if it's someone else who is saying it.*

The phrase "worried that you could get sick quickly" is also seen as not emphatic, or urgent enough in expressing the seriousness of the

	situation. This could create false hope in patients with poor illness understanding or acceptance. - *HW01: This is, for me, a good opportunity to bring a bit of reality into focus by saying something more like, "I'm aware that things, like sickness and life, is unpredictable, but this illness is also unpredictable. Things can change quickly." Rather more on the urgent side, without being emphatic, but just… for me it needs to be a little bit clearer and a little bit less on the emotional… about being worried and hopeful. I think for me it's more about the urgency of this needing to happen.*

Prompt 4b

Time: "I wish we were not in this situation, but I am worried that time may be as short as ___ (express as a range, e.g. days to weeks, weeks to months, months to a year)."

Prompt properties	
Face validity:	Yes, for most. The HCP wants to communicate to the patient that that death is approaching. They acknowledge that they cannot predict life-expectancy exactly, so they prefer expressing it as their subjective opinion, based on their clinical experience, and as a range. They also want to acknowledge the undesirability of the current situation. - *HW11: I liked what… I can't remember who said it, "I cannot predict what's going to happen." And I would add that, everyone is different. And then add, "according to my experience", or "according to medical history that at this stage people…" you know. I wouldn't give a specific time. I wouldn't say you might only be left with two days or with two weeks. I wouldn't give that specific time*
Item Equivalence:	Yes, for most, except for the phrase "I wish we were not in this situation". Many HCP found the phrase "I wish we were not in this situation" abstract and inappropriate and could lead to confusion in the local context. The concept of "wishing" was found to be removed from reality i.e. wishful thinking. - *HW09: I don't know if I would bring that word into a serious illness conversation. I think I would rather use the word prefer, "I prefer we were not in this situation," rather than wishful thinking. You know, there's no basis for wishful thinking.*
Content validity:	No, for many.

	Many suggested that a time-based prognosis should be preceded by a reference to the patient’s pace of deterioration e.g. visible deterioration over a short period of time. • *HW02: What I sometimes say is, “We don't know the future, but, you know, I'm worried that often, if you deteriorate quickly, it means”, if they ask, “that your lifespan is shorter than if you deteriorate slowly, and therefore I'm concerned, because it seems to me you have deteriorated quite quickly. …This does make me a bit concerned that maybe we should get a plan of action in place sooner rather than later”.* Many HCP felt the need to add a reference to the need for putting a plan in place to the current prompt, as in prompt 4a. They felt more comfortable talking about limited time when it could be related to preparing or putting a plan in place for care and reaching goals. • *HW10: Or I would just say, "While we have time now to discuss this, let’s get a plan of action before things get more difficult or before we don’t have time to talk.” Not meaning, I’m going to do this because you only have a few weeks left to live, but, "While we have time now, and we are relaxed, let’s talk about it and come up with a plan of action”. And that can change, but let's get a plan for what we understand now, and what we think now. That at least, when push comes to shove, I know what we planned already, rather than saying weeks or days, because I always tell them nobody can predict the future.*
Conceptual equivalence:	The concept of <u>Prognostic uncertainty</u> in terms of time, exists and is constructed in the same way, but it is not well understood or openly discussed by many in the community. It is relevant, as HCP acknowledged that local patients and family members often ask about time-based prognosis and they described specific scenarios where time-based prognosis sharing is preferred e.g. dying of old age, scenarios where the patient is deteriorating rapidly, and the patient or family do not grasp the urgency of putting plans in place for the impending death, or when specific logistical or financial arrangements would be influenced by time. HCPs however express lack of confidence in their own time-based prognostication skills and admit an aversion to sharing time-based prognosis. It has relevance for the implementation of advance care planning, but this is not widely acknowledged.

	• *HW18: …What jumped into my mind as I was saying that, were the patients who immediately jump and say, "So, how long?".* • *HW15: But they always want to know, "When doctor?" The families will always want to know. They always want to know, "How long, doctor?"* • *HW02: I think also if you need to… you know, if the patient and their family haven't quite grasped the fact that their loved one, or that the patient is deteriorating really quickly, and there actually do need to be plans that have to be put into place, because you know that the wheels are going to fall off. Then maybe… maybe it would be appropriate to bring in time,* • *HW13: From the medical practitioner's point of view, a lot of our patients in our clinic, though, do ask us, "Doctor, how long do I have?" . We can't tell them exactly how much time they have. But the months to years and weeks to months, does help us just to give them some form of answer. Because for us, if they're not deteriorating day by day, it's very difficult to say. But we can sometimes use, like, data and, you know, saying that statistically you have …weeks to months or months to years, but it's very difficult for us to say.* • *HW09: And I think, only if they have asked, when you said, "What information do you want?" and they said, "I want to know how much time I've got left." I think, then it's appropriate to bring in a timeline. But otherwise, just not even to go there.*
Semantic Equivalence:	No, for most. Many HCP felt that the use of the word "we" in the phrase "I wish we were not in this situation" could offend patients, as it could be interpreted as the HCP implying that they are also "in" the situation, when the patient sees themselves as the one who is primarily affected by the illness. This presumption could elicit resentment in the patient. • *HW13: I don't really like that part of the sentence. And the reason for that is because you're putting yourself as part of being in a situation that you… And patients can perceive that as offensive, and they can say that you are not in the situation.* Mant HCP suggested that prognosis in terms of time should only be shared on request of the patient, or that permission should be asked to share time-based prognosis. • *HW09: And I think, only if they have asked, when you said, "What information do you want?" and they said, "I want to know how much time I've got left." I think, then it's appropriate to bring in a timeline. But otherwise, just not even to go there.*

	• *HW18: Yes, there's a finality to giving a timeline. Even if you are boxing it, you know, days to weeks. And it's important. But maybe there should still be a door for me [patient] to ask for it before it's given.* The phrase, "But I'm worried…" is seen by some to be unacceptable. • *HW01: I would rather say, "I'm aware"… "It seems to me that time might be short. Looking at the clinical things, time might be short," rather than "worried."* Many HCP believe that sharing prognosis in terms of time will have negative repercussions and therefore they avoid using it. These negative outcomes include causing emotional distress or destroying hope, being wrong about the timeframe and losing the patient's trust, being wrong about the timeframe and causing caregiving or financial difficulties for the patient and family. • *HW16: The patient may not die in that quick timeframe, right? And you stop living or you stop having hope in yourself, or you just stop working with the people [caregivers]. You just want to lay there and wait for that time to come.* • *HW11: Because I think we all know that even if you give a specific time, some people live longer. And it... if it happens like that, people always feel that, you know what, doctors like to write people off and say I have 2 days to live, or I have 72 hours to live. I specifically wouldn't give a specific time. I would end it at saying, "I can't predict, everyone is different, but I'm hoping, to my experience and according to medical history, this is what normally happens. But I will not give you... because everyone is different". Yeah, so that they don't come back to you and say, "Look now, you said my mom is going to live for two weeks and look at her. It's been two years".* The phrase "that time may be as short as…" was unacceptable to many. HCPs felt strongly that it is not within the HCP's ability to determine a patient's time of death. They suggested that only "God" could "predict" when someone would die. This may elicit mistrust in religious or spiritual patients in the local context. • *HW17: Doctor can't predict. He's not God. He's just a human being.*

Prompt 4c

Function: "I hope that this is not the case, but I'm worried that this may be as strong as you will feel, and things are likely to get more difficult."

Prompt properties	
Face validity:	Yes, for most. The HCP expresses that, when looking at the patient's current illness situation, it is very likely that their physical condition or their health situation will never be better than it is now. • *HW13: The physical condition. That this might be the best you will be at physically.*
Item Equivalence:	No, for most. The phrase, "I hope that this is not the case," is too abstract and would not be understood in the local context. • *HW16: What case, now? What's "the case", "this is not the case". What case?* This phrase "this may be as strong as you will feel," was considered to be unfamiliar and ambiguous language, which makes the meaning unclear. It could be interpreted as being strong in terms of one's emotions, mental state, or physical state. • *HW06: "As strong as you feel", is a strange term.* • *HW09: It could, it could also imply, like, a purely emotional state, rather than a functional state at all. …Yes, being strong emotionally and things are going to get more difficult in that you may not be so emotionally strong. You may be depressed. So, it might be interpreted as an emotional question, and not a functional question at all. …The intention of the question is lost.* This phrase "things are likely to get more difficult," was felt to be too abstract, complex and vague in its reference to deteriorating function and inability to fulfil goals. • *HW10: I think that is too verbose. I would make it much simpler by saying, "You know, things can only get harder from here on forward".*
Content validity:	No, for many. Some HCPs wanted more direct references to functional deterioration, loss of independence and possible disease complications. • *HW08: "Get more difficult", is probably, yeah, probably saying, like, your care needs may be increased or your ability for independent function, as you say, might be… not really likely to… might become more…. You may become less independently functional.*

	One HCP wanted to add reference to the family experiencing more difficulty. - *HW18: But here, I think, it is important to point the patient's gaze a bit outwards now, a little bit. so we are vague with "things", but we broaden the landscape at which those things can exist by saying, "You and the people around you".*
Conceptual equivalence:	The concept of <u>Prognostic uncertainty</u> in terms of function, exists and is constructed the same. It has relevance in the local setting where low resources often require patients and families to make difficult decisions about care. - *HW13: I think so. I think they understand. They understand when they say "things", but it gives them a chance to ask further questions if they want to know. And if they don't actually want to know, because like the other speaker said, that they don't sometimes want to know the detail.*
Semantic Equivalence:	No, for many. The phrase, "I hope that this is not the case, but I'm worried that …" is interpreted as being insincere, apologetic, and creating false hope. It is therefore deemed unacceptable language in the local context. and could create false hope for cure in patients with poor illness understanding and acceptance. *HW01: But why would we say that [I hope that this is not the case] to a patient, though? …We can't apologize either. We can't apologize for the way things are because the truth is, they are as they are.* One HCP is worried that this way of sharing prognosis will be seen as uncaring by patients and could lead to mistrust in the HCP. - *HW02: I think it also depends on the type of patient, if the family is still trying to accept the diagnosis, and you say things aren't going to get better, they might get a bit of a shock, and you might lose that trust. They might say that this doctor does not have any hope, and they don't think anything is going to change.*

Prompt 5

"What are your most important goals if your health situation worsens?"

Prompt properties	
Face validity:	No, for most.

The intended meaning of “goals” in the setting of serious illness is unfamiliar and unclear to the HCPs. Three possible interpretations of “goals” were suggested, with the second interpretation pertaining to healthcare goals only suggested by clinicians.

Some understood it as the HCP exploring activities or tasks that are a priority for the patient. This could be activities or tasks that bring meaning or closure, improve QOL, create a legacy, or represent a milestone or life event for them.

- *HW02: I think of goals, like, if I was a mom and I want to see my son finish matric, or my goal would be to just be able to do some gardening every day. More about, maybe also time things, like see my son finish matric, or be able to go to a certain function, or see my daughter finish varsity, more time things. Then also maybe goals of day-to-day life.*
- *HW15: Yes. Because maybe with other family there is no peace. They are not talking to each other, so they want to go and fix all those stories with them.*
- *HW18: Yes, no, I mean, it’s getting a sense of legacy and getting an understanding of where the patient’s conceptualisation of legacy is.*

Many clinician participants understood it as the HCP exploring goals for medical care as it relates to an outcome that they want to achieve or a principle that should be supported. Such goals could include living longer, being comfortable or pain free, or to maintain quality of life by being with family, or by having a full-time caregiver. It could also encompass preferences for place of care or place of death.

- *HW13: But what do you want to know when you ask “goals”? Because for them to want... So, what I think this question is asking is regarding treatment planning. Do you want to prolong your life as long possible?*
- *HW18: Oh, because, I mean, if on the one hand the patient is talking about wanting to be in hospital, whereas there may actually be restrictions and there is something else that needs to be done. How we combine the practicalities of all that. I can’t think of a concrete example, but it comes down to the logistics of the type of care provided, the place, the where, with regard to what people want to do, you know. “I want to go to such and such a place,” well maybe I shouldn’t give you such and such a medication if you want to go to such and such a place. We should have a… you know, a holiday from that medication.*

	Some interpreted “goals” more vaguely as things that are important to the patient. • *HW02: I think this is definitely more about goals or important things in your life. More positive, like, “Tell me a bit about yourself”. It's almost like trying to get to know them. Or “what is important to you?”, which gives you a lot of information about their life as well. So, as you said, it's more about the positives in their life.* • *HW01: Ja, that’s why I think I'm saying like, “What are the things that are most important?” “What are the priorities for you now?” “What's most important for you now? And as your health situation worsens, as things change”.*
Item Equivalence:	No, for most. The phrase “most important goals” is felt to be unclear in the local context. The fact that HCPs often use examples to help patients understand the prompt, suggests that its meaning is not clear or understandable in the current form in the local context. • HW12: I think, what are your most important “wishes”? Not the goals. Goals is something that you want to achieve while you’re still alive. And then you need help because you got sick. I want to fulfil… So, if my health situation worsens… I don’t know. They’re not goals. • *HW08: Yeah, you need to define goals, in a way, which is hard, because at the same time you don't want to lead someone as to what their goals might be. I suppose you can say, you know, “what are important things that you would want to…” You see, if you say “do”, or “people that you would want to see”, or “trip that you would want to take” or …. You, you’re giving people, you know… it's almost too leading a question.* • *HW08: Yes, it implies that you didn't reach your goal. That you then may have, you know... because these are now goals that you’re setting. And if you don't get to the goal, there is an element, perhaps of failure, exactly. And so, maybe it's more about if, you know… what would be important to you to….to…. do? Or what would be important to you to… see through? if your health were, or before your health were to worsen. Something like that, you know. Something that kind of implies, that it's like a continuation, rather than just an achievement, maybe, I don't know.* The phrase, “if your health situation worsens” is seen as too vague and euphemistic, at a time when it is important to be specific about impending death. • *HW01: For me, this is a good opportunity to bring in the word death. Also, because it becomes sort of more tangible then, I think, that the patient is die…. At some point we need to bring it in, instead of skirting around it, you know. The “health situation” sounds, for me, a little bit too vague and impersonal. HW04: I think it's important to use the word death naturally and not in a contrived way. I would ask, "What is*

	important to you to get done before you die?", and "What are your fears around this process, as death approaches?"
Content validity:	No, for many. Clinicians imply that this prompt should also explore goals and preferences for healthcare. - *HW10: I would replace goals. I would rather ask about needs, "What are your needs when you become sicker?" Rather than goals for things that I won't be able to necessarily assist the patient with. It lies more with the social worker perhaps. I would rather ask about needs.* Some imply that this prompt should also explore tasks of dying. - *HW03: I think, for me, there's also a practical aspect to it. And my own approach would be: "there are some things that we need to look at because they're important. For instance, "do you have a will in place? Have you discussed with your family your wishes for the future? What you would like and would not like", introducing that, because those are important. They are functional goals in a sense that… it's stuff that needs to be done. As soon as possible.*
Conceptual equivalence:	The concept of <u>Priorities and preferences</u> exists and is constructed the same, but it is not considered relevant in the serious illness or palliative context by many. The concept of <u>perception of advanced illness trajectory</u> exists and is familiar to most. It is constructed the same and has relevance in the target culture.
Semantic Equivalence:	Yes, for most.

Prompt 6

"What are your biggest fears and worries about the future with your health?"

Prompt properties	
Face validity:	Yes, for most. The HCP is exploring things that make the patient anxious and scared as they think about the future. - *HW01: Hopefully leading towards what are your fears about dying, hopefully.*

	- *HW12: Fear of leaving my kids. What's going to happen to them? Yes. Fear that I will lose the job.*
Item Equivalence:	Yes, for many. Some felt that the phrase "about the future with your health" was incongruous with previous and subsequent prompts (1-4a, 7) that refer to "what lies ahead" and "your illness", and could lead to misunderstanding. Many suggested removing the phrase completely. - *HW04: The fears are about your deteriorating condition. It's not about "your health" really.* One HCP felt that the phrase "what are your fears?" was too abstract for the local population. - *HW18: You could say, "What scares and worries or concerns you the most?". Actually, you know, that for me sounds more accessible to me as a patient.*
Content validity:	Yes, the different dimensions are felt to be implied. - *HW04: Yeah [they are clear], they're [fears and worries] broad. they can be physical or emotional or financial or whatever.* - *HW11: I think, I like this question, because I think it's very, very open-ended. It can allow the patient to actually open up and tell you exactly what her fears or her worries are.*
Conceptual equivalence:	The concept of Fears and worries exists and is familiar to most. It is constructed the same and has relevance in the target culture. - *HW17: Fear of the unknown. Who will provide for my kids?* The concept of Perception of advanced illness trajectory exists and is familiar to most. It is constructed the same and has relevance in the target culture.
Semantic Equivalence:	Yes, for most. The need for both the word "worries" and the word "fears" was supported due to nuance differences. - *HW08: I kind of get the impression that a fear is something that you are afraid of, where a worry is something that bothers you. So, you know, a fear might be, having uncontrolled pain, but a worry might be, where will your daughter go and live, who lives with you. Whereas the fear is perhaps, something that genuinely is something that, that scares you, you know.* *It was noted that in the local setting many of the fears and worries relate to socio-economic matters.* - *HW12: Fear of leaving my kids. What's going to happen to them? Yes. Fear that I will lose the job.*

Prompt 7

“What gives you strength as you think about the future with your illness?”

Prompt properties	
Face validity:	Yes, for most. The HCP is exploring the patient’s sources of mental, emotional or spiritual resilience and support - *HW06: I think it also gives an opening… that strength can also be, where you get your support from. Your strength could come from your family. It could come from the support systems, structures that you have. So, what, you know, what gets you up in the morning? What, what helps you, what supports you? Which might be faith, and it might be your kids, your mother, you know, your friends.*
Item Equivalence:	Yes, for most. - *HW12: We do speak to our patients, especially the Xhosa ones, about that question, “what gives you strength?”, “yintoni ekwenza womelele” You are strong. What makes you stronger? What keeps you strong? What keeps you going?*
Content validity:	Yes, exploration of mental as well as spiritual resilience is included. - *HW13: This question is more based on your strengths from an emotional and from a spiritual point of view.*
Conceptual equivalence:	The concept of <u>Resilience</u> exists and is familiar to most. It is constructed the same e.g. mental, emotional, and spiritual resilience, and has relevance in the target culture. - *HW04: And then people will say their family or their spirituality or their friendships or the fact that their pain is well controlled. “At least I don't have pain, and I can still carry on”. It becomes quite meaningful.* - *HW15: No. We ask that to all the patients, not to only those that we know that they are... [religious]. Because the others will tell you that, “I never go to church. I don’t believe, also. So, you will see that my strength I get from the friend, from the family, from…”* The concept of <u>Perception of advanced illness trajectory</u> exists and is constructed the same way.
Semantic Equivalence:	Yes, for many. There were many references to spiritual sources of strength in the local population.

	- *HW13: I think most patients will give you a spiritual answer about God.* Many equated strength with hope - *HW09: I think, to me, initially, I would think of spiritual strength. That's what pops into my mind first. It's the first time that we have a question that could lead towards a spiritual discussion in this conversation guide, so far. Strength equates with faith, equates with hope.* - *HW18: I am just trying to see, if they [patients] say, "What do you mean by strength?", what will I say? My quick response was, "What gives you…", I mean, "What gives you hope?"* Some felt that the phrase "about the future with your illness" was unnecessary and should be omitted. - *HW04: But I don't think it's necessary to bring in "the future of your illness". You can just say, "What gives you strength? What inspires you? What keeps you going?"*

Prompt 8

"What abilities are so critical to your life that you can't imagine living without them?"

Prompt properties	
Face validity:	Yes, for most. The intended meaning of this prompt in the setting of serious illness is familiar and clear to the HCPs. Most understood it as the HCP exploring the specific functional abilities that would cause the patient significant levels of suffering, or reduction in QOL, should they be lost. The intention is to use this information to guide future treatment decisions. - *HW12: To do things on your own. Not be able to walk again, or... And you won't be able to go back to work, provide for the family. Ja. So, he was the breadwinner at home.* - *HW01: It would add to your suffering. If you were to lose certain abilities, you would suffer more. So, if possible, could we lessen the suffering by helping with the choices that you make? What are the things that you really would… would cause immense suffering? More suffering than others.* - *HW13: Yes. Instead of being awake when you are confused. And I'm specifically talking about a patient that is confused and aggressive. And would they want to be still awake, or would they want to be fully sedated? Would they like to be able to still have some form of conversation with their family, or would they be*

	able to not. So, that's what I think that this question is trying to lead to, but I might be wrong.
Item Equivalence:	No, for most. Many HCP found this prompt unacceptable in the local context due to the use of abstract language that would not be understood in the local setting. • *HW13: I don't understand that question. "What abilities?" The word "abilities". "What abilities are so critical?" I mean, if I must ask that to one of our patients, I don't think they will understand what I'm trying to ask.* • *HW04: I have to say, this "abilities" question, patients don't like hearing it. They don't like talking about it. If I ask it, they would say, "But what do you mean?"* • *HW12: They won't understand. I also don't understand "critical to your life."* • *HW18: Yes… no, no, no. Even within English I would rather say, "What are the things you are able to do?", or "What are the things that you can do that are so…", most people will understand "important" or "necessary" rather than "critical". I would never use "critical" with any English-speaking service area that I have worked in so far.*
Content validity:	No, for many. Some HCPs suggest that they want to explore a broader concept than just functional "abilities" by including emotional or social abilities like fulfilment of roles or continuation of relationships. • *HW11: I think it is nice and broad and one can interpret it the way one wants to. Like we said, it can be functional abilities. It can be anything. It can be emotional abilities. It can be physical.* • *HW06: To me it's quite open. It could be interpreted differently to, what's important for the person. So, I mean, for some people, critical to your life, like, being a mother, might be so critical to someone's life that they, if they can't be a mother, and that might be that my kid can get into bed with me and cuddle, then I can still do that. If I'm paralyzed from the neck down, I can't do it anymore, and that's a problem. What makes you, who you are? And that's very personal. Being part of the family, not being admitted to the hospital. But "abilities" is quite, is quite limited, I think. But I think the intention, for me, the intention of the question is… could be, more broad.*
Conceptual equivalence:	The concept of Quality of life exists and is constructed in the same way. However, its relevance in the EOL setting is not recognized widely and the concept of weighing it up against the potential

	benefit of palliative treatment interventions is not familiar to all. Some HCP did not see the usefulness of the prompt, because they did not know what they would do with the answer now that the patient is for palliation. They did not see how it would assist with developing a treatment plan. • *HW04: This is actually a discussion for earlier on, not in the palliative phase where we are having this discussion a year before this patient might be dying.* • *HW05: Yes, I also don't like this question, because what are you going to do with the answer? Because that what the patient fears, is most probably going to happen.* • *HW13: So, my answer can be like, "Walking Doctor. Like I can't imagine not having my legs or living without being able to walk". But how would that assist you in your treatment plan? Like, how would that assist them?*
Semantic Equivalence:	No, for many. Many HCP found this prompt unacceptable in the local context because the intensity of the question could be seen as threatening or fatalistic. Patients would not be comfortable talking about this topic. • *HW02: And I don't think it should be, like, a blanket question. Because some people might get a bit of a surprise and think …when it comes out of the blue, "Why are you suddenly asking about abilities I can't live without. What are you going to take away from me? What are you about to do to me that…?"* • *HW01: It seems a bit out of the blue, in a way. Because we haven't really talked about living without anything or being alive or death. We haven't really gone there.*

Prompt 9

"If you become sicker, how much are you willing to go through for the possibility of gaining more time?"

Prompt properties	
Face validity:	Yes, for most. The HCP is assessing how much treatment-related discomfort or suffering the patient is willing to endure if there is a chance that the treatment can prolong their life. The benefit of clarifying this for oneself is that it allows the patient to make informed decisions about their care in the future. • *HW08: Gaining more time, for me, means extension of life. And, for me, it is a concept that we use, because it's something like, "Would you want to undergo chemotherapy in a non-*

	- *curative setting to… for potential extension, you know, by months, for instance?”* - *HW04: I would ask patients, " So what does quality of life mean to you?” Then they would say, “To cook for my kids, etc.” And then, "Which part of the treatment you are receiving is stealing your quality of life?" and "What would you want... ?", “What can we learn from that in terms of future decision-making for your future with this illness?" So, I actually break it down and I address quality versus quantity of life with them. I oppose the two concepts and then we talk about it. And then it becomes a very meaningful conversation because they can identify with that. It makes sense to them. Then they can say, “I would rather have another chemotherapy and see my child’s Matric farewell, because that’s really important to me”.*
Item Equivalence:	Yes, for many. The phrase, “for the possibility of gaining more time” is felt to be unacceptable, because of not being clear, or too abstract. - *HW08: When you phrase that question, for me, it means, like, would you want to go through losing your hair and being in hospital, potentially, for treatment, in order to prolong your life, maybe, is a better word?* One HCP objected to the practice of HCP juxtaposing quality and quantity of life in the setting of palliative treatment decisions, as palliative interventions per definition are intended to improve QOL. This prompt was felt to favour the view that any worthwhile intervention is always associated with significant toxicity or discomfort. Which is not always the case. - *HW02: obviously, people get sick from chemo, but amazingly a lot of people actually respond positively and actually their symptoms improve quite significantly. And obviously that's what we’re aiming for. I think, the bottom line is that we don't know. You might be able to prolong your life with chemo, and you might have an improved quality of life with chemo, so you might be one of the lucky ones. You might be the unlucky one and have neither. I think the main thing is that you can't really say it's either more time or quality of life, like, it doesn't actually work like that. And you don't actually know, their quality of life could be shocking, because their symptoms develop really quickly.*
Content validity:	Yes, for most. Some HCPs felt that the extension of survival should also be related to the patient’s goals.

	• *HW08: I mean, it’s [quality and quantity of life] something I mention, in a consultation. I would sometimes, particularly for something like a palliative therapy, about saying, you know, "Do you want to travel all this way to have your chemotherapy and go home and be away from [your] family and potentially have side effects? And is that important for that extension of life? Is that what you would consider quality of life? Or would you prefer to focus on being at home with your family?"* • *HW09: Yeah, I think it is an important question to ask when it comes to advanced care planning. You know, if I can gain myself three months, and live to see my daughter's wedding, I'll go through any amount of hospitalization during those three months. Whereas somebody else might say, look, if I can have two months with my family, and be home with them, I would rather do that from today. And die a month or two, or a year earlier, but just let me have that quality time. So, it's planning around their goals, ahead of time. And I think that question is really very dependent on, on the patient's goals.* One HCP noted that the SICG does not directly explore the patient’s preferences for life-sustaining interventions. They suggested that this prompt should include a discussion on DNR preferences. • *HW13: That’s the thing. The state patients don’t have that [option for ventilation for palliative patients]. Even in the private sector, I mean, you wouldn’t… it would be, sort of, unethical to put a terminally ill, end of life patient, on a ventilator. It was just like a consensus that this patient is not for resuscitation. But there was never a conversation between the patient and the health care provider to say that this is a consensus, or this is an understanding between you and me, that you’re not being resuscitated. It was more of an understanding between the patient and the health care provider. It was never, you know, an explicit conversation. And it’s not addressed at all. It needs to be addressed more directly.*
Conceptual equivalence:	The concept of <u>Treatment burden versus benefit or “trade-offs”</u> exists but is not familiar to most in the context of non-curative treatment modalities. Its underlying constructs are also not well defined in the context of non-curative treatment modalities i.e. importance of time away from family, side-effects, cost, travelling, discomfort, symptom-relieving treatment, life-prolonging treatment. Its relevance is questioned in limited resource

healthcare settings where patients would rarely be offered an intervention that was not of significant proven benefit.

- *HW01: I think for me personally, in my experience they [patients] don't always [understand the difference between quality of life] … the majority of patients I've worked with have not really grasped the effects of the treatments that they've had, and not that they've… I haven't had many patients that have said they rather wouldn't have had them, but I have had patients that have said, "I think I could have functioned better, had I not felt so awful. I have got so many things to sort out with my family that I haven't had time to do, because I feel so awful. I don't know whether I should have just rather died." But not all of them have said that to me, but I have had some patients saying that. It really is a dilemma, because I don't know how much patients can really understand when we are explaining things like the effects of treatments.*
- *HW06: I find this an interesting question as well, because I think there are not a lot of examples I can think of where this would actually come into play in government. Maybe in private it's different, I'm not sure, but there's a certain amount that we would say, it's up to you. And maybe it is more obvious in the oncology setting where you have palliative care treatments that can prolong… that can give time but have the side effects. But in other areas of palliative care, usually in the government setting, [we] aren't really offering them anything else. So maybe it's just a question you wouldn't ask. Because, in government you can't opt for dialysis if you want it. It's not offered to you.*
- *HW02: The second point, I was just going to say, that this question, maybe also in the government sector is that... sometimes there aren't that many treatments. So, it's saying how much are you willing to go through, like, there actually might not be that many treatment options. Sometimes the patients don't have the luxury of saying I want to try one line of chemo and then stop. You know there might only be one line of chemo, so I think that's also something.*

The concept of Quality of life exists and is constructed in the same way. Its relevance in the EOL setting and the concept of weighing it up against the potential benefit of palliative treatment interventions is recognized by some.

- *HW10: Ja, well, that's [knowing the patient's understanding of "gaining more time"] difficult, because you never actually also know how the patient will feel after treatment. Those people will often say, "I would rather have one good month than six bad months". That comes from what is important to them. I also find that they would rather have quality of life than time.*

	• *HW03: I think this response would also probably be age related. An elderly person is… they'll far rather have quality, less time, where they want to be. A younger person would say "No, I don't wanna go now. I want to live."* The concept of Life expectancy exists and is constructed in the same way. It has local relevance, as non-curative life-prolonging therapies are available in SA, as are therapies that can artificially prolong life without any QOL. However, the concept of weighing it up against the potential burden of palliative treatment interventions is not familiar to all. • *HW01: That's what I want to know also… that part of the question "gaining more time"? What does this actually mean? Are we meaning that the patient is going to gain more time in their present state of health, or are we actually clear that gaining more time… Some patients have said to me, "They told me that I would live… that this would give me six months longer, but then they didn't tell me what the quality of my life would be in those six months. And six months of this, post-chemo, has been hell, worse than anything. For me, this is a very significant one, this "gaining more time". What are we meaning? What is the patient understanding?* The concept of Patient autonomy exists in as far as it is recognized in Health policy and legislation. However the extent to which it is applied in healthcare practice differs between healthcare settings and situations and cultural contexts. Shared-decision-making as an expression of patient autonomy is however not widely acknowledged by some HCP and patients, especially in the context of declining, withholding and withdrawing treatment. It is however considered to be relevant. • *HW06: And I'm willing to go through it [admission for IV antibiotics to treat a severe infection], if it's going to give me more time and if it's gonna make it better, but if I'm unconscious and I've got a UTI, and the UTI could kill me, then maybe let me go? I think I'm battling with that… I'm not sure if my patients can cope with this kind of question. Maybe I'm being, maybe I'm being too authoritarian or too, sort of, dismissive. But in a population that is, sort of, trusting the doctor, it's quite a difficult question to ask them.* •
Semantic Equivalence:	No, for most.

	The phrase, “How much are you willing to go through” is felt to be unacceptable, because it felt threatening and foreboding. • *HW01: No, no, it [“How much are you willing to go through”) doesn't sound right for me either. No, it doesn’t feel good at all, this one. This is a scary one. This sounds very scary* HCP expressed their concern that local patients will not understand the intent of this prompt i.e. why it is being asked. This could be based on poor illness understanding i.e. all cancers are fatal or not being used to being given the option of declining treatment “not doing everything”. • *HW06: And I'm willing to go through it [admission for IV antibiotics to treat a severe infection], if it's going to give me more time and if it's gonna make it better, but if I'm unconscious and I've got a UTI, and the UTI could kill me, then maybe let me go*? I think I’m battling with that… I’m not sure if my patients can cope with this kind of question. Maybe I'm being, maybe I'm being too authoritarian or too, sort of, dismissive. But in a population that is, sort of, trusting the doctor, it's quite a difficult question to ask them. • *HW17: Ja, but if people… most people now, if they hear they’ve got cancer, they know I’m going to die. So, what is the use of doing the surgery or whatever.* When asking patients about “gaining more time” HCP were concerned that some local patients tend to always favour anything that would give them “more time”, without thinking about the quality of that time. • *HW01: Except, again, I would still want to clarify what they mean by “more time”. Because more time as currently now, right now, this moment, in this condition of health or disease, or more time, but very sick with more time.*

Prompt 10

“How much does your family know about your priorities and wishes?”

Prompt properties	
Face validity:	Yes, for most. Most understood it as an assessment of whether the patient has shared their priorities and wishes with their families. • *HW04: …the priorities. How involved is the family? Do you share your priorities?*

	Some understood the intent being that the families would be able to speak for the patient when they no longer can. - *HW13: So, if it comes to patients… if there's decisions that needs to be made and the patient's unable to make that decision, the family knows that this is what the patient wants. So, I think it's a very good question*
Item Equivalence:	Yes, for most. Only one example of misunderstanding was given. The HCP felt that the new introduction of the terms "priorities and preferences" might confuse non-English first language speakers or those with low education levels, as these terms have not previously been linked to goals and what they have been asked about up to now. - *HW18: Yes, it's just the "priorities" that may not be [clear]… it's hard to sort of… So saying "what we have just talked about now," then… yes.*
Content validity:	No, for most. There were multiple aspects that HCP felt should be added to make this prompt more appropriate and meaningful. This prompt should be preceded by an assessment of what the family knows about the patient's diagnosis and prognosis. Many patients do not share this information with others. - *HW10: What I think this means is, "What did you tell your family. Did you tell them the truth? Did you try and spare them and not say all the detail? So, what did you tell them?" "Are they fully informed or are you trying to keep things from them?" Because you don't want to fall into the trap of saying something in front of a family member and then they actually don't even know, but you think they know. So, "What did you tell your family about your situation?"* This prompt should be preceded by an assessment of what the patient would like their family to know about their priorities and preferences.

	• *HW09: But I do think, by asking, “How much does your family know?” It almost implies that they should know something about the patient’s wishes. And a patient might not actually really want that, and they may feel guilty if you ask them, “How much do they know?” And their answer might be like, “Well, I really don't want them involved at all”. We've had a number of patients who've said, “Phone me on this number. Don't phone the number on my hospital card. That's my husband's number, and I want him not to know anything about this”.* • *HW11: Maybe one can say, “Is there anything that you want your family to know regarding your priorities and your wishes?”* The HCP should also offer to support the patient in sharing their priorities and wishes with their families. • *HW02: I think what's leading on from here, maybe, is, “Do you want me to assist you to tell your family if you don't feel comfortable?’* The HCP should ascertain if the family accepts and agrees with the patient’s wishes and priorities. • *HW02: Are they on board? Do they agree with your wishes? Because sometimes the family might want something different to what the patient wants.* This prompt should lead to naming of a healthcare proxy and/or a family contact person. • *HW10: That is also a question, “Which family member, would you like me to communicate with?” Because I find that you get calls from five different family members asking the same question. I often ask them, which family member would you like me to communicate with, then they can spread the news to the other family members.* • *HW16: We do that [ask the patient who will speak for them when they cannot]. We do it regular, yes.* One HCP suggests that a written record of the conversation or of the patient’s priorities and preferences can become useful to make family members aware of their wishes, when the patient does not feel comfortable discussing end of life wishes with their family. This could be because they don’t want to crush their

	hope, cause them distress. This is a common theme in the African culture. • *HW11: Is there a possibility that at the beginning of our conversation with the patient we can maybe ask her or him if we can document our conversation and then somewhere at the end or somewhere here, we can ask her or him whether we can share this information with her or his family? Yes, if the patient wants to write it down herself or himself, or we document it and we let her or him sign. So that if there is anything that, like, in this instance, we assume or she tells us, that the family knows, and at the end of the day the family doesn't know. But if it's documented, then it's something that we can give to the family, in the event of the patient dying.*
Conceptual equivalence:	Yes, the concept of Priorities and preferences for EOL care exists and is relevant but mostly limited to the constructs of burial and inheritance arrangements and not goals of care. • *HW12: On that question, "What does your family know about priorities and wishes?" Most of our patients from Eastern Cape, like the gogos [grandmothers] and the oupas [grandfathers], will say, "My children knows I want to be buried in Eastern Cape, I want to go back to Eastern Cape". Even when you speak to the family and they'll say, "Okay, my father said he wants to go back home", so when it came, if something happens, it must be done at home. So, they are…* • *HW15: When I die, this will be, we don't… Usually, most of the time there's not even wills that put things on places for us. If somebody died the elder one takes over, your family that's around. You know that if I die my elder sister will sit at our house, at my mother's house. She's the one who's going to stay there. It's going to be [her] house. It's cultural, you can say that.* The concept of the Family as unit of care is described in the SANPFPC and is relevant. • *HW18: Yes [it is an important question], I think even more so because family networks are so much more… play such a bigger roll [in the local context].* It is noted that in the local context the term "family" could encompass family, friends, or those closest to you. • *HW02: It just came to me, that I was thinking that we're always saying family, family… but I'm assuming this is family, friend, whatever your deemed family is, which might need to be stipulated at the beginning of this conversation that this does not need to be your immediate family.*

	• *HW04: Yeah, the persons closest to that person. Whoever they are.*
Semantic Equivalence:	No, for most. If the phrase, “how much do they know?” is interpreted literally, as is often the case in non-English first language populations, it could be seen to imply that it is expected that the “family” should know about wishes. This might make some patients feel uncomfortable or judged for not including their family. • *HW09: But I do think, by asking, “How much does your family know?” It almost implies that they should know something about the patient’s wishes. And a patient might not actually really want that, and they may feel guilty if you ask them, “How much do they know” they might feel guilty that they don't want them to know anything, and their answer might be like, “Well, I really don't want them involved at all”.* Many HCP report that many South-African people are not comfortable speaking about death and dying and therefore would not be comfortable sharing priorities and preferences for OEL care with family. This could be due to superstition or cultural norms. • *HW12: I am speaking about my own experience, my people… (African) “family know about priorities and wishes?” Huh-uh [no], it’s only few of them that they know what it is, only few of them that will know what is my wishes. But most of them, they don’t. I think because we are not opened up [about] what will happen. So, what are my wishes if I’m no more, you see. So, we don’t discuss about... we’re avoiding. We don’t want to talk about death and dying, honestly. I think it’s because we’re scared about it? Is that it?* • *HW15: We don’t talk about it. No [it's not because of fear]. I think it’s the way we grow up. We never hear from our families sitting talking about death. (African)* • *HW17: The same thing with my people (mixed ancestry), we don’t talk much about it [death and dying].* Sharing of EOL priorities and preferences may lead to conflict in some families. • *HW04: I think in our community there's a lot of conflict between family members, often times. It's especially in*

	Afrikaans… well not just in Afrikaans people, but oftentimes in low- and middle-income families. You do have a lot of conflict about money and debt and loans and all sorts of things that can really be a big deterrent in terms of palliative care planning. • *HW02: Are they on board? Do they agree with your wishes? Because sometimes the family might want something different to what the patient wants.* Sharing of EOL priorities and preferences may lead to emotional distress in some families and is therefore avoided by patients and families alike. • *HW03: Well, that's one part of it, but the other one that catches me more is, "No, no, I don't want to hurt them. Please, don't bring them into this".* • *HW05: Yes, that's often true. And we often find that the families don't want to talk about it. So, it leaves the patient feeling alone. So, they only have the health care worker or social worker and so on to speak to. And that shouldn't be that way. … The family doesn't want to talk about it. So, say for example, your husband and your two kids, they just want to stay on this positive route, and they don't want to talk about end-of-life conversations or advance care planning, or whatever.* Some HCP felt that the prompt would be inappropriate or premature if the patient has only just formulated their priorities and preferences for themselves. This could be because HCP assumes that local patients would not have thought about priorities and preferences before this conversation and therefore would not have been in a position to discuss them with family. This could be attributed to the low uptake of ACP in SA. • *HW06: I found the question as it is at the top quite strange, because you've just come through this whole conversation about what their wishes are, and this might be the first time they've thought about some of these things or verbalized it. Now you're saying at the end "So, does your family know all of this stuff?" "Of course they don't, because I just had the conversation with you for the first time!"*

Prompt 11

“I’ve heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we ___. This will help us make sure that your treatment plans reflect what’s important to you.”

Prompt properties	
Face validity:	Yes, for many. The first sentence indicates to the patient that the HCP is checking in that their interpretation of the patient’s responses is correct by highlighting and summarizing the things that the patient identified as important to them in their own words. The HCP communicates to the patient that they were heard. • *HW14: This question will also give the patient the confirmation that he was actually listened to. And that somebody is going to try and assist him as best as possible. The summary, that is always very helpful. And you can also get clarity if that what you’ve heard is what the patient really wants.* The HCP relate the recommendation made here to decision-making. • *HW16: Ja, so in this, you are actually helping your patient making a decision. Okay, your recommendations is helping the patient making a decision.* They are also affirming that the patient is the primary focus of the discussion, that they are seen as an individual, and that future decisions about their care should reflect what is important to the patient, not the HCP. • *HW04: That the patient is the centre of the treatment plan.* • *HW10: It’s a personalized thing, it’s an individualized thing. It's your plan, not a one-size-fits-all kind of thing. It’s a personalized thing for you as an individual.*
Item Equivalence:	No, for some. The meaning of the first and last sentence will be understood, but there is a possibility that the recommendations could be seen as treatment recommendations. • *HW01: This is really at the time when you’re wanting to… there are still options for treatment perhaps, and we're saying that we are recommending the next step. So, it's almost like ‘what's the next step now?’ Is it like that?*

Content validity:	Yes, for most. No additional questions suggested.
Conceptual equivalence:	Yes, the concepts of Priorities and preferences for EOL care and Goal-concordant care exist, but it is noted that people with lower education levels would not be familiar with the concepts in relation to EOL care. It has relevance, but the relevance of exploring it is questioned in the setting of limited health-care resources, where it might not be fulfilled. • *HW04: But again, here, there's also a cultural thing. So, people that are educated, they would be able to voice their needs very clearly. But people that are [less educated], they would not have an idea of what they could ask for. And the resources in those communities are less, and then the planning becomes more difficult. …We need to remember that in under-resourced state hospital settings, the need, the plan will be much simpler, and it has to be very specific.*
Semantic Equivalence:	Yes, for many. For some the phrase, “I recommend” is seen as not patient-centred enough. • *HW02: “How would you feel about discussing some short- and long-term plans?” Instead of saying, "I recommend that...".*

Prompt 12

“How does this plan seem to you?”

Prompt properties	
Face validity:	Yes, for most with regards to checking in with the patient. • *HW16: "Do you think this will work for you?" That is something also… "will this work for you". HW04: “Do you feel comfortable with it?” “Does this really reflect your thoughts? If it doesn't, please help me correct it so that we can get it to be really patient-centred”. “Do you feel comfortable with this? How would you like to change it, or personalize it?”*
Item Equivalence:	Similar to the face validity, the meaning of checking-in will be understood, but there is a possibility that “this plan” could be interpreted as referring to a treatment or care plan. • *HW05: Well, I think maybe with the last slide, slide twenty-four, you would write down that care plan. So, that when the next [prompt] comes, it’s something that is written, and then you would ask the patient, "is this what you want?"*
Content validity:	Yes, for all. No additional questions suggested.

Conceptual equivalence:	The concept of P<u>atient autonomy</u> exists in as far as it is recognized in Health policy and legislation. Getting agreement on a management recommendation as a form of shared decision-making is seen as relevant. HW04: I think consensus [about the plan] is important, to reach consensus of some degree.
Semantic Equivalence:	None noted

Prompt 13

'I will do everything I can to help you through this.'

Prompt properties	
Face validity:	Yes, for most with regards to the phrase, "I will do everything I can to help you". Reassuring the patient of continued care and support. • *HW12: We always say that. And we make sure that…"We will do everything to assist you" [In response to question about patients trust in these words] Yes, 100%, especially when we also say, "This is the number that you can call us, our WhatsApp number, and then we'll also WhatsApp you. If you have any problems at home, just contact us." From day one [we start to phone the patients], so… We also send a WhatsApp, because now most of the people have WhatsApp. We send a WhatsApp, "How's your mom doing? Did the carers come?" So… there is that trust.* No, for most with regards to the phrase "through this". There appears to be a misinterpretation of the intended meaning of this phrase. "Through <u>this</u>" is not intended to refer to your entire EOL journey. It pertains to your exploration of your priorities and preferences and not to exhaustive planning for medical care for all possible future eventualities. The reassurance given here is intended to be related to support for the ACP process (exploring goals and preferences, addressing fears and worries, meeting informational needs around treatment options, prognosis, future symptoms and functional deterioration, harnessing sources of support and strength, making sure the relevant parties are

	informed, documenting proxies, DNR orders or Advance directives), and not the drafting or execution of a care plan. • *HW12: Make sure that you are pain free. Make sure that you've got the support, make sure that you have the discharge plan, care continues… If your morphine runs out, you know, you must copy the discharge letter to the day hospital. You can also contact us.* • *HW10: I would maybe say, "I will be available, should you have a specific need" or "You can contact me when you need something". In our situation maybe, "I'm not always on call, but one of my colleagues will be available should you need something after hours". Practical things like that. Meaning, you will… You know, patients around here say, "Oh, it's Friday afternoon, and it's so hard to find a doctor over the weekends". So, "There will always be someone available, and this is how you will be able to contact them. Call my office to get the after-hours number", whatever. "There is help for you available".* • .
Item Equivalence:	Similar to the face validity, the meaning of reassurance will be understood, but the meaning of "through this" will most likely be incorrectly interpreted as referring to care planning and the entire EOL journey.
Content validity:	No, for most. In the local healthcare setting the concept of including the team in such commitments to care should be added. • *HW02: The one thing with the government that is important maybe, is to make sure the patients are aware that we are in the same team as [Hospice NGO] and [Cancer NGO]. And they are able to see them at home. So, although they might not be able to get seen by their doctors at [Oncology hospital], if they get seen by [Hospice staff] at home, she's also part of our team. So, that's still a commitment from the health team.* • *HW01: And [the principle here is] that it's a team effort. It's a team. It's not a singular support.* One HCP suggested asking if further assistance is needed. • *HW02: I think the question, I don't know if it comes in here, but, "Is there anything that we can do as a team to make this easier for you Something quite open-ended, but to let them know that you are there and that they can discuss things with you.*

Conceptual equivalence:	The concept of Commitment to care is described in the SANPFPC and is relevant. Its feasibility in resource limited healthcare settings is however questioned. • *HW01: So, you're trying to say to specifically state patients that, yes, you could come to [hospital 1] or [hospital 2] during office hours. But what happens on a Saturday night when the ambulances are full, what's going to happen then? I don't know the answer to that.* • *HW02: Because you can't do everything, you're overcommitting yourself completely and it's making out as if it is just you, not a team. It's me, and I am going to do absolutely everything in my power to help you. That's not…* •
Semantic Equivalence:	No, for most. One HCP was concerned that "through this" could be understood as implying recovery or cure. Which could lead to misunderstanding in patients with low illness understanding. *HW05: And yes, I definitely don't like the "everything I can", but also, "to help you through this" dying? If you put it that way, it seems as if there's going to be… it's a problem that can be solved in the end. You're just going through this and then, go on.* Most HCP found this statement unacceptable. The phrase, "I will do everything I can", is seen as overcommitment from the HCP working in a resource constrained healthcare setting. Promising something that cannot realistically be delivered could be interpreted as insincerity which could lead to mistrust. • *HW18: To say, "To walk along with you through this". I mean, when you are actually not. Even though you are in a professional relationship with the client, but because of the circumstances, you know that there are some moments where you will not be available. …So, it will be false and fake to say I would do that. "I'm walking along with you," that's, I'm not walking along with you*

APPENDIX D

Invitation to study participants

UNIVERSITY OF CAPE TOWN
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

FACULTY OF HEALTH SCIENCES

INVITATION TO TAKE PART IN A RESEARCH STUDY EXPLORING HOW PATIENTS WITH CANCER THINK AND FEEL ABOUT THE CARE THEY WANT TO RECEIVE AT THE END OF THEIR LIFE

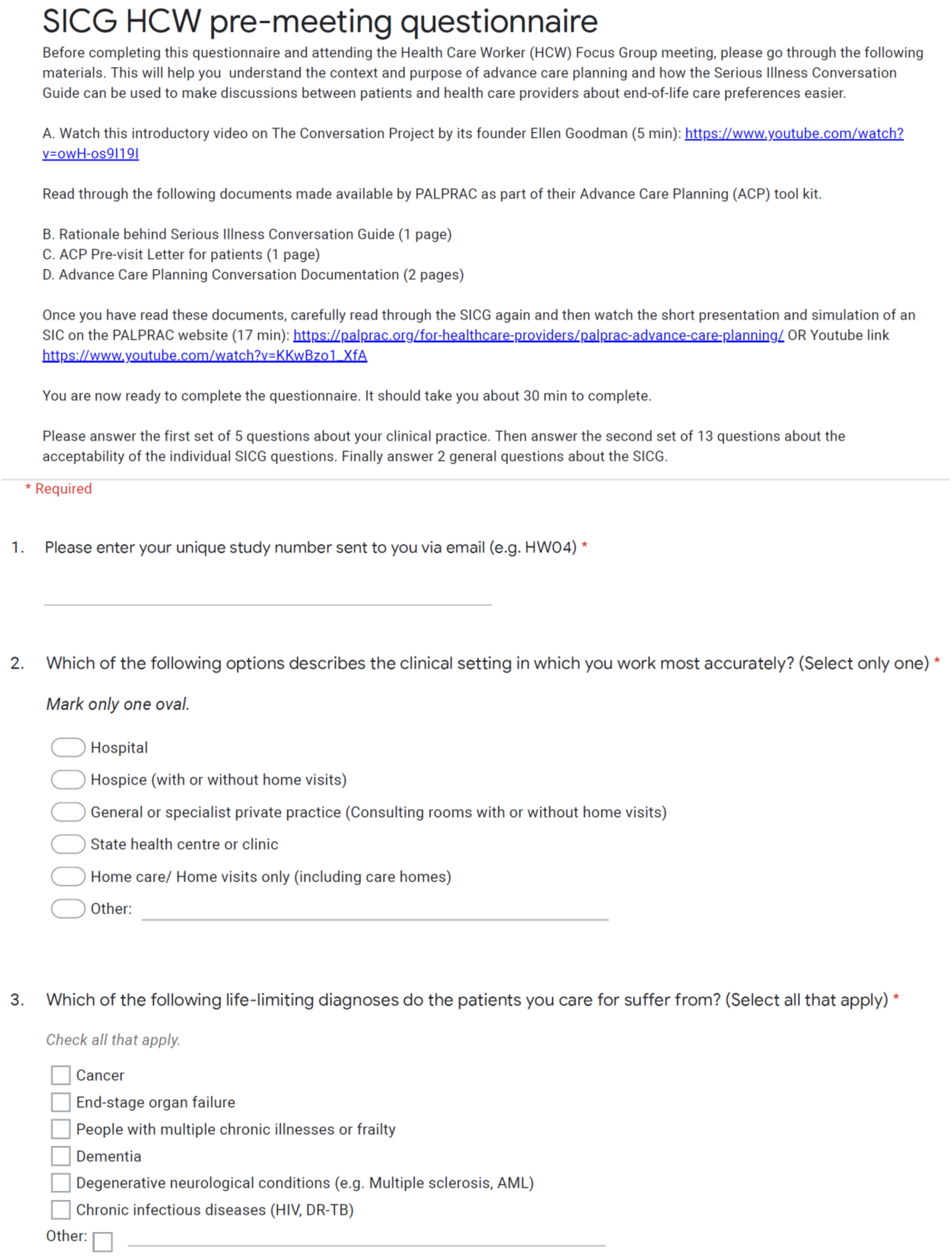
Are you a health care professional (doctor, nurse, medical social worker, medical counsellor) working in the Western Cape seeing patients with cancer as part of your daily work?
Are you willing to be part of a discussion group that will help doctors better understand how to communicate with their patients about what they find important at the end of their lives?

Please contact the study leader, Dr Riette Burger, on henrietteburger@sun.ac.za (Subject: SICG) if you would like to find out more about being part of our discussion group for health care practitioners.

You will be required to attend one 2-hour meeting during April 2021*#. Spaces are limited. Applicants will be notified by email if they have been selected for the study.

*Meeting will be conducted in person or virtually in line with COVID-19 regulations
Compensation for travel expenses will be provided if applicable

APPENDIX E



SICG HCW pre-meeting questionnaire

Before completing this questionnaire and attending the Health Care Worker (HCW) Focus Group meeting, please go through the following materials. This will help you understand the context and purpose of advance care planning and how the Serious Illness Conversation Guide can be used to make discussions between patients and health care providers about end-of-life care preferences easier.

A. Watch this introductory video on The Conversation Project by its founder Ellen Goodman (5 min): https://www.youtube.com/watch?v=owH-os9I19I

Read through the following documents made available by PALPRAC as part of their Advance Care Planning (ACP) tool kit.

B. Rationale behind Serious Illness Conversation Guide (1 page)
C. ACP Pre-visit Letter for patients (1 page)
D. Advance Care Planning Conversation Documentation (2 pages)

Once you have read these documents, carefully read through the SICG again and then watch the short presentation and simulation of an SIC on the PALPRAC website (17 min): https://palprac.org/for-healthcare-providers/palprac-advance-care-planning/ OR Youtube link https://www.youtube.com/watch?v=KKwBzo1_XfA

You are now ready to complete the questionnaire. It should take you about 30 min to complete.

Please answer the first set of 5 questions about your clinical practice. Then answer the second set of 13 questions about the acceptability of the individual SICG questions. Finally answer 2 general questions about the SICG.

* Required

1. Please enter your unique study number sent to you via email (e.g. HW04) *

____

2. Which of the following options describes the clinical setting in which you work most accurately? (Select only one) *

Mark only one oval.

○ Hospital
○ Hospice (with or without home visits)
○ General or specialist private practice (Consulting rooms with or without home visits)
○ State health centre or clinic
○ Home care/ Home visits only (including care homes)
○ Other: ________________________________

3. Which of the following life-limiting diagnoses do the patients you care for suffer from? (Select all that apply) *

Check all that apply.

☐ Cancer
☐ End-stage organ failure
☐ People with multiple chronic illnesses or frailty
☐ Dementia
☐ Degenerative neurological conditions (e.g. Multiple sclerosis, AML)
☐ Chronic infectious diseases (HIV, DR-TB)
Other: ☐ ________________________________

4. For how many years have you been in clinical practice? *

____

5. What percentage of your clinical case load would you characterize as cross-cultural i.e. the patient/client has a different cultural, ethnic or spiritual background from your own? *

Mark only one oval.

○ Less than a third (<33%)
○ 1 to 2 thirds (33-66%)
○ More than 2 thirds (>66%)

6. Have you used the SIC Guide (actual) in your clinical practice before? *

Mark only one oval.

○ Yes *Skip to question 8*
○ No *Skip to question 7*

7. Please select possible reasons for not using the SICG in your practice from the list below. (Select all that apply) *

Check all that apply.

☐ I was not aware of the SICG before now
☐ I think the SICG is too time-consuming
☐ I think the questions in the SICG will not be acceptable to my patients
☐ I am not comfortable using a conversation guide when talking to my patients
☐ I prefer to use a different advance care planning conversation guide
Other: ☐ ________________________________

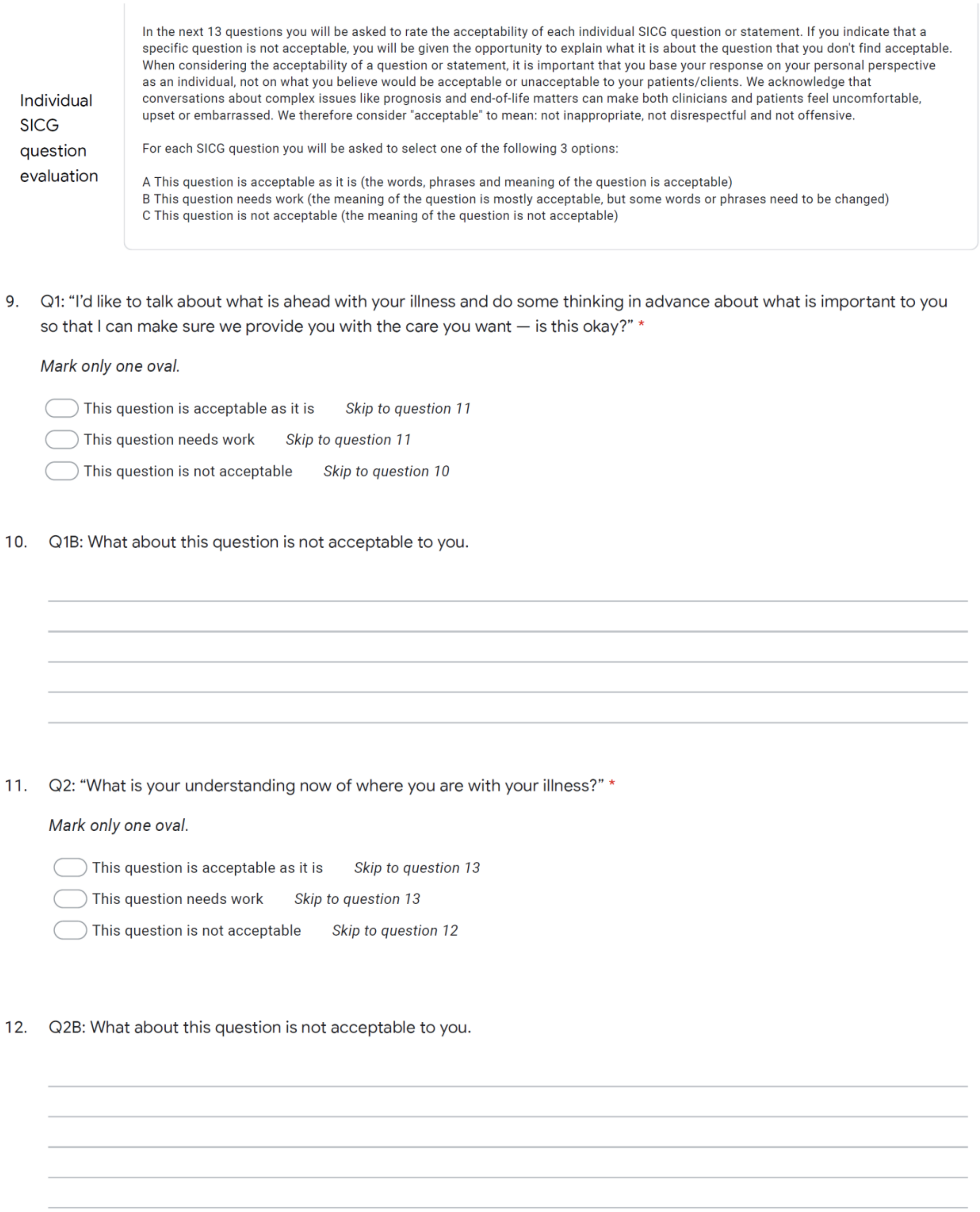
Skip to question 9

8. Approximately how many times per month do you use the SICG (partly or in its entirety) in your clinical practice? *

Mark only one oval.

○ >4
○ 2-4
○ 1
○ <1

Skip to question 9



Individual SICG question evaluation

In the next 13 questions you will be asked to rate the acceptability of each individual SICG question or statement. If you indicate that a specific question is not acceptable, you will be given the opportunity to explain what it is about the question that you don't find acceptable. When considering the acceptability of a question or statement, it is important that you base your response on your personal perspective as an individual, not on what you believe would be acceptable or unacceptable to your patients/clients. We acknowledge that conversations about complex issues like prognosis and end-of-life matters can make both clinicians and patients feel uncomfortable, upset or embarrassed. We therefore consider "acceptable" to mean: not inappropriate, not disrespectful and not offensive.

For each SICG question you will be asked to select one of the following 3 options:

A This question is acceptable as it is (the words, phrases and meaning of the question is acceptable)
B This question needs work (the meaning of the question is mostly acceptable, but some words or phrases need to be changed)
C This question is not acceptable (the meaning of the question is not acceptable)

9. Q1: "I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — is this okay?" *

Mark only one oval.

○ This question is acceptable as it is *Skip to question 11*
○ This question needs work *Skip to question 11*
○ This question is not acceptable *Skip to question 10*

10. Q1B: What about this question is not acceptable to you.

11. Q2: "What is your understanding now of where you are with your illness?" *

Mark only one oval.

○ This question is acceptable as it is *Skip to question 13*
○ This question needs work *Skip to question 13*
○ This question is not acceptable *Skip to question 12*

12. Q2B: What about this question is not acceptable to you.

13. Q3: “How much information about what is likely to be ahead with your illness would you like from me?” *

Mark only one oval.

○ This question is acceptable as it is *Skip to question 15*
○ This question needs work *Skip to question 15*
○ This question is not acceptable *Skip to question 14*

14. Q3B: What about this question is not acceptable to you.

15. Q4: “I want to share with you my understanding of where things are with your illness...” *

Mark only one oval.

○ This statement is acceptable as it is *Skip to question 17*
○ This statement needs work *Skip to question 17*
○ This statement is not acceptable *Skip to question 16*

16. Q4B: What about this statement is not acceptable to you.

17. Q4.1: Expressing prognosis in terms of uncertainty: “It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I’m worried that you could get sick quickly, and I think it is important to prepare for that possibility.” *

Mark only one oval.

○ This statement is acceptable as it is *Skip to question 20*
○ This statement needs work *Skip to question 20*
○ This statement is not acceptable *Skip to question 18*

18. Q4.1B: What about this way of expressing prognosis is not acceptable to you.

19. Q4.1C: Please suggest a statement that expresses prognosis in an acceptable way?

20. Q4.2: Expressing prognosis in terms of time: “I wish we were not in this situation, but I am worried that time may be as short as ___ (express as a range, e.g. days to weeks, weeks to months, months to a year).” *

Mark only one oval.

○ This statement is acceptable as it is *Skip to question 23*
○ This statement needs work *Skip to question 23*
○ This statement is not acceptable *Skip to question 21*

21. Q4.2B: What about this way of expressing prognosis is not acceptable to you.

22. Q4.2C: Please suggest a statement that expresses prognosis in an acceptable way?

23. Q4.3: Expressing prognosis in terms of function: “I hope that this is not the case, but I’m worried that this may be as strong as you will feel, and things are likely to get more difficult.” *

Mark only one oval.

○ This statement is acceptable as it is *Skip to question 26*
○ This statement needs work *Skip to question 26*
○ This statement is not acceptable *Skip to question 24*

24. Q4.3B: What about this way of expressing prognosis is not acceptable to you.

25. Q4.3C: Please suggest a statement that expresses prognosis in an acceptable way?

26. Q5: “What are your most important goals if your health situation worsens?” *

Mark only one oval.

○ This question is acceptable as it is *Skip to question 28*
○ This question needs work *Skip to question 28*
○ This question is not acceptable *Skip to question 27*

27. Q5B: What about this question is not acceptable to you.

28. Q6: “What are your biggest fears and worries about the future with your health?” *

Mark only one oval.

○ This question is acceptable as it is *Skip to question 30*
○ This question needs work *Skip to question 30*
○ This question is not acceptable *Skip to question 29*

29. Q6B: What about this question is not acceptable to you.

30. Q7: “What gives you strength as you think about the future with your illness?” *

Mark only one oval.

○ This question is acceptable as it is *Skip to question 32*
○ This question needs work *Skip to question 32*
○ This question is not acceptable *Skip to question 31*

31. Q7B: What about this question is not acceptable to you.

32. Q8: “What abilities are so critical to your life that you can’t imagine living without them?” *

Mark only one oval.

○ This question is acceptable as it is *Skip to question 34*
○ This question needs work *Skip to question 34*
○ This question is not acceptable *Skip to question 33*

33. Q8B: What about this question is not acceptable to you.

34. Q9: “If you become sicker, how much are you willing to go through for the possibility of gaining more time?” *

Mark only one oval.

○ This question is acceptable as it is *Skip to question 36*
○ This question needs work *Skip to question 36*
○ This question is not acceptable *Skip to question 35*

35. Q9B: What about this question is not acceptable to you.

36. Q10: “How much does your family know about your priorities and wishes?” *

Mark only one oval.

○ This question is acceptable as it is *Skip to question 38*
○ This question needs work *Skip to question 38*
○ This question is not acceptable *Skip to question 37*

37. Q10B: What about this question is not acceptable to you.

____
____
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____

38. Q11: “I’ve heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we ___. This will help us make sure that your treatment plans reflect what’s important to you.” *

Mark only one oval.

○ This statement is acceptable as it is *Skip to question 40*
○ This statement needs work *Skip to question 40*
○ This statement is not acceptable *Skip to question 39*

39. Q11B: What about this statement is not acceptable to you.

____
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40. Q12: “How does this plan seem to you?” *

Mark only one oval.

○ This question is acceptable as it is *Skip to question 42*
○ This question needs work *Skip to question 42*
○ This question is not acceptable *Skip to question 41*

41. Q12B: What about this question is not acceptable to you.

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____

42. Q13: "I will do everything I can to help you through this." *

Mark only one oval.

○ This statement is acceptable as it is *Skip to question 44*
○ This statement needs work *Skip to question 44*
○ This statement is not acceptable *Skip to question 43*

43. Q13B: What about this statement is not acceptable to you.

Please answer the following 3 general questions about the SICG.

44. Which member of the healthcare team do you believe is most suitable to initiate (introduce the topic for the first time) this type of conversation (discussing preferences for care) with a patient? (Select more than one option if you feel they are equally suitable)

Check all that apply.

☐ Nurse practitioner
☐ Doctor
☐ Social worker
☐ Spiritual counsellor/ Faith leader
☐ Traditional healer
Other: ☐

45. Considering the different cultural, ethnic and spiritual backgrounds of the people you care for in your practice, are there any questions in the SICG that you feel are inappropriate, disrespectful or might offend some of your patients/ clients? *

Mark only one oval.

○ Yes *Skip to question 47*
○ No *Skip to question 46*

46. Please list any questions or statements that you believe should be added to the SICG, because they could enhance a serious illness conversation or help provide patients with care that is aligned with their goals and preferences. (please separate your questions/statements with a semicolon [;].

Skip to section 39 (End of questionnaire)

47. Please select all the questions or statements that you feel might be culturally inappropriate or might offend some of your patients/ clients. *

Check all that apply.

☐ Q1: “I’d like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — is this okay?”
☐ Q2: “What is your understanding now of where you are with your illness?”
☐ Q3: “How much information about what is likely to be ahead with your illness would you like from me?”
☐ Q4: “I want to share with you my understanding of where things are with your illness...”
☐ Q4.1: Expressing prognosis in terms of uncertainty: “It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I’m worried that you could get sick quickly, and I think it is important to prepare for that possibility.”
☐ Q4.2: Expressing prognosis in terms of time: “I wish we were not in this situation, but I am worried that time may be as short as ___ (express as a range, e.g. days to weeks, weeks to months, months to a year).”
☐ Q4.3: Expressing prognosis in terms of function: “I hope that this is not the case, but I’m worried that this may be as strong as you will feel, and things are likely to get more difficult.”
☐ Q5: “What are your most important goals if your health situation worsens?”
☐ Q6: “What are your biggest fears and worries about the future with your health?”
☐ Q7: “What gives you strength as you think about the future with your illness?”
☐ Q8: “What abilities are so critical to your life that you can’t imagine living without them?”
☐ Q9: “If you become sicker, how much are you willing to go through for the possibility of gaining more time?”
☐ Q10: “How much does your family know about your priorities and wishes?”
☐ Q11: “I’ve heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we ___. This will help us make sure that your treatment plans reflect what’s important to you.”
☐ Q12: “How does this plan seem to you?”
☐ Q13: “I will do everything I can to help you through this.”

Skip to question 46

End of questionnaire	Thank you for taking the time to complete this questionnaire. We look forward to discussing the SICG further with you at the Focus Group Meeting.